The University of Hull

An Investigation of Rehabilitation
with Special Reference
to Lower Limb Amputation

Being a Thesis submitted for the Degree of

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by

Helen Crowther B.Ed.

Summary

Summary of Thesis submitted for

Ph.d. degree

by Helen Crowther

on

An Investigation of Rehabilitation with

Special Reference to Lower Limb Amputation

An investigation was carried out into rehabilitation. The author sought to clarify what appeared to be contradictory practices and the underlying issues. The study centred on the treatment of those who have lost lower limbs but the investigation was carried out in such a way as to reflect more generally on the state of medical rehabilitation.

First, the literature on rehabilitation and on amputation was reviewed. This review questions the rationale of the modern rehabilitation movement. In chapter three the concept of rehabilitation is redefined. An investigative and ethological method was devised with which to observe amputee mobility training. Five centres were investigated. The method was developed at a general hospital, centre A. Data was collected at centres B and C and the results checked at centres D and E. This sample includes a DHSS Artificial Limb and Appliance Centre and both NHS geriatric and accident and emergency units.

In the light of the redefinition of rehabilitation the data on rehabilitation was analysed. Serious problems in the daily practice and aims of amputee treatments emerged and services which are widely considered to be the crux of rehabilitation were seen not only to exclude truly rehabilitative elements but also to foster anti-rehabilitative behaviour.

This is a broadly based first study in an area where there is nothing similar. The study could provide an impetus for debate and point the way for further research into the treatment of those who have lost limbs. It provides both the ground theory and method for further research into many aspects of medical rehabilitation.

Preface

An investigation was carried out into rehabilitation. The author sought to clarify what appeared to be contradictory practices and the underlying issues. For reasons of special interest and knowledge and in order to limit an otherwise vast subject, the study was centred on the treatment of those who have lost lower limbs, but the investigation was carried out in such a way as to reflect more generally on the state of medical rehabilitation.

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Contents

•			pag	ge
Chapter One				
A REVIEW OF TH	HE LITE	CRATURE ON REHABILITATION 1	to	38
Section	A	Rehabilitation: Philosophy, History and Provision	1	
	1	Philosophy	2	
	2	History and Provision of Rehabilitation	8	
Section	В	Rehabilitation: Institutions and Stigma	13	
	1	Institutional Rehabilitation	14	
	2	Rehabilitation and Stigma	20	
Section	C	Rehabilitation Therapists	24	
	1	Prescription and Referral	25	
	2	The Nurse	27	
	3	The Physical Therapist	31	
	4	The Occupational Therapist	34	
	5	Other Staff	35	
Section	D	In Conclusion	37	
Chapter Two				
AMPUTEE REHAB EFFECTIVENESS		ION: AN ANALYSIS OF THE RESEARCH INTO ITS 39) to	75
Section	A	Discussion: The Patient who has Lost a Limb	40)
Section	В	A Review of the Research	46	•
	1	A general view of amputee rehabilitation	46	•
	2	The Patient	49)
	3	Amputation Surgery	50)
	4	The Stump	53	3
	5	Mortality and Morbidity	56	5
	6	Psychological Sequelae of Amputation	60)
	7	Neurological Sequelae	6	3
	8	The Artificial Limb	65	5
	9	Rehabilitation	7:	L

					pa	зe
Chapter Three						
	 	 4 M T 037	077	D-111 - D-11 - T-10 - D-10 - D		

DEFINING REHABILITATHEORY	TION: A CLARIFICATION OF REHABILITATION	76 to 100
1	Definitions	77
2	The First Boundary: Clinical Care	80
3	The Second Boundary: Physical Therapy	82
4	Further Definitions: Rehabilitation Proper	89
5	The Third Boundary: Gross Handicap	90
6	Rehabilitation and Amputation: Wider Horizons	95
7	Rehabilitation and Physiotherapy	98
8	Summary	99

Chapter Four

DEVELOPMENT OF A ME	THOD FOR THE STUDY OF REHABILITATION	101 to 139
Section A	The Setting	103
1	The Patient	103
2	The Walking Training Class	104
3	The Walking Training Process	108
4	The Therapist	110
5	Gaining Entry	113
6	Summary	113
Section B	The Method of Collecting Data	114
1	Observation	114
2	Ethological Methods	115
3	Investigative Methods	117
4	Recording the Setting	118
5	The Ethograms	119
6	Case Histories	125
7	Diary Notes	127
Section C	Critique	127
1	Observer Reliability	128
2	Validity	129

Chapter four cont	inued	page
3	Being Native	131
4	Observing the Observed Subject	134
5	The Self-Fulfilling Prophesy	135
6	Models and Perspectives	136
Section D	The Ethics of Data Collection	137
Chapter Five		
DESCRIPTION OF THE PRACTICE	E METHOD FOR THE STUDY OF REHABILITATION	139 to 164
Section A	The Sample	140
1	Description of the Centres and Staff	140
2	The Patients	140
Section B	The Method	144
1	The Quantitive Data, the Ethogram	144
2	The Investigative Data, The Case Histor	
3	The Diary Notes	159
Chapter Six FIRST RESULTS: A	REPORT ON CENTRE A	165 to 190
Section A	The Ethogram	167
1	Gross Activity	167
2	Taught and Non-Taught Activity	167
3	Staff and Patient Control of Activity	170
4	Communicative Style	171
5	Absenteeism	171
6	Rehabilitation Proper	171
Section B	Investigative Data	172
1	The Case History Material	172
2	Biographical Data: 23 Patients at Centre A	173
Section C	Diary Notes	174
1	The General Impression	174
2	The Staff	175
3	The Patients	180
4	The Prostheses	182

			•	
Chapter six co	ntinue	<u>ed</u>	page	
	5	Attendance	184	
	6	Group Exercise	187	
	7	The Limb Centre Used by Centre A Patients	188	
		•		
Section	D	Discussion	189	
Chapter Seven				
	SULTS	CENTRES B AND C AND REFERENCE TO	191 to	223
Section	A	The Five Groups of Activities	192	
	1	Minor Functional Activities	193	
	2	Conversation	193	
	3	Physical Therapy	195	
	4	Clinical Activities	196	
	5	Major Functional Activities	196	
Section		The Twenty-Eight Categories of Activity	198	
	1	Activities Comprising a Frequency of Less than .5% of the Total	-	
	2	Middle Range Frequency. Activities Comprising .5% to 5% of the Total	201	
	3	High Frequency. Activities over 5% of the Total	201	
Section	С	Taught and Non-Taught, Planned and Unplanned Activity	203	
Section	D	Staff and Patient Control of Activity	208	
	1	Results	208	
	2	Discussion	209	
	3	Walking	212	
	4	Prosthesis	214	
	5	Teaching	214	
Section	E	Communicative Style	215	
Section	F	Incidents of Special Relevance to Rehabilitation Proper	217	
•	1	Domestic and Mobility Criteria	218	
	2	Incidents Especially Helpful to Rehabilitation Proper	218	

s	4	•
Chapter seven cont	zinued	page
3	Incidents which were Unhelpful	
,	to Rehabilitation	219
Section G	Centre D: Checking the Results	221
Section H	Conclusion	223
. T2: -1- 4		
Chapter Eight		
CASE HISTORY RESUL CENTRE E	TS: CENTRES B AND C AND REFERENCE TO	224 to 267
Section A	Biographical Outline	225
Section B	The Case Histories	230
ı	Mr. F	230
2	Mr. G	232
3	Mr. H.	234
4	Mr. J.	236
. 5	Mrs. K.	237
6	Mr. L.	238
7	Mr. M.	240
8	Mr. N.	242
9	Mr. P	244
10	Mr. Q	245
11	Mrs. R.	247
12	Mr. S.	249
13.	Mr. T.	250
14	Mr. U.	252
15	Mr. V.	254
16	Mrs. W.	255
17	Mr. X.	256
18	Mr. Y.	258
19	Mrs. Z.	259
20	Summary	261
Section C	Attendance, Ambulance Journeys and Absenteeism	262
1	Attendance and Ambulances	262
2	Absenteeism	264

			•	
Chapter eight	conti	nued	pag	e
Section	D	Centre E: Checking the Results	266	
Section	E	Conclusion	267	
Chapter Nine				
DISCUSSION OF	RESUL	rs	268 to	294
Section	A	The Goal of Rehabilitation	269	
Section	В	Communication in the Rehabilitation Setting	276	
Section	C	Disfigurement, Disablement and Hopelessness	281	
Section	D	Bureaucracy	285	
Section	E	Power	290	
Section	F	Conclusion	293	
Chapter Ten				
CONCLUSION			295 to	309
Section	A	Conclusions	296	
Section	В	A Critique of The Study	305	
Section	C	Suggestions for the Future	307	
Appendices			310 to	331
Bibliography			332 to	351

List of Figures, Appendices and Bibliography

		page
Preface		i
Acknowledgemen	nts	ii
Contents		iii
List of Figure	es, Appendices and Bibliography	ix
Chapter one.	A Review of the Literature on Rehabilitation	1 to 38
Chapter two.	Amputee Rehabilitation: An Analysis of the Research into its Effectiveness	39 to 75
fig. 1	Rehabilitation Outcome: 215 patients, all ages and causes	47
2	Surgery Previous to Major Amputation (UK and USA)	51
3	Short term follow-up surgery following major amputation (UK, USA and Scand.)	53
4	Percentage of above-knee to below knee amputation (UK and USA)	56
5	Post-amputation mortality in elderly amputees (UK)	57
6	Amputees not considered suitable candidates for prosthetic fitting (USA and Scand.)	67
7	Some studies which have indicated lower limb amputee use of prostheses	70
8	Amputee Rehabilitation (UK)	73
Chapter three	• Defining Rehabilitation: A Clarification of Rehabilitation Theory.	76 to 100
Chapter four.	Development of a Method for the Study of Rehabilitation Practice	101 to 139
fig. 1	The Role of Physical Therapy in Relation to Lower Limb Amputee Rehabilitation	112
2	The Relationship of the Method to the Study as a Whole	116
3	The 28 Category Ethogram	120
Chapter five.	Description of the Method for the Study of Rehabilitation Practice	139 to 164
fig. 1	Data Collection Centres, Staff and Patients	141
2	The Ethogram	145

Chapter five of	continued	page
fig. 3	The Symbols with which the Ethological Record was Compiled	147
4	The Categories Divided by Taught and Non-Taught Activities	148
5	The Categories Divided by Staff and Patient Control of Activities	148
6	An Example of the Ethological Record	149
7	Recording Incidents of Special Relevance to Rehabilitation Proper	151
8	A Completed Ethogram. Patient L, Centre B	152
9	A Completed Ethogram. Patient V, Centre C	154
10	Biographical Information on Patient J, Centre B	158
11	Diary Notes on a Single Walking Training Session	160
Chapter six.	First Results: A Report on Centre A	165 to 190
fig. 1	The Gross Activity of the Walking Training Environment of the Lower Limb Amputee	168
2	Biographical Data on Patients at Centre A	173
Chapter seven	. Ethological Results: Centres B and C and Reference to Centre D	191 to 223
fig. 1	The Results of the Ethological Data, Centres B and C, given by Groups	192
2	The Incidence of Major Functional Activities or Rehabilitation Proper	197
3	Frequency Distribution of Activities in the 28 Categories, Centres B and C	199
4	The 28 Categories Simplified to 14	202
5	Distribution of Activity Given by Non-Taught (left) and Taught Activity (Right) in the 28 Categories	204
6	The Percentage of Taught and Non-taught Activity in each Category	205
7	The Taught and Non-Taught Activity in the Five Groups	206
8	The Activity Given by Columns	208
9	The Activity in the Five Groups given by Staff/Patient Control	211
10	Activity given by Participation in Minor Tasks and Physical Therapy Showing Total Therapy to be Less than Tasks done by Staff for Patients	e 211
ר ר	Dotoil of Walking Activity	213

Chapter seven	continued.	page	:
fig.12	The Taught and Non-Taught Activities given by Staff/Patient Control	215	
13	The Activity Classified by Symbols Denoting Communicative Style	216	
14	Incidents of Special Relevance to Rehabilitation Proper	1 218	
Chapter eight	. Case History Results: Centres B and C and Reference to Centre E	224 to	267
fig. 1	The 19 Patients from Centres B and C who are the Subjects of the Ethological Records	225	
2	The 19 Patients: Their Amputated Limbs	225	
3	The 19 Patients: A Comparison with National Statistics	226	
4	The 19 Patients: Their Prostheses at Walking Training	226	
5	The 19 Patients: Their Surgical Procedures	227	
6	The 19 Patients: Their Social Circumstances	229	
7	The Times of Arrival of Patients Booked to Atter Walking Training Commencing at 9 a.m. (Centre B)		
8	The Times of Departure of Patients Attending Walking Training for a Full Day (Centre B)	263	
Chapter nine.	Discussion of Results	268 to	294
Chapter ten.	Conclusion	295 to	309
Appendix I D	erivision of the Five Groups of Activities from the Twenty-Eight Categories	310	
fig. 1	Derivision of the Five Groups from the Twenty- Eight Categories	312	
Appendix II	The Ethological Results: A Comparison of Centres B and ${\tt C}$	314	
fig. 2	The Ethological Results, Centre B	316	
3	The Ethological Results, Centre C	318	
4	Results Distributed by the Five Groups, Showing the Same Pattern for Centres B and C	320	
5	Results Distributed by Taught and Non-Taught Activities, Centre B and Centre C	321	
6	Results Distributed by Columns, Centre B and Centre C (i.e. distributed by initiative and control of events)	321	

ge 2 7
7
2
3
8
3
5
6
7
3
3
9
L

Chapter One

A Review of the Literature on Rehabilitation

"Hands and eyes, like ears and legs play a part in so many operations that a man could only be said not to need them if he had no wants at all. That such people exist, in asylums, is not to the present purpose at all: the proper use of the limbs is something a man has reason to want if he wants anything.

I do not know what someone who denies this proposition could have in mind. Perhaps he is thinking of changing the facts of human existence, so that merely wishing or the sound of the voice, will bring the world to heel? More likely he is proposing to rig the circumstances of some individual's existence within the framework of the ordinary world . . "

Introduction

Rehabilitation is seen as a worthwhile pursuit. In this thesis the ways in which it is conceived and carried out are examined in relation to lower limb amputation in particular. First the literature on rehabilitation is reviewed. In this chapter we look at the philosophy, history and provision of rehabilitation, the setting in which it takes place and the professional workers who administer its course. This reveals the pressing need for research in this area.

A. Rehabilitation: Philosophy, History and Provision

What is immediately apparent in trying to collate literature for review is that there is very little that strictly appertains to the subject. There is instead a vast array of peripheral material which is widely dispersed throughout the medical literature. Recent texts have drawn aspects of this material together (e.g. Nichols 1976, Mattingly 1977, Goldenson 1978, Bitter 1979,

^{1.} P. Foot Moral Beliefs 1958 from A. Flew (editor) The Is/Ought Question Macmillan 1969 London Ch.XIX pp. 196 to 213 (1973 reprint) p.207.

Wright 1980, Brechin and Liddiard 1981) but for the most part the subject remains diffuse and, as we shall see, incomplete and rather superficially considered.

1. Philosophy

Philosophy is the business of thinking around a subject. It includes definitions of terms and parameters and no major work on medical rehabilitation fails to glance in this direction. However, such statements which can be identified are short or they are superficial or muddled. To give examples. Very recent publications have turned to philosophical examination of the issues relating to rehabilitation but, as in the case of Brechin and Liddiard, 1981, the work is based on the briefest and most general definition.

"We would suggest that what they (other rehabilitationists) are in essence describing is the promotion of a state of health and well being such as we all might strive for, disabled or not, and this is how, for the purposes of this book, we should like to define rehabilitation."

This 'promotion of health and well being' might refer to almost any human activity. As well as being short and superficial, this introduces another weakness of these statements; the lack of boundaries. In order to be useful a requirement of such statements is that they define the boundaries of the subject. We shall see, again and again, that this does not take place. Government reports provide some of the most wide ranging, meticulous and critical material on rehabilitation services yet are exiguous on theory. The Tunbridge Report 1972 rests upon such vague phrases as 'physical cure' and 'social cure', arguing unconvincingly that 'to avoid the risk of rigidity' rehabilitation should not be defined more strictly. In similar vein the Mair Report, 1972, relies upon the following:

^{1.} A. Brechin and P. Liddiard Look At It This Way: New Perspectives In Rehabilitation Hodder and Stoughton in assoc. O.U. Press 1981 Kent. Page 2.

". . . Rehabilitation is a concept whose meaning varies from the precise to the vague, according to individual taste, practice and experience. In the past, it was frequently taken to mean the application of physical methods of treatment aimed at restoring local function and general fitness after disease or injury. In recent times, a much broader meaning has been given to the word, which now implies the whole complicated process of the restoration of individuals rendered unfit from any cause to a degree of social and economic independence within the limits imposed by any residual restriction of function. For the purpose of this report the following simple definition was adopted: Rehabilitation implies the restoration of patients to their fullest, physical, mental and social capability."

The illogicalities of this and similar definitions are taken up to be analysed in detail in chapter three. What we note here is that the subject relies on an amalgum of general terms. Too often definitions and parameters are dealt with in a few sentences but where authors have devoted introductory chapters to the subject the result is not necessarily more explanatory or substantial. For example, Stryker 1972 concluded a review of a number of approaches to rehabilitation in the following imprecise and unhelpful terms.

"Rehabilitation is a creative process that begins with immediate preventive care in the first stages of an accident or illness. It is continued through the restorative phase of care and involves adaptation of the whole being to a new life" and "Rehabilitation is basically an optimistic process which concedes that despite continuing and even catastrophic disability, a better way of life for the patient is possible."

^{1. (}The Mair Report) Medical Rehabilitation: A Pattern For the Future H.M.S.O. 1972 Edinburgh page 5.

^{2.} R.P. Stryker Rehabilitation Aspects of Acute and Chronic Nursing Care W.B. Saunders 1972 Philadelphia p.13.

From this we feel no nearer a definition of what precisely rehabilitation is. On the concept of rehabilitation Krusen, 1964, a widely quoted author, has written mostly rhetoric and anecdote. Introductory chapters in otherwise sound texts e.g. Nichols 1976, Goldenson 1978, Bitter 1979, describe trends, services, legislation and so forth rather than defining rehabilitation in any but the most broad and general terms. We find in the literature such statements as that by Millard, 1976; after a lifetime's work in the field of rehabilitation measurement for him it is still not possible to define the subject. Other authors have set out to define the subject but have overlooked it in discussions on related issues e.g. Blaxter 1975. One could continue. Examples of the inadequacy of the thinking as shown in the writing on rehabilitation could be drawn from every major source.

Across the literature the sum of such statements which can be determined and the sum of the topics which are dealt with under this heading - refer for example the scope of contributions to the International Journal of Rehabilitation Research - depict rehabilitation as medical, physical and mental, personal, domestic, recreational, social and vocational, restoration and adjustment. The subject appears to be all things to all men. Unacceptable contradictions are revealed in attempts to define its boundaries. For example, to some (Piercy 1956, Nichols 1979) rehabilitation is an integral part of medicine, while to others it is depicted in a way that separates it from preventive and curative medicine (Rusk 1968) and distinguishes it from clinical care (Mair 1972). Many authors include physical treatments in rehabilitation (W.H.O. 1958, Rusk 1958, Humm 1977, Nichols 1979) while others separate these two (Grant 1963). On the one hand rehabilitation is discussed in the context of restoring the patient to home and work (Rusk and Taylor 1949, Grant 1963, Krusen 1964, Wright 1980) and on the other hand in the context of those who can never be restored within the usual understanding of what this entails (Groble and Nichols 1971, Wright 1980). Similarly, rehabilitation is described as dynamic (Rusk 1958) and creative (Krusen 1971, Nichols 1976) yet it is also discussed in the context of the more caring and custodial features of medicine (Nichols 1971 and 1979). The rationale for these dichotomies is uncertain for explanations are largely absent. Yet it matters a great deal in the business of coming to understand the subject just which aspects of medicine it may or may not be said to comprise.

Academic publications normally distinguish ends and means but this is not so in the rehabilitation literature. Hence 'rehabilitation' may refer to treatment or outcome, process or aim. There is careless use of passive and active forms and lack of use of adjectival and adverbial forms of the term. It is not clear whether rehabilitation is essentially a verb or a noun or legitimately both.

For unexplained reasons rehabilitation is inextricably bound up with treatment for 'the disabled'. This is doubly unfortunate as the term 'disabled' is mishandled on a par with rehabilitation, as we shall see in chapter two. Throughout the literature rehabilitation is depicted as having moved away from its old image of custodial care for incurables and adjustive treatments for the chronic sick to restorative treatments and, latterly, from the restorative with solely economic goals to restorative in the sense of full social independence for young and old, the acute and chronic sick alike: paralleled by a shift from charitable and long stay care to rehabilitation in special units, general hospitals and the patients home. Yet it is throughout discussed in the context of those with residual disability. Nichols, 1976, has stated that it is specifically the after care of those who require more than acute, short term or definitive care. Since the 1940s rehabilitation has been hailed as 'new hope for the handicapped' (Rusk and Taylor 1949). This may be true historically and empirically but its logical defense is not presented. While those who have been ill or injured are merely treated, get well and go home, those with residual disability - or who are, for

seemingly arbitrary reasons, classified to have such disabilities - are the subject of rehabilitation.

There are, without doubt, many shortcomings and illogicalities in what is written on rehabilitation. Just as important however is an uneasy suspicion that there ought to be much more to this subject. The texts are repetitious and many topics are not represented. The subject seems remote from its practical applications, remote from serious living - indeed remote from its clientelle.

In recent years there has been increased interest in rehabilitation research. In 1978 the Society for Research in Rehabilitation was founded, so too the International Journal of Rehabilitation Research. Open University publications (Boswell and Wingrove 1974, Brechin and Liddiard 1981) begin to bring together the major themes and problems in medical rehabilitation and Open University courses promote interest and re-examination (Health and Social Welfare). In England there are journals catering specifically for this subject (Rehabilitation, Rheumatology and Rehabilitation) and other quality publications which regularly include related material (British Medical Journal, British Journal of Surgery, Lancet). As yet, however, these have not substantially contributed towards a philosophy of rehabilitation, though their material is very wide-ranging and excellent in many other respects.

To the author it does not seem possible that further research can be wholly worthwhile until the underlying issues have been clarified. This is not to say that valuable studies have not been done or will not continue to be done but that many of the publications are weakened by muddled phrasing and lack of focus or frames of reference. To use an analogy to explain this view: to many, it will seem to be possible to study the properties of a subject - let us take the subject, the physics of light - without ramification on its definition, not least where it is a subject with which there is general

familiarity. It will be possible to measure the intensity of light, to devise instruments of measurement and instruments to control light, to record its effects on other substances and so on and so forth. However, there comes a point when far more can be achieved through analysis of the idea of what light is. This serves the purpose of uncovering errors in common assumptions and errors in academic theorisation. Because it is a process that develops and unfolds the subject and its related issues, it stimulates new ideas and research in new directions. So, research is both channelled and enlivened by philosophical investigation. In rehabilitation this aspect has been neglected. Too many of the increasing numbers of papers include the errors, assumptions and contradictions that have been touched upon here. Too many areas appear to be ignored or avoided because the full scope of rehabilitation has not been formulated. For these reasons, the theory of rehabilitation becomes the primary focus of this thesis, with field studies on amputee treatments in the role of support. The issues raised in this section will be dealt with specifically in chapter three, where the thinking on rehabilitation will be clarified and developed, but they provide the theme of the whole study.

Conclusion

Coming as an outsider to the subject the literature on rehabilitation fails to inspire confidence as a sound basis for further research. Rather it is seen as an impoverished area of medicine where a basis is yet to be established. Such statements on definition and intention which can be identified are not sufficiently clear or comprehensive to bear the weight of the discipline which is based upon them and at a profound and academic level a philosophy of rehabilitation barely exists. Establishing such a philosophy becomes the primary purpose of the work which follows.

2. History and Provision of Rehabilitation

It is not within the province of this thesis to do much more than mention the history of rehabilitation services and their present provision. Broadly speaking, all research must incorporate an understanding of the historical development of its subject and knowledge of the politics of its modern setting. For, after reviewing the philosophy, enquiry into these topics is the second most useful course of action in defining and delineating the issue in hand. However, these historical and political considerations are peripheral to the focus of this study which is, in the first instance, the over-riding requirement to re-define rehabilitation and, in the second, as will be developed, the author's special interest in the career or experience of the human subject of rehabilitation, the patient.

There is no scholarly, that is to say no full history of rehabilitation medicine. Those histories that are available are fairly short, too often uncritical and reflect too easily the prevailing ideologies of the time of writing. They include Krusen 1941 and Kessler 1953 whose special subject was the movement towards total rehabilitation, a sociological perspective by Strauss 1965, Stryker 1972 writing for nurses, Gill 1971 on the development of the NHS, Blaxter 1976 on provision of facilities for the disabled and Cartwright 1977 on the history of medicine. Transcultural and transhistorical insight is noticeably absent. Examples of care given in other ages or in other societies does not allow them to have held a normal or average or 'civilised' approach to deformity and disability. The result is a unanimous view that a new and enlightened era is beginning for the disabled. And in an easy though less than overt slide from what is the case to what ought to be, this trend is seen as morally good, therefore wholly defensible. The following is not atypical of the very limited view of other ages and cultures.

"The history of rehabilitation is intimately tied to the development of medicine, physical medicine in particular, and the growth of a social consciousness and sense of responsibility. Throughout history the handicapped have been ridiculed, persecuted or ignored. Primitive man abandoned the disabled with the philosophy that only the fit should survive. It took centuries before even a minimally humane attitude was exhibited. today we often segregate them. As one traces the history of treatment methods as well as attitudes of people toward persons with deformities and disabilities, one sees that it has taken centuries to achieve today's standards which are probably just a beginning." 1

Yet it is the author's experience of living, working and travelling in four continents that North American or British societies are not, on a broad canvas, any more favourably disposed towards the old, infirm or disabled than are Communist or right wing regimes, African or Asian peoples. Neither is there anthropological or biological material to support the view that man has become in any way more intelligent or more humane. Also to be discounted is the idea that uncivilised, primitive or simple societies can properly be described by any of these adjectives. The Weltshauungen of the American Rehabilitationists is a moderate, Christian and superficially egalitarian ideology in keeping with modern trends in Western social democracies. The author does not argue against this being the general or accepted view of rehabilitation medicine but cautions against its being seen as the definitive view and notes that the moral imperative follows only in as much as one shares the ideology. Hence, in so far as it is possible, it is intended that this investigation should stand back from the modern rehabilitation movement.

^{1.} R.P. Stryker. Rehabilitation Aspects of Acute and Chronic Nursing Care. Ch.1 p.5. W.B. Saunders and Co. 1972 Philadelphia.

Rehabilitation has been closely linked to physical medicine and services for those with residual disability. In Britain, the work of the agencies which provide these services is described by for example Blaxter 1976, Nichols 1976, Brechin and Liddiard 1981 and Evans 1981. They are administered by local government, central government and independent offices. i.e. The National Health Service (NHS), The Department of Health and Social Security (DHSS), The Department of Employment (DoE) and various independent and voluntary bodies and to a lesser extent the Departments of the Environment and Education and Science (DES). The major agencies are the hospital and rehabilitation unit, consultants and general practitioners, nurses, therapists, social workers and disablement resettlement officers (DROs), retraining agencies, sheltered housing and employment, social and housing services, national insurance and supplementary benefits, voluntary and selfhelp societies. Of special interest is the number of agencies - Blaxter noted 59 of these excluding services for the young, the old, the severely handicapped and mentally ill - and the clients' lack of information (Blaxter 1976), the unhelpful split in rehabilitation services between physical and occupational treatments, DHSS and D of E administration, and what the author sees as the continuing contradiction of independence training on one hand and custodial care on the other.

Present health services have attracted major criticisms and incorporate major areas of concern. Through the work of Friedson, Robinson, Strauss, Illich, Zola and others medicine is seen to have become institutionalised and bureaucratised in keeping with post-war trends in Western social welfare and Western democracy and there is a substantial literature on a number of conflicts and problems this gives rise to, in medicine generally though not strictly on the subject of rehabilitation. Gill, 1972, noted how interprofessional and government/professional conflicts shaped the present three

tier structure of the NHS. The split between hospitals, general practice and public health is neither the best nor the most rational organisation and has profound effects on continuity of care and prevention of disease. Milio. 1967, and Hart, 1971, have shown how the egalitarian philosophy of the NHS has not, as yet, equalised health opportunity in Britain. of such critics as Zola 1977 and Illich 1976 is that further health resources cater for an increasingly unhealthy population. Specifically on rehabilitation, Friedson, 1965, looked at the ways in which rehabilitationists institutionalise and bureaucratise their clientele, offering services in a way that diminishes the potentiality of the client. Recent critics have suggested 'that the patient gets lost in the routine' (Cleary 1979), even that hospitals are 'sometimes frankly dangerous places' (Kitzinger 1979). A point is reached at which there is a temptation to declare existing institutions bankrupt but to be more realistic, to use what exists and learn from the past 'we must build a new type of service based on the knowledge of today' (Grunewald 1972). From a great many sources we see that health care is institutionalised and its institutions are unsound.

Rehabilitation has also become professionalised. Again, the literature relates to medicine in general rather than rehabilitation in particular but makes many relevant points. Becoming ill is both a biological and a social process (Robinson 1971 and 1973)¹. The person who is incapacitated has a

^{1.} This is as relevant to loss of a limb as to any other infirmity. There are many examples of the cultural determinants of amputee treatments. Surgery may be performed for cosmesis alone. In the very elderly it is carried out as a life saving measure despite its very high mortality (refer chapter two) because the patient is seen as suffering from peripheral vascular disease rather than dying of old age. The site may be determined by skirt lengths, hence the avoidance of through knee amputations for women. The appearance of the prosthesis is as important as its physical functions. Mobility therapy for the elderly is also culturally determined. In the East the elderly are seen as deserving total family support. In the West they are judged as happier if they are independent.

legitimate basis for exemption from normal obligations and is not held responsible for the incapacity but to remain exempt he must be seen to cooperate with the qualified medical agencies. The elaborate rituals this can involve are documented by Robinson. This model is based on that of Parsons 1951. Parsons saw the doctor/patient relationship as reciprocal but this is disputed as tautological by Bloor and Horobin 1970. Both they and Friedson 1962 saw this relationship as problematic. For example, the patient is expected to judge the seriousness of his illness before seeking medical advice but is then expected to follow naively the doctor's instructions. There are difficulties for the patient in judging between actual error and his relying on the doctor despite misgivings. The prestigeous position of the doctor is stressed and the subordination that is required of the patient. The patient who questions the professional authority is pressured to conform by both health experts and friends and family for, as well as encroaching on professional domains, if he fails to co-operate he jeopardises his exemption from normal obligations.

The authority and structure of the medical professions have been documented by Friedson 1970. Authority and power arise from public prestige and exclusive rights. The medical profession determines its own rules and standards and monopolises the right to practise and to judge. Doctors have the power to define illness and to label patients accordingly. In many respects the authoritative practices of the paramedical occupations are similar to those of the professions. Nurses and therapists organise their own standards and control rights to practise. They too have systems for the routinisation of crises. The new patient meets a massive machinery which seems to demand total submission while under its care.

Conclusion

From this very brief resume of the historical background and present provision of rehabilitation services we see that rehabilitation operates under an unsound ideology, its organisation and services have been questioned.

And, its professional experts demand a degree of compliance that seems at odds with the notion of rehabilitation. It is, on the other hand, the prevailing and not unreasonable assumption that present health services are also exceedingly beneficial. However the purpose of research studies, such as this one, is to investigate such assumptions. The present outcry against cut backs in the health and social services is evidence of overwhelming support for these services. The cuts are seen, at worst, as evil, at best, as a necessary evil. So, without unduly magnifying criticisms or belittling the strengths and benefits of such services, through this study the author investigates primarily the soundness of the thinking on rehabilitation and also its day by day organisation and practice.

B. Rehabilitation: Institutions and Stigma

As well as providing definitions and parameters, philosophical examination also contributes towards the formulation of major themes and problems. The author's interest lies in themes which are the most fundamental to the subject. The first has been introduced in previous pages, i.e. the thinking and theorising of rehabilitation. The second, the subject of this section, is the setting in which rehabilitation takes place. It is divided into two parts for the setting is depicted in two forms. Firstly the setting is discussed in terms of its institutional practices. In sociological terms this equates with the more Durkheimian view of society as an object facticity of defined systems in which man moves (Berger 1963). Secondly the setting is discussed in relation to the attitudes of its participants. This equates with the more Weberian view of internalised social systems which structure the roles men play in society (Berger 1963). The most convenient and clear model in both cases is taken largely from the work of Goffman.

1. Institutional Rehabilitation

Rehabilitation is concerned with the restoration of patients and their ability to live again in the unyielding and unpredictable outside world. (Its full definition is the subject of chapter three). Yet institutions are islands of taken-for-grantedness, refuges from the outside world. Rehabilitation is associated with functioning independently and with autonomy while in institutions there is social control and group activity dictated by staff. What sort of institution is the hospital? Can it be compared with Goffman's understanding of a total institution (Goffman 1961)? If so, is this conducive to rehabilitation?

Goffman's work is seminal in throwing new light onto institutions at the time it was written; since which is has been widely accepted. It is cross-referenced to hundreds of other studies. A point of criticism is a certain use of emotive language but the inmate bias is sound. It provides here an illustration or model of an institution which can be used to unravel the character of the general hospital. Within a sociological framework there is no major work which has disputed these characteristics though their generalisation to less formal settings must be employed with care. A major and recent review of the work of Goffman while highlighting its complex weaknesses, shows that it deservedly continues to remain in the fore front of modern sociology (Ditton 1980).

At the beginning of his essay, Goffman defines total institutions by example; homes for the incapable and harmless, asylums for the incapable but harmful, prisons for the intentionally dangerous, barracks, boarding schools, ships and manor houses for the better accomplishment of some work like task and religious retreats. Though he does not include modern general hospitals,

^{1.} E. Goffman Asylums Pelican 1961 G.B. On the Characteristics of Total Institutions. pp. 3-124.

either in or out-patient care, in his examples, he does include other hospital settings, such as long stay wards, asylums and sanitaria. Also, the example of boarding schools and manor houses compares closely with the general hospital where the institution serves the better accomplishment of some work like task - one cannot envisage pre and post operative amputee treatment being carried out in the patient's home - yet where the inmates are not without holidays or means of release.

Total institutions are places where all aspects of life are conducted in the same place under a single authority, where daily activities are carried out in the immediate company of a large batch of others who work, play, eat and sleep together, these activities comprising a tightly scheduled round of activities dictated from above and legitimised by purporting to fulfill the aims of the institution. One group, the staff, are there to care for the other group, the inmates, and there is bureaucratic handling of batches of people. Staff and inmates become stereotyped in each others eyes, the role of the staff becoming one of surveillance predominating over guidance. Passage of information is restricted, patients are not shown their records or told of their treatment though each has a paper shadow following their progress through the institution. Work incentives for the patient are not those of the outside world, therapy activities are unrelated to serious living and there is an incompatibility between life on the inside and family life, economic life on the outside. Total institutions are forcing houses for changing persons. There is an admission procedure which includes physical and emotional nakedness, bathing, reclothing, taking records and doing tests. For the new inmate there is a forced reappraisal of the self image. Inmates have to be appropriately deferential to staff, they lose freedom of movement, of dress and choice of food. Verbal autonomy and civil status are diminished. Defense mechanisms operating against these losses often collapse into the situation and the patient is cajoled, tyrannised, ostracised or

ridiculed into conformity. There are classic adaptations to inmate life; the invalid role, the obedient and helpful role, the uncooperative and aggressive role and the co-operative yet distant role. Inmates experience self pity and fantasy release and a sense of dead and heavy hanging time. Discharge is greeted with mixed feelings and apprehension of stigma.

The staff world presents an image of rational organisation yet embodies contradictions. The staff enact a custodial role yet one which aims to be restorative. In dealing with inmates there is conflict between institutional efficiency and humane standards. The mechanisms of staff control are common to all societal control but here they are more overt and intense.

The institution has ceremonies such as open days, Christmas parties, an internal magazine, official visits and weekly religious services.

There are many direct similarities here between total institutions and general hospitals. In many ways Goffman's description fits our ordinary understanding of the hospital. It is the author's impression, as a result of past membership of both the staff world and the inmate world, that the characteristics of total institutions given by Goffman never contradict the underlying structure of general hospitals. There is an underlying sameness; a likeness of quality and in important respects of quantity or intensity.

The question of intensity is however crucial. Goffman did not intend that each characteristic should be peculiar to total institutions or shared by them all. What distinguishes these institutions is their encompassing nature, their exhibition of an intense degree of the family of attributes. The short stay, acute and out-patient aspects of general hospital treatments would seem to count against this intensity. In the investigation which is

^{1.} ibid pp. 12 to 74 The Inmate World.

^{2.} ibid pp. 74 to 92 The Staff World.

^{3.} ibid pp. 93 to 112 Institutional Ceremonies.

to follow the author looks for not only the characteristics of total institutions in rehabilitative treatments but also for evidence of the all-encompassing or all-pervading nature of institutional control to see whether or not this is relevant in any significant degree.

Already, observation suggests that long and short stay care for amputees is not dissimilar in its day to day practices. Also out-patient physiotherapy classes employ similar routines for in and out-patients. Just as boarding schools and day schools are run on similar lines with some schools including boarding and day pupils, so hospitals incorporate long and short stay wards and therapy departments for in and out-patients meshing together on similar lines.

In the literature of medical sociology there is a great deal to indicate that medical services generate an intense and all-pervading control over the clientele. There is possibly too little literature that has seriously analysed a opposite view here. Typical care patterns are seen to demand almost total submission from patients through the roles ascribed to patients (Robinson 1971), through the dominance of the professional expert (Friedson 1965 and 1970) and the bureaucracy of the institutions in which the care is given (Mechanic 1968, Robinson 1973). Zola 1971, described medicine as a major institution of social control, a new repository of truth where judgements are legitimised in the name of health. In an insidious and undramatic process medicine becomes relevant to an ever increasing part of human life.

In recent years, community care and deinstitutionalisation have become by-words in medicine. This move, taking health care into the patient's home, has important implications in the context of this study. Both in and out patient treatments are under the microscope here, and if even out-patient attendance can be seen to generate institutional control and patient submission, might community care take this control right into the patient's home? The sheer numbers of hours of medical care may not be the deciding

factor but the pervasiveness of the care in which the knowing expert offers to the naive new patient a programme which defines and structures their roles and delineates what is to count as success or failure. A parallel may be drawn from education. Consider the child from his earliest experience of schooling, learning what is to count as education, learning when he is doing well and when he is not. His attendance at school will be four and a half hours per day for barely half of the days in a year, but the school has an undeniable massive influence on the child. Reimer (1971) noted that only vacationless boarding schools can strictly be called total institutions - as only vacationless long-stay hospitals can be - but he adds:

"Perhaps the strict definition gives too much attention to the body and too little to the mind and spirit. Schools pervade the lives and personalities of their students in powerful and insidious ways and have become the dominant institution in the lives of men during their most formative years."

It is in this sense, exactly captured by Reimer, that hospital departments which dispense rehabilitative treatments will be investigated to see what their influence is on the naive new amputee during his most formative period.

That hospitals are like total institutions is, on its own, only of general interest. The important question is, is this state conducive to rehabilitation? Already there are hints that it is not.

There are, amongst the few accounts by patients, illustrations of the effects of institutional practices which cannot be held to be rehabilitatively beneficial. Wallace and Robson, 1976, describe an institutionalised

^{1.} E. Reimer School Is Dead Penguin 1971 England 2nd reprint 1973 p.25.

^{2.} Throughout this study 'the patient' is referred to in the masculine and all therapists in the feminine for no other reason than simplicity.

Most patients were men. Most therapists were women.

child weighted to the floor and immobile as a result of treatments to increase his mobility, though highly mobile when released to the care of foster parents. Battye 1966, the handicapped inmate of a residential home, portrays the shrinking horizons and disproportionate importance of day to day trivia in such settings. Ritchie 1960, describes his feelings as a member of the inmate world of a physiotherapy day centre which echoes much in Goffman's descriptions of prisons and asylums. Ritchie variously likens his condition to that of a school boy, a prisoner and a baby.

"I felt like a concentration camp prisoner with my tongue cut out, standing before the commandant. He had all my papers in front of him, my previous convictions."

Medicine has been described as disabling (Illich et al 1977) and iatrogenic (Illich 1977), in terms of its having insidious control (Zola 1977) and creating need and dependency (McNight 1977), none of which can be reconciled with our ordinary understanding of the idea of medical rehabilitation.

As will be shown in chapter three, rehabilitation is a socio-economic entity. It refers to a person's reliving in the world after disease and illness, and a person's world is structured socially and economically. So the suggestion that work incentives for patients might not be those of the outside world or that therapy activities may be unrelated to serious living would have the most grave consequences for rehabilitation. Whether or not this is the case is to be investigated in this study. Equally, is there unwillingness on the part of patients to terminate their treatment? Is the role of the staff largely custodial? Do patients suffer the losses described by Goffman and how does this effect rehabilitation? These and other questions will be examined in relation to the rehabilitation of lower limb amputees. If the hospital environment is a forcing house for changing people - and amputation of a limb would seem to force just such a reappraisal

^{1.} D. Ritchie Stroke Faber and Faber 1960 London p.120.

of the self-image - do the staff enhance wholeness and usefulness in patients or do they in any significant sense compound disability and dependency?

Clearly research is needed.

2. Rehabilitation and Stigma

Goffman provides the framework for a second model which is incorporated into this study, a model of those whose deviation from health and ability makes them the subjects of rehabilitative treatments (Goffman 1959 and 1963). Once again detailed characteristics are available. This enables the drawing up of a clear picture of the physiological or health deviant and the attitudes he may encounter and this will greatly facilitate the study of the effects of this state on rehabilitation.

There are many theoretical frameworks from which one can view society. are not mutually exclusive and the truth of how society operates may lie interwoven in an amalgum of many of these frameworks, but it is conceptually impossible to handle them simultaneously. Goffman's work on stigma is part of a larger sociology on deviance. Some of the theoretical frameworks on deviance are now outmoded, e.g. the social pathology view. Some are valid though less to the fore, but have a place in providing part explanations of the whole, e.g. theories on value, conflict, anomie and the construction and disruption of norms. The interactionist perspectives are the most commonly used modern frameworks with which to study deviance, and are seen as closest to our normal understanding of how society operates. They do not have the status of scientific theories but are essential in their role as illustrations, perspectives and models without which research cannot take place. Goffman is a dramaturgicalist, i.e. he depicts society as a drama acted out by its participants. His vividly illustrative and intensely detailed work is

In this section the stigma experienced by disfigured and deformed is examined but discussion on disablement is largely held over to chapter two where it is dealt with in the specific context of lower limb amputation.

part of the interactionist and labelling perspectives of society.

Goffman describes society as having normative expectations of social behaviour and stereotyped ideas on those who deviate. He distinguishes three groups of deviants who are stigmatised in the eyes of non-deviants, these are the disfigured and deformed, those of blemished character and the tribally or racially deviant. Perceived or known-about deviancy, e.g. skin colour, facial disfigurement. is distinguished from unperceived deviancy, e.g. criminal record, mastectomy. In the first instance a poor social identity is attributed to the deviant when he comes into contact with normals. 2 In the second instance a discredited social role will be attributed when the deviant condition is known and so information control becomes especially important for this group. Goffman shows how the stigmatised person is not accorded the normal social standing of an adult in society. He is treated differently, as less than fully adult, less than fully human. Typical reactions by normals include patronage, low expectations, blunt approaches, derision, self-consciousness, the fixed stare, the taboo of normal words, artificial levity, compulsive loquaciousness, awkward solemnity, naked exposure and invasions of privacy and simpering helpfulness. Goffman identifies three territories, the forbidden place where the stigmatised are not welcome, the civil place where the stigmatised must behave as normal and the back place where deviants expose their deviancy and meet fellow deviants.4 Again, information control or confidentiality is essential so that the

^{1.} E. Goffman, Stigma: Notes on the Management of a Spoiled Identity, Pelican 1963 London Ch.1.

^{2.} ibid Ch. 1. Goffman discusses the continuum between stigma and nonstigma, deviant and normal. He uses the word normal in the everyday sense of the less obviously stigmatised. This is useful shorthand for otherwise lengthy descriptions and a useful anchor for a problematic but essential term. Its continued use here is on the same understanding.

^{3.} ibid Ch. 1.

^{4.} ibid Ch. 2.

stigmatised do not lose face in the civil place. Goffman further differentiates groups he calls the Own and the Wise. The Own share the stigma. The Wise do not but have special knowledge through family or occupational connections. For the stigmatised there are problems in alliance with the Own and the Wise as well as with normals and in ambivalence between groups. Contact with the Own draws one into the deviant and stigmatised subculture. Alliance with the Wise can reinforce the stigma for those offering themselves as Wise may employ prejudicial attitudes under cover of specialist or professional knowledge. Alliance with normals is also problematic because in effect normal society tells the stigmatised to cheerfully and unselfconsciously accept themselves as essentially the same as normals while at the same time voluntarily withhold themselves from situations in which normals would find it difficult to give lip service to their similar acceptance of The stigmatised are obliged to act as though they were no different while at the same time removing themselves sufficiently to ensure normals remain uncontaminated and confirmed in their beliefs about the stigmatised. No authentic solution is offered in this maze of paradox.

This picture of the consequences of deviancy is supported by Battye 1966, who depicts the crippled man subject to ancient and pagan attitudes. He does not think these attitudes exceptional or out-dated

"A cripple is still a man, but, as it were on a smaller scale. His totality is diminished, his image distorted. He is not whole. It inevitably follows then that there must always be this barrier of difference and distortion between us and the inhabitants of the normal world . . . we are forever barred from the deepest and most intimate levels of human intercourse."

^{1.} ibid Ch. 3.

^{2.} L. Battye 1966, The Chatterley Syndrome p.96 from D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community, Tavistock and O.U. Press 1974 London Part III Ch.10 pp.93-99.

So, through Goffman's work, the characteristics of stigma can be established and used as a model from which to formulate a method of data collection. Like the characteristics of the all-encompassing institution, they seem at odds with the idea of rehabilitation. For rehabilitation has to do with re-living in society and, by definition, those set apart from society by the mechanisms of their stigma cannot be said to be accepted into the mainstream of society. Two points emerge. Firstly, do these typical prejudicial attitudes operate to a significant degree within the treatment systems, against the subjects of the treatments, if so they would seem to negate the rehabilitative aims. This is one of the themes on which data will be collected and conclusions drawn. Secondly, if amputees are stigmatised people can they ever be successfully rehabilitated into society, i.e. is the term meaningful in the context of treating those who have lost limbs?

On the second point amputees are stigmatised by virtue of disfigurement and deformity. The popular concept of disability and the obvious example of it is loss of a limb (Tunbridge 1972, Garrad 1974, Blaxter 1975). Rehabilitation professionals have categorised it as a condition of irretrievable damage and loss (Partridge 1980). Ostensibly the stigma operating against amputees would seem to be considerable. In chapter two the disabled status of those who have lost limbs is examined and in chapter three the parameters whereby amputee treatments may be accepted under the umbrella of rehabilitation are redrawn. Rehabilitation is meaningful in the context of amputee treatments but only with certain qualifications.

As evinced by the work of Scott (1969 and 1970), there is already evidence of stigma operating within rehabilitation programmes in a way that negates the overtain of reintegration into society.

"When those who have been screened into blindness agencies enter them, they may or may not be able to see at all or they may have serious difficulties with their vision. When they have been rehabilitated, they are all blind men. They have learned the attitudes and behaviour patterns that professional blindness workers believe blind people should have. In the intensive face to face relationships between blindness workers and clients that make up the rehabilitation process, the blind person is rewarded for adopting a view of himself that is consistent with his rehabilitators' view of him and punished for clinging to other self-conceptions. He is told that he is 'insightful' when he comes to describe his problems as his rehabilitators view them, and he is said to be 'blocking' or 'resistant' when he does not. Indeed, passage through the blindness system is determined in part by his willingness to adopt the experts' view about himself."1

Might blindness be transposed to limblessness and blind men to disabled men? An unwitting example of the prejudices of a professional expert against amputees and orthopaedic disabled comes from Gingras 1975. At psychologically the lowest point the patient is persuaded by Gingras to see himself as 'disabled' and in a classic example of the looping effect of inmate rebellion² the patient is given psychiatric counselling if he fails to accept this view. Paternalism, emotional blackmail, praise and ostracism are used to reinforce the experts' view.

C. Rehabilitation Therapists

Rehabilitative therapies are prescribed by doctors and dispensed by nurses and therapists with the aid of auxilliary staff and the option of referral to other paramedical professional experts. The role of the principle characters is examined here. This is done in order to assess the theoretical basis of each and to judge the likely effectiveness of present rehabilitat-

^{1.} R.A. Scott. The Construction of Concepts of Stigma by Professional Experts, p.119 in D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community, Tavistock and O.U. Press 1974 London Part III Ch. 12 pp. 108-121.

^{2.} E. Goffman Asylums Pelican 1961 G.B. p.41.

ion practice. Specific reference is made to lower limb amputation in order to contain an otherwise vast subject.

1. Prescription and Referral

Little is known about the basis on which a rehabilitative therapy may be prescribed, or the basis for further referral. Preliminary observation shows that therapists treating amputees usually receive only the instruction 'physic please' written in the patients' notes (a practice noted in the literature, Thompson 1979), and that lower limb amputees are routinely referred to physiotherapy departments while upper limb amputees are referred for occupational therapy. Further referral for lower limb amputees rests largely on the discretion of the physiotherapist and the availability of resources at the particular hospital. Frequency and duration of treatment is frequently also left to the therapist's discretion (Ward et al 1978, Thompson 1979). Physiotherapists express preference for this state of affairs because it increases their role in decision making and the diagnostic procedure and hence increases the status of their profession. Clinical decisions in physiotherapy remain a major issue and to date the profession has not formulated a clear policy on this. (Gyretveit et al 1982).

^{2.} A parallel is being drawn here between physical and occupational therapy prescription and drug prescription. Although physical and occupational treatments may be varied at the discretion of the therapists in a way that drug treatments are not and although the mere encouragement of physical or even recreational pursuits by nurses and therapists can barely be termed prescription, the comparison with medication is a useful one. It raises the status of the therapy and more correctly depicts what is taking place.



^{1.} Rehabilitation itself, as will be discussed in chapter three, is the act or state of being set up in proper condition in society. The physical and occupational treatments or therapies are best described as rehabilitative in style or aim. While they are carried out in hospitals they do not of themselves comprise 'rehabilitation' but are the means to that end. Hence, to define them as rehabilitative therapies becomes the most exact term even if this seems a little clumsy or unusual at this stage.

Though there are DHSS recommendations, neither it seems does the medical profession hold to a clear policy on prescription and referral. From a survey of physiotherapy prescription for orthopaedic out-patients, Ward et al 1978, found that doctors referred 29% of new out-patients for physiotherapy but that the rate of referral varied from 15% to 56%; the differing characteristics of the patients failing to account for this variation. The majority of the prescriptions specified the type of treatment but duration was specified in less than half and frequency and aims of treatment hardly ever. Tunbridge, 1972, noted that few doctors had sufficient knowledge of the work of therapists and were unable to prescribe accurately as a result. McMillan 1973, urges a greater flexibility, co-operation and understanding between doctor and therapist. Though this is not a study of the referral system general conclusions will be drawn on the suitability of referring lower limb amputees for physical therapy and the frequency and duration of such treatments.

On the subject of amputee referral for limb fitting, a number of studies have noted unhelpful delays and the associated poor condition of patient and stump (e.g. in England, Hutton and Rothnie 1977, and in America, Kerstein et al 1977). Van de Ven 1973, commented that incidence of incorrect referral can show a complete lack of understanding of the role of limb fitting.

Hamilton and Nichols 1972, noted a 22% incidence of delays of over three months due to re-amputation, illness, industrial dispute and so forth.

They associated these delays with poor rehabilitation results. For those who have lost limbs it seems reasonable that the real business of their rehabilitation cannot begin until the patient has an artificial leg.

Limblessness aggravates other disorders and narrows one's view of the future. Yet Clarke-Williams 1978, has described these delays as a boon, a period in which to treat concomitant disorders and to improve the patient's view on life. To the author this seems unconvincing. The amputee's seemingly obvious

and urgent requirement of a leg is not given quite the emphasis one would expect. Positive use of periods of delay - such as to allow a period of mourning - are not mentioned in the literature and the research to follow illustrates that unproductive delays are all too apparent.

2. The Nurse.

Nursing incorporates two roles. One is custodial, the other restorative.

Nurses care for the dependent sick and work towards the rehabilitation of those who are recovering. Except in a minority of cases where limb ablation becomes part of the care of a dying patient and where mobility training cannot be considered, the nursing responsibility towards lower limb amputees includes both of these roles; the custodial role predominating in the immediate pre- and post-operative periods, giving way to a restorative and rehabilitative programme. Amputation surgery is fairly common (refer chapter two) and the prospective amputee may be admitted to almost any ward of a general hospital. What is the state of the rehabilitative nursing of lower limb amputees as reflected in nursing literature?

Firstly, the literature does not distinguish custodial and restorative nursing as it does for example medical and surgical nursing or paediatric and geriatric care and so on. Hence there is no well-defined literature on the nursing role in rehabilitation and one searches instead for sentences, paragraphs and occasionally chapters in more general texts. Nursing, since the days of Florence Nightingale, has relinquished rehabilitation to the therapy professions. Though the custodial and restorative are possibly less easily separated than are other major themes in nursing, the result is that nursing lacks clear appraisal and vigorous debate in this area. Texts on the rehabilitation of the lower limb amputee are oversimplified to a point of being misleading and mistaken. To take a fairly typical example,

"As soon as his amputation stump has healed, the patient is referred to the artificial limb and appliance service for the area. Even before this correct bandaging will have helped to form a good stump shape for an artificial limb. This will initially be of a temporary type (pylon) while the individual artificial limb is made. An elderly patient may stay in hospital until he is walking well on this."

This is the entire comment on the subject. It is too brief to be helpful to the novice and there are errors in every line. For instance, the inference is that healing is the indicator of walking readiness and referral to the Artificial Limb and Appliance Centre. Neither are true. Walking may be used to promote healing and referral may be made (one may say should be made) before healing, indeed before amputation. The vital importance of this referral, of prosthetic replacement and mobility training, each are omitted. So the purpose of amputation is overlooked. It is inferred that stump bandaging shapes the stump. Neither is this true. Bandaging is done to hold the dressing in place and control oedema; the surgeon shapes the stump. It is also mistakenly inferred that the pylon is not an individually tailored artificial limb. Mass production and individual workmanship go together to produce temporary and definitive limbs. The final statement serves no purpose. 'An elderly patient may stay in hospital until he is walking well', or he may not! What are the criteria and what are the consequences of prolonged stay in hospital or early discharge? Many topics are not covered but if they are beyond the scope of the book this should be stated in the passage and the reader warned of the complexities of the issues and referred to further material.

There are numerous British and American textbooks and journals for the nursing profession projecting this clumsy understanding of limb amputation

^{1.} J. McFarland <u>Basic Clinical Surgery</u> Butterworths 1973 London 2nd edition 1980 p.22.

(e.g. Barker 1978, Donahoo and Dimon 1977, MacInnes 1977, Moroney 1975, Nash 1980, Orem 1977, Powell 1976, Rapier 1970, Siegel and Chodoff 1976, Taylor 1977). It is as though a text on the paraphenalia of amputation had been written in stone to be faithfully transcribed for every nurse; similar omissions, assumptions and sentiments occurring in every transcription. They are written, as it were, from a distance, failing to get involved in the practicalities of administering their idealised directives. That nursing texts do contain much sound information is of no comfort when it is interspersed with so much that is not.

Sometimes the information is extremely poor. A common misconception is the idea that

"Amputation is usually accompanied by a more or less profound degree of psychological shock . ."

Recent research has shown that reaction to loss of a limb is very variable (refer chapter two). Not only are these varied reactions omitted from the literature, also their practical and general causes are ignored in a narrow focus on the limb itself. Instruction is missing on how to deal with the patients' feelings and lack of grief is interpreted too readily as unhealthy.

Perhaps for reasons of sheltering the sensitivities of the nurse the idea has been developed that limb ablation is not unduly painful

"Curiously enough, the pain after amputation is almost always quite mild. Mild analgesics usually suffice, and often no analgesic at all is necessary after the first 24 hours." 2

"The rigid dressing tends to prevent severe pain when weight bearing is instituted soon after amputation and phantom pain has not been a problem."

^{1.} C.B. Larson and M. Gould Orthopsedic Nursing C.V. Mosby Co. 1943 St. Louis 8th edition 1974 p.444.

^{2.} ibid p.444.

^{3.} ibid p.453.

Again in chapter two we shall see that this idea is not tenable. It reflects a lack of true concern for the patients' well-being and contradicts basic observation on the subject.

Nurses are urged to get to know patients, to reassure and give advice and encourage independence.

"Nurses are in an excellent position to supply reassurance that he is not to become a cripple . . ."

But the impracticalities of these directives are overlooked. Cassee, 1970, has shown how a culture has developed which keeps personal contact with patients to a minimum and the institutional setting in which amputees are nursed can be seen to negate opportunities for independence training (Crowther 1982). And we shall see in chapter two that it seems by far the majority of patients are crippled by limb amputation and the situation is not helped by encouraging nurses to shatter hopes in this way.

Over and above what is mistaken and missing, the way in which the subject as a whole is projected is wrong. In the first place the model of 'the amputee' is too simple and too singular. This statement is developed throughout this study. The homogeneity of the idea of lower limb amputation will be broken down and further it will be depicted in many respects as a continuous process rather than a single event. Consequent upon its mistaken model the literature presents too simple and uniform a picture of the sequelae of loss of a limb. In the second place, the literature does not emphasise the purpose of modern amputation surgery which is sound prosthetic replacement of a dead or deadly and useless limb. Information on artificial limbs is dealt with in a way that isolates the subject from the patients' needs. Such topics as the consequences of delayed fitting, the discomforts of limb

^{1.} ibid p.444.

wearing and the many functions of the new limb are not discussed. The old image of limblessness and dependency is not effaced and the capabilities of the modern amputee are not grasped; patronage and sentiment hiding the truth from the nurse and the patient. Finally, one doubts the nursing commitment to patients so largely ignored at the centre of treatments so lavishly described. We read of amputation, the stump, the prostheses but not the person who loses a limb.

In the previous section the efficiency of prescription was in some doubt.

In this section we have seen that the nursing of lower limb amputees is unlikely to be satisfactory. We turn now to the literature of the remedial professions.

The Physical Therapist

While nurses have a dual role, restoration and rehabilitation is the raison d'etre of the therapist. And while nurses are expected to encourage rehabilitative efforts, therapists receive written instructions to that end. Is the literature of physiotherapy more comprehensive on the subject of rehabilitation and better disposed towards amputees?

On the whole the answer is that it is not. The literature of the physical therapy professions has almost nothing to say on rehabilitation theory. To give examples, two texts accepted by the profession as standard works have no introductory chapters on the history, aims, related skills or related professions or problems and uncertainties within the profession (Cash 1976 and 1977). Where introductory chapters are included a pedantic style covers lack of depth (Shepherd 1980). Unacceptable reasons are given for not discussing the relative merits of treatments, for example, the dearth

^{1.} The physical therapy professions are those of Physiotherapy and Remedial Gymnast. The two are not greatly differentiated in this study as their theoretical basis within amputee rehabilitation is similar.

of controlled trials and the tendency of physiotherapists to be untheoretical (Scrutton and Gilbertson 1975). Contributions by physiotherapists and remedial gymnasts to multi professional texts on rehabilitation are notably poor both in content and lack of references (Evans 1981). The literature focuses on techniques and materials and a proper place is not found for other issues.

The journal Therapy does not pretend to be scientific, and though it may serve well its social function, in doing so it reinforces all society's myths about the worthiness of people-work, the benefits of modern medicine and the prejudices which determine the role of 'the disabled' therein. journal Physiotherapy employs the hallmarks of scientificism and reflects a vigorous profession but the status of both journal and profession are brought into question through some of the material it publishes. For example, two articles on motivation, 1975 indicate a disturbing view of psychology. O'Gorman appears to be trying to repress patient autonomy by operant conditioning. Hawker suggests that motivation is a quality unique, for uncertain reasons, to some patients and not others. By comparison a third paper by an occupational therapist, Ibbotson, manifests sound knowledge and application of modern learning theory and only here the limitations of the hospital setting are recognised, the therapists preference for docile and obedient patients and the mis-application of the label unmotivated. Recent multi professional contributions on amputation (e.g. special issue on amputation, Physiotherapy Jan 1970) though sound, and pleasing in many respects, omit major themes. Weaknesses in the present systems of treatment are not discussed, neither is there guidance in problematic areas. Tasks, techniques

^{1.} M. Hawker. Motivation in Old Age: The Physiotherapists View, pp. 183-184. J. Ibbotson. Motivation - The Occupational Therapy Approach, pp. 189-191. G. O'Gorman. Anti-Motivation, pp. 176-179. Physiotherapy. June 1975, Vol. 61(8).

and prostheses take precedence over patients. Rehabilitation is barely brought into the picture. And at a time when amputee rehabilitation is so dubiously successful (refer chapter two) the most senior therapists argue the intricacies of stump bandaging to the exclusion of all else.

In respect of amputee rehabilitation, physiotherapy and nursing literature suffer from similar failings. The complexities of the psychological sequelae of amputation are not dealt with, nor the patients' discomforts, the many practical problems following loss of a limb, the many functions of the prosthesis and so on. Humm, 1977, offers an excellent guide on basic treatment but the therapist has no guide on subtle, problematic or uncertain issues. Physiotherapy literature like its nursing counterpart has developed a style that speaks at a distance from the needs and interests of its clients. But, whereas in nursing one sees the emergence of patient-centred care, in physiotherapy no such move is underway. And, where in nursing higher degree research is bringing about the reappraisal of basic concepts, again, in physiotherapy this is not the case. Even the term 'amputee rehabilitation' is not used correctly, being used to refer to physical exercise in hospital and not the patient's re-living in society. mistakes of this view are discussed in chapter three. Hence, built around mistaken concepts in the most fundamental issues, one must question the direction and effectiveness of physiotherapy for lower limb amputees, as one questions the restorative aspects of nursing and, as expressed earlier, the lead given by consultants and theorists in rehabilitation medicine.

^{1.} Refer S. Callen. A Modern Method of Stump Bandaging.

Physiotherapy May 1981 67(5) pp. 137-8.

Letters: H. Gowland and E. Joy.

Physiotherapy July 1981 67(7) p.213.

Letters: P. Buttenshaw, D. Dixey, C. Van de Ven, J. Jackson and M. Hallett

Physiotherapy September 1981 67(9) p.272.

The lack of research has been noted. In-service research is minimal and post-graduate studies are in their infancy though there are appeals throughout the literature for research to be undertaken. These appeals reflect the task-orientation of the professions and are couched in terms of evaluating techniques and not investigating the direction of physiotherapy as a whole or examining the views or activities of the clients and their families, though very recent work by Partridge touches upon the dynamic and interactive aspects of physiotherapy and the role of descriptive studies (Partridge 1980. 1982 (b)). More generally the way ahead is not seen as hopeful (Evans 1981). This is seen to be due to the difficulties of devising clinical trials and measuring results, the paucity of comparable patients and the impracticality of blind techniques. This illustrates the state of infancy of para-medical research, in the narrow view of science which it embodies and the limited view of where the ills may lie. In this study an attempt is made to overcome this methodological deadlock. Through prior clarification of the ground theory of rehabilitation (chapter three) an investigative and ethological method is devised (chapter four) with which to examine physiotherapy practice. This method represents a formula which can be infinitely adapted and developed for further research in para-medical fields.

4. The Occupational Therapist

Occupational therapy has already been brought into this discussion in a favourable light. The meagre crafts and diversional image of this small

Health Services Research Unit, The University of Kent at Canterbury. (Partridge 1982 (a))

^{1.} A recent letter to Physiotherapy perhaps best expresses the present state of research.

CONCERN FOR PRIORITIES

Madam - I was saddened to read in the proceedings of the Council meeting in the January issue of the Journal that Council had agreed to fund a further two industrial relations officers and a secretary. Is this 100 per cent expansion justified when the Society at present spends nothing on research? When we are unable to demonstrate the effectiveness of any aspect of our practice, should salaries really be our first concern? CECILY J PARTRIDGE BA FCSP

profession is in contrast to the standard and scope of its literature. The texts do not lack introductory material (MacDonald 1976) and are presented in a more discursive style (Mountford 1971). Occupational therapy appears to provide a proper link between hospital and home. Here, rehabilitation is seen in its true terms, having personal, domestic, social and economic goals. The work of occupational therapy specifically includes assessment and training in personal care and domestic activities, assessment of fitness to return home and training in outside mobility. It includes assessment of vocational ability and re-training in light or remedial work, consideration of the patient's psychological state and the need to stimulate interest and enjoyment. Though again there is a dearth of research, occupational therapy literature is, as it were, painted on a broader canvas than its physiotherapy counterpart. Reading its texts one can believe this profession to be making a significant contribution to restoring and rehabilitating its patients and to their individual care.

Seen as the province of physiotherapy, the older texts include little on lower limb amputee treatment (Willard and Spackman 3rd edition 1963) but more recent material brings in the lower limb patient (Shopland 1979), and the aims considerably overlap physiotherapy but have additional socio-economic elements. In common with nursing and physiotherapy there is no material specifically on the difficulties and complexities of amputee rehabilitation but one has the impression that occupational therapists will employ a more sensitive and individually tailored approach, though the validity of this impression is yet to be tested.

5. Other Staff

The literature of social workers and Disablement Resettlement Officers has not been examined because it is outside the scope of this study. For the lower limb amputee referral to these professions depends largely upon success or failure on the wards and in the physical and occupational therapy depart-

ments so the effectiveness of these later interventions becomes a separate problem, one which is dependent upon these preceeding issues.

Literature, especially research on the role of clerical, auxilliary and ancilliary staff on wards and in therapy departments would have been invaluable but none exists. This investigation includes data in this area for the first The author is deeply suspicious of the statements made in the McMillan time. Report on the remedial professions, 1973, that it is wasteful of professional skills for therapists to provide secretarial, clerical or portering services and that qualified staff should not be used for these duties, and that full advantage should be taken of the availability of aides (auxilliaries) and their employment extended. Part of the impetus for this study is the misery afforded to patients as a result of the fragmentation of labour in the hospital setting and the lack of training of so many staff. The McMillan recommendations would seem to aggravate this situation. They have no research base and, unintentionally, echo the worst elements of class consciousness. This reveals a need for investigation of minor and routine activities within rehabilitation settings and the impact they may have for the patient, together with a clarification of the activities of auxilliary staff.

Summary

Prescription, nursing and physiotherapy have each been shown to suffer serious inadequacies. Of special note is the lack of material in many areas and the lack of research. Clearly there is a need for the theory of rehabilitation to be revised, and a method developed with which to investigate rehabilitation attitudes and practices. Incorporating characteristics given by Goffman, it may circumvent the present deadlock in physiotherapy research. Review of the literature creates a poor impression of rehabilitation and it is this that the data will test.

D. In Conclusion

"To see the present (day) clearly, let us imagine the children who will soon play in the ruins of school buildings, air terminals and hospitals. In these concrete castles turned cathedrals, built to protect us against ignorance, discomfort, pain and death."

On the one hand is the leviathan of modern medicine, on the other the view expressed by Illich (1976). Between these two, critical analysis is modest by comparison with that available in education where critiques range through every shade of opinion from the extreme right and reactionary to the extreme left, from deschoolers and free-schoolers to quietly concerned teachers and inspectors and parents. Every aspect of schooling and the curriculum has been scrutinised and revised and revised again. Philosophies on education abound to a point where they have afforded to be trivial. The roles of child, parent and teacher have been viewed and reviewed from every angle. Debate extends to parliament, the popular press and peak hour television. Medicine has neither equivalent volume or vigour. There are areas of excitement and prestige such as genetics, bio-engineering and transplant surgery, and areas that are almost devoid of interest or awareness such as those touched upon in this chapter, the philosophic, para-medical and patient-centred aspects of medicine.

It is of interest that government reports most loudly testify to this unsatisfactory even desperate situation (Piercy 1956, Mair 1972, Tunbridge 1973). On the subject of rehabilitation Tunbridge notes the lack of interest in rehabilitation and the lack of action since the Piercy Report, the failure to include rehabilitation in medical education, the disorganisation and divisions in the health service, lack of communication and co-ordination

^{1.} I. Illich <u>Disabling Professions</u> Marion Boyars 1977 (2nd edition original 1976) London page 12.

of services, lack of careful assessment of patients needs, an artificial distinction between physical and occupational therapy and between therapy and work and a lack of local authority provision at many levels. The size of the problems being unknown. Tunbridge deplores the lack of research and notes that not only are there virtually no figures there is also a paucity of research as to the requirements of rehabilitation and into evaluating its treatment and techniques. Rehabilitation it seems is not a healthy business.

If one disturbs lifelong concepts on medical care, it could be said that rehabilitation is not less successful where clinical, therapeutic and prosthetic treatments are not available, i.e. in those countries without the means to provide such care. It is the author's experience of African and Indian societies that where the village social structure or extended family still exists or where deformity and disfigurement are commonplace, an unselfconscious or unwitting reshuffling of family roles may take place to accommodate a revised role for those who have lost limbs or become handicapped in some way. Revised roles include those of minder and craftsman, beggar and menial and are associated with reduced marriage chances, low income and physical hardship - as is the role of 'the disabled' in the West - but a type of rehabilitation undramatically takes place; one that in its relative social and economic terms is not less successful and not to be disdained. Cross-cultural and trans-historical studies in rehabilitation may have much to offer western medicine. Certainly this author does not subscribe to the premiss that the ills of rehabilitation medicine can be cured by making available more money or more care.

Chapter Two

Amputee Rehabilitation:

an analysis of

the research into its

effectiveness.

Introduction

The theory, the research and possibly the practice of rehabilitation are seen, in chapter one, to give rise to concern. In this thesis each of these issues are taken up, the theory revised, a research method developed and the practice investigated. However, in order to limit an otherwise vast subject and to introduce more detail, one aspect of rehabilitation must be singled out for study. Making use of the author's special interest and knowledge, the area chosen is that of the rehabilitation of the lower limb amputee.

In this review, the recent research papers on all aspects of their treatment are examined. There are three themes; to define and clarify what is involved in being 'an amputee', to reveal the likely state of rehabilitation in this area at the present time and to formulate the questions for the research which is to follow.

A. Discussion: The patient who has lost a limb

Having a limb broken and then repaired is a very different matter from having a limb broken and then replaced. In the first instance one is merely a person who was once an orthopaedic patient. In the second instance one becomes 'an amputee'. One never outgrows or leaves behind the condition of being an amputee. Not only do certain clinical treatments continue - the artificial leg requires regular attention for the rest of one's life - but so too do certain social labels and implications and expectations. Together with the wheelchair bound, the amputee epitomises the popular concept of the disabled person (Garrad 1974) and cited as the obvious example of disability (Tunbridge 1972, Blaxter 1975). All limb amputees have automatic entitlement to regis-

^{1:} The word amputee is an unfortunate but short form for anyone who has lost one or both lower limbs or has artificial lower limbs.

tration under the Chronic Sick and Disabled Persons Act 1970. The proposition that this view is problematic will be examined.

Harris 1971 defines the relevant terms:

Impairment: lacking all or part of a limb, having a defective

limb, organ or mechanism of the body.

Disablement: the loss or reduction of functional ability which

results.

Handicap: the disadvantage or restriction of daily activities

caused by disability.

In the case of lower limb amputation impairment therefore relates to the loss of physical or locomotor ability. Handicap is the effect on the person's lifestyle, i.e. the socio-economic personal and domestic effects. These definitions are used throughout this study.

These distinctions are lost in popular use and it is a tribute to the strength of popular opinion on disability that having established these terms Harris bows to this pressure and misuses them in the immediately following paragraphs and thereafter throughout the text. Colloquially the term 'disabled' is effortlessly transposed from limb to function to person and to carry moral implications far beyond this. It is in this sense that amputees en mass can be categorised as disabled. To some extent there is no point in arguing with popular ideas on loss of a limb for in rehabilitation one is concerned primarily to reintegrate the patient into society whatever the prevailing mores rather than to change society to suit those with disabilities. But academic enquiry should not rest on popular prejudice and misconception. These attitudes will be shown to be unhelpful to rehabilitation.

Indeed rehabilitation may be enhanced if the issues are fully understood and

^{1:} A.I. Harris The Handicapped and Impaired in Great Britain H.M.S.O. 1971 London Section 1:1 pp. 2 and 3.

the knowledge incorporated into the treatments.

To depict the lower limb amputee as limbless and therefore dependent and disabled is a hundred years out of date. In Britain there is an advanced prosthetic industry and massive outlay of NHS funds for the free provision . of artificial limbs to all who can make use of them. Amputation surgery can. in the 1980s, be regarded as replacement surgery. Once seen as the most serious consequence of trauma and disease short of death, it now enables sound prosthetic replacement in a way that non-amputation of diseased and deformed limbs does not. Though it may always have a small part to play in the care of the terminally ill who can never be regarded as candidates for prosthetic fitting, it is essentially a replacement procedure. amputation of a leg, failure to apply an artificial leg is as illogical as failure to insert the new heart in a transplant operation. Prosthetic mobility is never preferable to the normal healthy state. There are basic incompatibilities between human flesh - especially where it has been cross-sectioned - and all the materials from which artificial limbs are made and man has not improved on nature from the point of view of bipedal locomotion or aesthetic acceptability. Yet modern prostheses are adequate to enable a meaningful degree of rehabilitation to take place. Their adequacy depends upon optimum condition of patient and stump but the industry has advanced to a point already where the majority of prosthetically equipped amputees may be to all intents and purposes as able as any of their contemporaries.

The term impairment remains relevant. Though the amputee no longer lacks all or part of the limb, the limb is defective per se, as compared with the normal healthy state, though this in itself says little.

The term disablement becomes ambivalent. It depends upon how one interprets the notion of physical ability. One cannot with an artificial leg wiggle

the toes, rotate the ankle or hop successfully. Some physical functions are irrevocably lost or reduced and one must conclude that amputees suffer disablement. But if one considers the more important or gross physical functions, the ones that prostheses have been designed to perform, amputees fare better and the notion of disablement begins to become inappropriate. are both young and elderly amputees whose gross physical or locomotor abilities are on a par with their contemporaries, who can stand and walk and climb which are the chief daily activities of the lower limbs. That is not to say that these more successful amputees do not have minor physical disabilities, but, when these disabilities are viewed in proportion to the persons overriding state, which is one of ability, they can be seen to form poor reason for attaching the label of disablement which slides so easily from the physical to the social and moral and carries so many pejorative connotations. An elderly man who can walk (around home and garden), climb (his stairs), stand (in a bus queue), rise (from a chair) and so forth cannot, by virtue of his ability to do these things appropriate to his age, be said to be unable to do them or dis-able. Similarly, such able amputees as the mountaineer Croucher (1976) and air ace Bader (1954) are more appropriately described, in comparison with their contemporaries, as super-able rather than dis-able. It is not the author's intention to write new definitions of these terms which would involve an analysis of locomotor skills beyond the scope of this study but to point out from personal knowledge of a number of able-bodied amputees that the automatic equation of amputation and disability is unfortunate and not wholly accurate.

Harris, 1971, recognises that amputees may not be handicapped and cites the example of a man with a satisfactory prosthesis, sedentary job, a car adjusted to hand controls and leisurely recreational pursuits. Harris underestimates the conditions under which amputees may not be handicapped but the argument is correct nevertheless. Handicap will depend upon wholly individual

personal, domestic, social and economic circumstances. A young footballer will be seriously handicapped. An elderly retired man may not be restricted to his usual pursuits. Again, it will be possible for those who have replaced limbs to accommodate minor handicap (as minor disability), as everyone accommodates their strengths and weaknesses, in finding an acceptable and appropriate level of social and economic performance. It is not necessary that the amputee should be able to perform every act of normal daily living to earn the distinction of being non-handicapped for this would imply a standard that is far more strict than is applied to the rest of the population. It is only necessary for amputees to achieve a sufficient spread of appropriate socioeconomic activities in keeping with other citizens.

What is the view of amputation manifest in rehabilitation practice? It would be helpful to investigate this question. Where amputation is equated with serious disability one would expect to find custodial care rather than restorative therapies, fairly low criteria of success and an orientation towards coping with disability rather than competing with the able-bodied. There might be evidence that prosthetic replacement is not wholly appropriate or worthwhile. Where amputation is seen as only temporarily disabling one would expect to see rapid, intensive and positive treatment, the emphasis on sound prosthetic replacement and on restorative therapy which uses criteria on a par with able rather than disabled living.

Some of the literature on amputee rehabilitation embodies positive views of amputee ability. Much of it does not. The idea that some amputees may be able-bodied is used guardedly by Nichols (1976). He encourages an energetic

^{1:} The restricting factor for the elderly is most often the decline in general health not the loss of the limb and where the cause of amputation in the over sixties is traumatic and not vascular this can be demonstrated in excellent rehabilitation results (Van de Ven 1973).

rehabilitation programme for younger amputees, notes that an almost perfect gait can be achieved, and states that young lower limb amputees need not be particularly handicapped. In conversation, Humm recognises the abilities of amputees but his writing does not do justice to this view (1977). (1977) states that in time the patient can become as active as he was prior to amputation but fails to draw out this point. Near normal ability is the subject of single sentences. In-ability, illness and handicap is the subject of whole chapters. Garrad, 1974, and Blaxter 1975, discuss the ease with which clinical definitions can be made in the face of such obvious conditions as loss of a leg and paraplegia, hence the popular concepts of disability which centre around these conditions. Neither points to the role of modern prosthetic replacement which compensates for loss of a leg in a way that there is no comparable compensation for paraplegia. Partridge, 1980, similarly ignores the role of prostheses. Amputation is grouped with cerebro-vascular accident, spinal injury, cerebral palsy and deformity as a condition of irreversible loss and permanent disability. But amputation is not a condition of irreversible loss in the way that the other conditions in this group are and more care must be taken in laying down these definitions for practising therapists. The irreversible loss of function of a damaged and useless limb must be differentiated from the modern purpose of amputation surgery by showing the extent to which a prosthesis replaces the lost function of an amputated limb in a way that is not possible where amputation does not take place. The journal Therapy (1981) describes exceptionally able amputees (Ted Kennedy Jnr and Norman Croucher) not as able or super-able but, patronisingly, as disabled

P.J.R. Nichols <u>Rehabilitation Medicine</u> Butterworth 1976 London Refer Ch. 10, pp. 217-219.

^{2.} B. Davis Amputations Ch. 12, p.294, from J. Cash (editor)

Physiotherapy in Some Surgical Conditions Faber and Faber 5th
edition 1977 London.

^{3.} C.J. Partridge The Effectiveness of Physiotherapy Physiotherapy May 1980 66(5) p.154.

heroes. Doubts arise as to whether the most positive modern attitudes prevail in amputee rehabilitation.

Two models taken from education underly the author's investigation into the professional workers view of 'the amputee'. Is the curriculum pupil-centred i.e. does it cater for mixed or variable ability? Is there a standard curriculum and does this fully cater for the most and least able? Second, in view of what is known in education on the evils of low expectations (The Crowther Report 1959, Jackson and Marsden 1962, Hargreaves 1967, Lacey 1970, Coard 1971) does a poor view of the patient suffer the same self-fulfilling results as were found to operate in schools.

B. A Review of The Research

The recent research into treatment for lower limb amputees is patchy and incomplete. There has been no previous attempt at whole and systematic study. The purpose of this survey is to bring together the many disparate investigative and statistical threads and to work for the first time towards as complete a picture as is possible of the present state of amputee treatment and the likely state of rehabilitation.

1. A general review of amputee rehabilitation

In 1950, Schultz reported that of 100 lower limb amputees at a New York general hospital at least 50% could not adequately use their prostheses, and this at a time when large numbers of patients were not even fitted. The intervening thirty years have seen very important improvements in amputation surgery, the provision and design of artificial limbs and the provision of mobility training. Are Schultz's findings tragic but outdated?

Therapy Vol. 8(10) 9 Sept. 1981 p.12 and Vol. 8(11) 11 Sept. 1981 p.1.

It seems not. In 1977 Stern and Skudder, again in a study from New York, reported on 215 lower limb amputees. The 15% increase in vascular patients, 50% decrease in bilateral amputees and 50% increase in unilateral below knee amputations reflect changes in medicine and surgery since Schultz's survey. In figures seen by their authors as representative nationwide, they judge less than 1% of these patients not to be handicapped. Refer Fig. 1. Together with those whose rehabilitation was described as good though restricted, a total of 13.5% demands further investigation: particularly as 54% of these patients had lost only one leg below the knee.

Fig. 1. Rehabilitation Outcome: 215 Patients, All Ages and Causes.

Class		Description	Percent
Class I	Full Restoration	socially and vocationally unrestricted. limited sports. on the whole unrestricted domestically.	1%
Class II	Partial Restoration	perform regular job with some exceptions. some recreational and walking restrictions.	12.5%
Class III	Self Care Plus	seated indoor work. social restrictions and walking stress. no help required domestically.	42%
Class IV	Self Care Minus	need domestic and walking assistance. fatigue cannot tolerate prosthesis all day.	32%
Class V	Cosmetic Plus	little activity. wearing prosthesis and moving room to room. fatigue. discomfort. stress.	9%
Class VI	Non- Prosthetic ²	reject prosthesis. wheel- chair mobility.	3.5%

^{1.} This scale used by Stern and Skudder is based on that of Russek 1961.

^{2.} An unspecified number of amputees were not prescribed prosthetic fitting in the same period. If these were to be taken into account the overall percentage of successfully rehabilitated patients would be smaller.

Performance is not known to improve after discharge and follow-up studies show up to a third of patients may give up using their prostheses (Kihn et al 1972, Green et al 1972, Weaver and Marshall 1973, Goldie 1978, Sneppen et al 1978). A disconcerting picture begins to emerge.

In informal discussion, prosthetists consider 50% of the artificial limbs they supply are not used; a further 40% underutilised. A figure of around 10% is suggested by them as a fair estimate of the number of artificial limbs supplied in this country that are fully used by those who receive them. Although rehabilitation for lower limb amputees depends unquestionably on their having and using prostheses there is no easy equation between prosthetic usage and rehabilitation so these figures do not automatically spell 50% failure and 40% underachievement. However, as each amputee is entitled at any one time to have available two artificial limbs (or two sets of limbs) which they may wear alternately, change with their occupation or shoe styles or use when the other is repaired, the 10% of limbs regularly and fully used could belong to only 5% of the amputee population.

The search for answers is hampered by there being little data in some areas and none in others. Such data as there is is often confused, outdated and poorly presented. The available studies are rarely comparable with each other and are addressed to varying questions using varying subjects. There are few studies done over a sufficient period of time. There is almost no material truly relevant to rehabilitation. Amputation is not a single and simple complaint and studies may include above or below knee patients only, the more elderly peripheral vascular patients or all ages and causes or only those with prostheses. The enthusiasm of some authors for programmes they have commissioned colours their results and high success rates exclude patients unlikely to be successful: the notion of rehabilitation success being as variable as the numbers of studies and rarely defined by any of them. This survey pieces together as much as can be known but its function is as

much to show the gaps in our knowledge as to show the state of play.

2. The Patient

In this study the conditions surrounding amputation are not mentioned in proportion to their severity, but the age, illness and infirmity of these patients and the undoubted gravity of their situation should not be underestimated. Lower limb amputation is most often a life-saving measure. Most new patients are elderly, their amputations resulting from peripheral vascular gangrene in association with all the diseases and debilities of advancing age. Younger patients have experienced serious trauma, malignancy, paralysis and deformity. For some, physical and psychological shock accompanies amputation which aggravates the disease process, sometimes with quickly fatal results. there are approximately 100,000 amputees (Nichols 1971). In 1980, 5,200 primary lower limb amputations presented for limb fitting in England, Wales and N. Ireland (DHSS 1980). Men outnumbered women 2:1 and 73% of new patients were over 60 years. Cause of lower limb amputation was 88% peripheral vascular insufficiency and diabetes, 7% trauma, 4% malignancy and 1% deformity. Additional numbers of those who had undergone limb amputation but were not referred for limb fitting are unknown, being omitted from DHSS figures. Once referred the policy is to offer limbs to most patients at least on a trial or temporary basis. Significant wastage is to be expected from this generous and humanitarian policy. Temporary, even definitive limbs will be made for patients too feeble in body or mind or who do not live long enough to make anything approaching optional use of them or for whom re-amputation begins the treatment cycle again.

^{1.} In 1979, interviewed by the author, two medical officers reported non-prescription of prostheses to only one or two patients per annum of those referred to the Limb Centre. Reluctant patients were persuaded to attempt limb wearing.

3. Amputation surgery

On this topic there are large numbers of papers by those who carry out surgery. General practitioners publish much less material and so little is known about the effectiveness of community treatments prior to surgery. Clarke-Williams 1978, noted that family practitioners often pursue superficial treatments for peripheral ischaemia which include too much rest and inactivity. Referral to the hospital consultant is frequently delayed by eighteen months to two years by which time patients may be weak, hopeless, in pain and even incontinent and mentally confused as a result of toxaemia and are poor subjects for amputation. Eventual hospital treatment may not be speedy or positive. Nichols, 1971, observes that amputation is frequently regarded as indicative of failure of other methods of management, as a mutilation rather than a positive technique to restore function.

Although amputation of a leg is an obvious milestone in the treatment of an ischaemic limb, an injury and so forth, as will be shown, it is a mistake to see it as a single and definitive procedure separating all that went before from all that comes afterwards. For most patients most of their treatments not least their surgery - is continuous from pre-amputation to post-amputation phases. As recently as 1980, Fleurant, reporting on a series of fifty-eight patients of all ages and causes, stated that one third of these patients had pre-amputation surgery. A third also had pre-amputation amputations, i.e. toes, part-foot. For a further third, major amputation was carried out in two parts, firstly a cleansing disarticulation or guillotine followed by a definitive amputation. Still a tenth required surgical revision of the stump or conversion to a higher level within the immediate post-operative period. Later ipsilateral and contralateral surgery is not recorded. Amputation is characterised by repeated surgical procedure and this is evident throughout the literature though nowhere is it presented as a central feature; rather the surgery. is mentioned by way of showing how few procedures were carried out in any

particular series. One is left to ponder unwritten reports from less favourable angles on less favourable series of patients. Only controlled studies of case histories will properly reveal this feature of the amputee's estate. The effects of delayed surgery and repeated procedures, conservative or radical approaches to amputation are unknown in terms of the quality of human life and the patient's overall rehabilitation success.

Pre-amputation surgery is probably in the order of 50%. (Refer Fig. 2).

The difficulty of drawing conclusions from disparate figures is also illustrated here for totals are variously given for patients, total surgery or single procedures. It is notable that the two studies written in more critical vein, those of Harris et al 1974 and Stern and Skudder 1977, record significantly higher levels of pre-amputation surgery.

Fig. 2. Surgery Previous to Major Amputation (UK and USA)

author	year	description of procedures	patient	percent
Chilvers & Browse	1971	numbers of patients	elderly	45%
Finch et al	1980	previous surgery	vascu-	54%
Green et al	1972	reconstructive surgery	lar	50%
Harris et al	1974	lumbar sympathectomies	patients	65%
		plus arterial reconstruction	(U.K.)	29%
Couch et al	1977	pre amputation surgery	all	37%
Malone et al	1979	at least one, arterial reconstruction	ages	45%
		plus ipsilateral sympathectomies	and	36%
Potts et al	1979	vascular reconstruc- tion and part foot	(U.S.A.)	36%
Stern & Skudder	1977	vascular surgery, toes and part foot		69%

Post-amputation surgery is also substantial, though it now becomes difficult to define post-amputation, to separate it from pre- and minor amputation and major amputation. This is not merely a semantic riddle. Papers on amputation focus on surgery and not people and to their authors major amputation becomes the most recent or the ideal procedure regardless of the level of previous surgery that was seen by the recipient as a major procedure. The lack of studies of the careers of patients over long periods makes it impossible to put a figure on the numbers of surgical procedures young or elderly amputees may undergo. Figures on this topic will be collected during the research and results are given in chapter eight. The aim is to provide sufficient information on the careers of amputees to know whether or not more detailed research would be worthwhile at a later date. It seems to the author the many procedures patients may undergo is an important facet in the argument against amputation being envisaged as a state of sudden, shocking and irreplaceable loss. It is also important to rehabilitation.

Some indication of the amount of short-term follow up surgery is given in Fig. 3. Later major amputation, i.e. in the following months or years, or indeed previous major amputation to the ipsi-lateral or contralateral leg is rarely recorded. Ebskov and Josephsen 1980, investigated over two thousand amputees over a four year period and found there to be a relentless increase over time in contralateral amputation but ipsilateral procedures were few after six months. In Kihn's study (1972) 25% of the patients were already unilateral amputees and primary amputation here refers to the first major procedure to the second leg. Poor presentation, lack of focus on this aspect and early mortality figures obscure satisfactory analysis. Where reasons are given for further surgery healing failure in vascular disease is the most common cause. Finch et al (1980) noted in addition severe pain, contracture and protrusion of bone. 50% of peripheral vascular patients will lose the contralateral leg if they survive three to five years (Hunter 1976, Ebskov

and Josephsen 1980). What reamputation means in terms of either human resilience or underutilisation of prostheses is unknown.

Fig 3. Short term follow up surgery following major amputation.

(U.K., U.S.A. and Scandinavia).

author	date	descriptions of procedures	percent
Chilvers et al	1971	BK 17% revised 32% reamputated	49%
14 11 11	**	TK 18% revised 50% reamputated	68%
Finch et al	1980	3.5% revised 9.5% reamputated	13%
Hutton & Rothnie	1977	BK 20% debridement 16% to AK	36%
Berardi & Keonin	1978	conversion part foot	100%
Burgess et al	1971	BK 10% revised 7.5% to AK	17.5%
Couch et al	1977	conversion to AK	22%
Fleurant et al	1980	revised and reamputated	10.3%
Kihn et al	1972	17.2% revised 19.1% reamputated	36.3%
Potts et al	1979	conversion part foot and Symes	100%
Ebskov & Josephsen	1980	ipsilateral re-amputation within six months	18.8%

4. The stump

To create good function the stump and prosthesis must work as one unit and rehabilitation depends upon a good stump. Data is sparse but it seems that problematic stumps may outnumber the unproblematic and that many patients still unnecessarily lose the knee joint.

Nichols 1971, noted a failure on the part of surgeons to liaise with prosthetists, hence the prosthetist is frequently presented with a stump unsuitable for current artificial limbs instead of a stump which is the result of co-operation and appropriate to the patient's prosthetic and ultimately re-

habilitation requirements. Brodie 1970, noted that for the vascular surgeon amputation is often considered as a sign of failure and the operation may be assigned to a junior resident without special training. In order to obtain healing at all costs he may perform a mid thigh amputation. Yet Murdoch 1970, stated that selection of the best level and successful surgery depends upon experienced clinical judgement. The survival of the stump is influenced by the surgical technique and it is not credible that inexperienced physicians perform limb amputations in an optimal fashion. Murdoch also noted, 1970, inadequate policies in the amputation of deformed limbs where static ugliness is replaced by a less redeemable and equally unpleasant prosthetic ugliness. In preliminary conversations with para-medical and prosthetic staff poor stump conditions were a constant grievance. The author's experience brings to mind a number of instances of unsuitable stumps: the deformed, painful, chronically sore, bony, too short, too long and too wide.

Three studies indicate something of the severity of this problem. At walking training Goldie 1978, noted that most patients had stump problems and discomfort - 40% sweating problems plus 40% skin problems, while 44% of below knee stumps and 21% of above knee had either troublesome redness or sores. Commenting on surgery and nursing, Stern and Skudder 1977, noted only 31% of patients had optimal conditions of the stump. Problems were those of bulbousness 32%, healing failure 50%, infection 17% and contracture deformity, bony protuberances and post-operative oedema. They added, the two most commonly observed and avoidable problems were depression in association with phantom pain and hip and knee contracture deformity. Hamilton and Nichols 1972, in a study of amputees again in a rehabilitation unit, all ages and causes, noted sixty-nine stump problems in this series of fifty patients which were severe enough to be described as likely to interfere with limb fitting and walking training. These were delayed healing in 28% of cases, flexion con-

tracture 24%, phantom pain 20%, poor stump shape 14%, ischaemic stump pain 12%, oedema 12%, infection 10%, tenderness 8%, stump too short 6%, haematoma 2%, extensive scarring 2%. Lack of research which focuses on this problem makes it impossible to give even the most provisional estimates as to its size, its exact causes and its effects on NHS resources. Collation of figures by ALAC staff would be invaluable here.

On the subject of unnecessarily high amputation with consequent loss of the knee joint, studies have noted 'widespread deficiencies in amputation programmes' (Lippman et al 1972) and a greater variation in the percentage of above knee procedures than demographic factors will allow (Glattly 1964). Hunter 1976 concluded that on the whole amputations were being performed above the knee where below knee surgery was not contra-indicated, though he found firm conclusions were difficult because of the tendency to report only certain levels, to hide instances of wound failure in mortality statistics and failure to differentiate primary and secondary healing. Certainly, available studies show remarkable variation in the above to below knee (Ak:Bk) ratios for roughly comparable groups of patients which suggests that at some centres there is a policy to more readily dispense with the knee joint but where there is a policy to retain the knee, e.g. Burgess et al 1971, this can be successful. Refer Fig. 4.

While it is not possible to condone the needless loss of any part of a limb surgeons must weigh preservation of the knee against the likelihood of further surgery to probably frail and elderly patients. Even arguments for retaining the knee are not decisive. Pedersen 1968, Burgess et al 1971 and Malone et al 1979, saw retention of the knee as the single most important factor in successful rehabilitation of elderly patients. While Finch et al 1980, found only limited evidence to support this view; 56% of below knee amputees being mobile outside their homes and 45% of above knee patients which may be

Fig. 4. Percentage of above knee to below knee amputation (UK and USA)

Author	Date	% AK (to BK)
Chilvers et al	1971	30%
DHSS	1980	59%
Finch et al	1980	32.5%
Harris et al	1974	68.3%
Hutton & Rothnie	1977	40%
Berardi & Keonin	1978	67.5%
Burgess et al	1971	27.5%
Couch et al	1977	50%
Potts et al	1979	50%
Stern & Skudder	1977	32.5%

seen as equal if the probably more advanced disease process of the above knee patient is taken into account.

In conclusion, amputation surgery it seems is insufficiently selective of level. Poorly fashioned stumps testify to its inelegance. The incidence of repeated surgery (nibbling) suggests negative and over cautious attitudes. The picture as a whole indicates this to be a problematic area but also a less than prestigeous one.

5. Mortality and morbidity

Amputation is associated with advanced age and illness, debility and it seems imminent death. Only a minority of elderly vascular patients will survive the three years following major amputation. Many will not survive the immediate post-operative period. (Refer Fig. 5.)

The long term prognosis for vascular and diabetic amputees is not couched in hopeful terms (Weaver and Marshall 1973, Finch et al 1980). Sneppen et al

Fig. 5.	Post-amputation	mortality in	elderly amp	utees (UK)
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author	date	early	3-6 mths	l yr ^l	2 yrs	3 yrs+
Clarke-Williams	1973	-	-	-	. -	66%
Devas	1971	25%	-	40%	53%	-
Finch et al	1980	20%	25%	31%	45%	63%
Green et al	1972	47%			-	70%
Hall & Shucksmith	1971	9%	-	-	-	-
Harris et al	1974	33%	50%	60%	66%	
Hutton & Rothnie	1977	14%	_	19%	-	
Weaver & Marshall	1973	10%	18%	25%	-	75%

1978, found only a third of cancer amputees survived six years. Only the remaining 8% of patients whose amputations are caused by trauma and deformity can hope to have a life expectancy on a par with their contemporaries; even so their lives will be shortened by arthritic and cardiac problems.

Death is one, seemingly all too familiar characteristic of the amputee's estate. Its very high incidence is indicative of the poor general health of the erstwhile survivors. For example, Berardi & Keonin found 261 associated diseases (excluding diabetes) in 97 patients. Hamilton and Nichols 1972, found only 18% of a group of fifty amputees, all ages and causes, to be in

^{1:} These figures for mortality at one year which are taken from recent UK studies compare with a survey of UK, USA and Scandinavian studies by Huston 1980, who found mortality at one year to vary from 23% to 60%. Yet, though mortality is high, in Denmark Ebskov and Josephsen did not find it to be higher than the comparable non-amputee population at six months post-operatively to four years.

a good general condition, the remainder being judged fair to poor. 76% had a history of clinical evidence of respiratory or cardio-vascular disease.

Of the unilateral amputees, 60% had clinical evidence of impaired circulation in the contralateral leg.

Studies from the USA reflect the high risk amputation represents to the elderly (Hunter 1976, Couch et al 1977, Berardi and Keonin 1978, Potts et al 1979, Huston 1980).

Over and above inevitable mortality and morbidity it is possible to detect a worrying trend. Its first aspect is that, what is variously described as post amputation, early or hospital mortality seems too high. In the USA, taking in the results of Malone et al 1979, the range from 0% to 42% early mortality for roughly comparable patients is in itself surprising. In Britain, post-amputation mortality is much higher than that for other surgical procedures in the elderly. Griffiths 1972, recorded an early mortality of 6.4% following elective surgery in those over seventy years which, when separated from deaths resulting from progress of malignant disease, give a figure of 2.5% for elective surgery in the over seventies. Early post-amputation deaths averaging 22.5% (fig. 5) do not compare favourably with this.

A second aspect of this trend is that death seems to be associated with lack of volition. Harris et al 1974, state a 'marked lack of volition' in many post amputation patients, which together with their physical frailty and post-operative pain, their immobility and their inability to co-operate with nurses and therapists resulted in hypostatic pneumonia being the commonest cause of death. Huston 1980, in a survey of British, American and Scandinavian studies also found penumonia to be the commonest cause of death at 28% to 60%, Huston did not find a higher mortality where there was extensive disease but related it instead to general weakness. He concluded dismally that the outlook for amputees is so bleak reconstructive procedures

should be considered even where there is little hope of saving the limb.

The third and last aspect is that isolated studies indicate that the quality of life for these patients could be much improved. The report by Malone et al 1979, which follows the work of Burgess, Romano and others a decade earlier, is worth looking at in some detail. There were no deaths in this series of 133 patients in a thirty day post-operative period and 100% primary heal-The clinical condition of these ing below knee was eventually achieved. patients was not especially favourable. At only 30 days the measure of early mortality is short and later mortality and later surgery is not recorded but this seems to represent a commendable approach to amputation surgery. most remarkable aspect of this study is its commendable approach to rehabilitation. On average these patients were using definitive prostheses at 32 days. So, when a tenth or a quarter of patients in other series are dead, here, all the patients were walking and most had full cosmetic replacement for their missing limbs. There was emphasis on close co-operation with the prosthetist and therapist, accurate determination of level of amputation, advanced surgical technique, immediate prosthetic fitting and an accelerated rehabilitation programme.

It is the author's opinion that Malone et al misjudge to some extent the role of immediate prosthetic fitting. It is glibly described as a boost to the patient's morale. Though it is the most radical attack on the problems of apathy and immobility, it is the author's experience that this is also an extremely harrowing experience for the patient. The plaster and iron prosthesis is a more disturbing spectre than a missing limb and the pain

^{1:} This conclusion is doubtless that of many general practitioners and consultants who pursue hopeless and superficial treatments. There are of course no figures for the numbers of patients spared amputation as a result and who die of their associated illness before amputation becomes necessary.

of weight bearing described by patients as akin to crucifixion. It seems therefore the main advantage of this otherwise gruesome procedure may be the boost it provides the morale of the staff and the friends and relatives of the patient. Usually their best efforts are frustrated by delayed healing, stump and prosthetic problems, repeated surgery and hence cumbersome and limbless subjects who cannot play a proper part in daily activities and whose rehabilitation cannot therefore get underway. Here walking commences immediately and family and friends react accordingly.

To summarise the evidence so far, there appears to be a certain hopelessness in the treatment surrounding amputation which over and above its pathology contributes to its high mortality. There is delayed surgery and poor surgery, a feeling of failure, the pursuit of hopeless procedures, illness and early death. There emerges also a 'lack of volition' as a characteristic of amputation which though it is not easily pinned down is too much in evidence to be overlooked. In previous studies it has been mentioned in many guises but, in favour of harder facts, it has not been pursued. The special contribution of this study is to pursue these less tangible issues. Is 'a certain hopelessness' a feature of staff or patient attitudes or practices?

6. Psychological sequelae of amputation

Parkes has written extensively on this topic (1970, 1972, 1975). He compares the grief which follows loss of a limb with the grief following the death of a spouse. The immediate reaction is one of numbness followed by denial, pain and distress. Reminders of the loss cause severe anxiety and attempts to avoid its memory are without success.

"He loses the limb itself, of course, his body image is disrupted and he is no longer a complete, intact person. He loses the sense of his body boundary being a secure, inviolate defence around himself; he becomes mutilated. He loses all the practical and expressive functions which were formally carried out by means of the limb and since most motor activities

are habitually performed as a whole and using the whole body, there is hardly any activity which the amputee has not got to relearn. For a time it will seem to him that he is completely helpless and many patients imagine, in the early weeks after amputation of a leg, for instance, that they will never walk again. As well as the physical functions which are lost are all the hopes, plans and ambitions which depend upon these functions. In effect the amputee has not lost a limb, he has lost a slice of his world and a large part of his future."

So the amputee, at a time of illness and pain and separated from his familiar and secure environment, lives through a cycle of shock, pain, distress, anxiety, depression and eventually towards some degree of acceptance and adaptation.

Although it is felt that the above description is substantially accurate and shows considerable insight into amputee grief, it is the author's opinion that too uniform an interpretation would be a mistake. Parkes acknowledges that reaction varies and some states pass fleetingly. The author would want to place more emphasis on the variety of reactions to loss of a limb and bring to the fore examples of much less intense sequelae. Parkes' model of amputation is one of a loss that separates two distinct phases in one's life, whereas amputation contains more of the elements of a continuous process. There is most often a gradual decline in health, a gradual move towards amputation, and repeated surgical procedures. The point at which major amputation occurs is not always clear. Amputation is less clearly demarked than it is generally understood to be. Consequently the psychological sequelae are more diverse. Long requested ablation of a deformed or painful limb brings satisfaction even joy. Where the disease process is protracted fairly mild reactions may follow

^{1:} C.M. Parkes and M.M. Napier Psychiatric Sequelae of Amputation Br. Jnl. Hosp. Med. Nov. 1970 pp. 610-614.

an inevitable amputation. This view is borne out by Reinstein 1980, and MacBridge et al 1980. Reinstein did not find shock and denial to be present when amputation resulted from peripheral vascular disease, neither did he find so great an indication of acceptance and adaptation in cancer amputees as in trauma or vascular patients. MacBride found 46% of amputees, interviewed while still undergoing treatment, regarded their amputations as 'a minor upset' or only 'moderately stressful'. Some described the amputation as a relief, as something of a cure to previous pain, illness and incapacity. Only 23% described the immediate post-operative period as one of 'great stress. MacBride related significant pre-amputation illness to prior adjustment. Where anxiety was great it was related to the many practical problems of amputation, such as fear of falling, financial hardship and general ill health, rather than being narrowly concerned with the amputation itself. Shock, grief and depression were not so much products of amputation as of attempts to re-enter the world the patient left while in hospital. this series reported not knowing what to expect beyond the hospital ward. what may be another face of lack of volition, MacBride noted a 'hazy euphoria'.

Parkes and Napier note that reactions in hospital signpost eventual adjustment; already on the ward there are three easily recognised types, the hero, the dependent and the depressive. They realise that it is a fact of being in hospital that imposes these roles yet no allowance is made for a middle-of-the-road, average or orderly reaction between denial of disability on the one hand and anxiety, depression and dependency on the other. Here are clues about the way in which people see amputees and force them into playing roles which are alien or more extreme than their true feelings dictate. Amputation is never allowed to be ordinary. This is a very important issue in rehabilitation terms. Those who are not ordinary are stigmatised and held apart from the mainstream of society. Stigma and rehabilitation operate in inverse proportion. Anything which legitimately develops milder or less exceptional

aspects of amputation must be beneficial. In both the heroic and the dependent and depressive roles we see the consequences of stigma: the hero subject to patronage and inappropriate praise, the dependent/depressive subject to cajolement, ridicule, tyranny and a focus of the many facets of the less-than-fully-adult status ascribed to those with disabilities. Where the patient reacts intensely to loss of a limb in the interests of rehabilitation one would want to eventually play down such a response but, as shown, loss of a limb has more moderate sequelae because it is not generally a condition of sudden, shocking loss and certainly not of irreversible loss. Typical reactions of normal society to the stigmatised are in the first place not helpful to rehabilitation and in the second not generally in accord with the patients true feelings. It would be interesting to find out if heroic or dependent roles are upheld or whether less exceptional reactions are given rein.

7. Neurological sequelae

Post-amputation pain is related to the physiological consequences of dividing the nerves going to or coming from highly innervated parts of the body such as toes and painful consequences are particularly concerned with the posterior tibial nerve fibres in lower limb amputation; injury to these being notoriously liable to develop a painful causalgia type of syndrome. Painful consequences may result from injury to these complex sensory paths at any level of the peripheral neurone. After division of these sensory paths during amputation surgery any activation of them will cause sensations which are referred to the missing limb. Thus after amputation there are not only unpleasant sensations of the stump but also a variety of experiences referred quite distinctly to precise areas of the missing limb. (Russell 1970).

It seems to the author that the pain associated with amputation, whether stump pain, phantom pain or the discomforts of limb wearing, is underestimated. There is a myth curiously developed in the nursing literature that the pain

and discomfort of amputation are not of great prominence or consequence. Physiotherapy literature skirts this topic - Humm 1977 is an exception. Of the many recent papers on amputation few deal with this. A comprehensive picture is not possible. On the one hand the incidence of chronic or severe pain to the stump (DHSS 1980) and phantom limb (Russell 1970, Parkes and Napier 1970, DHSS 1980) is put at around 5% though notoriously difficult to deal with in these few cases. On the other hand the following five studies provide more detail and possibly something nearer the truth of how patients feel on this subject.

The first deals with pain in hospital. Buck and Lee 1976, recorded a case of painful phantom which began ten days post-operatively. The patient's inability to sleep because of his pain and consequent irritability and lack of concentration are of special note, as is the severity of the pain, the variety of the sensations, the distress to the patient and the ineffectiveness of the methods of control. A year after surgery the pain had reduced to a tolerable level and the patient slept with the aid of alcohol or valium. The increase in phantom pain during the post-operative weeks can seem to be a distressing set back to patients who feel that they are making no progress.

During rehabilitative treatments Hamilton and Nichols 1972, found a 20% incidence of phantom pain severe enough to affect limb fitting and walking and in addition 12% severe stump pain.

At follow-up Kolind-Sorensen 1974, noted 20% of lower limb patients to have 'considerable pain', 29% to have 'mild pain' and 51% no pain. Similarly Kegel et al 1977, found a 25% incidence of 'extreme discomfort' and 10% 'moderate discomfort'. 33% of this series expressed dissatisfaction with the

^{1:} This survey of 350 amputees suffers from only a 45% response to the questionnaires.

available prostheses. The employed and active reported less pain.

At long term follow up in a survey of war veteran amputees Chadderton 1978, saw pain as a major characteristic of amputation continually and for years after surgery. (This is supported by Russell 1970, who described types of pain which are continuous or return after many years). Discomfort and pain were expected and accepted by limb wearers. He noted an 'alarming degree' of pain many years after amputation. Most had either back or arthritic pain or gastro-intestinal problems associated with long ingestion of analgesic drugs and the tensions arising from the continuing discomfort of amputation. Universally phantom pain was a problem. Many remedies were used.

Data on the incidence and treatment of pain is given in case history form in chapter eight.

8. The artificial limb

An excellent and substantial work on prosthetic practice is that of Murdoch 1970. Resumes include Brodie 1970, Humm 1977, and Troup and Wood 1982. Limbs may be grouped by site of amputation, i.e. Symes limbs for Symes amputation, below knee limbs for below knee amputation, through knee, above knee, hip disarticulation and hindquarter. Transmetatarsal and part foot amputations require a surgical appliance rather than an artificial leg. Sometimes a deficient limb can be housed inside a prosthesis and no surgery is required. In the interests of saving as much length of leg as possible amputation will be carried out at other than classic sites, e.g. giving a long below-knee stump rather than the preferred, fleshy, seven inch stump for a patella tendon bearing prosthesis, or a long above knee stump rather than the preferred ten to twelve inch stump. The over-riding aim is to restore function and every limb is distinct and individual. Ideally surgeon and prosthetist weigh the relative merits of ablation and replacement. A hospital consultant surgeon performs the amputation. An ALAC medical officer prescribes the limb. The prosthetist

is employed by private industry.

Currently the patella tendon bearing limb, the total bearing above knee limbs and the tilting table limb are seen as 'great advances' (Brodie 1970). Already in this chapter the author has expressed the view that these modern limbs are sufficiently advanced to allow a meaningful degree of rehabilitation (what is meaningful in terms of rehabilitation is discussed in chapter three) but it is the author's experience that due to the inherent shortcomings of artificial limbs the new patient views his first replacement limbs with dismay and only gradually accepts the discomforts and embarrassments that are involved with limb wearing. The two North American studies, Kegel et al 1977, and Chadderton-1978, noted the general dissatisfaction amongst limb wearers on this subject, their wish to be consulted on design and their lack of information on limbs and sports limbs in particular. Whether this is borne out remains to be seen in the study to follow.

No description of artificial limbs can convey anything of what they represent to their owners. Parkes and Napier 1970, noted that the limb serves many functions. It becomes a means of concealing the loss, replacing the lost functions, a means of restoring wholeness, a substitute for the loss of a precious belonging and a recompense for the sacrifice of the limb. Its function involves far more than its potential to increase physical mobility. It should generate personal wholeness and social acceptability. One can speculate that the effects of limblessness or of an ugly or ill fitting limb will be very great indeed.

In this chapter the conditions surrounding amputation are under examination for the purpose of getting to know the subject, the patient, for the purpose

^{1:} The word owner is used in the loosest sense. There is perhaps no more depersonalising aspect of the amputee's estate than the fact that the owner of the limb remains the DHSS.

of judging the likely state of rehabilitation and in order to formulate the most effective questions. Limb wearing is seen as an essential element in the rehabilitation of those who have lost limbs. What we require to know here is how many patients have limbs and to what use are they put?

An unknown number of amputees never receive artificial limbs because they are not referred for fitting. DHSS figures commence only after this referral has been made. Such studies which do mention this topic do not always differentiate failure to refer patients from failure to prescribe or fit a limb after referral and tend to remove numbers of unsuccessful patients before a total is given for those not referred or not fitted. For example totals of 10%, 23% and 9.5% are given for those not fitted (Weaver and Marshall 1973, Finch et al 1980, Fleurant and Alexander 1980), which may be as high as 55%, 70% and 20% respectively when one brings in the original totals of patients in these series. The results of more explicit studies are given in Fig. 6.

Fig. 6. Amputees not considered suitable candidates for prosthetic fitting (USA and Scandinavia).

author	date	subject	not fitted	reason
Berardi & Keonin	1978	elderly vas- cular	66%	disease, lack of motivation
Couch et al	1977	all ages and causes	46%	debility, dementia, pain
Malone et al	1979	Bk all ages	7%	not previously ambulant
Sneppen et al	1978	hemipelvec- tomy cancer	27%	progress of disease

Death and advanced disease are given as the overriding causes of failure to refer patients for prosthetic fitting. It is not generally possible to see

this in terms of rehabilitation failure. When the removal of a foul or toxaemic limb becomes part of the care of the dying patient this becomes outside the province of rehabilitation. Equally, where the degree of injury or loss invalidates limb fitting in favour of wheelchair mobility again this is outside the scope of rehabilitation proper. This is discussed in chapter three. the most part those with gross handicap participate in society on different terms and the notion of their success or failure must be measured differently. However if there were failure to refer patients who could make use of limbs this would represent real failure in rehabilitation terms. If this occurs in this country then the rate at which it occurs is unknown. Experience of the very poor health of some of those who are referred and fitted suggests it is unlikely and there is no general complaint from amputees that limbs are withheld. Yet, in the U.S.A. differences in clinical policy result in limbs being withheld from a great many elderly patients. With reference to Fig. 6, the subjects in the studies by Berardi and Keonin, Couch et al and Malone et al were broadly similar: the elderly, vascular/diabetic patient being by far the majority in all three. Some variation in subject does not account for the 7 to 66% variance in referral for limb fitting. In Malone's series all previously ambulant patients are fitted immediately post-operatively. While Couch et al and Berardi and Keonin, over the weeks and months following amputation, judged half of their patients to be too ill to be fitted. Doubtless, most of these patients were very ill but in one series the patients spend their remaining months with the opportunity to walk whereas the patients in the other series were bed-ridden or in wheelchairs. In conclusion, where a patient is too ill to be considered for fitting of an artificial limb the notion of rehabilitation failure is not applicable but whether or not the patient is too ill is a matter for debate.

In Britain of those referred for limb fitting 21.5% (1121:5202) were not fitted (DHSS 1980). (An unknown number of amputees have already disappeared

from the figures at this stage; perhaps an additional 20% given the figures for early mortality, refer previously). Non-prescription is not properly differentiated from failed prescription but for most of this figure of over 1000 persons limb fitting was commenced but unsuccessful. The reasons for not fitting limbs are not well presented in the DHSS figures which cite 'not required' and 'other' in 25% of cases. 50% of those not fitted died before artificial limbs could be made ready. 'Organic lesions' and 'locomotor' accounted for the remaining 25%. Again death and debility feature prominently and for these patients protracted fitting schedules mean that the patients remaining days are spent without limbs.

Around 60% of patients remain who lost limbs and are fitted with artificial ones. A general conclusion is that 'a high proportion of these patients never use their limbs in an optimal fashion and a considerable proportion do not use their limbs at all' (Nichols 1971). What sort of figure or comment have other authors put on the 'high proportion' of underuse and the 'considerable proportion' of non-use?

Studies which give information are rarely explicit and not generally comparable but a resume of such studies is given in Fig. 7. From this what is variously described as full satisfactory good or successful use of a prosthesis is around 50%, with under use 25% and non-use 25%. However these totals are seen as only the most general guide because of the limitations of the material available.

It is the author's impression from Fig. 7 that good use of prostheses is lower than 50%. Where good use is high (DHSS) it is a measure of early success or only the successful survivors (Roon et al) but this is not borne out in follow up studies (Van de Ven, Weaver and Marshall, Welch and Helsby, Kolind-Sorensen, Hunter and Holliday) where lower figures point to a decline in use, supporting the general conclusion that limb use decreases over time (Green et

Fig. 7. Some studies which have indicated lower limb amputee use of prostheses.

author	date	subject	good use	under-use	non-use	comments by authors
DHSS	1980	outcome limb training 0-59 years	88.5%	11.5%		
DHSS	1980	outcome limb training 60 years plus	73%	27%	-	
Finch et al	1980	elderly. supplied with prostheses	55%	27.5%	17.5%	95% of survivors, successfully integrated back into community
Harris et al	1974	elderly		68%	32%	using limbs to some extent wearing rather than walking
Van de Ven	1973	elderly bilateral with prostheses	48%	36%	16%	one patient was exceptionally independent
Van de Ven	1981	elderly bilateral. with and without	29%	7%	64%	mobility severely restricted. many patients stayed at home
Weaver & Marshall	1973	elderly with prosthesis	53%	17%	30%	pt. in geriatric accommodation not encouraged to use prostheses
Welch & Helsby	1973	elderly. home follow-up	2%	not	given	98:100, limb was never used to full extent or even correctly
Kolind-Sorensen (Scandinavia)	1974	all ages and causes Ak and Bk	49%	15.5%	35•5%	
Sneppen et al	1978	hemipelvectomy with prostheses	50%	- 1	50%	reject prosthesis due to poor fit, poor health, too heavy
Couch et al (USA)	1977	all ages and causes with prostheses	63%	not	given	satisfactory rehab frequently enough to justify optimism
Hunter & Holliday (Canada)	1978	bilateral with prostheses	49%	17%	34%	unilt. to bilat., grounds for some optimism
Roon et al (USA)	1977	unilateral Bk all ages	100%	-	-	follow up of 44% survivors - 91% using prosthesis
Stern & Skudder (USA)	1977	all ages and causes with prostheses	13.5%	73%	12.5%	a fair representation of nationwide statistics

C

al 1972, Kihn et al 1972, Goldie 1978, Sneppen et al 1978, Haworth and Hollings 1979). Also where good use is high the criteria of success are not high (Finch et al) and where the criteria are more strict and explicit good use is notably lower (Stern and Skudder).

As a general conclusion it seems that less than 60% of those who have legs amputated progress to a point of receiving limbs and less than 50% of those who receive limbs make good use of them, the incidence declining over time. Broadly speaking we have returned to the conclusion of Schultz 1950 that a half of those fitted did not use their prostheses to great extent.

It is easy to equate poor use of prostheses with poor and deteriorating health, advancing age and bilateral amputation but in fact the relationship is not known. Many authors point to death, debility, dementia, age and site of amputation. Some begin to suggest other causes. Van de Ven 1973 and 1981, commented on the patients lack of information and how domestic and architectural barriers defeat prosthetic use. Weaver and Marshall 1973, commented on the lack of encouragement by the staff of geriatric accommodation. With rehabilitation so heavily dependent upon patients making good use of artificial limbs the study of how patient and limb are united and the ways in which good use is encouraged or discouraged in walking training seems particularly important and should be done in such a way as to allow, if they exist, new variables to emerge in the relationship between patients and their use of limbs.

9. Rehabilitation

It is very difficult to abstract from the literature any information that is strictly relevant to amputee rehabilitation, its success or failure. Not only are there very many less papers on this topic, under the oft quoted heading 'rehabilitation' few give any truly rehabilitative facts. The outcome of surgery and prosthetic replacement tends to be measured in terms of mobility rather than domestic, social and economic gains, e.g. Adler et al, 1977, Gryfe

1979. As will be discussed fully in chapter three, this is not a measure of rehabilitation but the outcome of a particular phase of treatment en route to rehabilitation. Lack of research by outsiders causes the material to be patchy and difficult to interpret.

Results of a number of British studies which include some information on amputee rehabilitation are given in Fig. 8.

From Fig. 8 it is difficult to draw any overall conclusion. In the broadest terms it may be said that they show the majority of amputees to have personal and domestic restrictions/problems, they under-utilise the health and social services available to them, many have limited mobility out of doors and economic activity is reduced. It is unclear whether these conditions are directly attributable to amputation itself or an accompanying decline in general health or to other causes which have not been suggested or investigated.

There are additional studies which list activities in which amputees felt they could no longer take part (Kegel et al 1978) and in which the rehabilitation of amputees compares unfavourably to that of the most severely ill, e.g. those with cancer, spinal injury, cerebrovascular accident and so forth (Forer et al 1980). Amputees were found to move into the most restricting environments and to be the least socially active. Other studies give examples of successful and active patients (Smith 1970, Caine 1977, Greenspun 1977) and note the majority of amputees did not consider themselves to be handicapped and led what they described as normal lives (Kegel et al 1977). DHSS figures suggest limb fitting increases the activity of the previously inactive, decreases the activity of the very active and on the whole activity continues at a moderate pitch (DHSS 1980).

Conversations with therapists commonly reveal the idea that rehabilitation success or failure depends for the main part on motivation. This is expressed in terms of 'some patients have it, some do not': 'it' being something of the

Fig. 8. Amputee Rehabilitation (UK)

			·	
author	date	personal & domestic	community & social	economic
Chamberlain et al (general study)	1978	houses unmodified. aids safe but delivered late. 18% not using bath	· •	-
Chilvers & Browse (vascular. successful unilateral)	1971	40% hospitalisation prolonged reaccommodation. 55% could not return home	•	-
DHSS (all ages)	1980	outcome a. previously inactive of limb b. previously moderate fitting c. previously very active.	- 41% inactive, 65% moderate, 39 - 19% inactive, 72% moderate, 99 ve- 5% inactive, 52% moderate, 4	% very active
Finch et al (elderly)	1980	of survivors 95% returned to community: home, relatives, long stay care, lodgings	50% confined to home 29% limited outdoor mobility 21% fully mobile	26% previously employed reduced to 7% after amputation
Harris et al (elderly)	1974	of survivors 84% return to own home	limited outdoor mobility one patient had contact with social worker	· -
Thompson (all ages)	1977	59% emotional problems	41% no knowledge of services 36% no social work contact	19% practical and financial problems
Van de Ven (bilateral)	1973	40% could not reach bathroom/ toilet. many personal and domestic restrictions	48% unable to reach public highway. lack of services	-
Van de Ven (bilateral)	1981	75% bathing difficulties domestic and personal restrictions. 25% sheltered accommodation	one pt. using public transport unaided. 14% unaided on stairs and 11% on pavements	25% working: part time, full time or housework
Weaver & Marshall (elderly)	1973	30% unsuitable accommodation	-	77% of those previously working continued to do so
Welch & Helsby (elderly)	1973	home conditions 'poor to appalling' 92% had no aids	hardship and neglect. lack of services	-

nature of an indefinable ebullience. It is little wonder that the state of amputee rehabilitation is summed up in this way for all that can be firmly stated from its research reports is that some patients succeed and some fail; the reasons for which are unproven or unknown. More serious than the lack of answers is the lack of questions.

If this sketchy and confused picture is to be filled out and clarified then three moves are necessary. There must firstly be a clear and accurate definition of rehabilitation. Without this, the business of assessing rehabilitation leads to confusion. Chapter three deals with this requirement. In order for there to be a sufficient body of knowledge there must, secondly, be more research. In time, the move towards degree studies in the paramedical professions may contribute here. Thirdly, there must be a shift from the unhelpful and infertile 'before and after' comparisons in favour of treatment towards and assessment of amputee capabilities as such.

To enlarge upon the third point. No fit man would be made more fit by exchanging his natural limbs for artificial ones. Viewed in this light one must always conclude that there will be a deterioration of some sort or another after amputation and prosthetic replacement. On the other hand, an artificial limb is always preferable to the diseased, damaged, deformed limb or the certainty of death which it replaces. Here, it must always be concluded there will be an improvement of some sort or another following amputation and prosthetic replacement. Studies which compare states before and after amputation reveal little that was not a foregone conclusion and the reader is left to unravel the results in terms of the relative health of the patient and the relative damage to the limb. Deterioration measures illness and improvement measures prosthetic compensation of limblessness. What is required instead is a clear definition of rehabilitation, treatment towards this state, followed by research on whether or not amputees succeed or fail against this measure

and not against previous states of either health or incapacity. Otherwise, for example, we learn how many previously employed patients are still employed instead of how many patients were at the end of their treatment gainfully or suitably employed. At present it cannot be known whether numbers, e.g. reported to be employed, represent rehabilitation success or failure, appropriate response to the patients needs or not. At the same time emphasis on the previous state distracts attention from the positive aspects of limb replacement. There seems for example no attempt to increase employment amongst those not previously employed. So these before and after comparisons measure very little, they distract from positive gains, they fail in their stated aim to measure rehabilitation and they draw a red herring across the real business of the patients present welfare. In short these random contributions are not on the right track.

This section must be concluded as it began by stating that there is little that can be abstracted from the literature as to the state of amputee rehabilitation, unless it can be concluded that the impoverished state of the literature is indicative of an impoverished state in rehabilitation. It ought to be a cause of alarm that a multi million pound industry, the NHS, catering for these thousands of patients cannot in real terms demonstrate that it is beneficial or effective in improving the patients lot.

There is a need for research to fill this gap. It should be centred on the needs and capabilities of patients and their rehabilitation proper.

Summary

Throughout chapters one and two there seems to be no grounds for optimism or complacency in rehabilitation generally or amputee treatment in particular. The remainder of this study is directed to the most crucial aspects of rehabilitative treatments in order to find out if a degree of failure is generated at this point over and above a failure which may be accounted for in terms of normal distribution.

Chapter Three

Defining Rehabilitation:
A clarification of rehabilitation theory

Introduction

It is necessary to anchor the term rehabilitation and this is the object of this chapter.

This study arose out of the author's uneasiness as to the effectiveness of rehabilitation programmes and of physiotherapy classes in particular. The treatments seemed to bear little fruit by comparison with the generous resources, the efforts of the staff and the co-operation of sufficiently able patients. This suggested misdirection in the treatments themselves. Were there misconceptions in the overall idea of what should occur and what should result? Turning to the literature, its review did indeed reveal a confused, contradictory and incomplete understanding of rehabilitation and suggested that this had an adverse effect on services. On the specific topic of lower limb amputation, lack of clear objectives suggested that treatments were not effective but lack of precise and sufficient agreement on what it is that rehabilitation should comprise resulted in the outcome being unknown. The issues raised in chapters one and two highlight the need to examine the various forms and manifestations that the concept of rehabilitation takes.

1. Definitions

The Shorter Oxford Dictionary defines the word 'rehabilitate' as a verb meaning to restore or to set up again in proper condition. The word 'rehabilitation' is a noun and has two meanings. It is both the act of and the state of being restored or set up in proper condition. So the word can refer to either the process of restoring or the end product, the restoration.

From the Latin, the literal meaning of rehabilitation is recapacity for action. Alternately one could say re-furnish in working order or re-qualify for office. At its most simple it means re-able to act.

In common usage the word rehabilitation is a portmanteau term having many shades of meaning and applicable to many things. Roget's Thesaurus lists

many words centre around two main ideas. These are a) restoration and b) adjustment. The need for rehabilitation presupposes an interruption in the previous state of things and this is followed by either restoration to the previous state or adjustment to an alternative state. In medicine, restoration involves such notions as cure, recovery and healing. Adjustment involves amelioration and resettlement.

Although rehabilitation has many shades of meaning, it is specific on one point. It is specific as to its object. It does not mean merely to restore or to set up or to recapacitise. Inherent in its meaning is the reassumption of proper condition, of being fit to take office again. Where such a term as revitalisation is non-specific on the condition to which it revives, rehabilitation is revival to a former or a proper condition.

The historical relationship with residual disability (refer chapter one) is not supported etymologically. From the literal meaning can be derived the idea of re-enabling the disabled. This interpretation will be shown to have a number of shortcomings, not least, its inaccurate slide from 'dis-ability' to 'the disabled'. Otherwise, the acute and chronic, curable and incurable aspects do not feature prominently in the definition which encompasses many forms of restoring and adjusting. As words have no intrinsic meaning the most common uses of the term rehabilitation may be said to be the correct ones but, as will be shown, there are shortcomings in the common uses which can be removed by establishing the strict or more correct definition. This will be justified by being shown to have direct benefits for the process of rehabilitation and its subjects.

At this point, as represented both here and in the medical literature, rehabilitation is an extremely broad concept. It has been noted to be as broad as the term medicine (Nichols 1977) and integral with all parts of medicine (Nichols 1979). With the exception of terminal care and the critical phases of illness it has had some application in almost every context of the health and social welfare services. Rehabilitation has boundaries however and these are the special subject of this chapter. To the author it seems that the post-war years have ever widened the boundaries of rehabilitation and what specifically has been neglected is not so much a definition of what rehabilitation is but delineation of what it is not.

Rehabilitation is a moral obligation to the less than able in our society.

Its ideology is a blend of liberation and paternalism. Throughout the work of the fathers of the modern movement and continuing in the many recent works this branch of medicine is seen to develop in recognition of and response to the unequal status, the misery, poverty and inactivity of those with handicaps. It is a move towards establishing their inalienable rights and has many modern parallels for example in the moves towards universal education and universal suffrage and racial and sexual liberation. One may see in it less altruistic motives such as the cost effectiveness of having a working rather than a housebound and dependent handicapped population. One may see in it also the Western shift from collectivism to individualism, the shift from the extended to the nuclear family, for liberation of the handicapped liberates both the handicapped individual and their minders. It is also an extension of bureaucratic democracy and of state power and control. Whatever the impetus, the

^{1.} One thinks in this context notably of works by Krusen, but also of contributions by Rusk, Grant, Buchwald and Kessler referred to in Chapter One.

^{2.} These include in Britain, government reports, e.g. Tunbridge & Mair, the work of Mattingly & Nichols. This topic is expressly dealt with in Wright 1980.

^{3.} In this study the model is of physical handicap but, as evinced by the scope of the contributions to the International Journal of Rehabilitation Research, medical rehabilitation has encompassed physical and mental handicaps of all types and many forms of cultural deprivations and human weaknesses.

ideology of modern Western medical rehabilitation is a commitment to people.

It is first and foremost a social and moral commitment from which other obligations arise. It is not, to take examples from other disciplines and endeavours, primarily a scientific or artistic pursuit.

It is the author's impression, from the literature of physical handicap and rehabilitation that this social or human aspect has become obscured or confused. For despite its humanitarian stance it fails to do justice to its human subjects. It centres instead on the clinical, physiological and bureaucratic and employs a language based only in a clumsy interpretation of the literal 're-enable the disabled'. If it is at all clear what is intended by 'rehabilitation' then it must be deduced that it pursues a course which is full of contradictions.

In this chapter the language of rehabilitation is the focus for attention. In the following chapters the course pursued by rehabilitation becomes the focus. What will be argued in fixing the boundaries of modern rehabilitation is that its thinking and language are a muddle. What will be shown in the remainder of this study is that these logical and semantic considerations have an important bearing on the course subsequently taken by rehabilitation practice, which will be shown to be similarly muddled. Investigation and clarification of both is seen to be in the patients best interests.

2. The First Boundary: Clinical Care

Though rarely explicit, the first boundary to rehabilitation is apparent to some degree in the literature. Rehabilitation is not clinical treatment or clinical recovery and it is distinct from the critical phases of illness.

Defined - as it is almost exclusively - as the restoration of those with residual disability this would seem, of logical necessity, to exclude the critical phases of illness: residual being that which remains after the initial phase. Yet in employing this definition it is variously noted in the liter-

ature that clinical care should be given throughout with a view to the patient's eventual rehabilitation: rehabilitation being the whole process of restoring disabled persons to normal life (Nichols 1976). This would make it much more than clinical care rather than other than clinical care. Though the brevity of many definitions and their imprecise use of key terms makes it difficult to conclude with certainty where the authors have placed the boundaries or if such boundaries were intended at all, e.g. Tunbridge 1972, Mair 1972.

The present author wishes to distinguish, quite clearly, clinical care from rehabilitation. There is no intention to dispute that the drive towards rehabilitation should begin 'almost in the ambulance' (Mattingly 1977). On the contrary clinical treatments and rehabilitation are being set apart in order eventually to enhance their relationship. What is intended is that clinical care should be seen to have different components which makes it other than rehabilitation. The difference lies in the object or focus of attention. In short, the focus of clinical care is the physiology of the parts of the man which is in turn bound up in the physiology of the whole man. While the focus of rehabilitation is the man.

Using the example of the damaged leg, clinical treatments may be exemplified as acting upon the limb and being concerned with such activities as surgery and suture, reducing infection, oedema and deformity, and stabilising the reactions of the body as a whole. The limb merely healed, though living, may be exemplified as inert. Rehabilitation, on the other hand, has already been shown to have two identifying characteristics which take it into a different sphere of operations. First, it is a directly social concept, having humanitarian motives and human subjects. The human subjects are both participants in society and the product of social interaction - of which more will be said. Second, it has been defined as restoration to proper condition. It follows from these two characteristics that repair of the limb is excluded.

On the first count, the physiological and task orientation of clinical treatments does not have directly but only obliquely social goals. Regard for the limb involves different operations and orientation from regard for the person's daily living. Neither are the two necessarily compatible. On the second count, the limb repaired is not restored to proper condition. The proper condition of the limb only comes about in relation to performance and is totally bound up with its use to the man. Only in certain branches of pure science and art can the limb alone or the limb inert be in a perfect or finite condition. Similarly, the deaf man is not rehabilitated when the parts of the ear are repaired and the hearing is restored. Rehabilitation comes with the ability to assemble the sounds into such things as language.

Clinical treatments are inextricable with rehabilitation; either as the means to the end, the parts of the whole or through their interrelation in daily practice. They do however have a different focus, a different theoretical basis. By distinguishing them in this way their relationship is enhanced where the practitioner is made more aware of the level at which he assists the patient. At present there exists a situation where the institutions geared to providing clinical treatments in many respects operate against the rehabilitation of the man (refer chapter one), or where, for example, a clinically perfect stump may be produced which is unsuitable for prosthetic fitting and human locomotion (refer chapter two). The rehabilitationists have, over the past three decades, made many appeals to unite clinical and rehabilitative treatments but this is in vain until it is appreciated what it is that divides these issues.

3. The Second Boundary: Physical Therapy

From this point major misconceptions in the definition of rehabilitation dictate its course. Though clinical treatments are recognised to a lesser or greater degree to be of a different type, the physical and mental aspects of restoration are interwoven with the domestic, social and economic aspects.

Where this occurs it is a mistake. Typical definitions, for example Krusen,

define rehabilitation thus:

"Rehabilitation has been defined as the restoration of the handicapped individual, physically, mentally, socially, and vocationally to the fullest extent. . ."

The Mair Report defines it thus:

"Rehabilitation implies the restoration of patients to their fullest physical, mental and social capability."²

The implication is that each of these aspects are of equal status; that they are comparable parts which make up the whole. This is not the case. Physical (and mental) restoration is not rehabilitation. This is the second boundary.

The term physical rehabilitation is used by rehabilitationists to mean 'restoration of physical function' (comparable with restoration of economic function, domestic function and so on). It is used in such a way as to refer to either the limb or the man. Hence, physical rehabilitation is the restoration of the physical function of the limb or restoration of the physical abilities of the man. In both forms, illogicalities arise.

The idea of physical rehabilitation of limbs is a curious one though sometimes the context in which it appears allows no other clear meaning to emerge. For long periods the man, as it were, disappears from the argument. So, the idea is not so much intended as inevitable and unavoidable within the present rehabilitation framework where the thinking is grouped around cases, diseases,

^{1.} F.H. Krusen Concepts in the Rehabilitation of the Handicapped W.B. Saunders Co. 1964 Philadelphia, p.8.

^{2. (}The Mair Report) Medical Rehabilitation: A Pattern for the Future HMSO 1972 Edinburgh preface p.5 para. 3.

^{3.} The term has two other meanings both of which are incorrect and not formally intended. Colloquially one may hear the phrase physical rehabilitation used as a short form of 'the rehabilitation of those with physical handicap'. It is also used to refer to physical treatments such as heat and exercises when the terms physical medicine and physical therapy are intended and should be

treatments and so forth rather than the needs of the patient and his rehabilitation proper. To rehabilitate a limb must be taken to mean the literal 'to re-enable the limb to act' or to restore the limb in proper condition. Yet rehabilitation is a social commitment, - a social concept expounded from a socially conscious doctrine - and limbs do not live in society. Even if limbs were recapacitised for activity they would not act alone. It is not possible to get away from the commitment to the person either because of the stance taken by modern medical rehabilitation or the necessity de facto of limbs having owners. Wherever the term rehabilitation refers to the physiology of the parts rather than the man as a whole it is mistaken on two counts. Firstly, because it breaks faith with its own philosophy. Secondly because of the difficulties in medicine of knowing what is meant by the proper physical function of a limb alone. The parts of the body are the province of physical treatments and not physical rehabilitation.

It is more generally intended (e.g. Krusen, Mair, refer above) that the idea of physical rehabilitation refers to the man. It is the restoration of a man to a proper physical condition. Underlying this is the common model of man as an amalgum of body mind and spirit for the restoration of physical aspects are seen to be on a par with the restoration of mental and social functions. On examination, this initially comprehensive interpretation is seen to be a sham. For just as the parts of the body are not the province of rehabilitation, so too the parts of the man are not its province either. In short, this is because it is not within the nature of physical rehabilitation to be truly concerned with the man. These two entities are ultimately mutually exclusive.

This is best shown by example. Supposing a man newly learning to walk with an artificial leg was able to climb nine steps and walk one quarter of a mile. These criteria, borrowed from Garrad 1974, are representative of those used by

rehabilitationists to judge physical ability and are in turn representative of the activities taught by physiotherapists. A pause for thought reveals that the ability to climb nine steps is without significance to the man. Being approximately two-thirds of the distance of an average flight of stairs, two thirds of the distance between floors, it comes as a novelty to our ordinary understanding of our abilities. Whereas, men are concerned, for example, to climb one step onto a bus or to ascend a full flight of stairs to a bathroom or bedroom. Without these social dimensions physical capabilities are peculiarly abstract and have no immediate meaning to the man. The nine steps example represents an obvious and extreme case of the difference between physical and rehabilitative activities for it is quickly seen that is is nonsensical to the restoration of a man to proper condition for him to acquire the ability not to reach the upper floor. Less obviously, the ability to walk one quarter of a mile is similarly abstract until given social applications. People do not know and are not concerned with the sheer distance they may or may not be able to walk unless we return again to areas of pure science and art. People know instead their ability to walk around home and garden, to the club, pub or shop, to the homes of friends or to their place of work. Integral with this they are concerned with such activities as standing in a bus queue, stepping over rough ground and walking carrying parcels. The sick man is aware as he regains his strength that he can walk one step or two or half the distance of the ward and so forth and receives physiotherapy to encourage the development of these skills. But it involves treating him as less-thanfully-human to label these early physical treatments as rehabilitation. They are qualitatively different. On their own they are without the domestic, recreational or vocational applications that matter to the man. been labelled rehabilitation because they are a forerunner or a means to that end but physical treatments in hospital settings do not in themselves comprise the social ingredients which would make them the province of rehabilitation proper.

As can be seen, the idea of physical rehabilitation is not able to hold together. The words 'physical', 'rehabilitation' and 'man' are in strange juxtaposition. Either the idea of physical rehabilitation rests upon criteria which are without significance to the man which results in the uncomfortable conclusion that there exists an aspect of medical rehabilitation not centrally concerned with its human subject. Or, bringing the man back into the picture, the notion of physical rehabilitation disappears. On the one hand is the legitimate area of physical treatment but this cannot be transposed into physical rehabilitation without adding social elements which effectively convert it into something other than physical rehabilitation - for the time being this may be termed social rehabilitation.

To return to the definitions with which the chapter opened. Rehabilitation was established as 'restoration to proper condition'. In medicine the restoration in question is that of a person: the person is the raison d'etre of medicine. The idea of restoring parts of people or only certain aspects of people as an end in itself would take medicine quite outside our understanding of its purpose and into the realms of abstract expressionism, pure science or perhaps sport. Only in these areas of human endeavour can the properties of the parts of a man be developed as ends in themselves. So medical rehabilitation is 'restoration of a man to proper condition'. And the proper condition of man is social. Although a great deal of work remains to be done to unravel the nature of man, there is no reason to deny his essential sociality. Men live in societies and their higher functions, those which distinguish them as human, are created and maintained by society. Such works as that of Durkheim 1912 and G.H. Mead 1934 remain classics in this area. Of the very many more recent exponents of the various manifestations of this idea, the work of Goffman (1959) and Berger (1963, Berger and Luckmann 1967) have been looked to in this study. So rehabilitation in medicine becomes the restoration of the man to a proper condition, which is social.

It was noted that rehabilitation was both the process or the state of restoration. The physical and physiological have been eliminated because of their lack of social components but, it may be argued, they represent the process of restoration. This not the case however. This argument eventually leads back to the situation where the man is eliminated from the process of restoring. Whereas both the process and the state of restoration must carry social components. The physical and physiological are legitimate areas of medical care and physical treatment but they are not, on their own, aspects of rehabilitation proper.

Some points of qualification may be found helpful. Such measures as nine steps and one quarter of a mile are used by professional workers in this field because they are convenient and from them a therapist or doctor can, with experience, judge a great deal. But mere convenience will not make them meaningful. It is the author's contention that the convenient use of such criteria has masked the error that has equated them with rehabilitation, though this will be developed in much greater detail as the subject of the investigations to follow. Here it will be shown that not only have these measurements of ability a tendency to disregard their human subjects, so too have the physical treatments themselves. It is also of interest that these physical criteria which are without significance to people generally should be seen as meaningful or useful as measures of the abilities of the disabled or handicapped population. It suggests that lower standards are acceptable in the rehabilitation of 'the disabled' than are acceptable to the non-disabled.

It may seem too fastidious an exercise to split physical therapy from rehabilitation as, in practice, the two will go hand in hand. Yet it is important that they are seen to be different. The reason for this is to develop the thinking behind each and in turn to develop a proper regard for the human subject. Not least, this will prevent the costly and tedious repetition of therapy

exercises which may prove to be worthless, and prevent the premature discharge of seemingly able and mobile patients who are left unable to cope at home.

Again, it is by setting apart the various aspects of treatment that their relationship can in time be enhanced to the greater benefit of the patient. Physical therapy must have directly social applications before it becomes rehabilitation.

In the literature it is not unusual, under a general heading of rehabilitation, to find it to fail at the crucial point, dealing with physical treatments at some length while personal, domestic, vocational and recreational applications are rapidly passed over. (In respect of this on the subject of amputation refer Nichols 1976, Mattingly 1977, Goldenson 1978). A further general impression from the literature is, that despite commendable sentiment, only lip service is paid to the patient as the key member of the rehabilitation team. The orientation is that of the staff world and there is no careful and considered attempt to identify with the needs of the patients. There is, for example, no parallel in physiotherapy of the patient centred approach to care that the nursing process seeks to innovate. The situation this gives rise to may be illustrated from Humm 1977, Rehabilitation of the Lower Limb Amputee. The themes of this work are clinical treatments, e.g. stump bandaging, prosthetics, e.g. sites and types, physical therapy, e.g. walking training. Application of the physical skills do not include domestic and recreational trials outside the hospital environment. Vocational applications are noted to be outside the scope of the book. Yet without emphasis on these skills of actual daily living this otherwise excellent manual of physiotherapy is not as its title states - the rehabilitation of people who have lost limbs. focus is stumps and legs and prostheses. Task orientation obscures its author's deep personal commitment. The gap between the skills being taught and their use to the patient in his daily life is not closed. A more correct title

would be Physical Therapy in Lower Limb Amputation.

This study does not deal with mental aspects of rehabilitation but a parallel argument is envisaged. That is, mental therapies are also logically distinct from rehabilitation, though the two may be inseparable in practice, each acting as a spur to the other. T group discussions and psychiatric consultations are not the mainstream of social intercourse, and mental treatments would be required to show direct applications in daily living before becoming the province of rehabilitation proper.

4. Further Definitions:

Rehabilitation Proper

Because of the portmanteau use of the word rehabilitation the author's revised and clarified use of this term has been given a new name. This is rehabilitation proper. This denotes the intrinsically social nature of medical rehabilitation and the boundaries to which this gives rise. So, rehabilitation proper is the restoration of the man to a proper condition, which is a social condition.

The term social rehabilitation might have been chosen but as well as being both clumsy and tautological, like the term functional rehabilitation, already it has other uses in the medical world.

The word social is a very broad one on which to base the key term, rehabilitation proper. What is intended is to re-focus attention on the human subject. Rehabilitation proper may equally have been described as person-orientated or patient-centred. This may, however, allow attention to fix on the individuality of the patient and stray back to physiological and physical aspects of the individual rather than developing towards the sociality of the patient and his eventual return to home, family and job. The word social is being used therefore as a short form for personal, domestic, vocational and recrea-

tional pursuits. Alternatively, one could say rehabilitation proper is a socioeconomic concept.

5. The Third Boundary: Gross Handicap

In a further important sense the modern all-encompassing definition of rehabilitation is over-stretched. Those very aspects of severe residual disability with which historically it has been most strongly associated, are not the province of rehabilitation proper. Gross handicap is the third boundary to rehabilitation.

It was established at the beginning of this chapter that a half of the words commonly associated with rehabilitation refer to adjustment rather than restoration. In medicine too there is recognition of both restoration to a previous lifestyle and adjustment to an alternative, even diminished lifestyle. The strict and literal definitions suggest restoration to the previous working order but, can refer to either the previous state or an alternate state so long as it is a state of working order. For these reasons the author has been careful to define rehabilitation in terms of a proper condition rather than the (previous) proper condition. We may conjecture that severe residual disability, in some circumstances, will not allow a man to return to his previous role in life but this does not place his treatment outside the bounds of rehabilitation for an alternate, even diminished role can be pursued. What will place his treatment outside the bounds of rehabilitation is the pursuit of a role that is not of a proper condition. Frequently, and with

l. Gross handicap is a product of many things, in particular severe disability or deformity, the unyielding physical environment and the reactions of the non-disabled. The phrase severe disability is used on a number of occasions in the following argument, referring as it does to the person's physical differences and dysfunctions, but it is the more severe forms of handicap that are seen as the barrier to rehabilitation, the contributory factors of which are under discussion.

some justification, health and social services for the chronic sick or severely disabled embody such roles. These should not be confused with rehabilitation.

What, exactly, is being excluded?

What is being excluded are those treatments and care through which patients adjust to the diminished daily round of 'disabled' rather than able-bodied living: where care encourages its patients into the company of the similarly disabled and where the accourtements of their disabilities make of them freaks in society. In short, rehabilitation ceases to be so when the personal, domestic, vocational and recreational aims of treatment do not have normal social significance and the patient cannot be set up in any decent approximation of proper condition. The more gross forms of handicap are, almost by definition, excluded from any condition thought proper for a man.

To enlarge on this argument; treatments which lack socio-economic dimensions were shown to be other than rehabilitation. Some services for the grossly handicapped are of this nature and are already understood to be excluded. Some services do have socio-economic aims but, it is argued here, these will not be rehabilitative where they do not sufficiently attempt to approximate normal living. This is because despite the vast and various spread of abilities that are seen as normal, reactions differ in many ways to those who deviate too greatly from these norms. The abnormal are set apart and, by definition, those set apart from society cannot be said to be accepted into society. They are not 'able to act' within society but on the far fringes. Their social and economic gains cannot be measured in real terms. We simply do not believe that it is a proper condition for a man to be grossly disfigured, deformed or disabled. It would be a contradiction of the aims of medicine to argue otherwise. Hence, the person who is bedfast, housebound, institutionalised and dependent, unless he has a special skill which makes the world beat a path to his door, lives on goodwill and the welfare state and

if these are withdrawn, his sham rehabilitation is exposed.

Perhaps the reader doubts the degree of prejudice that sets those with severe disabilities apart in this way. While society acknowledges that such people are still people, they are in fact barred from the deepest and most intimate levels of human intercourse; a point brilliantly argued by Battye 1966. treatment is that towards the less-than-fully adult (Goffman 1963, Scott 1969). They are set apart at best to be car park and lift attendants. Consider the widely accepted reasons for, and the standard practice of aborting deformed These potentially disabled people fare worse than society's murderers whose deviancy is no longer sanctioned by death. Through garrulous praise, low expectations, job discrimination, reduced marriage chances, derision, ostracism and even regular legalised killing, for those with severe physical disability one may find evidence at every level of society of segregation from its main stream. Therefore, when, for example, a therapist teaches a patient to live in the subculture of other disabled people she is not rehabilitating the patient into society but segregating him from society. When the patient is to remain - albeit for sound reasons - limbless, bed-ridden or only wheelchair mobile their treatment is not the approximation of proper condition. It is quite different from the treatment of those who are to have and use replacement (artificial) limbs. The sheltered alternatives and the more gross forms of technological support are a more humane answer than the neglect of former years but are rarely rehabilitative.

Once again the modern movement breaks faith with its own philosophy in including these aspects of care. Yet include them it does for it is the clear intention throughout the post-war literature to encompass all forms of disability in all age groups. This has included, for example, those with multiple handicaps and in wheelchairs (Grant 1963), long term sheltered employment (Bitter 1979), institutional care (Wright 1980), tetraplegia (Goble & Nichols 1971), and the variously crippled, incontinent and bedfast (Goble & Nichols 1971,

Nichols 1971). It thereby includes those who would be without the least degree of freedom and against whom there operates gross forms of discrimination. The intention of the modern movement is to enable personal freedom where there would be none, to break down prejudices, to overcome or remove environmental barriers, to recognise the rights of all people, and to place no-one outside the succour and support of the health and social welfare services. There is acknowledgement that rehabilitation cannot be total (Wright 1980), but any small improvement in the quality of life gives it its justification. The movement does not recognise, however, that the almost limitless activities of this enterprise cannot be subsumed under the single term rehabilitation. Some forms of its care are not rehabilitative. In including them within the sphere of rehabilitation the movement employs classic forms of the prejudices it seeks to break down.

In the first instance a paramount activity of the movement is labelling and segregating: indeed, rehabilitation becomes that which is offered to 'the disabled'. Its clients are classified by physical imperfection. The literature is divided and subdivided by cases and treatments. The human subjects become disabled regardless of abilities; their limbs taking precedence over their needs and interests and their problems looming far larger than their assets and aptitudes. This approach leads to such arguments as expressed by Jachnig 1972, that local government should seek out, count and register all their disabled, as though these people could, by some obvious identifying feature, be singled out from the population as a whole, and as though the disadvantages (the stigma) of official registration counted as nothing against the advantages of official services. Here are the ingredients of the brave new world. Such appeals, if it were not for the cloak of health but applying instead to Jews or Jamaicans, would be repelled as sinister or facist.

On a second count, this approach embodies patronage, undeserving praise and low expectations towards those with disabilities, which, the reader is reminded,

matised in their daily dealings in society (Goffman 1963). This state arises because the modern rehabilitation movement, while intending to be humanitarian, has adopted criteria which are outside normal human relations. The reason for this is tied to its having become the management of residual disability and therefore failing to judge rehabilitative treatments in real terms, i.e. against the requirements of normal or near normal living. The result is that rehabilitation has come to include practices and states which, though proper to clinical medicine, are not held to be valuable or useful by the society in which it is intended that the patient should live. At this point the whole enterprise is in danger of being stripped of meaning. By including the care of those who cannot be set up again in decent approximation of proper condition rehabilitation is debased for all those who can benefit. It is a patronising approach to those with gross handicap, it lowers expectation of those with less serious disability and leads to undue praise at all levels.

Firm guidelines on what constitutes supportive services as opposed to rehabilitative treatments, and on success and failure in each of these, will rarely be possible. The related issues are imprecise and inconstant. Social values are ever changing. What is socially acceptable does not vary in proportion with the severity of disability. Rehabilitation outcome is not static. Disability itself is rarely static. Each of the major themes of this study are bedevilled by their human complexity; nor is it the issue here to unravel these complexities and establish firm measures within rehabilitation. The issue here is the business of defining what rehabilitation is and what it is not. What it is has been defined in socio-economic terms, in terms of setting up in a proper condition. What it is not has been clearly marked by three boundaries to rehabilitation. It now remains to widen its horizons in certain respects.

6. Rehabilitation and Amputation: Wider Horizons

Rehabilitation presupposes an interruption in the previous state and amputation of a limb represents just such an interruption. There is disease and injury and considerable alteration to the body which affects the patient's capabilities, self-image and the image presented to others. This is where the need for rehabilitation arises. This is fully recognised throughout the rehabilitation literature though in chapter two the author suggests that, in view of what is most often gradual loss of the limb and in view of the availability of prosthetic compensation, neither the severity of the loss nor its long term consequences may be as grievous as it is generally understood to be. A shift in the emphasis of rehabilitation practice may subsequently be required.

Additional to this amputee rehabilitation has been qualified in certain respects. It has been shown to require social and economic dimensions before it can properly be called rehabilitation. The importance of prosthetic replacement becomes evident - the need for near normal gait and appearance and near normal activities. This is where the proper rehabilitation of the amputee lies, not in limblessness and gross handicap.

Much less well recognised is a second predisposition to rehabilitation. Amputation of a limb involves a substantial period of incapacity, hospitalisation, convalescence and out-patient attendance, especially where there is repeated surgery and associated illness which has been and will be shown to be the majority of cases. This disruption to routine living creates its own losses and this in itself gives rise to the need for rehabilitation. This is an additional dimension to the concept which has had too little attention. There is implicit recognition of it in the more urgent and positive approaches to surgery and prosthetic fitting discussed in chapter two and evinced by the work of Burgess et al 1968, Devas 1971, Hutton and Rothnie 1977 and Malone et al 1979. Speed of treatment was a pre-eminent consideration of their work. More generally in medicine, evidence of the harmful or debilitating effects of hospitalisation

and treatment schedules has to be inferred from aspects of studies on related issues rather than being directly available. From Menzies 1961, Stockwell 1973, Hayward 1975 and Cleary 1979 are hints of institutional practices operating in the staff world against the patients best interests. This is expressed in more radical form by Zola (1971) and Illich (1977). Much more research is required along the lines of the many studies in education on such topics as the effects of institutionalisation on children and the harmful by-products of schooling. The disruption caused by prolonged out-patient attendance has not been previously researched and is a special consideration in the study. The author judges these - what might be termed - 'institutional' precursers of rehabilitation to have been underestimated. Rehabilitation's close ties with the disease process has caused it to overlook not only the patient but also the hospital environment in which it operates. Yet, independently of the disease process, it may be conjectured with some certainty that incapacity, hospitalisation or repeated out-patient attendance may result in physiological complications such as muscle wastage, contracture deformity, pneumonia, increase or loss of weight, or social and psychological disruptions such as the breakdown of a marriage, sensory deprivation, boredom, depression, anxiety, loss of confidence and autonomy or vocational and economic hardships such as loss of earnings, absence from work or study. The speedy treatments which would reduce these effects are not always conducive to treating the clinical condition. These 'institutional' precursers may be likened to the need to rehabilitate ex-prisioners who have been institutionalised but not ill.

So, rehabilitation following amputation has two distinct predeterminants. The first is loss of a limb. The second is the treatment for loss of a limb. In chapter two the disruptions and losses following limb ablation were examined. The crucial aspects of the treatment given to compensate for these losses will be investigated in the research to follow. Does it respond effectively to the needs of the new amputee? What is the manner in which patient

and limb are united? Over and above this the patterns of treatment and the length or urgency of treatment is also investigated in order to find out if the detrimental effects of loss are dealt with and overcome in rehabilitation practice.

The need for positive attitudes and rapid, intensive treatment is recognised in the treatment of temporary disability or acute illness and certain less disabling conditions. Whereas the accent is on repeated assessment, prevention of morbidity, maintenance and support in cases of severe, chronic, permanent or residual disability (Nichols, 1976, 1977). Its close connections with residual disability would seem to make rehabilitation a ponderous business for it is always in danger of becoming the maintenance and support of the chronic sick and disabled. However, as shown, its links with 'the disabled' are more historical than either necessary or correct. From this there follows consequences for the rehabilitation of those who have lost limbs. Neither rehabilitation nor amputees - as was discussed in chapter two - need to be tied to the old image of chronic sickness and disability. A wider horizon is needed here also. Tied to permanent or residual disability it involves labelling the recipient as disabled which carries stigma. It focuses attention on the impaired limb and limitations of function rather than the patients' needs and the social context of those needs. And it prevents the patient from outgrowing the condition; no matter how able, he is patronisingly depicted as successfully rehabilitated despite disability. Whereas the abilities of amputees vary widely. Appropriate treatment would seem to require the whole gamut of services from those normally associated with acute or temporary illness to those of mild, moderate and severe or chronic conditions. For some amputees, rehabilitation will automatically embody low expectations where the patterns of care are not those of acute or temporary disability. The work of Hutton and Rothnie 1977 and Malone et al 1979 - the former on early fitting and intensive therapy, the latter on immediate fitting of prostheses - goes further. They suggest that

positive, rapid and intensive patterns may be appropriate for most amputees rather than the currently more able few. Hutton and Rothnie's patients were neither young, fit or able having a mean age of 72 years and, in all but one case of melanoma, had peripheral vascular disease.

To sum up, when examined in the light of a specific condition, the concept of rehabilitation has to be broadened in two respects. Additional to the disease process, its need arises from factors more closely related to the setting in which treatment is given. Also, where it remains tied to residual disability, it limits its operations in a way that may have an equally limiting effect on its clients. Whether or not amputee rehabilitation is hallmarked by permanent disability remains to be seen. Research is needed for evidence of positive attitudes and a sense of urgency, of a range of treatment catering for the more able and less able, of confidence in and priority given to full use of a well fitting prosthesis, as well as consideration of appropriate social and economic goals.

7. Rehabilitation and Physiotherapy

Physiotherapy has been singled out for special attention because it is the crux of lower limb amputee treatment (as shown in the following chapter) and because of its crucial role in the rehabilitation of the physically disabled. Yet its province is physical therapy and this would seem to place it outside the scope of a study on rehabilitation proper. But, like clinical treatments, physical therapy is an essential forerunner to rehabilitation, often the only rehabilitative therapy the lower limb patient will receive. In its present form, does physiotherapy sufficiently enhance the patient's rehabilitation or does it in any important sense hinder this process? To put the question another way, are amputees taught the skills of mobility in such a way that they are encouraged - or at the very least not prevented - from generalising these mobility mechanisms towards their social and economic applications?

This question is to be investigated through means described later. The study will incorporate the many issues that have been raised so far. In particular it will look at the minute by minute practice of physiotherapy and provide the means to both establish and analyse its content.

Physiotherapy will be investigated at two levels. In the first, we look to the question of whether it succeeds or fails in its own terms. In respect of lower limb amputation Humm 1977 will be used as the model for walking training procedures. On the second count we will examine the question of whether physiotherapy provides a sufficient basis for the patient in terms of rehabilitation proper.

8. Summary

Rehabilitation was defined as the restoration of the man to a proper condition. The modern approach represents a moral obligation to people who are, temporarily or permanently, less able in our society. Their proper condition was seen in terms of the usual interests and activities of all people in society. In the light of these social considerations, the very broad term rehabilitation was given three boundaries. From it was excluded clinical care, physical treatments and services for those whose disabilities were so great as to exclude them from approximation of a man's proper condition. The term rehabilitation proper was used to denote this new understanding of medical rehabilitation. With the accent on the patient, the need for rehabilitation was seen to arise from hospitalisation and treatment patterns as well as the disease process. It was suggested that the best interests of the patients may be served by breaking the ties with residual disability and promoting patterns of care associated with acute illness. Physiotherapy, which is seen as crucial to the rehabilitation of those with physical disability, will be examined to see if it sufficiently centres on the needs of the patient and sufficiently enhances his rehabilitation into society.

In Conclusion

In this study it is not the intention to establish firm criteria of success or failure in rehabilitation: nor to determine what might be thought a proper condition for a man. What it does aim to do is to show both logically and empirically that some of the thinking on rehabilitation and that some of its practices are conducive to the well being of its human subjects and that some are not. The issues in question are the most basic to the subject. In this chapter important areas of firm ground have been established. Emerging for the first time in rehabilitation is a clear idea of what the subject is and what it is not. Using this, a method is established with which to investigate rehabilitation practice.

CHAPTER FOUR

Development of a method for the study of rehabilitation practice

Introduction

In chapters one and two the literature on rehabilitation gave cause for concern. In particular it did not provide the parameters for further research. So, in chapter three the concept of rehabilitation was examined. It was redefined in terms of a person's being set up again in a proper condition. The aim of this study from this point is to investigate the extent to which rehabilitation practice furthers or interferes with this.

This aim has been presented in a number of ways in the preceding chapters. There is a need to test the poor impression of rehabilitation found in the literature (chapter one), and to investigate whether rehabilitation practice is beneficial or whether there is a degree of failure over and above normal distribution (chapter two) and, more specifically, to investigate physiotherapy practice in order to see if it sufficiently enhances the patient's rehabilitation or hinders this process in any important sense (chapter three). The institutional setting in which rehabilitation takes place was questioned. So too the professional workers view of the amputee patient. Do staff enhance wholeness and usefulness or in any sense compound disability? Do prejudicial attitudes operate to a significant degree within treatment systems (chapter one)? Is a certain hopelessness a characteristic of interaction? Are patient stereotypes reinforced? Are there low expectations and self-fulfilling results (chapter two)? Or is treatment positive and urgent (chapter three)? Other topics were the need to investigate the work of ancilliary and auxilliary staff, to collect data on surgery and pain, to collate case histories, to look at the relationship of patient and limb and the ways in which loss of a limb is compensated by the rehabilitation process.

Examination of the literature revealed little research on these topics. In this chapter the method for collecting data on rehabilitation practice will be developed and discussed.

It was decided to investigate rehabilitation in terms of walking training

of lower limb amputees. What are the reasons for this choice and the characteristics of the setting?

A. The Setting

1. The patient

The reasons for choosing lower limb amputee patients are thus. First, they are clearly in need of rehabilitation. This arises from their hospitalisation, the seriousness of their illness or injury and their having to learn a changed form of mobility. Second, their treatment is segregated which makes its study easier. Third, therapists play a crucial role so this is a means of studying their attitudes and practices. Fourth, amputees can be clearly defined. Either one has a leg amputated and an artificial limb fitted or one has not, and for this there are fairly standard treatment patterns. This avoids the difficulties of basing an introductory study on patients who cannot be so easily set apart in this way. Fifth, the author is familiar with those who have lost limbs and has experience of the staff and inmate world of amputees. Finally, as shown in chapter two, there are economic and humanitarian justifications for placing this neglected area at the centre of this study.

Necessity dictates frequent use of the words patient and amputee. The word patient carried no special weight here except as an opposite to the word staff and is sometimes used, though in a less pejorative sense, in similar vein to Goffman's use of the term inmate (Asylums 1961). The term amputee is an uncomfortable though necessary short form. It denotes anyone who has lost one or both lower limbs and would normally require prosthetic replacement of those limbs. The term establishes the clinical and prosthetic characteristics of these patients but does not, and does not mean to, suggest any other similarities.

It was decided that the amputee population sampled in this study would be <u>all</u> those patients attending walking training at any one centre at the time of data

collection and that they would be taken in alphabetical order of surname. This decision was made as a means of avoiding observer bias in choosing the patient sample. It carried the added bonus of representing the patients actual experience of walking training and the therapists' actual workload. Comparisons with national figures would be made later.

In practice this decision was problematic. Many changes were made by the observer in reaching the final patient sample. We shall see that late arrival and absenteeism were prominent features of amputee walking training. This caused the author to compile with the therapists a list of all those likely to attend sufficiently regularly to become subjects for study and to sample the first to arrive from - alphabetically - the next three names. These changes were made because one must have, in an ethological study, a subject in a given setting to observe. The observer's choice was based solely on attendance factors - ensuring that there would be an observed subject - but this had its effects on the type of patient who became the subject for study and the amount of data collected on each subject. These effects are discussed in chapter five in relation to the actual patient sample.

2. The Walking Training Class

One of the reasons for choosing to study rehabilitation through amputee treatment is because of the existence of the phenomenon 'the walking training school'. These patients are set apart for separate therapy sessions, sometimes in separate buildings used exclusively for amputee training, and this has obvious advantages for data collection. Where people are the subject of study, establishing a setting in which to study their behaviour presents massive methodological problems. These have sometimes been resolved by using laboratory settings which leads to problems of generalisation to the mainstream of human activity in everyday life. Here is a situation which occurs naturally in human rehabilitation which has some of the useful set-apart characteristics

of the experimental situation and so makes observation easier. Walking training classes, while occurring naturally, are separate in the sense that they have a limited and set number of participants and have clear starting and finishing points, between which activities are largely confined to one room. The staff and patients are a small enough group for behaviour to be observed, but a large enough group for the observer to avoid being drawn into the situation. In the ward, many and varied activities take place over twenty four hours but here activities are more narrowly concerned with rehabilitation and with amputees. Non-amputees in this setting are clearly distinguishable and their treatment given by different members of staff. Problems of reliability remain and these will be discussed, but the setting, while still typical of physiotherapy and relevant to the issue being investigated, has lent some practical assistance.

Walking training classes for lower limb amputees have been established in a haphazard manner. Almost on a chance basis amputees may attend separate and autonomous schools or residential rehabilitation units or classes in general hospitals either using facilities with other amputees or having lessons on an individual basis in large gymansiums where other treatments are being carried out with other patients. These may be administered either by the Area Health Authority or the Department of Health and Social Security or by them jointly or be primarily governed by a hospital committee acting for an interested party such as a trades union. Treatment may be given on an in or out-patient basis or in a residential convalescent environment. It may be for five full days per week or as little as one hour per week. The therapist may be a physiotherapist or remedial gymnast. Sometimes occupational therapy liaison is close. Sometimes it is not. The three main stages of treatment - surgery, prosthetic fitting and walking training - are not commonly carried out at the same hospital or centre, indeed three separate authorities and three separate localities may be involved. Early and later walking training may also be given by different therapists who may be from different departments or professions.

Against this varied and changing background decisions had to be made on choice of centres for study. The first was how many centres were needed?

In both the natural and social sciences detailed studies of single events and single institutions have thrown light on the general picture. In this study the work of Hargreaves (1967) and Lacey (1970) has been used as a model. Their studies of single schools have remained relevant in education long after the institutions concerned have ceased to exist. Could a similarly detailed study at a single walking training class be equally valuable and provide equally fertile data?

The answer is, probably not, not least because amputee schools have only one or two therapists and the study would degenerate into a study of personalities. The work of Hargreaves and Lacey on single issues within single schools came at a time of fervent debate and research in a long-established graduate profession. They investigated details of issues already established in an institution already closely recorded. This study did not begin in a similar climate. It sought to establish the feasibility of an idea in an unknown area. Here post-graduate research is exceedingly sparse, no similar rehabilitation research exists, the framework of daily practice is not known and the concept of rehabilitation being used here is new to medicine. With the ground theory still to be established, it is more in keeping with the introductory and general nature of this enquiry that more than two centres are investigated but not so many as will make the study unweildy.

So the decision was made to collect data at five centres - descriptions of which are given in chapter five. One was used for a pilot study. Two were used for data collection. A further two were observed to test the author's analysis and conclusions.

The centres were chosen by the following means. The author at first observed walking training wherever the opportunity arose, gradually structuring these visits to fill specific gaps in the emerging picture. Then the centres were chosen on a representative basis. Centre A was chosen because it was an unexceptional setting in which to formally establish a method. Centres B and C were then chosen to represent the two main forms of walking training, the school attached to an Artificial Limb and Appliance Centre and the class at a general hospital. Centre B was renowned for its work with amputees. Centre C had no special recommendations but amputee walking training was something of a speciality. Centres D and E were chosen specifically with a view to reappraising the results in the most favourable environments, having the most modern facilities and younger patients. The centres represent a broad spectrum of amputee walking training without taking in the unusual or contraversial.

The choice of centre A was particularly important because it was here that the data collection method was developed which, as will be shown, already begins the process of formulating conclusions. It was a walking training class at a general hospital. This choice avoided the possible extremes of specialised or residential schools or individual lessons. Amputee mobility training had recently been given higher priority here - a room set aside and an experienced therapist put in charge who sought to improve inter-professional liaison - and although facilities were somewhat meagre a very positive attitude prevailed. This was important. The method should not be influenced by negative attitudes. Amputees shared staff and facilities with non-amputees which suggests the setting was not atypical of physiotherapy in general but the use of a separate time and room made observation easier. There were both in and out patients, pre-operative, pre-prosthetic and prosthetic.

The global and versatile nature of the method of data collection meant that it could be successfully transferred to other settings. This was checked in brief trials but no problems arose. In part, methodological preprogramming

fixes the observed reality so the success of this transfer is not surprising but the method was capable of responding to individual circumstances.

How might the sample of centres have biased the results? It seemed a reasonable possibility that in rehabilitation practice there were covert behaviour patterns which undermined rehabilitation. In order to weight the evidence towards this view it would be necessary to choose centres where these covert patterns were more intense and avoid centres where they were less so. This would be extremely difficult. Covert patterns by their very nature are not available for the casual observer to appreciate or manipulate. These patterns are only available after one has left the centre and analysed completed records of the breakdown of behaviour. Some obvious incidents of patronage, guardianship, low expectations and so forth are evident at all centres but the distribution of total activity and the minute by minute ratios of staff and patient initiative in minor tasks cannot be judged in advance. In short, the choices of centres were made on known administrative variables while data searched out unknown behavioural variables and the details of private lives. The choices were biased towards superior practice. Gaining access was not problematic so this did not limit the choices.

3. The Walking Training Process

In order to assist the reader and in order to assist differentiation of the themes of walking training and rehabilitation proper, an outline is given here of the walking training process.

The room or rooms comprise of a large, clear, non-slip floor area. The main furniture is parallel bars, a short flight of wooden stairs and wooden slope, an examination couch and chairs arranged around the sides of the room and at the ends of the bars. The chairs are of a safe metal type. Other equipment includes walking aids and wheelchairs, wall mirrors and carpeting. There is usually a small office, a kitchen, toilets and a screened area used when patients

undress. The surrounding corridors, courtyards and garden space are often available for patients to use to extend their walking area. Usually both male and female patients, young and old, attend at the same time. They rarely attend with relatives. The staff include trained and trainee therapists, therapy aides, porters, orderlies and clerical staff. Other personnel may visit, e.g. occupational therapist, social worker, nurse.

Humm (1977) has provided the soundest guide to physical therapy for lower limb amputees. Other useful sources are Davis 1977 and Troup and Wood 1982. The work is described in terms of teaching safe and correct mobility skills and is, briefly, as follows.

1. Pre-operative:

psychological preparation and information giving mental and physical assessment general fitness training use of wheelchair or crutches.

2. Post-operative,

pre-prosthetic:

(as above if not previously given, plus following)
prevent joint contracture
chest therapy, stump bandaging, stump
exercise and general fitness
prepare for discharge from ward.

3. Prosthetic:

- a) educate the amputee in the use of his prosthesis
- b) test for correct fit of prosthesis
- c) basic principles of walking (in parallel bars)
 e.g. standing, transfer weight, first stride,
 even gait, full weight bearing, etc.
- d) walking (out of parallel bars)
- e) functional activities, e.g. sit, stand, walk on uneven surfaces and around obstacles, etc.

f) assessment and referral.

ion bail Precise time schedules are not practicable but Humm recommends a one to five day preparation period before amputation. At ten days post-operatively he envisages physical therapy moving from the ward to the 'amputee unit' and continuing there on an in-patient and later out patient basis until a limb is supplied. It is expected that the patient will be measured for a temporary limb at around four to six weeks post-operatively and that a three month delay here would be exceptional. Humm gives a five day schedule for teaching basic principles of walking. Thereafter both Humm and Davis talk in terms of one or two weeks of treatment on a daily basis - rather than in terms of months for unilateral amputees to learn to walk outside the parallel bars and to master functional activities. Schedules for bilateral amputees are twice as long. Basic principles for bilateral patients follow a two week schedule and a four to six week walking training period follows with functional activities coming after this. In each case therapy recommences when long leg pylons and cosmetic prostheses are delivered. At many centres it was found that walking began on a pneumatic limb (PPAMA) at around ten days post-operatively. This preceded delivery of a temporary limb at around six weeks.

4. The Therapist

The role of the therapist is chosen for study because theirs is the central professional role in rehabilitation. Most hospital and community health workers are involved directly or indirectly with rehabilitation but some predominantly care for the dependent sick while others work towards the patients' rehabilitation and independence. Nurses for example, typify the middle ground. An introductory study of this nature would be difficult to handle if developed around a profession whose central role was not rehabilitation. It is for this reason that the amputee/nurse relationship is not being used as the data basis: though an obvious choice for a second study once trends have been isolated and tenets established. The role of the therapist in amputee treatment is not so

ambivalent. Even where caring and custodial responsibilities encroach, rehabilitation remains their raison d'etre. This makes their work an ideal component of the setting for data collection.

Further, in lower limb amputation, the physical therapist is in every sense at the centre of the patient's rehabilitation efforts (refer fig. 1). Success here will determine the other agencies to which the patient is referred. It is for this reason that the amputee/occupational therapy relationship is not used as the basis for data collection because of its low priority in present treatment patterns, with many lower limb amputees receiving little or no occupational therapy. Again, this is an important area for future research.

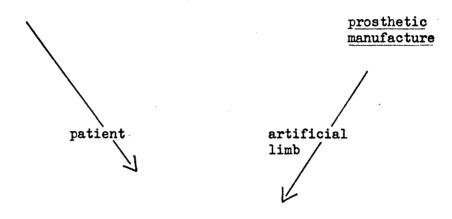
Throughout the rehabilitation literature it is understood that therapists are rehabilitationists. In chapter three however this assumption has been shown to be problematic. In relation to the physical therapist whose role is at the centre of this investigation we saw that there were good grounds for differentiating what was strictly physical therapy from rehabilitation proper. The logical basis for this distinction causes it to be maintained throughout this investigation but this was also done for reasons of equity. Having established a new - and at the time of data collection - undisclosed definition of rehabilitation it is not equitable to judge the therapy professions by this yardstick alone. So the activities of walking training outlined in the previous section are used as a measure of the therapists' work and the state of rehabilitation judged over and above this.

As will be discussed later data collection focused upon the patients. This means that not all the staff activities were observed but those times when a member of staff was involved with a patient were documented in a detailed way. This is a legitimate focus since the patient and his experiences are the raison d'etre of the rehabilitation setting. It also means that non-therapy staff interaction with the patient was included in observation.

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Fig. 1. The Role of Physical Therapy in Relationship to Lower Limb Amputee Rehabilitation.

clinical treatment



physical therapy (walking training)

patient and prosthesis united

occupational therapy social worker DRO community services, benefits, housing, etc. The decision was made to include interaction with all members of staff. This included proportionally larger numbers of ancilliary and auxilliary staff. Being an introductory study in this field, the aim was to record the patients entire experience of attending walking training. There was no literature to indicate which interactions might be the most frequent, intense or significant, so the patients' entire interactions became the sample. Most centres had only one or two qualified therapists and two or three times the number of non-therapy or student staff. Their role is part of the physiotherapy process and an extension of the therapists capabilities. From the patients point of view these staff have authority and affect patients behaviour. There was therefore no logical cut-off point at which other staff could be excluded from the investigations.

5. Gaining Entry

It seemed likely that access would be difficult, the author being an outsider seeking sensitive material. Yet entry was freely granted wherever a request was made. Those approached by the researcher included medical officers, prostheticians and prosthetists, physical and occupational therapists, nurses, social workers, managerial and clerical staff, D.R.O.s, porters, aides, orderlies and ambulance personnel and both patients and relatives. It was possible to get into all the relevant settings, into treatment rooms, offices, wards, homes, porters' store and orderlies' kitchen. Once invited into these settings the degree of open-ness and co-operation varied. On the whole, so many of the staff, the patients and their relatives had grievances and problems or heightened interest or enthusiasm and information was very forthcoming.

6. Summary

The patients require rehabilitation after illness, hospitalisation and limb amputation. Walking training is the crux of their rehabilitative therapy and

to which all patients are referred. The set-apart nature of amputee walking training facilitates its study though the setting is not atypical of other therapy settings. Physical therapists whose work is centrally concerned with rehabilitation are also at the centre of amputee treatment. So the setting is chosen for its all-round appropriateness; a microcosm of rehabilitation practice. Within this, walking training is seen as the means or route to rehabilitation proper.

The aim of data collection was to find out how far the prescribed treatments contribute towards the broad aim of rehabilitation proper: to find out whether this whole issue was worthy of further investigation. The sample was adequate and fair for the purpose of providing evidence about this.

B. The Method of Collecting Data

1. Observation

The author considered various methods of collecting data but most were discarded. In an exploratory study of this kind it seemed best to start by description. One could have described by interviewing staff and patients to gain their opinions. However, as actors in the situation their purpose is not observation and so whilst such data is useful to gain their perceptions it does not on its own give an adequate first description.

The choice of observation for investigation of the practical setting reflects the state of rehabilitation research. Where there is no information other than the experiential or the hearsay there is no other starting point. Lengthy contact with the setting was necessary before it was even possible to formulate

^{1.} Non-referral of an amputee for physical therapy would be unusual, if not poor practice. As such it is outside the scope of this study. Those who are not considered suitable for prosthetic fitting are referred for physiotherapy for general toning and assessment and for wheelchair mobility training.

a means of describing what was observed. Documentary evidence was used where it exists but it was sparse compared to the scope of the issues.

Preliminary observation suggested that the natural patterns of amputee walking training should be observed and recorded in their entirety. In this way the make-up of rehabilitation practice would be empirically determined for the first time. But there is little purpose in such a description on its own and this was not merely to be a descriptive study. Instead description was to be used to test the presence or absence of key issues which are known - namely the elements of rehabilitation theory which were established in the previous chapter together with the elements of walking training described by Humm. Descriptive observation was tailored to meet these latter requirements and the method included specific components to this end. The relationship of the parts of the method to the study as a whole are given in fig. 2. The controls and limitations of the method are given throughout chapters four and five.

During preliminary observation it was found that even within the limited behaviour setting of the walking training school data was so rich that some method had to be used which would allow observation without the observer being overwhelmed whilst retaining much of the richness. An ethological method was chosen as meeting these requirements.

2. Ethological Methods

The exclusive use of description for research has been seen this century as the province of what have been termed the behavioural sciences. The scientific status of these descriptions has varied from study to study, discipline to discipline, not least with the philosophies of social science prevailing at the time. Ethologists have developed observation and description to a very precise level. Their painstaking tabulations of behaviour in natural settings have been carefully steered away from the inferences and assumptions common to much behaviour study technique, e.g. ecological psychology. Hutt and Hutt (1970)

Fig. 2. The Relationship of the Method to the Study as a Whole.

Ch. 1 & 2

rehabilitation theory.
Overt aims.

rehabilitation practice. covert attitudes and practices.



establish the overt and logical aims of rehabilitation theory

Ch. 4 and 5.

develop a method to

- a) empirically determine rehabilitation practice.
- b) test for the overt aims of rehabilitation in the practical setting
- c) observe for elements of walking training (as prescribed in Humm).

data collection

data analysis

Ch. 6, 7 and 8

establish the attitudes and practices of rehabilitation practice and walking training practice.

Ch. 9 and 10

compare and conclude

have provided a useful discussion of the advantages of ethology over other types of description and something of its development over this century. Connolly (1973) has demonstrated its recent use in the direct observation of human subjects in the field of learning psychology. Other references include Grant (1968) on ethological description of behaviour during interviews and Blurton-Jones (1972) on ethological studies of child behaviour.

The ethological approach and much of the detail of its methods are borrowed for use here. This approach both tempers and validates research impressions. It steers the data away from human thoughts desires and opinions. It produces a method which others can use and test and analyse. It yields tabulations directly relating to the issues under investigation since ethology deals with socially meaningful units of behaviour. The results are in a clear and useful form which avoids additional inferences during its analysis. Through the use of an ethogram - an essential element in an ethological study - there will be a framework within which to record the directly observable events of walking training. The method provides a means of recording unmodified behaviour in its natural setting in a process that lays open the process as it is used.

3. Investigative Methods

Data collection had a second observational aim; one not immediately reconcilable with ethology. It was also investigative. That is to say it pokes and pries and adapts to whatever it finds (Douglas 1976), allowing much greater insight into the human facets of the setting. The need for this second approach in what was to be basically an ethological study arose from recognition of the difficulties of transferring a method primarily developed for the study of animal behaviour to the study of the activities and attitudes of people and the problems of bias surrounding the human observer. When man studies man he is always, so to speak, a fellow atom studying other atoms. This carries the advantages of a special inside understanding of the nature of the 'atom' but the disadvantages of insufficient distance from the 'atom' from which to make

detached observations. In this study the investigative aspects of data collection - which take the form of diary and case notes - develop the advantages of additional insight to give a qualitative and more valid form of data. The ethological aspects - in the form of ethograms - gives the data its structure and act as its control. So the qualitative investigative data provides illustrative material while the quantitive ethological data is looked to for its statistical support.

Douglas 1976 has discussed the intrusive nature of the human observer/researcher and the many self-deceptions on the subject of objectivity. While ethological methods carried many advantages, if the observers role was liable to intrude then it must be dealt with openly and developed constructively. So in this and the following chapter we shall examine the observer's role in compiling the ethogram and the observer's role in compiling the investigative data. This latter takes the form of case history and diary notes.

4. Recording the Setting

are discussed later in this chapter.

Recordings were made on recording sheets with the observer openly present in the observed setting. Natural cover did not exist and its introduction would have been disruptive. Research hardware such as film cameras and tape recorders would have been equally out of place and more seriously would have prevented access. Used surreptitiously massive ethical problems would have arisen. Pens and papers on the other hand were ordinary. There was no mystique surrounding a quiet, aimiable, seemingly absent-minded person taking notes. All the participants were informed that the extra person was making notes on their activities and this could be seen by them to be taking place. The openness decreased suspicion and resentment. This gave rise to another sort of ethical problem for this openness and ordinariness was a sham to some extent and lulled the staff and patients into a false sense of ease and co-operation. The ethics of this

5. The Ethograms

In its final form the ethogram was a check list of 28 categories. These categories express in the shortest form all that might occur during walking training sessions. They were developed, as are all ethograms (Hutt and Hutt 1970), through intimate and sustained contact with the research setting. Through a process of analysing and grouping, the continuum of action, the initially infinitely variable behaviour gradually took on certain patterns. Categories were added until no more were possible; later it was seen that some were redundant and a reduction process followed.

The process of developing this ethological framework becomes a process whereby patterns are established and data collected. There are two points here. This process becomes the first stage of data collection. The results are given in chapter six. We must also look at how the categories are determined by the observer for choices were involved over and above the necessity of including all the gross activity.

The behaviour which was recorded was that which could obviously and overtly be said to be taking place. It is a characteristic of ethological methods to record gross activity. For example, the patient walked or stood, the therapist passed a cup or fetched a chair, praised the patient or commanded him to act. Intricacies of eye and hand and body and language have largely to be left for future studies. None the less the method allows for patterns of behaviour. The gross nature of the activities greatly curtailed inference as to what may or may not be said to be taking place.

With reference to fig. 3, despite broad agreement it is the case that a different observer would categorise the events in different ways. Even allowing that each observer understood that the task was to record all behaviour within prescribed boundaries, there can be no definitive or absolute form for an ethogram of any given situation. The present observer believes the 28 categories rep-

ambulance to dept.	coat	dressing	tea	return cup	toilet	ADL (in dept.)
home	neighbourhood	recreation	work	cosmesis	prosthesis	stump
page one						

furniture walking	g aids	sit down	stand up	walking	standing	conversation 2
falling trans	fers	upper body exercise	lower body exercise	stairs ()	walking - uneven surfaces	walking - out of dept.
page two						

resented the most useful form for study of the subject in hand. There were more than 20 versions of the ethogram before it took on its final form. Categorisation was discussed with a second observer and some simplification made at this point but, for example, the other observer would have amalgamated the categories 'tea' and 'return cup' believing it not worthwhile to distinguish providing and clearing away refreshments. But in a study of the attitudes and practices surrounding the development of lower limb amputee capabilities this, to the author, was seen as a most useful distinction, capable of shedding light on important skills. Carrying an empty cup and saucer is to a lower limb patient an important preliminary skill en route to the more difficult task of balancing a full cup and an important point at which a therapist might intervene. Nevertheless the overall pattern was the same and all of the gross activity surrounding 'refreshments' was recorded. The order in which the categories occurred on the ethogram was determined by practicalities.

Whilst in some observational studies it has been found necessary to do time or activity sampling (Hutt and Hutt 1970) it was found possible to do continuous recordings in this study. The global nature of the categories and significant periods of inactivity allowed the observer a number of breaks.

In one important sense the ethogram departed from the spirit of ethology for the categories were also designed for their relevance to rehabilitation proper. That is to say the ethogram is empirical and experimental. Onto a record of all the gross activity found to occur in the research setting is superimposed a search for the (previously determined) purpose that the setting exists for. While none of the traditional elements of an ethogram are lacking, a quite different element is included. This aspect directly affects only four of the categories though it indirectly touches upon the whole of data collection.

^{1:} These are the four categories which refer directly to rehabilitation proper - domestic, social, economic and recreational skills. We need to know what happens when these arise.

The reason is relevance. There being nothing previously established, the method tackles in concise and economic form the questions a) what occurs and b) how does this relate to rehabilitation.

Ethograms have not in the past so obviously included categories that are meant to test a particular hypothesis but this has been done less obviously through the empirical process of developing all ethograms, through the choice of subject and setting and through the influence of one's conceptual models on what one sees in a situation. In this study the ethogram is more blatantly tied to its origins but this does not make it doubly subjective. This additional element reflects the rationally and reasonably determined criteria of rehabilitation layed down in advance of their testing. So the ethogram retains its characteristics of direct and lengthy observation and the impartiality of clipping of behaviour into its constituent parts to which goals and end points are not ascribed. In addition categories of behaviour are sought whose impartiality rests in the validity of the argument which established them. Together they form a method which is acceptable and useful in its own right.

Here are two useful tools to break the deadlock in para-medical research, ethological observation to record and unravel basic behaviour patterns and a simple checklist to test for the presence or absence of previously established criteria. In this study a check list based entirely on the logical or necessary elements of rehabilitation would produce a small amount of data omitting most of the context in which they occur. An ethogram developed entirely on empirical observation of the setting would produce a great deal of day to day information which may have little bearing on the issues. So a balance between the two has been reached which favours traditional ethological approaches but is tilted, without loss of impartiality, in favour of relevance.

As a footnote to this point, inclusion of elements which ought logically to occur does not necessarily introduce a moral ought. This is because the log-

ical issue is independent of any moral issue. It may be, for example, that that which is done in therapy practice - though it may conflict with the logical aims of the work - is, in society's terms, morally preferable. As with the need to school children into conformity, society may need its disabled subcultures for various evolutionary, economic and socio-psychological reasons. There may be a need to separate the impaired to reduce breeding potential, or to fill low income menial but necessary jobs, a subculture against which the normal can feel whole and well, or simply as an outlet for charity.

The 28 activities can be classified into five areas or groups of activity.

The way in which this was done is given in appendix I. The groups are mentioned here because they are useful at the stage of data analysis. They are:-

- a) physical therapy
- b) the minor functional activities involved in attending the class
- c) the major functional activities directly related to rehabilitation proper
- d) clinical, prosthetic and cosmetic care and understanding
- e) conversation (other than that included in the above)
 - 1: chat 2: knowledge-seeking exchanges.

Group a) comprises the therapy which was found to exist in the walking training departments, e.g. mobility of various types, upper and lower body exercises, transfers and so on. Group b), the minor functional activities, include all those activities necessarily involved in attending a walking training class such as arrival and departure, drinking tea and returning the cup, taking off and hanging up outdoor clothes, dressing and undressing, going to the toilet, picking up dropped items, lighting cigarettes, delving into pockets and so on.

Group c) covers the major functional activities of rehabilitation proper which are presented in the four categories, activities of daily home living, social and community activities, recreation and work. Group d) are the activities which relate to caring for the stump and prosthesis and to the amputee's better understanding of his limb. There are three categories here, cosmesis, prosthesis and stump. A fifth group e) was found necessary to denote conversation not already dealt with elsewhere and where no gross activity takes place. This single category is divided into chat - banter, pleasantries, joking - and enquiries or knowledge seeking exchanges.

An obvious and simple form for the single researcher would have been an ethogram for these five groups or the twenty eight categories and their times.

This is usual in ethological check lists. However this provides little information on the questions in hand. In as much as it need be it is covered by diary notes. We need to know not so much what and when but what and how and who. What events occur, how are these carried out and by whom? So the ethogram developed in different directions in answer to these questions.

The categories were divided into columns to denote who carried out each activity and whether the activity was part of a deliberate teaching and learning programme or an unplanned or incidental activity. Scores were made by means of symbols which denoted communicative style. Details of how the records were made within this ethological framework are described in chapter five.

6. The Case Histories

A search of the literature revealed that very little is known about the lives of amputees over periods of time, and preliminary observation at Centre A high-lighted this as a rich source of information. The case histories were compiled by investigative methods and a 'participant as observer' stance (Denzin 1970) was adopted. The reasons for this were as follows. Investigative methods were called for because of the human nature of the subject and because of the need

to infiltrate all aspects of the setting to check and cross-check information (Douglas 1976). Participant observation was chosen because gaining access was not probelmatic and, as we shall see, many of the participants had reasons to pour information on the willing listener. Complete participation, where the scientific intentions of the observer are unknown to the subjects, was deemed unethical and unnecessary. The stance of 'observer as participant' (Denzin 1970) where contact with the subject is brief and formal, was also dismissed because it is a method for testing quite specific hypotheses. Whereas an open-ended and unstructured method was looked for which would make use of the author's previous experience of both the staff and inmate worlds and maximise the discovery and verification of propositions. Participant observation allowed the observer's role to change and adapt as the situation required and for the experiences of the participants to come to the fore. It pinned the study to its human dimensions and opened up new thoughts and speculations on rehabilitation in a way that could not be opened by other means. Each of these points are taken up in the critique which follows.

The case histories are compiled from many sources, from free flowing discussions with staff and patients, from the patients documents, from observation of performance in walking training, and from events and conversations in waiting rooms, during coffee breaks and so on. They focus on rehabilitation and make special reference to problems and complications which hinder its course and to special help which enhances rehabilitation. Pursuit of these topics as they arise involves contact with all grades of staff throughout the hospitals and limb centres and occasionally visits to patients homes.

Case notes were compiled on each patient on whom there was an ethological record.

The practical problems of compiling and interpreting these histories and their format is described in chapter five. The results are the subject of chapter eight.

7. The Diary Notes

The diary notes were long-hand descriptions of the events in the walking training classes. The notes were made against the times of the occurrences. It was found necessary to collect material in this form to provide a description of the room as a whole and thereby assist the observer to interpret the ethological and case history material. Their format, compilation and interpretation is described in chapter five.

C. Critique

In chapter one it was shown that para-medical research has faltered for want of suitable methods. This hurdle had to be overcome. So the first requirement was lengthy and sustained contact with a rehabilitation setting, not as a member of staff or as a patient but with no other employment than to observe and consider not only the subject in hand but also a way of drawing it into the open and capturing it on paper in a useful and scientific form. In this way one began anew and from this developed the two tier observational method.

Science is a quest for the truth. The question here is, what <u>really</u> happens in a rehabilitation setting. To answer this one must infiltrate all aspects of the setting and build a complete picture from the many and fragmented views of its participants. This the author felt able to do for very many opportunities presented for gathering information. Problems were not those of sparseness of data but of establishing cut-off points. Beginning at each centre in a vague and general way one worked towards the particular and innermost aspects, checking and double checking for the truth.

The difficulties of observation in the social sciences have already been introduced. There are problems of:-

reliability and detachment validity and intimacy

the participant observer observes an observed situation

the self-fulfilling prophecy.

How are each of these dealt with in the business of testing for the truth of walking training?

1. Observer Reliability

The ethograms were developed to increase reliability. They force the observer to record every incident not merely those that may seem to support a particular view. This is a characteristic of an ethogram. It curtails discretion. During the process by which it is compiled the observer is engrossed in 'ticking and crossing' and so, is at a distance from the opinions that shaped the hypothesis. Human behaviour is always open to variable interpretation but little inference need encroach on deciding between whether the patient is walking or not, with a therapist or not, for exercise or to an ambulance.

Practical problems hindered ethological observation. There was sometimes no excuse and no reason to remain in a room to observe. While it was usually possible to wait with patients in waiting rooms and to follow them along corridors and to remain during breaks, as a guest of the staff one was drawn into their world and observation had to be halted until one could reasonably return, e.g. lunch had to be taken with the staff and not the patients. This provided a very useful opportunity to make contacts and to gather information from staff of all grades but it interrupted the ethological record. When a single patient was taken out of the walking training room, for example to practise walking on the uneven outside surfaces, it was not always possible to follow closely for fear of disrupting the activity. Where activities could not be observed they are not recorded. This resulted in omitting a substantial slice of minor functional activity and patient to patient conversation. At the more crowded Centre C it was sometimes difficult to hear the content of what was said between patients. It was always more easy to record actual therapy as opposed to everything else. As a result non-therapy activities are under estimated to the order of 10% to

These figures are not added to the eventual totals but are borne in mind

when considering the results.

Observer accuracy is a constant battle especially for the single observer.

Many factors impinge upon it (Mash and Makohoniuk 1975, Reid 1970). Absolute vigilance and fidelity is unattainable. But the ethological record is invaluable in providing a numerical measure against which the views, opinions, impressions, fallacies and evasions of the patients and staff, and not least the author, can be tested. And as will be shown its results are not vague or marginal.

A method should not yield significantly different data when used by a third party. This ethogram can be taken in its entirety and used by others and when this was done during its development an independent, though relatively untrained, scorer produced recordings which were up to 93.3% in accordance with the author's. In the lowest correlation, 84%, the discrepancies were half omission and half disagreement. Connolly (1973) stated that observer agreement is not necessary. At the end of mutual training, agreement arises for obvious reasons. What matters is that each observer adheres strictly to the conventions they have decided upon. Hence in this study the method is presented at some length so that it is available for others to use and to check. Where discretion encroaches there are conventions - given in chapter five - which in each case make the record more bland.

2. Validity

The investigative aspects of the method increase validity. Intimacy with the subject was achieved by infiltration into all aspects of patient and staff routines. The degree of co-operation was so great as to require some explanation. From a resume of fruitful informants (Dean et al, 1969) it can be seen

^{1.} The independent scorer, L. Cronin, M.Sc., Department of Psychology, University of Hull. As the second scorer became familiar with the ethogram and research setting it quickly became apparent that close agreement could be reached if enough training were given, thus defeating the object. However, the author was able to judge the impact of the ethogram on an independent observer and some simplification was made at this stage. Complexity of coding categories is known to decrease observer accuracy (Mash and McElwee 1974).

that the subjects of this study include disproportionate numbers of those who can be looked to as more willing to talk. Dean gives examples of informants who are especially sensitive which includes those who are in states of transition and those who are more reflective and objective. This included student staff, and describes the state of many of the patients. Dean gives examples of the more-willing-to-reveal informants. Four of these six categories were very strongly represented. All of the staff proved to be naive informants, giving information the significance of which they were unaware. Many of the staff and some of the patients were frustrated and saw the investigator as an outlet for their blocked ambitions and impulses. Most of the patients were needy and fastened onto the investigator for attention and support, talking for as long as the investigator would listen. Some staff and some patients were willing to relieve their feelings even to the point of maliciousness on occasions when they felt most powerless. Dean also mentions those with special training who are in close touch with the subjects. A nursing sister, an administrator, a prosthetist, a physical and an occupational therapist, an author and a social worker all gave especially valuable specialist information. To sum up. most of the information arose from need and frustration and from a cheerful willingness to co-operate where genuine concern was expressed. The ease with which much of the information was acquired does not in any way invalidate it.

Access to documents was also found to be surprisingly open. Only the lack of information in many of the case history notes made information gathering difficult. Both patients and staff were unsure and inexact when offering information on dates and procedures to fill these gaps, and the staff of the physical therapy departments knew surprisingly little about the patients' social domestic and economic circumstances. The case notes compiled during this study do however form a substantially complete background on the patients and are compiled from many sources.

Neither was it difficult or disruptive to compile the diary notes. The ethological scoring was fairly unobtrusive. The diary notes are less so because they involve almost continuous writing even when no therapy is taking place. Being completed after the ethograms, when the observer's presence was familiar to patients and staff, and seeming to take little interest in the proceedings, these long hand notes were successfully compiled.

There are many reasons to doubt the efficacy of the classical co-operative view of researcher and subject (Douglas, 1976). So, although the degree of co-operation was very great indeed there remains the need to substantiate the information from a number of sources. Where staff were dissatisfied one talked in addition to the patients, to their colleagues, superiors and subordinates. Where patients expressed dissatisfaction one talked to their prosthetist, social worker or relative as well as their therapist. And so forth. The wards of all inpatients were visited and the Artificial Limb and Appliance Centre staff of all the patients were informally interviewed. Sometimes a unified story emerged from all sources but the author's investigations over and above this could show it to be ill-founded. To give a small example, one patient walked badly and participated minimally. However, the staff were lenient with regard to this patient's poor approach to walking training for all agreed - patient and staff - that this elderly lady managed her personal and domestic activities with competency. Capitalising on the patient's need to talk, the author encouraged her to talk in detail about daily home routines. It became apparent that this lady physically did very little at home but supervised a willing husband, relatives and neighbours. The situation was not at all what it seemed. On larger matters, both staff and patients agreed that walking training was valuable and vital. Later chapters discuss whether this is the case.

3. Being native

In this study validity is reinforced by the observer's 'being native' (Douglas,

1976)¹. Douglas discusses the once widely held view of classical field research, the positivistic view, that involvement and objectivity vary in inverse proportion. The researcher was expected to infiltrate the setting but not become a member of it. 'Going native' was to sin against science. 'Being native' to begin with was unspeakable. The classical compromise produces such studies as Mead, 1942 and 1943 where Eastern societies are interpreted through Western ideologies. Douglas shows that to unravel the truth of a situation one must quite literally speak the same language. Whyte's work in 1955 exemplifies this new mode of investigation. The author has 30 years experience as a fellow patient and three years experience of the staff world.

In this study 'being native' carried immense advantages. It largely accounted for being able to collect the data for it broke down hostility, embarrassment and resentment. It drew patronage from the staff and comaraderie from the patients. It made available additional strategies which were used to gather new information that could not be known by other means. There were two distinct types of information. Picasso is credited with the comment that when art critics assemble they discuss colour, tone and texture and when artists get together they talk about brushes and turpentine. Such was the case here. As a researcher one learnt about pathology and physiology. As a fellow patient one discussed faulty rivets and the availability of tea. The author passed as normal or exposed the deviancy depending on which state was the most useful.

An interesting example of the greater insight that is made possible occurred at Centre B. The patient, Mr. F, was an inarticulate and elderly man. While walking with his new pylon, he complained to the therapist that 'the foot did not reach the floor'. The foot of the pylon patently did reach the floor for the man was walking. The therapist presumed the patient alluded to his imagined

^{1.} Douglas, 1976 (5th reprint 1981), Ch. 6, p.110.

real limb and sympathetically explained that this would not now reach the floor because it had been amputated, hence in its place the artificial limb which did reach the floor. Later the incident was recounted to the author as suggestive of the patients being confused. However, the sensation of the 'foot' not touching or reaching the floor has a number of meanings to an amputee, especially one newly learning to walk. Conversation with the patient revealed the meaning here. The foot in question was not an image of the real foot, nor was it a phantom limb or a euphemism for stump but the wooden foot of the ptb pylon. When walking, this foot did not step squarely onto the floor. sation of placing the artificial limb is transmitted through the remaining limb and this patient could feel that he was walking on the outer edge of the foot. This sensation of misalignment was further evinced by the patient's ineffectual tugging at the limb. Were the observer not an amputee insight into the varying sensations of 'foot' would not be available. The author would not have been led to enquire further and might have agreed, on the evidence available to the therapist, that the patient was indeed a little confused. This sort of error would produce a very shallow study of the patients' experience adding little that is not already known. This instance is one of failure to deal with the patient's problem and not one of sympathetic explanation. One must bear in mind that these were the patient's first steps with a prosthesis. By the time he attends a routine ALAC check-up he will in all probability have acquired a walking pattern and a walking experience that has accommodated this unusual sensation and will no longer be able to offer constructive comments to the medical officer and limb fitter. Uncorrected, if there is actual misalignment, he may damage both limb and stump.

This sort of example can be repeated many hundreds of times over a study that encompasses over a hundred and fifty amputees. Any careful observer might have noticed much that was not apparent to busy members of staff but much more is only fully to be appreciated by a fellow amputee. 'Being native' exposes text-

book myths, staff fallacies and uncertainties and patients evasions and fronts. The disadvantages are that one may be excessively partisan or that one may apply solutions that were once one's own to situations with distinctly different components. The ethological data tempers inmate bias. But, it should be emphasised, 'being native' tests the truth of inmate pronouncements as it tests those of the staff.

4. Observing the observed subject

This is always a problem in observational social studies. One is left wondering what the unobserved setting is like. The effects of there being an observer intruded in a number of guises. There were obvious, even comical instances of changed behaviour because of the observer's presence, as when the staff carried out techniques in an elaborate manner or patients exaggerated their activity for the stated benefit of the observer. These fronts were most noticeable during the first few days of observation at any centre so data collection was delayed.

when the situation settled into its more usual routines there were changes resulting from the observer being drawn into the routines by staff and patients. This did not disrupt the ethological scoring which can be done many minutes retrospectively and includes symbols for the observer's involvement. It nevertheless represents a change from the unobserved state. The observer quickly learns to reduce these small changes, feigning absent mindedness or studiously watching a patient not required for observation and so on. However the author commonly joined in the general exchange of pleasantries because it would have been too disruptive not to do so. This increased acceptance and opportunities to gather information.

There were small changes brought about by the presence of the observer which did not affect the data. Where the observer sat had some effect on where patients sat and the direction in which they walked but gross behaviour and the ethological record of the patients sitting or walking is not affected. Yet there must

have been changes which were not detectable. Did coffee-break conversation remain light-hearted because it was observed or did the patients use this as an opportunity to voice their complaints, knowing their comments would be heard, perhaps recorded? Did observation increase walking training activity?

On the whole it was thought that the changes were small and the effects on the data were also small. The patients did not know that for most of the time the observer noted the activities of only one of their number, and the staff never knew in advance which patient this would be. Despite the observer's presence the business of walking training had to continue. It followed well established routines and it was these routines - the broad content of treatment sessions - that the data was designed to capture.

5. The self-fulfilling prophecy

The author began with doubts as to the effectiveness of rehabilitation practices in NHS hospitals. The study is designed to test the legitimacy of those doubts. How has automatic self-fulfillment of this ideas been avoided?

In all research this question is ultimately left to the reader. The scientific process is not so much the testing of ideas by their author as the testing and retesting by others. Ultimately, one is never able to step outside one's frames of reference. To a lesser or greater degree every author offers his view of the world. This does not exempt the researcher from full and proper use of scientific controls. What are the controls here?

In chapters one and two the literature on rehabilitation and amputation was reviewed. Doubts as to the efficacy of rehabilitation were seen to be expressed by other authors, though, these doubts are supported more by careful analysis of what is erroneous or omitted from the literature than by that which is made explicit by other authors. In chapter three, the author's views are examined logically and syntactically, rationally and reasonably. The socio-economic

definition of rehabilitation, which is thereafter used as a measure of rehabilitation practice, is found to be firmly based. The logical case for this supercedes all historical or empirical arguments. Having tested one's Weltschauungen against the views of other authors and the constraints of rationality, and in the process shedding and reformulating unsupported opinions, a method for testing one's remaining doubts is established. The method chosen permits the author to remain alert to both the detrimental and the beneficial aspects of rehabilitation practice and to the repetitions and ordinary aspects of treatment. Whereupon follow further constraints to be equally open and objective in abstracting the results and conclusions from the data. Retesting by others is possible because in this and the succeeding chapter the method is fully explained.

6. Models and Perspectives

In the opening chapters the dramaturgical view of social behaviour in institutional settings and of reaction by normal society to the stigmatised was set out. The labelling effects of deviancy were touched upon and man's social construction of reality. It is impossible for an observer to observe in an unbiased way. Even the categories one uses are derived from an implicit or explicit position. In this investigation the notion that hospitalisation and rehabilitation are separate and not necessarily compatible entities is explicit, as are the models and perspectives from which it is derived.

Data collection centred on the patient. Client-centred perspectives have been developed with the move towards phenomenology in the social sciences but patient-centred studies remain rare: Goffman's study of asylum inmates (1961) and Scott's study of blind men (1969) being classics in this area. Goffman argues that if his work reflects an inmate bias then it is a long overdue bias. Though this must not be an excuse for emotional and woolly thinking, it is a sound approach and will be used in this study which aims to record the attitudes and practices of the staff world but does so largely through the experiences of the patients. This view is taken not least because of the truism that

rehabilitation does not exist without its clientele and in any study which professes interest in the patients' welfare, especially an introductory study on the subject, no other view of events is entirely defensible. The strengths of the inmate bias and the author's special interest in those who have lost limbs has been discussed in this chapter.

The overall perspective is that of the outsider; though a privileged one with an expressed patient-bias. In any field the outsider provides new insights into systems and the relation between their subsystems. In this field the outsiders contribution is entirely missing. This research, it is hoped, will spur research by those on the inside to evaluate the techniques on which the author is not qualified to comment.

As a footnote on the subject of perspectives it should be added that this investigation omits the role of physiotherapy education and condenses the therapist's experience of events. In short, it omits therapy input and concentrates on therapy output. This is because in the terms of this study it is not necessary to do any other. In its crudest form the question posed here is one of value for money. Are the patients, the consumers, receiving the goods and services they pay for? They expect the minimisation of infirmity and the maximisation of health. Is this what they receive? This may be said to be an investigation of the buyers interests. How the goods and services are produced becomes another matter.

D. The Ethics of Data Collection

The social science researcher is always a Peeping Tom. It is always either not fully possible to explain one's actions or not fully desirable. The legitimacy of making public the results is always dependent upon the legitimacy of the interests of scientific research over and above the interests of the individuals who have been its subject matter. It is, however, very difficult to argue that science as an object facticity can be held above morality, though

these two can be brought more closely together if one argues along the lines of common utilitarian agreement. That is, to take the view that the general good which might come from the research - an especially strong point in the case of para-medical research - outweighs the harm to a very few and anonymous individuals who themselves might readily be persuaded to consent to contribute to the general good in this way. Inevitably the social scientist concludes 'publish and be damned'. This is the conclusion here though it is possible that neither patient or staff will welcome such material. There are however certain provisos and sefeguards.

None of the centres are named or closely identified in any way. None of the staff or patients are named. None of the subjects represent in any way an undesirable or atypical element in this field. There is no need for the reader to search out these identities because it would add nothing to the study. Also, the researcher was not an anonymous spy. In all of the settings, in all of the conversations, the researcher was always just that - a research worker.

A great deal of time was spent in explaining to patients in clear and full terms the object of the observations, questions and notes. These explanations were far in excess of staff introductions to the patients. They were made at varying lengths and varying levels. The single most difficult problem was thrusting information on patients who co-operated without asking or understanding any details of the researcher's intentions. Patients were asked in many ways and at many times whether they had any objections to the observer being present. Information withheld from every patient was that, for some of the time the observer would be recording all the activities of a single person. This was to prevent embarrassment, self-consciousness and disruption of usual behaviour. The degree of detail was also withheld. The ethological data records the most minor activities and it is impossible to explain to the layman the research significance of this without profoundly changing behaviour patterns and losing co-operation. It can only irritate those who are in pain, struggling to use

new limbs and worrying about their future role in life to know that the researcher counts the number of times a patient blows his nose or lights a cigarette.

No patient refused to co-operate. Many gave the most sensitive information;
frequently information not known to their therapist. It is the author's firm
opinion that it is not possible to argue that unscrupulous use was made of any
of these patients. On the contrary, they received sensitive attention in an often impersonal setting.

The staff surprisingly asked less about the researcher's intentions than did many of the patients and it was often more difficult to thrust information on them; even staff who themselves had instigated research. The need for compiling records of each patient's moment by moment behaviour was explained though staff were not told in advance which patient was the subject of the day. The staff were told that the researcher's particular interest was the unfolding and recording of patterns of behaviour associated with failure and under-achievement. The staff, working to their fullest capacity, felt unable to offer the care they would have liked to give. They were aware there was failure and underachievement but saw this as a result of lack of resources and failings in the patients themselves. They welcomed research into amputee treatment. The staff generally felt their best endeavours to be frustrated by powers beyond their control and saw research intervention as a slim chance of promoting change.

Footnote. It was felt that this research benefitted considerably from being without profit or professional interest. Neither was it pursued in haste. Eventually lack of funds curtailed data collection but this provided a much needed cut-off point and drew the research together.

Chapter Five

Description of the Method for the Study of Rehabilitation

Practice

Introduction

In this chapter the sample used for data collection is described. The method and its application are also described and there is discussion on problems of data analysis. As with chapter four, the purpose of presenting this material is to set out the parameters and limitations of the method so that the status of the data is not in doubt.

A. The Sample

1. Description of the Centres and Staff

One walking training class was used for the development of the method. This will be referred to as Centre A. Data was then collected using that method at two other centres, which become Centres B and C. The results were appraised at two further centres, D and E. The author has experience of some twenty centres variously undertaking limb surgery, prosthetic manufacture and fitting, physical and occupational therapy. These provide background knowledge.

The main characteristics of Centres A, B, C, D and E are shown in fig. 1. The choice of these centres has been discussed in chapter four. Centre A was intermittently observed for a period of one year, Centres B and C for three months and four months respectively and Centres D and E for two weeks each.

The walking training centres were staffed by Remedial Gymnasts and Physiotherapists and the two are represented in equal numbers. Fig. 1 shows the proportion of therapists to non-therapy staff. The departments included both the newly built and the long established, the most prestigeous and the less well known. There were classes with many patients and classes with few.

2. The Patients

During the course of this investigation over 150 patients were observed.

Following preliminary observations the patient sample was to be all those present when records began at centres B and C. The choice of centres was purposive and

Fig. 1. Data collection centres, staff and patients

description	Centre A	Centre B	Centre C	Centre D	Centre E
place	general hosp. (esp. geriatrics)	A.L.A.C.	general hosp. (esp. geriatrics)	A.L.A.C.	general hosp. (acc. & emerg.)
city	industry/ agriculture	large industrial	industry/ agriculture	heavy industry	industry/ agriculture
walking training	class - separate room in larger dept.	school - amputees only	class - separate room in larger dept.	school - amputees only	lesson - individually in mixed gym
facilities	crowded and poor	spacious and good	fair	excellent	good
attendance pattern	l hour (3 x weekly)	full day (5 x weekly)	l hour (2 x weekly)	half day (1 to 3 x weekly)	$l^{\frac{1}{2}}$ hours (2 or 3 x weekly)
patients	23	29 ¹	20 ¹	30	8
surgery (at above centre)	86%	22% adj. hosp.	90%	93% adj. hosp.	100%
limb fitting (at above)	0%	100%	0%	100%	0%
<u>staff</u>	2 therapists 2 students 2 aides 1 porter & clerk	2 therapists 1 student 1 orderly porters	2 therapists students 2 aides 2 volunteers 1 porter & clerk	2 therapists 1 orderly 1 porter volunteers clerks	3 therapists 1 student porters clerks volunteers

^{1:} At Centre B 9 patients are the subject of ethological and case history study and a further 20 patients are included in diary notes. At Centre C there was ethological and case history investigation of 10 patients and a further 10 are included in diary notes.

the choice of patients within those centres was to be all the patients on the books at the centres during the time of the study (refer chapter four). In practice the patients! haphazard attendance caused the sample to be chosen from those with regular and early attendance. There were 9 such patients at centre B when records began and 10 at centre C. These 19 patients became the subjects of data collection. Lists were compiled with the therapist before data collection started. At centre B this became a sample of the full staff register - omitting only those patients who were imminently to be discharged because the register was made up only of those likely to attend. At centre C it became a sample of less than half the full register (10:23) because the staff register included very sick and rehospitalised patients, those whose treatment was postponed awaiting altered or new limbs and those who attended occasionally for 'topping up' exercises; those who for one reason or another were unlikely to attend. In some instances patients from these two original lists became absent during the period of data collection but joined the group before the period ended and so it was eventually possible to observe each patient from the original lists. Patients were taken as far as possible in alphabetical order but frequent late arrival resulted in the second or third name from the list being taken.

We shall see in chapter eight that this small sample corresponded closely to national figures: there being a high proportion of vascular patients over sixty years, of men with unilateral amputation. Though close to national averages it does not include either ends of the spectrum. Younger and fitter patients passing more quickly through the walking training regimes were under-represented. The youngest patient was 48 years. For example a patient of 32 years was allowed to attend on an irregular basis and use facilities in another room. If his attendance patterns had been those of the older amputee he might have been included in the data. On the other hand the oldest patient was 77 years and no patients of 80 and 90 years were included. A few such patients on the register

at centre C were too ill or rehospitalised and could not attend. Hence the 19 patients represented the more fit and able of elderly patients and also those with slightly less prosthetic problems. By chance all 19 had standard below or above knee amputations resulting from major causes, i.e. vascular disease or trauma.

In a purely investigative study a 'full register' of an amputee population could have been used and the patients sought out in their homes, day centres, hospitals and so forth. This is suggested as a basis for further research into the lives of amputees. In this study the case histories are those of the 19 patients who had been ethological subjects. This is because they were more familiar to the author and more readily available. So, investigative data was also biased towards the more fit elderly patients, those who were able to receive prostheses and attend walking training on a regular basis.

At centres B and C further patients were included in the diary notes. At centres A, D and E observations included patients from 13 to 92 years whose cause and site of amputation was more diverse.

Choosing patients who attended regularly caused the ethological data to be as much as 75% more 'full' than if the patient sample had adhered strictly to the class register and alphabetical order of surnames. If these changes had not been made the data would show the degree to which treatments are fragmented and disrupted but there would not be a record of the sort of session that is seen as normal and desirable. So the sample is adjusted in the interests of relevance. Through this study one firstly seeks to know what the patient's experience is when present at full and prescribed treatment before one could usefully study the effects of absenteeism.

B. The Method

1. The quantitive data, the ethogram

The choice of ethological observation has been discussed in chapter four together with discussion on the basic design of the ethogram. Here we look in detail at the way data was collected.

The observer, taking the patients in alphabetical order of surnames - as far as was possible (refer chapter four) - recorded all that occurred to and around a single patient through a single walking training session from their arrival at the door of the department to their departure. This record was made twice for each patient on two separate days, giving 38 completed ethograms. The results are the subject of chapter seven.

Within the 28 category framework (which is given again here, refer fig. 2) the record was made by the brief symbol 'o'. As each act occurred an 'o' was entered in the appropriate space. However, two refinements were found useful. The first indicated patient to patient interaction, using the symbol '5', and patient to observer interaction, using the symbol '6'. As will be shown below the subdivisions of the categories into columns indicated who carried out each activity but the addition of further columns was found unwieldy hence patient to patient and patient to observer activity was noted by symbols. The second refinement indicated the communicative style used by the staff when there were extended or intensive verbal exchanges. Four symbols (refer fig. 3) indicate praise, negotiation, command and reprimand. The symbols are tabulated in fig. 3.

The scale was not difficult to apply because the symbol 'o' was used far more often than all the others added together, as for example when patients acted alone. When communicative style was in doubt the symbol 'o' was used because

ambulance to dept.	coat	dressing	tea	return cup	toilet	ADL (in dept.)
12341234						
home	neighbourhood	recreation	work	cosmesis	prosthesis	stump
page one						

furniture	walking aids	sit down	stand up	walking	standing	conversation 1 2
falling	transfers	upper body exercise	lower body exercise	stairs (no.)	walking - uneven surfaces	walking - out of dept.
page two					:	

Fig. 3. The symbols with which the ethological record was compiled.

description		symbol
a single activity occurs -		o
a) absence of obvious interpersonal attitudesb) brief and non-committal verbal and non-verbal communication		
activity - patient to patient		, 5
activity - patient to observer	•	6
communicative style (staff)	praise	
·	negotiation	n
·	command	С
	reprimand	x

by the definitions used here the alternatives should be readily apparent. The author's preference had been to use symbols in a way which distinguished activities accompanied by verbal communication from those not accompanied by verbal communication but this was not found to be suitable. There were attitudes expressed verbally that it was impossible to ignore and which were quite distinct from brief and non-committal use of language, verbal and non-verbal. The symbols which were eventually agreed upon represent therefore the patterns of behaviour as they were found to occur. Each activity was represented by a single symbol. If the activity changed in style a second symbol was used.

Each of the twenty-eight categories were divided into columns and the symbols entered into these columns. The columns firstly denote whether events were part of the deliberate teaching and learning programme or were non-taught or unplanned. Refer fig. 4. They secondly denote who initiated and carried out (or we may say controlled) the activity, staff or patient. Refer fig. 5.

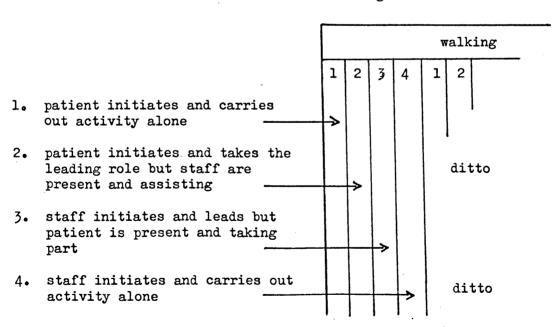
Fig. 4. The categories divided by taught and non-taught activities.

one category

wa	alking
non taught	taught
activity is unplanned or merely entailed in attending the class, e.g. patient walks to the toilet, therapist walks to hang up patients coat.	activity is part of a teaching or learning programme, e.g. patient exercises with new limb, therapist teaches patient to walk.

Fig. 5. The categories divided by staff and patient control of activities.

non-taught columns of one category



To give examples based on the category of walking (illustrated in fig. 6), if a patient stood up alone to exercise between the parallel bars the symbol 'o' would be entered in column 1 in the therapy or taught side of the category of 'walking'. If the therapist had first commanded the patient to get on his

An example of the record.	furniture	walking aids	sit down	stand up	walking	standing	conversation 1 2	
An example of the record.		left side - no column 1 - no the toile columns 3→1 patient who the	t taught atient walks alone t therapist comm	ands	0 0	right side - tau column 1 - patient exercises alone columns 3 -> 1 - therapist commandatient who then	5 patient che other pt. ng ling about pist) nt 5 pt. smok loss ds with	(grumbotheraction) discussing (recorded of ling other
of the	falling	transfers			stairs (no.)			Fig. 6.
								An example of the ethological record.

feet and then the patient walked and the therapist departed, the symbol 'c' is entered in the taught column 3 and then a symbol 'o' in the taught column The activity was one of walking and also of walking exercise so the category and the right hand or taught side of the walking category is determined. Into this the symbols are entered depending upon who is doing what and how they are doing it, in this case the patient was exercising alone and the therapist's tone was commanding. The same symbols and entries but on the left hand or non-taught side would denote that the patient had walked alone for example to the toilet or the therapist had commanded the patient to walk to the open doorway to smoke then left the patient to do so. If the patient at the doorway chatted to another patient about staff reaction to his smoking the symbol '5' would be entered in column 2 on the 'chat' side of the conversation category (presuming the other patient has replied). If the first patient had initiated instead a serious conversation about how smoking might have been a factor in the loss of his limb, then the symbol '5' would be entered in column 2 of the conversation category on the 'serious conversation' side.

Finally, a single additional column to the far right of each category was found to be necessary in order to add certain comments. This was in response to a felt need to record incidents of exceptional practice which made special impact on the observer, incidents which had special bearing on rehabilitation proper, e.g. the therapist related an activity specifically to the patients domestic circumstances or the therapist insisted on procedure despite protestations that home or personal circumstances were different. The results of these comments are interpreted separately from the other ethological data because of their more discretionary nature (refer chapter seven). The symbols are tabulated in fig. 7.

Fig. 7. Recording Incidents of Special Relevance to Rehabilitation Proper.

Symbol	description
Н	(Home) activity linked to patient's domestic circumstances
М	(Mobility) mobility criteria supercede domestic criteria
/	Helpful to rehabilitation proper
х	Unhelpful to rehabilitation proper

This, together with brief biographical notes as to which patient and which day the record refers, is the complete ethogram and recording technique. Initially it may seem complex but because of the routinisation of the observed behaviour and because only one patient was observed each session, the various facets were easily handled. The categories were global and in each completed ethogram there were many categories with a low or nil score, though these were in themselves significant. The extent to which one activity can be interwoven with another was very limited. A patient cannot simultaneously be taking off his coat, drinking tea, walking, having his stump bandaged, and so on. Attendance involved regular patterns. Behaviour became predictable. Brief symbols told the story of whole events. Entries from one category to the next tend to be evenly spaced, sometimes with lengthy gaps while patient and observer rest. The observer's main concern became entering the most appropriate symbol in the most appropriate column, the categories being easily determined and the timing usually fairly steady.

Examples of completed ethograms are enclosed. Refer fig. 8 and 9. The first, taken from Centre B, records patient L who attended for half a day but because of prosthetic problems was only able to carry out a little walking exercise. There was good negotiation about these problems as indicated by the frequent use of the symbol 'n' in the category 'prosthesis'. But the patient's incapacity caused the staff to undertake many minor acts on his behalf; note frequent

ambulance to dept.	coat	dressing	tea	return cup	toilet	ADL (in dept.)
1 2 3 4	1 2 3 4	1 2 3 4	1234	1 2 3 4		1 2 3 4
		0 0 0	1 2 3 4 5 5 0 0 0 0 0 0 0 0	0		0
home	neighbourhood	recreation	work	cosmesis	prosthesis	stump
					1 2 3 4	
					0 n 5 5 5 n 5 n 5 n 0 n 5 o	
Centre B Pati	ent L					

furniture	walking aids	sit down	stand up	walking	standing	conversation 1 2
1234	1234	1 2 3 4	1 2 3 4	12341234	1 2 3 4	1 2 3 4
00000	5			o		5 6 6 n n o
falling	transfers	upper body exercise	lower body exercise	stairs (no.)	walking - uneven surfaces	walking - out of dept.
I .		1			المصحف سما	
Centre B	staff/pat. ratio	Patient L unil fitting problem	ateral below knee		pt. irritable b pain when walking	reathless

ambulance to dept.	coat	dressing	tea	return cup	toilet	ADL (in dept.)
1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4 1 2 3 4
	0 0 0 0	0	1 2 3 4	0		
home	neighbourhood	recreation	work	cosmesis	prosthesis	stump
					1 2 3 4	
					1 2 3 4 5 5 6 6 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	
Centre C Patien	ı+ ∇					•

furniture	walking aids	sit down	stand up	walking	standing	conversation 2
12021	1 2 3 4	1234	1 2 3 4	1 2 3 4 1 2 34	1 2 3 4	1 2 3 4 1 2 3 4
0	0	0 0 0 0 0 0 0 0 0 0 0 0 0			0 0	0 5 5 5 5 5 5 5 5 5 5 5 5
		upper body	lower body	-4-3 (7)	walking -	walking -
falling	transfers	exercise	exercise	stairs (3)	uneven surfaces	out of dept.
 		1234		1234	1234	
				0		
Centre C	staff/pat. ratio 3:7	Patient V unil definitive pros	ateral below knee thesis.		works quietly and	i alone

•

use of column 4 in such categories as coat, cup, furniture and non-therapy walking. The patient discussed walking aids, refreshments and his prosthetic problems with other patients - symbol '5' - and at one point the observer had a lengthy chat to the patient to allay resentment in this easily irritated subject - symbol '6' - category 'conversation'.

The second ethogram may be similarly 'read'. Patient V undertook much more walking training and staff initiative was a feature.

It is worth stressing to the reader the usually steady timing of events and the global nature of the record. An activity may continue for five minutes but unless its nature changes a single symbol is sufficient. Occasionally rapid succession of events was confusing. Here the observer relied on the conventions determined in advance. When the symbol was in doubt an 'o' was used. When the column was in doubt a central column 2 or 3 was used. Decisions affecting the taught or non-taught nature of an activity veered towards non-taught/ unplanned. When the content of conversation was in doubt, when it could not be clearly heard or the subject changed rapidly, the symbol was entered in the miscellaneous or chat category. In general the record was made less exceptional by these conventions.

Data analysis begins with addition and comparison of the scores, by columns, categories and by groups. Simple quantification makes available for the first time a record of all the activities and the main elements of those activities in which patients are involved in a physiotherapy setting. This information is at present totally lacking (Ward et al 1978) (Partridge 1982(a)) as was shown in Chapter one.

Accuracy in data collection is especially problematic for the single observer (Reid 1970). Because of this and because of the global and introductory nature of this thesis it is felt that the ethogram results should be seen as indicators

of trends rather than precise measurements of behaviour. This helps to reduce the effects of errors in recording the data and restricts over-zealous interpretation. The results are the subject of chapter seven.

2. The Investigative Data: The Case Histories

The issues surrounding this aspect of the data have been discussed at some length in chapter four. Here we look at the format of these histories and the practical problems of compiling and interpreting them.

Using every available and relevant source of information biographical data was compiled on each of the 19 patients. Taking the example of patient J at centre-B (refer fig. 10 overleaf) we can examine the sources of this material.

In this instance sources of information were as follows. The patient was a poor source of information. Though friendly, content and willing to talk he was vague and unintelligent. Documents, checked against other sources, provided the chronological framework of events and information on disease process. Personal and social information was corroborated by an occupational therapist who had come to know this patient well and taken a special interest in him. Amputation and prosthetic information was corroborated by the physiotherapist who had seen the patient daily for six months. A social worker discussed attempts to find suitable accommodation and events that had taken place when visiting with the patient. Spending three months at the centre there were many opportunities to speak to staff but lunch time conversations with each of these were especially helpful. No information was sought where it was not freely forthcoming and biographical outlines such as that presented in fig. 10 were put

^{1:} It was rarely possible to get full or accurate information from physiotherapists about patients personal, domestic, social, recreational or vocational activities because physiotherapists tended not to have this knowledge of their patients.

Fig. 10: Biographical information on patient J, centre B.

personal/social	name J. age 55 years. sex male. marital status - single. employment - casual labour. bed-sit prior to admission, now homeless. no visitors but friendly to other patient. low intelligence but coherent and can read.
ward	in-patient. acute surgery ward. hospitalised 7 months (to date) awaiting accommodation.
amputation	cause p.v.d., intermittent claudication R calf. 14 Jan R above knee amputation, single procedure. post-op retention of urine requiring suprapubic catheterisation. stump infec- tion 3 to 4 weeks. increased weight in hospital, approx. 30 lbs.
prosthesis	pneumatic limb (PPAMA) 14 Feb to 12 March. pylon ordered 22 Feb delivered 12 March. May, refit socket due to increased weight, 2 weeks.pt. has a wheelchair and walks with 2 sticks.
physiotherapy	daily a.m. and p.m. since 14 Feb to date (August) except during refit of socket. pt. has completed and is competent in all walking training routines.
occupational therapy	bathroom and kitchen assessment. Outdoor mobility training. recreational outings.
prognosis	physio: uncertain pt. will cope even in a hostel. o.t: pt. is institutionalised and will do well when discharged. social worker: no immediate prospect of accommodation. patient: sees no problems. other: no referral to DRO. no decision on cosmetic limb.

together almost exclusively by observing and listening. Documents were offered by staff, visits to other departments were suggested by staff and so on.

Though the process of collecting the case history data began by following where others led it gradually changed its style as specific issues on each patient came to light and were pursued. At this point the business of pursuing these issues gradually merges into the business of interpreting them. In the case of patient J the observer noted during investigations in the walking training department that on some days this patient undertook far less walking exercise compared to other able patients and that the physiotherapist and occupational therapist complained that their efforts were not supported by the ward staff.

The first move made by the observer in following up this information was to change her route home thereby being able to see the patient sitting each afternoon on the ward balcony in a wheelchair, in pyjamas and without his limb.

Many such clues suggested that the ward routines should be investigated and issues such as motivation and institutionalisation considered in the light of this patient's actions. Formal and informal visits were made to the ward.

Methods of transporting patients around the hospital were then found to be relevant and the work of porters was observed in more detail. A chance conversation with a talkative porter revealed that patient J was apt to truant - confirmed by senior though more reticent members of staff. In such a way the case history data was compiled. From many sources it was possible to judge the effects of hospitalisation on patient J and the consequences for his rehabilitation.

The results of the case history data are the subject of chapter eight.

3. The Diary Notes

The role of the diary notes was to assist interpretation of both the ethological and case history material. The form which these notes took is given in fig. 11. The discussion which follows looks at the way in which they were compiled and how they were used to interpret the data.

Fig. 11 describes an actual walking training session. It began at 9 a.m. and finished at noon. It shows one therapist assisted by porters working with eight patients. The patients are at different stages of training, five are out-patients and three are in-patients.

These notes were made in the same way as the ethological data, that is, by sitting in a walking training room making notes with pen and paper, but they were made in longhand against the time of the events and described the session as a whole and not the activities of one patient. Columns at the right hand

Fig. 11: Diary notes of a single walking training session.

9.00 a.m.	(senior therapist) dealing with paperwork in the office (post, files), comments on the large amount of office work and the little time available to do it.					
.10	assistant absent today (health). observer in corridor, later in w.t. room.					
.15	patient ② arrives wearing Ak pylon. ② is pushed in a wh.chair from the amb. and	2				
.20	left in the centre of the empty w.t. room. Hel does not remove his coat or move the wh. chair which has no means of propulsion by the occupant.					
•25						
9•30	patient 3 arrives, likewise pushed in a wh. chair from the ambulance by the amb. staff and left in the centre of the room.		3			
•35	(3) is wearing a limb which he has had for some months. 2 and 3 sit and wait and talk briefly.					
•40	enters (therapist) and quickly does a number of minor acts for pt. 2 i.e. helps pt. with					
•45	coat, hangs it up, pushes him to parallel bars, fetches chair, returns wh. chair. 1 telephones then pushes 3 to fitting room.					
•50	Ward-patients (4) and (5) arrived pushed in wh. chairs by porters. (4) remains in wh.chair (5) gets up and walks to a chair.			4	(5) 	
•55	l returns pt. 3, walking, (wearing new cosmetic limb) and 4 and 5 commence walking training immediately therapist enters.					
10.00	l with pt. 2 a) adjusts limb b) asks if pt.			. !		
a.m.	has walked at home c) walking training instruction - clear and slow. d) negotiates				'	
•05	the question of pt, giving up prosthetic mobility due to pain and poor progress. Pt. shows no distress, calmly considers but is					
.10	undecided. 6 arrives in wh.chair carrying limb. 1 examines tender stump before allowing 6 to				(6	
•15	put limb on and walk in parallel bars. l careful walking instructions to 2 l to kitchen to prepare coffee.					
			ш	4		

^{1:} Patients are referred throughout as 'he' and therapists and aides as 'she'. This is for reasons of convenience and anonymity. Most patient were men and most of the therapists were women.

Fig. 11. continued.

		2	3	4	5	6	7	8	9
	****	1	1		l i	1			
10.00	With new cosmetic limb 3 walks in parallel			}					
10.20	bars, teaching himself to hold one rail only.		11				-		
	3 complains to patients and later to 1 that			١,					
25	limb is too heavy - little response. 1 dis-	$ \cdot $							
•25	courages use of one hand, can result in uneven					!			
	gait - negative reaction to pt. initiative.	1		Ι΄		1			
10 70	Full instruction to 3 on use of two sticks.				}				
10.30	l has informative and sympathetic discussion		'			'			
	with pt. 2.					1			
•35	l brings in the tray and hands out coffee.	İ		1	l				
•)	patient 7 arrives - 1st day - pt. has no limb						7		
	and is pushed in a wh.chair. Limb in store. Room quiet. Conversations brief.	1]				
.40	Therapist engaged in returning wh.chairs to	1							_
•40	reception, hangs up coat for 7, takes 2 to								
1	toilet in wh. chair to change catheter bag,				l	İ			
•45	ignores telephone, makes tea for late arrival,]				
•47	collects empty cups, asks each pt. re. lunch								
	arrangements and telephones canteen.			İ					
.50	8 arrives, in-patient pushed in wh.chair by		li					8	
•,•	nurse, pt. has been an amputee for 38 yrs.		Ш		١.	Ì		٥	
	A confused elderly man wearing ill-fitting			11			·		
	pyjamas and slippers.] [ı			
•55	pt. 9 arrives and 1 takes wh. chair, hangs			'					9
	coat and so forth. Therapist wipes spilled				'				
	tea. 1 pushes 8 to parallel bars but pt. is		Ш			11			
11.00	strapped into wh.chair and tried repeatedly to		'		Ì	l '			'
a.m.	walk but fails to do so. Therapist too busy	1							
	to unstrap pt, or to stay with him while he					ĺ			
	walks.								
•05	pts. discussing phantoms and pain, stairs,		ļ			1			
	prostheses, and new pt. 7, who has waited for	ł	11		l				
	half and hour, asks "what are you supposed to]			
.10	do here?" and "how long do they allow you?".			1	۱,				
	Pt. ans., information correct but disappoints								
	7. 1 pushes 7 to fitting room. New limb too						ļ		
•15	tight. 1 bandages stump hoping size will			١.					,
	reduce and puts limb on.		Ш		1]		
	Administrator to see therapist.						ļ		
.20	Room is quieter than on other days as most			'					
	pt. to pt. conversations are 1:1. Topics are				l	11			
	walking amputation prostheses, etc.								
•25	Porters enter. In-patients 4 and 5 walk			4	5	1	}		
	to wh.chairs and sit. Without speaking, porters								
7.70	push them out of the room. Pt. 4 and 5 have								
11.30	attended for 1 hr and 35 mins. and each has		11	1					
7.5	walked 8 times. Neither spoke to the therapist.								
•35	7 propels himself from the fitting room but								
	as administrator leaves therapist takes over		1						
40	and pushes 7 to parallel bars. 1st walk -		,						
•40	left alone, hampered by 9 in same bars. 1								П
	unstraps 8, lengthy explanation and helps him to walk.								
	VO HELLA]	}	1	,	
L			Ш	<u> </u>	<u> </u>	<u></u>	$oldsymbol{\perp}$	Ш	

Fig. 11. continued.

		2	3	4	5	6	7	8	9
	·		li						i
11.45	9 left parallel bars so 7 could walk but 9	1.				,	'		
	is called back by 1 so 7 sits again. 1								l i l
	assists 2 to stand, unsuccessful.	'	}				'		
•50	6 asks 1 to re-examine stump. Does so. 1	ļ	1			<u> </u>			
	brings in patients files and discusses attendance with each. 2 decides to continue	ļ							
•55	w.t. 1 tells 7 to cancel day centre and								
•))	attend w.t. 7 agrees "yes we've got to get								
	on, no messing around with this game. I'll								
12.00	tell the amb. men to get a move on". 7 was								
noon	$1\frac{1}{2}$ hrs late. 8-confused operation of knee								
	mechanism. 7 objects to long lunch break								
•05	$(1\frac{1}{2} \text{ hrs})$. He wants a sandwich and then to								
1	"get on".					1			
•05	Therapist pushes 8 back to ward,	1						8	-
į	fetches wh.chair for 3 and pushes him to	1							
.10	fitting room and checks stump, then office	1							
1 1	work. 2 asks observer to fetch money and	1	1						
	tablets. Porter puts each pt. in wh.chair	1							
.15	for lunch break, takes each to toilet,	ł						1	
	brings lunches, collects money, passes								
	cigarettes and so forth.								
			1	1	<u> </u>	<u> </u>		L	

side, one for each patient, were entered with a line denoting the time patients were engaged in walking activities, the line stopping and starting against the times patients sat or stood. Names are abbreviated here to numbers to protect anonymity and encircled for clarity. So an informal description of a walking training class was built up. These diary notes were repeated over a two week period after the ethograms were completed and the situation was fairly familiar to the observer. Some of the patients recorded previously had left the setting and new ones had taken their place. This was unavoidable but the overall situation remained the same.

The layout was that of other ethological check lists (Hutt and Hutt 1970) but the descriptions do not profess to be wholely in keeping with their impartial style. The entries tended towards what has been termed an ecological approach (Hutt and Hutt 1970), though they fell far short of the inferential, novelese style advocated by, for example, Wright (1967) for his studies into children's

behaviour which attributed motives and colourful descriptions to every act. While describing the daily organisation and order of events in the walking training sessions - the bland facts of what could be seen and heard in the room as a whole - something of the observer's impressions were included. Also the process of recording the main events was necessarily one of recording what the observer saw to be those main events. So inferences were included at two levels, overtly through the descriptive comments and inevitably through the selection of events. This was allowed on this limited scale for the following reasons. Long sequences of events with their precedents and antecedants could be described; behaviours which are snipped into their constituent parts in the ethograms could be described in full by this method. This produced data which is more in keeping with our ordinary understanding of human behaviour - goaldirected, sequential and multifacetted - which is not to be ignored in a study of human beings. Diary notes can record the tenor of behaviour through the use of adjectives, e.g. abrupt, cheerful, slowly, which provide a richer insight into the situation, though their use was not prolific. These notes also provided an opportunity for the observer to experience the research setting from another viewpoint, to record incidents specifically related to those areas of concern which provided the initial impetus for this study; to note sequences of events relating to the amputees' self-image or the socio-economic goals of rehabilitation. These notes serve as a reminder of original questions to be refuted or verified by the statistical evidence.

During data analysis these features were brought to bear. Fig. 11 illustrates the way in which a description of the session as a whole and long sequences of events are made available. The examples below show how these notes support the main data and assist interpretation.

1. In chapter eight results are given on attendance patterns. These are taken from the observer's and departmental records. The diary notes provide further evidence supporting the claim that patients arrive late. During this three

hour class which commenced at 9 a.m. we can see from fig. 11 that patients arrived from 9.15 a.m. at intervals until 10.55 a.m. We can also see the effects of this on the session as a whole, e.g. the way haphazard arrivals disrupt walking training, and so forth.

- 2. From the ethological data a quantitative account of walking training is given in chapter seven. It is important to be able to relate this to its human dimensions and this the diary notes do. For instance it is stated in chapter seven that staff undertook a fifth of all activities on their patients' behalf. The diary notes enable us to see when and where and how this occurs, for example, note the sequence of events on each patient's arrival. Also in chapter seven it is stated that only a small proportion of each session comprises actual walking training but diary notes enable qualification and expansion of such statements, showing that some patients may walk for as much as a half of the time they spend in the walking training room, e.g. patient 3, and showing the points at which walking opportunity is lost.
- 3. The case history material given in chapter eight has many sources. From these sources problematic issues arose. Frequently the diary information related to these issues and helped to resolve their interpretation when they captured moments at which a relevant activity took place or showed a sequence of relevant events.

Conclusion

In this chapter the method for data collection has been given. It comprises of an ethogram, case history records and diary notes. Descriptions of each allow the reader to judge the results which now follow. They can also be used as a basis for further para-medical research.

Chapter Six

First Results: A Report
on Centre A

Introduction

The process of devising the method establishes certain results. These are the subject of this chapter which links the method and its conclusions in a way that is not seen in experimental science.

The status of science is undergoing change. The grip of positivism in the natural and social sciences is receding, but, in this largely Oxford debate, the way ahead for the social sciences is unresolved. On the one hand it is argued (e.g. Ryan, 1970), that there are differences in the nature of causality between physical and social properties which keep the sciences apart. Alternately it is argued (Harre and Secord, 1972) that there are similarities in the fields of models, powers and natures which bring the natural and social science methods together. The experimental approach still commands the general and public view of science but it has long been superseded in both branches of scientific practice by the exploratory and phenomenological.

In experimental science the devising of a method is, theoretically, physically removed from the pilot study which tests the method and from data collection which tests the hypothesis. Both Ryan and Harre and Secord doubt that this was ever truly the case but this is ostensibly what is taking place. Exploratory science moves away from these clear distinctions, acknowledging the scientist's ideas and speculations which link each phase. In this study the ontology and epistemology are inextricably linked. This is the case in both investigative and ethological research. Development of the method, its testing and application, and to some extent its results are physically merged in the lengthy procedure of devising the ethogram. Beginning at a pre-hypothesis stage, it becomes a long process of modifying ideas and methods: a process rather like that of painting in oils where one constantly corrects and adds to one's first daubs on the canvas. It is both a technique and eventually an illustration. What sort of picture emerges?

A. The Ethogram

Observation continued at centre A until the best format for data collection was established. There were 20 pilot versions of the ethogram before it took its final shape. Not only were ideas modified, sometimes long exposure to the setting diminished its impact. This was off-set by review of earlier material and the incorporation of early themes into the later forms.

1. Gross Activity

Formulating 28 categories in itself becomes one of the results of this thesis. It established the gross activity. Refer fig. 1.

These categories were not absolute and different observers would categorise the setting differently as has been discussed. In the author's experience this framework represented the most useful breakdown of behaviour from the point of view of testing for the activities of rehabilitation in amputee walking training classes.

From fig. 1 we find that walking training classes included a great many activities other than walking training and physical therapy. There were in addition an equal number of categories for minor, routine and incidental activities which came to the fore more than had been anticipated. Understanding these is important to understanding the daily life of an institution.

2. Taught and Non-Taught Activity

A second result was established. Each activity may be taught and part of a planned programme of events or it may be an <u>untaught or unplanned activity</u>, occurring merely as a necessary entailment to the business of the patients' being present at such a session. The unplanned activity, like the minor and routine activity, was observed to be of no mean order, thus each of the 28 categories was divided (left and right on the chart) so that the unplanned aspects of each activity could be recorded. The criteria of choosing between

Fig. 1. The gross activity of the walking training environment of the lower limb amputee.

Personal Comfort: Settling In.

- 1. amb. to dept. The journey from the ambulance or ward to the walking training room, and return.
- 2. coat. Activities concerning outdoor clothes, e.g. putting on and taking off coats, hats, etc., and hanging them up.
- 3. <u>dressing</u>. All the activities concerning clothes; dressing and undressing, fetching and carrying clothes.
- 4. tea. Activities involved in providing and consuming refreshments such as tea, coffee, biscuits and lunch. (This excludes actual preparation of food and drink but includes all fetching and carrying activities.)
- 5. return cup. Returning empty and used cups and plates, etc. (Here again the cut-off point is the patient's immediate environment).
- 6. toilet. Activities concerning using the toilet and washing.
- 7. <u>adl (in dept.)</u> Miscellaneous minor acts of daily living carried out in the department, e.g. smoking, reading, delving into handbags, etc.

Rehabilitation Proper - domestic, social, recreational and economic.

- 9. <u>neighbourhood</u>. Activities of the patients' out-of-doors, community or social life brought into events in the department.
- 10. recreation. The patients' own hobbies, games, sports, passtimes.
- 11. work. The patients' work or economic affairs, e.g. pension, benefits, job, as brought into events in the department.

Amputee

- 12. cosmesis. Presentation of the self and limb.
- 13. prosthesis. All the activities concerning the prosthesis, e.g. putting it on and taking it off, discussion, portage, adjustment, etc.
- 14. stump. All the activities concerning the stump.

Walking Training Routines

- 15. <u>furniture</u>. All the activities concerning furniture and equipment used by patients. Wheelchairs as furniture are included here.
- 16. walking aids. All the activities concerning the patients' walking aids, e.g. sticks, crutches, tripods.

Fig. 1. (cont'd).

- 17. sit down. The act of sitting down.
- 18. stand up. The act of standing up.
- 19. walking. All the activities concerning moving around the walking training room. This includes all forms of walking by and for the patient. Wheel-chair mobility is included here.
- 20. standing. Standing, balance and posture.
- 21. conversation. 1 chat, exchange of pleasantries.

 2 knowledge seeking or serious conversation. (This category records those conversations not recorded elsewhere as part of other gross activity.)
- 22. falling. The act of stumbling or falling or getting up after a fall.
- 23. <u>transfers</u>. The activity of the patients! transferring from wheelchair to chair, chair to bed and so forth.
- 24. upper body exercise. All activities concerning upper body and chest exercises.
- 25. <u>lower body exercise</u>. All activities concerning lower body and stump exercises.
- 26. stairs. The act of ascending and descending steps and stairs.
- 27. <u>uneven surfaces</u>. Walking on uneven surfaces, e.g. carpets and rough ground, around obstacles and on slopes.
- 28. walk out dept. Walking that extends beyond the bounds of the prescribed walking training area, e.g. corridors, out-of-doors.

the two was based upon whether there was implicit assumption that the act was either part of the behaviour repertoire that an adult is expected to have or taught as a skill they were not expected to have. The lay man and even the doctor prescribing physiotherapy assumes one attends such sessions a) to be taught and b) to be taught certain locomotor skills. Though understood to exist, incidental and unplanned activity carries no weight in such a view, only the possibility of being badly taught or receiving the wrong treatment. Whereas the ethogram established that both incidental activity and unplanned or non-taught activity are major factors. The large proportions of each and their effects are dealt with in the chapters which follow.

3. Staff and Patient Control of Activity

Each planned or unplanned aspect of the gross activity had to be further subdivided to show who carried out or controlled the activity. In early versions
of the ethograms the author tested the use of two, three, four and five subdivisions. The author's preference from the point of view of manageability was
to have three subdivisions of each planned or unplanned act, but this did not
accurately reflect patient/staff interaction. So four subdivisions were used.
The first recorded the patient acting alone. Two central subdivisions recorded
staff and patients together, one denoting that staff led or controlled the act,
the other denoting that the patient led. A fourth subdivision recorded the
member of staff acting alone for the patient. A minor conclusion was established.
Where staff and patient interacted or were together, one led and the other
followed.

The fact that a fourth subdivision exists at all may be another new facet of physiotherapy practice which is established at this point. For scores in column 4 denoted that a member of staff initiated and carried out the activity alone without opportunity for the patient to take part. The ethograms did not record the staff workload but the experiences of the patients. Hence scores in column

4 did not denote administrative or other staff activities but referred to activities happening to and around patients and directly for them yet done by staff. It may therefore be surprising that every category caters for the possibility of recording behaviour of this type in a setting dedicated to rehabilitation or independence training. Results on this are given in chapter seven and reflect a high proportion of this type of activity.

4. Communicative Style

In addition to the most commonly used symbol 'o' which denoted that an activity carried no obvious overtone, there was felt to be a need to collect information on interpersonal attitudes and communicative style. It was hoped that the results would give statistical support to observations on teaching styles which were emerging as an important theme. This they did to a modest degree. Also, in line with Goffman's characteristics of institutions, overt incentives needed to be recorded (Goffman, 1961). There was a need to separate interaction with other patients and with the observer. The content of patient to patient activity was observed to be significant at this stage.

5. Absenteeism

Whilst attempting to observe patients in rotation, by using the alphabetical order of their surmames, absenteeism and late arrival was found to be surprisingly high. A decision was made to adhere less strictly to alphabetical order and to record full treatment sessions at centres B and C. A record of attendance and absenteeism is given in chapter eight. At centre A haphazard attendance emerged as an important feature, and there were many blank and barely scored ethograms, discussion on which is taken up later in this chapter.

6. Rehabilitation Proper

During the development of the method scoring rarely resulted in the recording of the activities of rehabilitation proper. This was so surprising - even in

view of what is known from the literature of the unsound thinking on rehabilitation - that the observer examined the setting more closely in an effort to find such activity. Activities relevant to cosmetic acceptability of patient and limb were similarly not observed. As a result a greater incidence of rehabilitation proper was uncovered when specifically searched for but a more careful eye on cosmesis did not increase scores here.

B. Investigative Data

1. The case history material

This investigation might have looked at the activities of physiotherapy classes to the exclusion of case histories. What emerged at centre A was the need to collate such histories. This was a rich and untapped source of new material. It was an especially relevant form of enquiry in a study of people. It helped to fill out and to understand the ethological data. And it presented new avenues on the mechanisms of success and failure in rehabilitation. The information would fill gaps in the literature and present new topics for research.

In particular the case history view showed something of the magnitude of the patients' problems and the bleakness of the amputee's estate. It has been recognised to a limited degree that prospects for <u>some</u> amputees are not favourable (Van de Ven, 1973, Welch and Helsby, 1973). What began to be apparent from observations at centre A was that the rehabilitation of <u>each</u> patient was blocked in some way. Each appeared to have problems which delayed or curtailed or defeated their rehabilitation efforts. Many of the issues were small in themselves and were overlooked but had important consequences. Many went untreated because they were not seen as important to rehabilitation under the present terms in which - it appears from the literature - it is understood.

At centre A examples of the issues were as follows. Loneliness made one patient reluctant to progress towards being discharged. Two patients whose marriages

were intolerable since amputation looked to walking training for comfort and companionship. One patient was so repulsed by the appearance and touch of the pneumatic limb a feeling of nausea took precedence over mobility. Excessive body weight defeated one patient's attempts to walk and flexion deformity of both hips defeated another. One patient could not wear his prosthesis because of a badly fashioned stump, another because of weight loss, a third because of pain. And so on through a list of personal, domestic, social, psychological, bureaucratic, clinical and prosthetic problems which left no patient untouched. Systematic study was imperative.

2. Biographical data: 23 patients at centre A

Twenty-three patients were observed for long periods. For a description of these see fig. 2. Many more passed through the setting but were not followed closely.

Fig. 2. Biographical data on patients at centre A.

Patients		Comments		
No. of patients	23			
men to women	7:3			
age range	13 to 92 years	80% were over 60 years compared		
mean age	64) to 73% DHSS 1980.		
cause of amputation	vascular 83% trauma 13% cancer 4%) DHSS 1980 - vascular 88% trauma 7%, cancer 4%		
unilateral to bilat.	17:6	26% bilat: 10.5% DHSS new bilat. patients.		
above to below knee	14:9	61% Ak compares to 59% Ak DHSS 1980.		
ground floor accom.	48%	active policy of rehousing		
living alone	± 35%			
outdoor mobility	low	difficult to assertain		

Amongst these patients chronic and severe illness was characteristic. Though many had been rehoused into ground floor accommodation it became apparent that much of this was unsuitable. There was little outdoor mobility. These patients relied on neighbours and relatives and social services to fulfill many essential needs. What was surprising was that most were discharged from walking training still heavily dependent upon the goodwill of others. Therapy was not related to serious living. It taught abstract skills which were not translated to daily and domestic need; a point which becomes a major theme of the histories from centres B and C.

C. Diary notes.

The diary notes helped the descriptive process. They helped in the development of the method and in discussing and interpreting the results. At centre A they formed the bulk of the material that was accrued. An outline is given here because it provides an outsider's 'first' impressions which cannot be recaptured. Also it gives a general description of daily walking training events which later detail bypasses.

1. The general impression.

As to the class as a whole it was busy and cheerful. The staff liked this work and were conscientious and hardworking. The patients were eager to attend. Working to the walking training programme layed down by Humm 1977, patients regained mobility in a gradual progression from standing briefly to walking unaided around the room and out of doors. There were moments of delight and congratulations as when a patient strode into the room on newly delivered definitive limbs or when a bilateral amputee took his first faltering steps out of the parallel bars. In a study as critical as this, the patients' occasional intense pleasure should not be overlooked. A vast amount of NHS money paid for transport and limbs and treatment that in days gone by would have been out of the reach of all those present.

There is little more that can favourably be said. What prompts such a conclusion?

2. The Staff

It was felt that the supervisory staff, of whom there were two more senior than the therapist in charge of amputee training, did not give proper support to the staff. Under the guise of expressing confidence in those they had placed in charge of patients they absolved themselves from involvement. During the period of observation they failed to guide or advise or offer their greater experience. They did not utilise their potential for leadership of the department and so confirmed rather than redirected its activities. Their knowledge of the needs of individual patients was sparse, as it appeared was their knowledge of the role of ancilliary staff. Like heads of departments in all walks of life they were willingly misled as to how much can be known through the impromptu tour.

To the author it seemed that the life of a therapist is career-structured and pension-orientated. It is arduous and frustrating and, in a general hospital, it often revolves around trivia and is subject to numerous social controls. Similar observations have been made in nursing. Saunders, 1954, depicted nurses torn between a patient centred role and a managerial role, stating that the function of the nurse is not to nurse but to see the patient is nursed. Goffman too noted the frustrations and dissatisfactions of professional workers in institutions (Goffman, 1961). The only way out is up. But promotion, prestige and reward depend upon a degree of success in treating patients. The therapist in charge of the amputee treatment was obstructed in all facets of the treatment she aimed to provide for these patients. There were surgical failures to provide stumps adequate for prosthetic walking and the referral of patients in

^{1.} One new amputee with a R below knee stump had a flexion deformity to the R knee of 30° to 40°. Though the stump was healed and sound the deformity was an old one and untreatable by physiotherapy. Adequate prosthetic mobility was unattainable. The therapist recommended above knee amputation and expressed the view that the below knee procedure had been fruitless.

hopelessly debilitated states. Liaison with the surgical team depended not on hospital policy but the approachability of individuals. Documents were inadequately compiled and instructions to the therapist were of the briefest nature. There were nursing failures, both by community and hospital-ward nurses to provide the correct stump dressings and to encourage fitness and mobility. Ward staff frequently failed to have patients ready in time for treatment sessions and sent them without essential equipment. There were frequent transport failures. Also late arrival caused amputee treatments to overlap the therapist's other commitments. Liaison with the Artificial Limb and Applicance Centre was poor, partly because of distances, partly because of feuds amongst-ALAC staff. The prostheses were cumbersome and ugly and there were long waits for alterations. Interdepartmental assistance of all types was frequently inade-

^{1.} A 92 year old patient attended walking training for over one year until prosthetic mobility was abandoned in favour of wheelchair mobility. The patient was weak, heavy, very deaf and a little confused and lived with a daughter who was willing to care for him. In retrospect the therapist's initial judgement that he was an unsuitable candidate for walking training was correct, but once having received this patient for training the interest and encouragement of the surgical and prosthetic staff made it difficult for the therapist to end treatment and appear to fail.

^{2.} Half of the patients at centre A were under the care of surgeon X and half, surgeon Y. When problems arose, surgeon X was accessible and approachable and the therapist felt that she could get help here. This was not the case with surgeon Y.

^{3.} Documents were too narrowly concerned with the disease process and did not provide social and personal information essential to rehabilitation. For example, one patient had been widowed only weeks prior to loss of the limb and was worried about a teenage child left alone at home. Only details of the loss of the limb were in the patient's case notes.

^{4.} The words 'physic please' in the patients notes, without frequency, duration or other comment, suggested little knowledge of what was entailed.

^{5.} Stump bandages prescribed to control oedema were removed by nurses when the wound healed. Sometimes the effect of the bandage was more of a tourniquet than of an evenly pressured cone. Flexion deformity of knee and hip was not uncommon and one patient was wrongly nursed with a pillow supporting the stump.

^{6.} One patient arrived for walking training wearing pyjamas and a slipper and without teeth, spectacles or prosthesis. The aides who received this patient thought him to be senile and confused and to be a new amputee. Commencing preprosthetic exercises they commented to the author "here's one for your study,

quate, problematic and time-consuming. That some of it was fair or good is not to the point if it may break down on a random basis and be seen daily to frustrate the work of both therapist and patients. The review of the literature on nursing and physiotherapy (Ch. 1.) and amputee treatment (Ch. 2.) anticipated many of these problems, e.g. poor stumps, inadequate prescription, etc., but, as shown here, many more problems were uncovered that are not dealt with in the literature.

The staff were further at a disadvantage because they were too busy. Yet the ratio between therapists and their aides working with patients during actual walking training was on average one member of staff for every two patients - varying 1:4 and 2:1. This does not include ancilliary staff. There was not a shortage of staff. The reasons for the staff being excessively busy appeared to be organisational. They undertook numerous tasks for patients. (This is discussed in chapter seven). Patients were too rarely put in a position where they could initiate their own walking training and other acts. Staff had custody of many of the patients' limbs and spent a large part of the beginning and end of each class putting on these limbs and taking them off, storing them until the next session.

The staff were also hindered by their mode of training. Basic training did not appear to have equipped its students with the modern educational theory required

^{6. (}cont'd) how do you get one like this going?" Yet the patient had been an amputee since 1932. He had been hospitalised for chest problems. His prosthesis was in the ward office. Without his spectacles he was nearly blind and did not know where he was or why. After mild recriminations he co-operated for fear of giving offense.

^{7.} Manufacture, repair and alteration of limbs seemed unduly slow. This was commonly blamed on private industry. But, in addition, misgivings emerged at this stage as to the way in which DHSS organisation of ALAC services delayed the patients! access to facilities.

to teach the physical skills. There were none of the subtle incentives one sees between teacher and child in the modern primary school. There was little evidence of planning and structure. Communication skills and information giving were very poor. Post-basic training in amputation was minimal and undervalued. Only the therapist in charge had read the literature on amputee walking training (Davis, 1977, Humm, 1977) which she felt had not adequately met her needs. The staff lacked criteria against which to analyse their workload and their failures. Thus they expressed their problems in terms of lack of resources and the patients lack of motivation. These themes are taken up in the following chapters. Generally the poor impression of the profession which resulted from the review of its literature was not dispelled.

^{1.} The regime was activity-centred and not patient-centred. While education became child-centred in the 1960s and nursing moved towards being patient-centred in the 1970s, physiotherapy appeared from observation at centre A not to have made this move. Although walking training began in the parallel bars in easy stages, other evidence of individually tailored training, of small but attainable goals, or judicious praise and so forth, these were not apparent. Group activities were favoured and these included patients who were easily able and bored, and those who were unable and unready who consequently failed. Praise was a characteristic of the communicative style of some staff and not others and appeared not to be used psychologically for best effect.

^{2.} For example ball games were used as 'fillers' at the end of sessions. As he was leaving patient A was commanded to remove his jacket and take part in a rapid game of throwing a large and heavy ball. He was tired, given inadequate instructions and failed to do well. He left feeling that he had failed. If upper body exercises were required a planned programme of graded exercise could have been given or encouragement in a socially useful or self-motivating recreational skill.

^{3.} One therapist consistently avoided replying to patients' queries. An aide told a patient that when his leg had been amputated his eyesight would improve.

^{4.} None of the staff had attended post-basic training and none had applied to do so. The member of staff with previous experience had learned from others working in the field.

The work of porters, volunteers and to a large extent students and aides comprised of doing things for patients. These staff busied themselves in fetching and carrying for patients and pushing patients in wheelchairs. The antirehabilitative effects of this have not previously been analysed and this will become an important feature of the results and conclusions. For, though their work was for the most part cheerfully and promptly carried out, it was seen by the observer to operate to the benefit of the department in a way that counteracted the rehabilitation of the patients. What became apparent at Centre A was that the patients' interaction with ancilliary and auxilliary staff could not be omitted on the grounds that their work was in some sense less to the point than that of the rehabilitationists. These staff interacted so frequently and closely with patients they they became a central part of the patients' walking training experience.

One might reasonably assume that ambulance staff would cosset patients. Their job is custodial, the safe transportation of patients. This would seem to make the work of the rehabilitation therapists all the more difficult; the patients being carefully helped immediately before and after independence training. However this was not observed to be the case. The role of the ambulance staff as observed in performance was not more custodial than that of the therapy staff. Indeed sometimes the reverse was true and patients who had been encouraged to be independent by ambulancemen, and who talked to them on equal terms, were suborned by the therapy staff who took over the initiative, even to the extent of putting patients who had walked from the ambulance into wheelchairs and pushing them the short distance into the walking training room. This was found to be standard practice at some hospitals, e.g. Centre E. Even where these wheelchairs for walking patients could be hand operated they were pushed by the porters and aides, even by the therapists themselves.

So, at many levels and in many ways the work done by the staff was undermined by outside influences or it was unhelpful, even detrimental, to the patients!

interests. Again, it is not to the point that some of their work was helpful and effective if it can be shown to have major or over-riding weaknesses. However, investigation of other centres was needed to show whether this was more generally true, and if so to what extent.

3. The Patients

The patients had a great many needs. They lacked confidence and mobility, companionship and information. They were unsure of the future, unable to move freely around their homes, even less able outside their homes. They were often ill, often worried and often in discomfort or pain. Because of their many needs they expressed the desire to attend walking training and made efforts towards attending. This was seen as the route towards becoming whole and useful again. Indeed, it was the only route these patients were offered. Yet attendance was haphazard, the sessions were not well planned and patients attended for months even years.

Their situation has been described as bleak. One may say unpromising or impoverished. Yet walking training was a lively social occasion and there were few incidents of rancour. In chapter four tactics were described whereby the author was able to obtain information on patients, not least by being a willing listener. This revealed an understandable but nevertheless wide gap between the patients' and the therapist's view of the situation. Patients put on a brave face to the world and this included the staff world of their rehabilitation department. Much of the patients' easy affability was a front. Walking training was a diversion from their problems. Patients and staff chatted on all subjects and the staff made enquiries on many aspects of their patients' domestic circumstances but it seemed to the observer there was a certain superficiality to these conversations. Gott, 1982, found nurse/patient communication to show the same superficiality. Each held themselves at a distance and avoided sensitive topics. The staff/inmate distinction used by Goffman, 1961, was borne out here. Hence, amongst those described by the staff as 'doing well'

were those whose marriages were breaking up, patients who reported to the observer to be too ashamed of their artificial limbs to venture outside their homes and those who were lonely or troubled to the point of suicide. The staff lost many opportunities for information gathering and information giving when replying to patients' queries. Often they gave vague, even incorrect answers even on prosthetic and health topics. Questions from patients were ignored, skirted or pushed aside in a narrow focus on mobility. Patients asked the most searching questions of each other and passed on ill-informed comment to each other. One patient who attended only as a 'social case' spoke to no-one.

The patients did not know what being an amputee involved. Their lack of information was asfundamental as not being able to formulate the right questions.

This was not fully appreciated by the author at Centre A and will be discussed in later chapters. 'Being native' at first blocked the author's view.

The staff used to a significant extent the attitudes and practices Goffman has delineated as typical of society's treatment of those with low status by virtue of being disfigured and deformed or 'disabled' (Goffman, 1963). These attitudes and practices were given in chapter one. There was no substantial evidence to the contrary at Centre A though whether this is a feature of amputee classes more generally remained to be seen. Even allowing that the participants included teacher and pupil, staff and patients were not on terms of reciprocal mutual dignity. The patients lacked autonomy and staff of all grades controlled their actions far in excess of what was necessary. Too often patients waited for cues to begin activity. Failure to wait was sanctioned by reprimand and rebuke,

^{1:} A patient rose from his seat and took one step towards the tea trolley in order to return his empty cup. His cup was quickly taken from him by a senior therapist and the patient reprimanded at first for this act then ridiculed in a joking manner. As the patient was particularly able-bodied this degree of staff control seemed inappropriate.

^{2:} A system had developed whereby patients waited and took turns with an aide or therapist to walk even when they were capable of standing up and walking alone.

sarcasm and ridicule, appeals for safety and general order and so forth. The order of the day was dictated by staff. It was not negotiated. blunt approaches, invasions of privacy and patronage. The patients had lessthan-fully-adult status, the examples of which were many. Staff began without permission to undress patients and cut short their activities or conversations in pursuit of staff business. Men and women were undressed in view of all the others in the room. Staff used pet names and patted and cajoled the patients. The praise was not excessive but it was often patronising and inappropriate. Patients were obliged to answer all staff queries but their own were not equally answered by the staff. Activities initiated by the patients were curtailed or taken over by staff. A particularly depersonalising act was the removal of limbs by staff sometimes without even the tacit permission of the patient. Expectations were notably low and the stated aim of treatment was to enable patients to 'potter about'. Amputee ability to walk and act normally was interpreted in the staff world, not as a matter-of-fact consequence of adequate prosthetic replacement but along the lines of being superhuman, courageous or mysterious.

4. The Prostheses.

Jurisdiction over the prostheses remained with the staff. Although there was overt encouragement to patients to put on their own limbs and become independent on these limbs, staff retained the right to touch, adjust or remove these limbs

^{1:} A patient who left the rather small walking training room to continue walking exercise in a larger adjacent room was reprimanded when he returned on the grounds that the staff were responsible for him and that he would get them into trouble if he went missing or had an accident.

at any point. Indeed patients attended for weeks, even months, before staff allowed them to take their limbs home and wear them outside the walking training environment.

We have seen in chapters three and four that it is both logically and empirically the duty of the physical therapist to unite patient and limb. Yet as observed in performance the first act of the therapist was to remove or withhold the limb from the patient and only gradually to give it back. The patient's first experience of limb wearing was the pneumatic limb (PPAMA). These limbs always remain under direct staff control. They were designed to be applied and removed by staff and used for brief periods of walking under direct supervision. This continued for some weeks until successful delivery of a pylon. A few of these new limbs were sent into store at the walking training class awaiting an opportunity for the patient to attend. Most were given to the patient. Some attended wearing the new limb, some carrying it. Many of these limbs were then withheld by the walking training staff. The reason was custodial, i.e. safety. The patient was allowed the limb when he had mastered the rudiments of walking. As patients attended for what might be only minutes of walking training each week (refer below) this process sometimes took many months, during which time the limbless patient we can only assume adapts to non-prosthetic forms of mobility. He may hop to the detriment of the contralateral leg or sit in a wheelchair to the detriment of his general health. Meanwhile a row of well-fashioned and expensive limbs waited in a rack in the walking school while elsewhere patients waited to walk. Here, it seemed, were the basic ingredients for the non-use of limbs noted in chapter two.

From the point at which they were delivered cosmetic or definitive limbs usually remained in the patients control in the case of unilateral amputees but were withheld as above for bilateral amputees, and many patients would not progress to definitive limbs.

Like other surprising conclusions from centre A, this aspect needed to be followed up at other centres. It seemed here that caution and poor planning operated against the object of providing limbs.

The PPAMA and pylon are both very ugly. One patient fainted at the first sight of a PPAMA being applied to the stump. This huge blue bag was an unexpected compensation for a missing limb. Generally the patients were encouraged by their ability to take their first steps with the PPAMA but found the limb unwieldy. They expected things to improve when their pylon was ready. Finding this to be equally ugly and often as cumbersome they expected improvement when they had a cosmetic limb. Many did not progress to a cosmetic limb. Some were disappointed when they did. Only slowly did they adjust to the disappointments and difficulties of being an amputee. The patients seemed to have no fore-knowledge of the sort of limbs they could expect to receive or when, or how they would be fitted. Little information was available at the Limb Centre.

5. Attendance

The general impression was that walking training attendance was low and haphazard and that when patients were present at their classes they did little, confirming institutional characteristics noted in the literature review; the sense of dead and heavy hanging time (Goffman 1961) and the lack of urgency. On some days there were no patients - and hence no walking training - due to industrial dispute affecting the transport services or all the patients individually being unable to attend. On other days there were patients but no walking training as such because either the staff, the room or the patients were required for staff training purposes. It was not unusual for only half of the expected numbers to attend or for half of the patients to be more than half of the session late in arriving. The attendance register listed further numbers of patients who had not attended for long periods, usually because of illness.

Out-patient attendance was hampered by transport problems, industrial dispute. communication break-down, poor weather, other hospital and ALAC appointments, social service appointments, home help visits, and often by poor health. Outpatients sometimes turned away their ambulance transport knowing it had arrived too late for their treatment session. Sometimes out-patients accepted these late and fruitless trips. Having sat and waited in hat and coat for up to two hours they wanted an outing, though they knew they would not be accepted for treatment. In-patient attendance was low. It was sometimes not convenient for the therapist to send for the patient, or ward staff did not prepare the patient, e.g. the patient was not dressed or not clean, still having lunch or being bathed or again the patient was too ill to attend or having further surgery. There was no evidence at this point that patients were avoiding their treatment sessions or failing to co-operate. The impression was the reverse, with no evidence of anything done by those in charge to improve attendance or alleviate the effects of non-attendance. Low morale did not seem to be a factor but the fact that attendance appeared to the author to be so unrewarding may have reduced the patients' motivation to attend, as observed by Revans, 1964.

Had attendance been excellent there appeared to be considerable evidence that the classes were in any case not well planned and that patients did far too little as a result. This cannot be judged against the treatment prescription because frequency and duration were not given. Also, because it concerns judgements on the patient's state of readiness, his health and the state of the stump, it deals with topics on which the author is not qualified to comment. Yet it did not seem that therapy was sufficiently intensive. In one week the maximum period of walking training was three hours, i.e. three classes of one hour each. In the most favourable circumstances this period can be reduced by a half for even the most able patients only very rarely walked for more than half of each session. Indeed the available floor space did not permit all the patients to walk at once. Often two patients shared a single set of parallel bars and walked

alternately, limiting each other. Other patients had to wait their turn to be accompanied by staff, sometimes because bars were not available, sometimes because patients were not permitted to walk alone. The walking time was further shortened by the practice of retaining many of the limbs at the centre so that each session began with ten to fifteen minutes of putting limbs on and ended with a similar period of removing them and dressing. Frequent puncture problems with the pneumatic limbs meant that sometimes two patients shared one such limb. So, months of walking training can be seen to comprise of only minutes in a week. As noted in chapter two similar tardy practices were found in the field of lower stream education (Hargreaves 1967, Lacey 1970). It was not uncommon for patients to walk only once or twice in a session. One patient who arrived on time stood only once, did not walk and had no other therapy because the staff were too busy to give him more attention. A patient who attended in order to wear his first limb for the first time was not seen by staff who were too busy. He had to return two days later when he did use the limb but only very briefly, and it was a further four days before he was reunited with his limb and given instruction with a therapist and aide. Patients with newly delivered limbs and requiring intensive treatments attended for the same intermittent short sessions as those who came for social contact or what were termed 'topping up' exercises.

When one considers that these out-patients spent four to five hours attending these sessions, sitting at home waiting for the ambulance, sitting in the ambulance and in the waiting room and again in the waiting room and ambulance, their few minutes of therapy barely seem to warrant such disruption of their domestic routine. And when one further considers that it is the patient's domestic routine that is of paramount importance - walking training being the means of assuring its success - it is ironic that its serious disruption is caused by the rehabilitation process. The logistics of this situation appear not to have previously been given serious thought. Attendance patterns varied considerably at Centres B, C, D and E. Optimum patterns will be discussed in the light of

data from these centres.

6. Group Exercises.

In conclusion, a feature of these classes were team games. The rituals of these illustrate something of the dichotomy that appeared to exist between walking training and the patients actual rehabilitation needs; what Goffman, 1961, has described as the incompatibility between institutional activities and the basic work - payment structure of our society.

The games began without explanation. There were commands to remove limbs, sit in a circle, lie on the floor, pass the ball to a team mate and so on. The rules changed with some rapidity. Observing these events it was impossible to reconcile the behaviour that was encouraged or reinforced with the rehabilitative purpose of physiotherapy. For example, staff displayed reluctance to part with their authority over the proceedings, the communicative style was commanding and patients' queries about what was to happen were met with 'wait and see'. So unquestioning obedience was encouraged which is contrary to the idea of rehabilitation, the idea of independent and autonomous living. removing limbs in the course of rehabilitation is equally contradictory and requires the strongest justification. Rehabilitation, for the lower limb amputee. is totally bound up with use of a prosthesis. In physical terms ball games are a means of toning muscles and developing co-ordination but in the socioeconomic terms of rehabilitation they encourage team spirit which is especially irrelevant to the elderly who live alone and ball skills are particularly

^{1:} Patients were reluctant to remove their limbs. Some complained to the staff. Those who did not remove limbs were told they were unco-operative and finally if the patients did not comply they were told that their walking training would be terminated. All patients eventually complied.

useless to patients who, in this instance could not comfortably move around their own homes or rise from a favourite armchair. As well as commanding the tone was also one of ridicule (amongst equals it might have passed for good-humoured banter but that was not so here), together with the rapid change in rules meant that failure was inevitable. Again, this style of training seems at odds with ideas on rehabilitation. On the whole it was felt that the physical aims could have been achieved in more relevant and less unpleasant ways. It is also of interest that here we have an example of 'the disabled' training to be 'as normal' by means that are divorced from the activities of serious living.

(7. The Limb Centre Used by Centre A Patients.

Investigation of the DHSS Artificial Limb and Appliance Centre (ALAC) used by patients undergoing walking training at Centre A revealed a great many shortcomings but it is difficult to present a case to support this statement fully and at the same time maintain anonymity. The shortcomings were in connection with lack of care of patients, lack of focus on their many needs and lack of information for patients. To give examples of lack of care, patients took elderly wheelchair patients to the toilet, elderly and diabetic patients were without refreshments for long periods, there was too little comfort for those who were disorientated or worried which included patients who felt too nauseous to eat or were in great need to talk. Lack of attention to patients' needs resulted in the patients' abuse of the appointment system in order to receive attention and circumstances whereby patients in effect prescribed their own limbs. To give examples of lack of information, an educationally subnormal porter undertook reception work and was left to answer patients' queries, almost none of the means whereby information might have been transmitted posters, leaflets, discussion - were put to use, and medical officers who knew little about their patients cut short patients! queries and contributions during consultations. The reasons for this state of affairs seemed to be as follows:

Staffing levels and routines were not well organised. The work of some members of staff was slip-shod. Feuds and temperamental outbursts on the part of staff were allowed to interfere with patient care. The bureaucracy did not operate to meet the patients' urgent need for limbs. The staff had too little knowledge of many of the circumstances surrounding loss of a limb. These and other short-comings were beyond the control or amelioration of Centre A staff. They illustrate other areas, other departments and services used by amputees where research might profitably be directed in the future.)

D. Discussion

To the credit of the physiotherapists of Centre A they taught patients how to put on their limbs and to walk with them, thereby increasing mobility and normality and thereby enhancing rehabilitation prospects. They also offered a safe and private environment in which patients could gain mobility and confidence. Some patients might have progressed as much on their own. Some certainly would not. Yet in order to attend such classes and gain the benefits of qualified assistance, the patients had to sacrifice autonomy and dignity, the authority for their replaced limb and a large slice of their domestic routine; each of which contradicts the notion of rehabilitation. These sacrifices are particularly weighty on two counts, firstly, because they affected the larger slice of the patients' remaining lifespan and secondly, because they are made at the crucial period when the patient is learning what is involved in being an amputee.

To weigh the gains of correct ambulation against the loss of such qualities as dignity leads into the most insubstantial areas of the subject. Much social science research fails to come to fruition because of its dealings with such imponderables (Douglas 1976, McCall and Simmons 1969). Yet the subject is worth pursuing because although conclusions will not always be quantifiable already areas of certainty begin to emerge. In walking training we find on the one hand mobility training which is rehabilitatively beneficial and on the other custodial

and authoritarian practices which are anti-rehabilitative. There is a process of independence training which at the same time confirms dependence. One cannot say at this stage which weighs the more heavily but already one can show that these two features exist.

Here at Centre A were strong reminders of Goffman's characteristics of total institutions (Goffman 1961) and his characteristics of normal expectations of those with stigma (Goffman 1963) each of which provide points to pursue. These occur in many guises throughout the results of data collection. They are drawn together for discussion in the concluding chapter.

Conclusion

At Centre A the rationality and order of amputee walking training is disclosed as problematical. With over 5,000 new patients each year it becomes urgent to find out whether these impressions are borne out in systematic investigation of other centres. For although Centre A was well disposed towards walking training, the apparent contradictions gave rise to the felt need to turn to other centres for the main body of data collection. The models given in the opening chapters were found to be relevant and useful and the practice of rehabilitation was found at this initial stage to be as problematical as review of the literature might suggest and thus worthy of further study.

Chapter Seven

Ethological Results: Centres B and C and Reference to Centre D.

Introduction

Little is known of the day to day process of physiotherapy. The purpose of this chapter is to describe that process for the first time. Description is based on ethological records from Centres B and C which establish a framework of events. Diary notes enable expansion of the framework and assist in discussion. Finally there is support from data collected at Centre D.

In the ethograms, 5106 incidents or activities were recorded. These represent activities relating to nine patients at Centre B and ten at Centre C whose attendances were observed and recorded in the manner discussed in chapters 4 and 5.

Results will be discussed in relation to the structure of the ethogram. It will be recalled that in Chapter 4 the twenty-eight activities were classified into five groups of activity. (Refer also Appendix I). Results will be discussed in relation to these first.

A. The Five Groups of Activities

Using the five major groups of activities as a useful classification - identified as above - we find the following distribution of events. Refer fig. 1.

Fig. 1. The results of the ethological data, Centres B and C, given by groups.

group	No.	%
minor functional activities	3119	61.08
conversation	763	14.95
physical therapy	620	12.14
prosthetic, cosmetic and clinical	560	10.96
major functional activities	44	•86
	5106	100%

1. Minor functional activities

The most striking thing is the preponderance of minor, routine and incidental tasks. More than half of the activities could be classified as minor functions which is five times the number of activities classified as physical therapy. As the method of data collection if anything underestimates the percentage of these minor functional activities - for the reasons given in the methods chapters that it was not always possible to observe minor acts in waiting rooms and during lunch breaks and so forth - the true figure may be higher than this. It becomes important to find out how these minor tasks were undertaken - which further breakdown of the ethological results will reveal.

2. Conversation

This refers to conversations other than those which were part of activities in the other four groups. Even this small proportion of the total conversation exceeds the amount of physical therapy. The figure does not over-represent these conversations. Often they were lengthy but the method by which they were recorded in many cases attributed to them a single score while in other categories actions which were short also received a single score.

From its beginnings as an observation category the data on conversation develops into a major finding with important implications for physiotherapy. It might usefully be discussed at this point. Three quarters of these conversations were banter or chat and a quarter were knowledge seeking exchanges. The banter had many functions, e.g. it established the status of the participants and served to introduce knowledge seeking conversation. In the more serious exchanges the needs of the patients and the attention given to those needs were

^{1:} The results were recorded and analysed as unitary activities and frequencies have been used to summarise the raw data. Whilst this type of analysis is not directly related to time spent, it reflects time; which was recorded in the diary notes. These latter help to validate the results as well as helping the author in interpretation of the ethological data.

often at their most apparent. Patients initiated conversation with other patients and with staff on all aspects of their treatment and rehabilitation; a far greater range of rehabilitation topics than were initiated by the staff. When pursuing enquiries with other patients their mutual lack of knowledge frequently prevented an accurate or useful outcome. But when pursuing such enquiries with staff the outcome was often not more successful. Often the staff were observed not to listen or to reply fully and all of them cut short these conversations for one purpose or another presumably because they failed to see the importance of these enquiries. This was true of porters and doctors, therapists and auxilliaries. The staff's lack of knowledge may have been a contributing factor as evinced by how little the therapists knew about their patient's social and domestic circumstances, also as evinced by the fact that one of the therapists at each centre not infrequently asked the observer how to carry out procedures. One therapist was observed to have extensive knowledge and to systematically give pertinent information to patients. She listened to queries and discussed the points raised though this was usually on a staff initiated basis and some topics raised by patients were regularly skirted, e.g. social events, out-of-door mobility. Also one porter sat with patients and talked at length to them on a variety of lively social topics but much of this conversation was also mischievious and malicious, e.g. undermining confidence in the medical officers and senior therapist by suggesting negligence and ill-temper. Excellent communication skills were shown by an aide who acted on small cues from the patients, elicited information and passed this on to those in charge. Otherwise, the picture was unsatisfactory. At the other end of the scale one therapist of many years experience did not allow patients to talk at all during walking exercise and cut short all queries with the catch phrase 'you do the walking and I'll do the talking'. Research has revealed similar shortcomings in communication between nurses and patients (Faulkner 1980, Gott 1982, McCleod Clark 1982).

In chapter eight the case history data illustrates the consequences of poor communication.

3. Physical therapy

Physical therapy comprised an eighth of the activities of these physiotherapy classes. This figure may be overestimated for two reasons. The proportion of minor functional activity and conversation may be greater. Also physical therapy activities were often complex and many scores were sometimes necessary as the initiative or tone of the activity changed. The true figure could be lower than 10%.

This figure seems small. It contradicts one's reasonable expectations of such an environment. (One would not for example attend a health studio, swimming baths, evening class or hairdressing salon if it were thought that such a small proportion of the main activity were available even where there is expectation of other activities such as chatting, changing clothes or taking refreshment). This is a crucial finding and raises serious misgivings as to the organisation of physiotherapy sessions. It was also unexpected as there is nothing in such authorities as Humm to suggest that physical therapy would be such a small proportion of total activity.

Taking a broader view of the value of all types of activities that occur under the auspices of 'the physiotherapy class' the implications are relevant to all facets of physiotherapy theory and practice. For in accentuating the importance of other and incidental activities the task and technique orientation of the profession is brought into question. It is no longer possible to see these classes comprising primarily of physical training and physical exercise and we look to the therapists for equal competence in a range of inter-personal skills which are required for the larger proportion of the activities.

If the proportion of physical therapy were to be given as a proportion of the

time an out-patient spends in direct NHS care and at direct NHS cost, that is from the point of departure by ambulance to their return home, then the proportion of physical therapy would be further reduced. For example at Centre C patients often spent longer in the ambulance than in the department. Added to the information that patients dislike the 'milk round' collection system (Welch and Helsby 1973) and as suggested in this thesis that it disrupts daily living and removes the patient from the environment with which he has to learn to cope, it may be more cost effective to move walking training out of the department and into the home.

4. Clinical Activities

These comprised a tenth of the total. They related for the most part to fitting and removing prostheses and examination of the stump. One would expect this proportion of activity to vary considerably depending upon the pathology of those undergoing treatment and that it should represent a fair proportion of events in the case of lower limb amputee classes because of the newness of the wound, the considerable prosthetic dimension and the specific aim of uniting patient and limb. Just such a 'fair proportion' is represented here but, as will be discussed in the further breakdown of the ethological record, it did not represent those activities one most looks for in rehabilitation.

5. Major Functional Activities

These activities of rehabilitation proper are barely represented. It is not the contention in this thesis that these socio-economic activities would be greatly represented in physiotherapy classes but that physiotherapy should enhance and not hinder progress towards them. Closer examination of the 44 incidents in this group indicates a failure to enhance or encourage rehabilitation. In most of the incidents no member of staff was involved. Of the remainder therapists failed to answer patients queries or halted patient to patient enquiries as often as they encouraged such topics. (Refer Fig. 2.)

Fig. 2	• The	Incidence	of	Major	functional	activities	or	rehabilitation	proper.
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description	no.	% of total		
Patient to patient (or observer)	.27	•52		
therapist blocks patient initiative	9	•18		
therapist encourages or initiates	8 44 : 5106	.16		

So, in what is universally held to be a rehabilitation setting the figure for direct staff encouragement or enhancement of rehabilitation proper was 0.16% (8:5106). Some under-estimation may have arisen because of the difficulties of recording accurately the content of patient to patient conversation but this does not affect the score for staff involvement. A figure of not more than 1% is felt to be substantially accurate for the proportion of rehabilitation proper. This has a bearing on suggestions made in Chapter one that rehabilitation services operate on an unsound ideology and that the institutional setting is of questionable value.

Discussion

During the period of observation rehabilitation was seen to be neither the focus nor a feature of walking training. The overt focus was the business of practising certain locomotor skills. In reality, incidental activity was its main characteristic. Lesser features were prosthetic and social.

These results beg the question, what is their relationship to time? Some distortion arises from this style of ethogram but it does not invalidate the broad trends of the results. For example much of the incidental activity was short and may be over-represented on this account but against this much of it was unrecorded and there is no record of time patients spent sitting and waiting which would greatly add to the minor and incidental nature of these sessions.

It was often the case that individual walking exercises were lengthy, i.e. of five or ten minutes duration, but the tendency of therapy activities to be complex and interactive and require more scores per activity counters this to some extent. Having neither duration or emphasis the 44 incidents of major functional activity may be less and not more prominent if measured against time.

B. The Twenty Eight Categories of Activity

The process of developing the 28 category ethogram in itself produced certain conclusions and these have been discussed in chapter six. Using this ethological framework the distribution of activity was as follows. Refer Fig. 3. These results can be discussed in three groups, a high, low and middle frequency range.

1. Activities comprising a frequency less than .5% of the total

Seven activities were barely represented. These include all four categories of rehabilitation proper, comprising the group which has been discussed in section A.

The action of falling or stumbling rarely occurred: the walking school does indeed provide a safe environment. As recommended (Humm 1977), patients were taught how to sit down safely and rise from having fallen, though only at one of the centres. It was overlooked at the other.

Walking outside the boundaries of the walking training room occurred at the instigation of the staff as a modest part of the programme. Patients rarely initiated this move which was subject to reprimand from the staff and appeals to custodial responsibilities, though more at one centre than the other. (At Centre B patients could not go to the adjacent toilet without permission and an escort). The low incidence of this activity was felt to be indicative of institutional control, i.e. the patients' loss of autonomy of movement and the staff role of surveillance as characterised by Goffman 1961.

Fig. 3. Frequency Distribution of Activities in the Twenty Eight Categories,

Centres B and C.

	category	no.	%
	walking	942	18.4
high	conversation 1 and 2	763	14.9
over	stand up	465	9.1
-4	prosthesis	460	9
5%	sit down	387	7.6
	walking aids	348	6.8
	tea	229	4•5
	furniture	193	3.8 -
	ambulance to department	153	3
	adl (in department)	150	2.9
	standing and posture	136	2.7
mid-	coat	127	2.5
dle	dressing	122	2•4
	lower body exercise	100	2 .
	return cup	92	1.8
	stump	91	1.8
	walking - uneven surfaces	81	1.6
	transfers	52	1
	stairs	48	•9
	upper body exercise	43	•8
	toilet	33	•7
	walking - out of department	22	•4
low	home	20	•4
	community	20	•4
under	falling	16	•3
•5%	cosmesis	9	•2
	work/economic activity	4	.1
	recreation	0	0
		5106	100%

Cosmesis was overlooked entirely. The term is used here as a short form for the patients' appearance and presentation in everyday life. This is important to rehabilitation because of its potential to minimise handicap through appearing ordinary or normal. This more than any other was an area of lost opportunity. The staff failed to advise or comment on dress and posture, noisy and obtrusive limbs and even sometimes on gait. Patients were observed to limp in the presence of therapists who did not comment. Long-stay in-patients were accepted for treatment wearing pyjamas and slippers, even in dirty clothes worn over pyjamas. Therapists taught forms of locomotion that are ridiculous to the normal eye such as the practice of ascending stairs wearing a walking stick around the neck and, when turning, always going in the direction of the non-amputated limb regardless of the direction the person needs to travel. None of the tricks of 'passing as normal' (Goffman 1963) were part of their repertoire. All scores in this category (9:5106) refer to the practice of one therapist who, regardless of the wishes of patients, fastened all buttons on cardigans and jackets. No direct attempt to teach new amputees to wear their new limbs unobtrusively and present themselves as whole and normal was observed. Again with reference to suggestions made in chapter one, here is important evidence of stigma operating within a rehabilitation programme. Amputee patients were not seen to have normal wants.

A major failing here was NHS failure to provide cosmetically acceptable temporary limbs. Patients commenced walking with large blue inflatable limbs and the very ugly iron pylons. One therapist noted the effects of these with dismay and with this handicap therapists may be forgiven for not emphasising their patients' appearance. To a lesser or greater degree every patient said the cumbersomeness and unsightliness of pylon wearing caused them to curtail outdoor mobility.

2. Middle Range Frequency. Activities comprising .5% to 5% of the total.

Most of the minor functional activities fall into this range, e.g. tea, dressing, furniture, coat, toilet and so forth, also therapy activities other than actual walking training, e.g. stairs, uneven surfaces, toning exercises, posture and so forth. And there is one clinical category, the stump. The minor functional, incidental and routine predominate. Such activities as moving furniture for patients or the business of getting from the ambulance and into the department were two or three times greater than physiotherapy activities such as attention to the stump, toning exercises, walking over uneven surfaces or climbing stairs.

3. High Frequency. Activities over 5% of the total.

Four of these six consist of walking and its closely related activities, i.e. sitting down, standing up and use of walking aids. Walking is the single activity most likely to occur. Together with its related activities it accounts for 40% of the total. But, as will be shown, much of this walking was incidental or done by staff, and actual walking training was not 40% but under 13%.

There was a 15% incidence of conversation which has been discussed in Section A, and 9% activities related to handling prostheses which will be discussed in Section D.

Discussion

The ethological record splits behaviour into its constituent parts but it is possible to draw this record nearer to our everyday understanding of behaviour

^{1:} This is a useful point at which to remind the reader that all scores refer to activities in which a single patient is involved during the course of a treatment session. So scores in the category 'furniture' are not a comment on the work load of the staff, e.g. preparing the room in readiness for the patient. The scores record events initiated by the patient or initiated or carried out directly on his behalf as part of his progress through the period spent in the department. Scoring under such categories as 'furniture' would have been increased significantly if the staff rather than the patients had been the subject of the ethological records.

by grouping related activities and their scores. In reality the categories are not so distinct and regrouping is possible in many forms. An example is given in Fig. 4. But this exercise yields the same pattern of results. In descending order, walking predominates followed by conversation and attention to prostheses. A broad band of minor and routine activities lie next, then other therapy and lastly the major functional and cosmetic.

Fig. 4. The 28 categories simplified to 14.

activity	no.	%
walking (standing and falling)	1181	23•4
sit down, stand up and transfers	904	17.7
conversation	763	14.9
stump and prosthesis	551	10.8
walking aids	348	6.8
tea and cup	321	6.3
coat and dressing	249	4•9
furniture	193	3•8
adl (in department) and toilet	183	3•6
ambulance to department	153	3
upper and lower body exercise	143	2.8
stairs, steps and uneven surfaces	48	•9
major functional	44	•9
cosmesis	9	•2
	5106	100%
	walking (standing and falling) sit down, stand up and transfers conversation stump and prosthesis walking aids tea and cup coat and dressing furniture adl (in department) and toilet ambulance to department upper and lower body exercise stairs, steps and uneven surfaces major functional	walking (standing and falling) sit down, stand up and transfers 904 conversation 763 stump and prosthesis 551 walking aids tea and cup coat and dressing furniture 193 adl (in department) and toilet ambulance to department 153 upper and lower body exercise 143 stairs, steps and uneven surfaces 48 major functional

Close similarities in the results from Centres B and C have allowed them to be discussed together. (Refer Appendix II). The single notable exception was upper and lower body exercise which was a feature at Centre C but not at Centre B. Otherwise the pattern of events indicated by Figs. 3 and 4 is supported

by events at two independent centres.

Distributed by categories the activities of a walking training class would seem to be primarily those of uniting patient and limb, of walking and related conversation. Though minor tasks encroach and cosmetic and socio-economic activities are overlooked, all may appear to be as it should be. However, in the study of human relations this form of presentation is superficial and is the least satisfactory. In pursuing how activities were carried out and by whom a much more appropriate distribution is possible. It is here the strengths of moving away from the more traditional forms of ethogram are revealed.

C. Taught and non-taught, planned and unplanned activity.

Using the classification of activity into 5 groups, as already discussed in Section A, the majority of activity was found to be minor and routine (61.08%) Using the categories themselves as in Section B, walking is the major single activity (18.4%). When the results are interpreted in terms of whether they were taught or non-taught activities we find by far the majority of events are unplanned or not part of a deliberate learning programme. This figure is 79.14%. (4041:5106). Only 20.86% of activities were planned or taught. (Refer Fig. 5 and 6).

It is now apparent that the greater proportion of walking and its related activities are not part of the walking training programme but occurred in an incidental manner when patients and staff carried out what were mostly minor and routine tasks. Walking training is 8.9% (454:5106). With its related activities (standing, sitting, using aids) it is not more than 13% of the total.

In this investigation which attempts to deal with the less hard facts surrounding amputation it is inevitably nearly always the case that classification is problematic. Additional to the problems of studying human interaction, there

Fig. 5. Distribution of activity given by non-taught (left) and taught activity (right) in the 28 categories.

NON-TAUGHT			TAUGHT		
category	no.	%	category	no.	%
conversation 1 (chat)	559	11	walking	454	8.9
walking	488	9•5	conversation 2	204	4
prosthesis	460	9	lower body ex.	98	1.9
stand up	401	7•9	uneven surfaces	79	1.5
sit down	350	6.9	stand up	64	1.2
walking aids	337	6.6	upper body ex.	41	.8
tea	229	4.5	sit down	37	•7
furniture	191	3.7	stairs	35	.7
ambulance to dept.	153	3	walk out dept.	16	•3
adl (in)	145	2.8	standing	12	.2
coat	127	2.5	walking aids	11	.2
standing	124	2.4	adl (in)	5	•1.
dressing	122	2.4	falling	4	.08
cup	92	1.8	transfers	2	•04
stump	90	1.8	furniture	2	•04
transfers	- 50	1	stump	1	•02
toilet	33	•6	ambulance to dept.	0	0
home	20	•4	coat	0	0
neighbourhood	20	•4	dressing	0	0
stairs	13	•3	tea	0	0
falling	12	•2	cup	0	0
cosmesis	9	•2	toilet	0	0
walk out department	6	.1	home	0	0
work	4	.08	neighbourhood	0	0
upper body ex.	2	•04	recreation	0	0
lower body ex.	2	.04	work	0	0
uneven surfaces	2	•04	cosmesis	0	0
recreation	0	0	prosthesis	0	0
	4041	79.14	*	1065	20.86

Fig. 6. The percentage of taught and non-taught activity in each category.

category	not	25 50 75	taught
and or service	taught	ty, and indeed chat, each of whi	5 2276
walking	52	Examples Company	48
conversation 1 and 2	73	mes can be longer by overlockely	27
stand up	86	errelator as help religions	14
prosthesis	100		-
sit down	90	constitution are to be reported to ton	10
walking aids	97		3
tea	100		-
furniture	99	of canada and a proper, the s	nor least
ambulance to dept.	100	THE OF RESERVE WAS TRANSPORT - COSTS	ds, care
adl (in)	97		3
standing	91		9
coat	100	and the first street.	-
dressing	100		-
low body ex.	2	Company of the Compan	98
cup	100	10 10 10 10 10 10	-
stump	99		1
uneven surfaces	2		98
transfers	96		4
stairs	27		73
upper body ex.	5	A STATE OF THE STA	95
toilet	100		-
walk out dept.	27		73
home	100		-
neighbourhood	100		-
falling	-75		25
cosmesis	100	one total activities which as	•
work	100	- Service but makely or not -	-
recreation	-	, , , , , , , , , , , , , , , , , , , ,	-



are etymological dilemmas in use of such words as minor, incidental, taught and unplanned. But firm ground remains, namely the large proportion of routine activity, and of untaught activity, and indeed chat, each of which have been measures in different ways. Physiotherapy classes comprise overwhelmingly of the mundane which the author argues can no longer be overlooked. Here are wasted resources and missed opportunities to help patients.

When the taught and non-taught activities are interpreted in terms of the five groups, the way in which opportunities are lost is apparent in the failure to teach the major functions of rehabilitation proper, the minor tasks of daily living, and the three facets of clinical treatment - cosmesis; care of the stump and prosthesis. (Refer fig. 7).

Fig. 7. The taught and non-taught activity in the five groups.

group	non- taught	25 50 25	% taught
minor functional	92.7	paring. Though one would not aim	7.3
physical therapy	.6	eday, et san te una recrait - esan Line	99•4
conversation	73	us lecked as wises of sell-knein	27
clinical	99.8	out giner tasks for themselves. I	.2
major functional	100	eses were not uniontains in a ninew	Nil

the 80% of the total activities which are not deliberate or taught but merely occur.

the 20% of activities which are part of a

teaching and learning programme.

The learning programme was one of physical therapy. Outside this there was very little deliberate teaching. Conversations consisted of 27% knowledge seeking exchanges and this has been included with the more planned and delib-

erate activities but as much of this conversation arose haphazardly and, as there was a high incidence of failure to deal adequately with queries, it is a dubious category for inclusion here. The diary notes show however, though cosmesis and care of the stump were neglected in the teaching programme, each patient had some instruction on artificial limb wearing. As this accounted for a relatively small amount of teaching time, e.g. occurring only once during the patient's first visit with a new limb, or once only on an unplanned basis, it is unfortunate that it is not present in the ethological record.

Discussion

On the question, posed in chapter three, of whether or not physiotherapy enhances rehabilitation in sections A and B we see that rehabilitation proper was not a feature of these classes. In this section we find, in addition, that activities which may be seen as the means or route to rehabilitation were not encouraged, reinforced or taught. Those are the minor daily tasks carried out in the department for which there are corresponding domestic acts such as moving furniture, taking tea and dressing. Though one would not expect a high incidence of the teaching of minor tasks, which would probably indicate tedious and repetitious teaching, the settings lacked an ethos of self-help. Patients were all too rarely taught to carry out minor tasks for themselves. It seemed to the observer that the classes were not orientated in a conscious manner towards the patients gradually taking over these activities as their locomotor skills improved. No patient was taught to carry a bag for example. move a chair, straighten an unsafe carpet. They tended to take on certain minor acts as they became more able and more familiar with their surroundings. e.g. hanging up coats and removing clothes, while other tasks remained the province of the staff, e.g. all tea and lunch arrangements. Indeed patient intervention here was reprimanded or even ridiculed and further, through the practice of employing voluntary workers, it was curtailed by displays of

assistance which were embarrassing to the recipients. Neither is it credible that a patient insufficiently versed in care of his stump, the wearing of a limb or the presentation of both in society is equipped for maximum rehabilitation. Patients were taught to walk and except in a haphazard and limited sense this was not developed to its domestic and social applications, hence the links with rehabilitation were not made. In chapter eight, case history material illustrates in more detail how this came about and what its effects were.

In chapter two it was noted that it was very difficult to abstract from the literature any information strictly relevant to amputee rehabilitation. These findings revealed the same tendency for rehabilitation to be overlooked.

D. Staff and patient control of activities

By further analysing the categories and ascertaining who carries out each activity we find more than failure to encourage rehabilitation but areas of outright discouragement.

1. Results

Adding the total scores or marks in each of the four columns of each taught or untaught activity the results are as follows. Refer fig. 8.

Fig. 8. The activity given by columns.

column	description	no.	%
1	patient acts alone	1536	30.08
2	patient leads, staff assist	1228	24.05
3	staff leads patient	1278	25•04
4	staff acts alone for patient	1064.	20.83
		5106	100%

As staff were involved to a lesser or greater degree in 70% of patient activity it would be difficult to employ any of these findings towards arguments for increasing manpower. Allowing for the walking training patients necessarily carry out alone, the social chat, tea breaks and all the minor movements each of us makes, to carry out 30% of one's actions without direct supervision would not seem a large amount. The word staff refers to all grades of employee, but footnotes from the ethograms show the therapist/patient ratio to have been 1:3 at Centre B and 1:5 at Centre C. This included some use of a finalist student at Centre B and a trained aide at Centre C but not other staff; ancilliary, auxilliary, student, volunteer, clerical or orderly.

2. Discussion.

Figure 8 presents a particularly worrying result. In this 'rehabilitation' setting a fifth of all activity in which each patient was involved was carried out entirely by the staff on the patients behalf without the patient being invited or able to participate in any way. Comparative analysis of this figure is impossible in the absence of similar research but this finding appears to be one of the most important of this investigation and should by itself raise serious questions about the nature and purpose of physiotherapy. These results represent the patient who is wheeled into the class by a porter, his wheelchair moved into position by an aide, a chair brought, his prosthesis carried from a rack at the far side of the room by a therapist who then lifts the patients clothes and applies the limb, the aide swapping wheelchair and chair, picks up the walking aids, hangs up the coat and asks the therapist about the patients treatment for the day and so on and so on. This level of staff control over patients movements appeared out of keeping with the rehabilitative purpose of the classes. It appeared both depersonalising and to confirm the patients disabled status. And it raises questions about efficient use of resources. Yet it seemed possible that the level of staff control could have been reduced by a number of simple measures. For example, patients

could more often have worn their limbs. Where wheelchairs were required these could have been of the sort patients can propel by themselves and they could have been encouraged to do so. Then patients could choose where they wished to sit and go to toilet when they wished, collect their own limbs and hang up their own coats on more accessible hooks. Walking patients need not have had so many items carried for them by staff. Therapist could have brought patients into discussion on their treatment and stood back more often or assisted in adjusting their clothes and limb rather than taking over.

The incidence of staff having total control of activity (scores in column 4) was at its highest in the following areas.

furniture/equipment	92% staff act	alone for patient
return cup	66%	**
ambulance to department	45%	Ħ
tea .	40%	
coat	34%	11
adl (in dept.)	28%	H
dressing	23%	tt
walking aids	12%	tt
prostheses	12%	11

As patients learn something - positive or negative - from all their experiences and as this is an especially critical time for them as they learn what is involved in being an amputee, they will not be unaffected by this large proportion of events in which they were treated as inert and dependent.

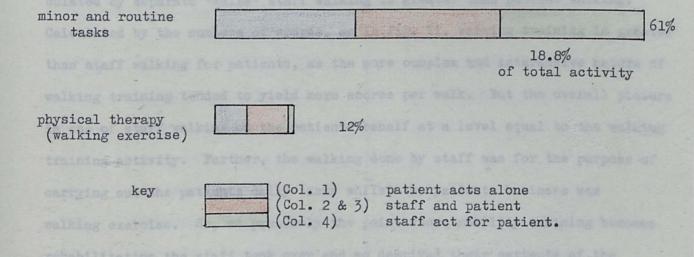
In previous sections we saw that walking training was not developed rehabilitatively because its major functions were omitted and its minor functions not taught. What we see in this section is that not only is rehabilitation omitted and untaught it is often actively discouraged. Hence of the minor tasks which

make up the first rung of the rehabilitation ladder 30% were done entirely by staff for patients; a figure that is greater than the total therapy. (Refer figs. 9 and 10).

Fig. 9. The activity in the five groups given by staff/patient control.

set	patient acts alone	patient and staff	staff act for patient	%
minor functional	34.6	34•7	30.7	100
conversation	4.5	92.7	2.8	100
physical therapy	42.2	55•5	2.1 -	100
clinical	25.8	62.1	12.1	100
major functional	9	86.5	4.5	100

Fig. 10. Activity given by participation in minor tasks and physical therapy showing total therapy to be less than tasks done by staff for patients.



When one considers that it is in the nature of many of the minor tasks that when taken over by another person the patients own role ceases to exist - for example a member of staff cannot stand up or sit down or drink tea for a patient without the act ceasing to be the patients but becoming instead an

event in the patients surroundings - then the level at which minor tasks were dominated by staff approaches the level at which any task which could be taken away from a patient and done by a member of staff was taken away. And at this level it is not sufficient to say that rehabilitation was overlooked. The patients participation in these first tasks towards their rehabilitation was discouraged. They were the province of the staff and the inmate participated at the cost of a variety of sanctions.

3. Walking

Further to this argument, the minor tasks patients were permitted to carry out alone were not as a rule those involving locomotor skills but were more confined and personal. Hence a most disturbing result emerges when the scores in the category 'walking' are analysed in terms of the participating parties. (Refer fig. 11).

We find that at these walking training schools the walking done entirely by staff on their patients behalf is equal to the entire walking training. Calculated by separate 'walks' staff walking is greater than patient walking.

Calculated by the numbers of scores, as in fig. 11, walking training is greater than staff walking for patients, as the more complex and interactive nature of walking training tended to yield more scores per walk. But the overall picture is one of staff walking on the patients behalf at a level equal to the walking training activity. Further, the walking done by staff was for the purpose of carrying out the patients daily tasks whilst the patients business was walking exercise. So, at precisely the point where mobility training becomes rehabilitation the staff took over and so deprived their patients of the opportunity to progress.

The answer to the question posed in chapter three would seem to be on this evidence that amputees are not taught the skills of mobility in such a way that they are encouraged to generalise these mobility mechanisms towards their social

Fig. 11. Detail of walking activity.

	walking						
		non-taugh	nt		taught		
	acts	staff and patient	staff act alone for patient	pt. acts alone	staff and patient	staff act alone for patient	
% of incidents	5 . 6	4	42•2	22•5	25	•7	100%
no. of						•	
incidents	53	38	397	212	235	7	942

488 incidents

488:942 = 51.81% of total walking is routine and incidental (42.2% done as minor tasks by staff for patients).

488:5106 = 9.5% of total activity comprises incidental walking.

454 incidents

454:942 = 48.19% of total walking is walking training.

454:5106 = 8.9% of total activity is walking training.

and economic applications. Indeed patients were prevented from generalising these skills.

4. Prosthesis

Staff were also observed to take total control of 12% of the activities in the category 'prosthesis'. Against this 29% were carried out solely by patients. But any incident at all in which anyone other than the patient entirely takes over the artificial limb needs the strongest justification. This would be true of anyone's limbs at any point in their lives. It is doubly true at the point at which the new amputee meets his new limb and is ostensibly being encouraged to see it as his own. But when the limb may be removed, handled and carried to the far side of the room - and dropped and broken which was observed twice - without the patients even tacit permission then these acts would seem to defeat the primary purpose of these classes.

5. Teaching

Use of column 4 was not appropriate to three of the five groups of activity. Therapy cannot be carried out by staff alone. Neither could conversation or major functional activities which comprised mostly of conversation. But a few scores in the fourth column in each of these capture incidents in which staff have excluded the patient from discussions on his treatment or have overtly prevented the patients conversation. Scores in column 1 in these groups capture patients asking questions and receiving no reply.

Taught activities are for the most part interactive. Fig. 12 illustrates that it is the non-taught areas where staff tend to take over.

It was the author's impression that there were two distinct styles of teaching; in one therapy was staff-initiated and in the other it was initiated by the patient. The deciding factor was the individual member of staff, not the department or profession. In the first instance patients waited for

Fig. 12. The taught and non-taught activities given by staff/patient control.

taught / not taught	pat. acts alone	pat. leads staff	staff leads pat.	staff acts for pat.	%
teaching programme	36.5	30•4	30.8	2.3	100
unplanned/not taught	29•2	22.1	22.6	26.1	100

their turn to walk with the therapist or aide or got up to walk as the member of staff entered the room, often sitting down as they departed. In the second patients walked whenever they were ready and were assisted as required. The second style, the patient-initiated style, produced more walking which took place at more opportune moments. Where two members of staff were present and operating different styles the patients switched rapidly from one to the other.

E. Communicative Style

Analysing the symbols used to classify communicative style we find the following distribution of activity. Refer fig. 13.

For the most part communicative style was not apparent or no comment was made, the patient possibly being alone. Patient to patient interaction was frequent and exceeded the total therapy. Their conversations were sometimes lengthy. Over a half of these conversations (399:380) were other than the exchange of pleasantries and general banter and were on such topics as walking training,

l: This style of approach accounts for the higher incidence of standing up as opposed to sitting down (refer fig. 3) because the act of standing more frequently had to have two scores: one for staff initiative and the second as the patient took over and the member of staff left.

Fig. 13. The activity classified by symbols denoting communicative style.

symbol	description	No.	%
0	absence of interpersonal attitudes/communicative style not apparent	3944	77•3
5	patient to patient	779	15.3
6	observer involvement	83	1.6
С	command (staff)	126	2•5
n	negotiation "	109	2.1
	praise "	38	•7
x	reprimand "	27	•5
		5106	100%

prostheses and rehabilitation. Some of their conversations pertinent to rehabilitation are discussed in chapter eight.

The incidence of interaction with the observer (1.6%) consisted for the most part of the brief exchange of pleasantries that was necessary in order to be accepted and less conspicuous in such a setting. On rare occasions the observer had to ask for information in order to clarify events as they took place. Occasionally patients made serious enquiries of the observer. Occasionally staff made such enquiries.

Communicative style of staff was most frequently 'command'. As commands occur for the most part in the taught programme of events they form 10% of the teaching. There were instances of good negotiation but these were not sufficiently in evidence to be compatible with reciprocal mutual dignity. The more senior therapists were observed to use praise judiciously but a style of rapidly alternating praise and command on the part of other therapists appeared con-

fusing.

This latter style was particularly in evidence at centre C as part of a series of lower body exercises. These were not pre-prosthetic toning exercises and the participants had to remove their limbs in order to take part. Sitting or lying on the floor they carried out group drill as dictated by the therapist (17% command, 3% negotiation, 1% praise, 79% instruction without overt tones). The rationale was prevention of hip and knee flexion deformity but the few at-risk patients were not singled from the rest or given individual instruction with a view to daily repetition of the exercises at home. Instead this drill became a 'filler' once a week. The time taken to remove and replace limbs was greater than the exercise time and their removal was greatly resented by patients. Patients obeyed a rapid series of instructions. Following on comments made in chapter 6 about team games at centre A, the way in which this team drill was carried out did not seem appropriate in a rehabilitation context. It did not meet individual need, not even the needs of 'at risk' patients. For the remainder it countermanded limb wearing and the tasks of daily living. On the whole it created resentment and increased authoritarian control.

F. Incidents of Special Relevance to Rehabilitation Proper

Scores in a ninth column in every category recorded incidents of special note. They are additional to previous totals. The results are given in fig. 14.

These results represent the limits of what the ethological data is capable of expressing; relying heavily on the diary notes for interpretation. They also border on topics on which the author is not qualified to comment. Yet they were felt to be sufficiently important to be worth reporting because they show something of the manner of events and generate ideas for future research. As

a point of equity they show another aspect or level of rehabilitation, for example, incidents where major functional activities have been overlooked but the domestic context of a therapy activity has been briefly mentioned.

Fig. 14. Incidents of Special Relevance to Rehabilitation Proper

symbol	description	no.
н	(home) activity linked to patients domestic circumstances	49
M	(mobility) mobility criteria super-cede domestic criteria	13
. 🗸	helpful to rehabilitation proper	8
х	unhelpful to rehabilitation proper	121 190

1. Domestic and mobility criteria

When activities were put into their domestic context (e.g. 'can you do that at home?') this was most often done by patients in conversation with other patients, raising problems often inadequately resolved. Only rarely did members of staff relate activities, even briefly, to the patients home or social circumstances. There were instances where staff stuck doggedly to the rules of locomotion or the use of standard equipment despite obvious irrelevance to the patients' circumstances. In these instances walking training was presented as a complete entity, as an end in itself and not as a means to an end. This observation is taken up in chapter eight.

2. Incidents Especially Helpful to Rehabilitation Proper

The low incidence of these acts may reflect observer bias or merely one's expectation of the setting that encouragement of rehabilitation proper should be normal and not exceptional. There were instances of first rate physiotherapy practice as for example when a chance mistake on the part of a patient

was grasped as an opportunity to teach an important skill - a patient stumbling as he sat down was taught to sit down safely and a discussion followed on the height of his chair at home. Other examples included an aide acting on an overheard chance remark made by a patient who said that he was glad to arrive too early. It transpired that this elderly man was cold at home and preferred the warm waiting room. The social service department were asked to act with some urgency. One therapist was particularly skillful in explaining to patients when it became necessary to consider giving up prosthetic mobility in favour of wheelchair mobility. The same therapist was active in increasing inter-departmental liaison. This was observed to have direct benefits for patients.

Another therapist organised sporting facilities for patients. Again, there were tangible benefits. Senior staff attended courses, taught and demonstrated their work and engaged in research. The often alarming results of this investigation mask the deep commitment and hard work of the senior therapists in charge of walking training at centres B and C.

3. Incidents which were unhelpful to rehabilitation

To the author there seemed to be many specific points at which rehabilitation was not enhanced. Sometimes these were incidents where an opportunity to teach was lost, that is, there was failure to encourage rehabilitation. Sometimes the incident was seen more actively to discourage or block rehabilitation. Events which were depersonalising to patients were seen as anti-rehabilitative because rehabilitation is so closely tied to the idea of normal adult status. Sometimes the incident was one of lack of care. This is logically quite separate from rehabilitation and these incidents were an unexpected finding. The following examples are given to illustrate these points. They are seen as representative.

1. Easily within the patient's hearing a therapist discussed the patient's treatment with the observer, including comments 'its useless', 'there's probably brain damage'. This is unprofessional and it is depersonalising.

The effects on the patient's motivation are unknown.

- 2. A therapist compiling a check list on a patient's abilities and domestic circumstances, in readiness for discharge, opened with the remark 'just answer yes or no to all questions'. This sort of failure to negotiate has been noted in nursing research (McCleod-Clark 1982, Gott 1982). It was observed here to result in essential information being incomplete and incorrect.
- 3. A patient being taught to climb stairs asked to be taught how to get onto a bus but was told by the senior therapist that he did not need to know and prevented from pursuing the matter further. Patently the patient did need to know by virtue of having asked. If the patient had not been a suitable candidate for this form of outdoor mobility this too should have been discussed. Here rehabilitation was actively discouraged.
- 4. A therapist stepped over the jutting out limb of a seated patient who had not operated the knee lock mechanism. Both the patient's sitting posture and prosthesis were ungainly. Here is an incident of failure to encourage rehabilitation as it relates to good presentation of oneself in society. The patient's habit of sitting in this way singled him out as an amputee and could have been corrected. The posture may have indicated that the prosthesis was not worn correctly and this too should have been checked.
- 5. At the end of a class a patient waited for 3 hours for an ambulance to arrive to take him home. This is unreasonable and represents a lack of care.
- 6. Without screens and in a room of male and female patients a male patient was undressed, naked below the waist, by a therapist. This again is depersonalising and suggests less-than-adult status.
- 7. A patient persistently queried the alignment of his prosthesis but the therapist avoided replying or acting on the information. Later the therapist made a number of ad hoc adjustments to the suspension of the limb. No satis-

factory conclusion was reached. No referral was made to the prosthetists in the neighbouring building. Amputee rehabilitation depends upon the prosthesis but it was apparent here and from other observations and conversations with this therapist of many years experience that she did not have the necessary knowledge to deal with the prosthetic dimension of walking training.

8. A patient sitting quietly in a wheelchair was, without notice, pulled sharply backwards. A moment later his limb was tossed into his lap. His journey backwards continued for some minutes. The unprofessional approach of untrained and unsupervised auxilliary and orderly staff resulted in many undignified incidents.

In chapter one glimpses of patienthood were illustrated from the writings of Ritchie 1960 and Battye 1966. It would seem that similar unhappy incidents continue in the hospital setting.

G. Centre D: Checking the results

In order to see whether or not this pattern of results might be more generally applicable another centre, D, was observed for a short period. It was chosen because it was the most prestigeous of centres, purpose-built and only recently opened.

There were no indications that the pattern of activities at centre D was substantially other than that at centres B and C. A brief outline of observations based on the 28 categories is given in Appendix III.

The walking training itself was properly carried out - so far as illness, fitting problems, transport difficulties, etc., would allow. But it did not have direct bearing on minor tasks, domestic activity and rehabilitation proper. There was no occupational therapy at the centre and no direct occupational therapy liaison. Many minor acts were carried out by staff for

patients and once again the important role in this was played by ancilliary staff whose duty it was to do things for patients.

The more modern architecture and design of equipment slightly increased patient control of activities but human failings countered this. For example every wheelchair had hand rails and could be propelled by the occupant but were routinely pushed by therapists and ancilliary staff. A self-service refreshment bar and lounge was available but therapists served drinks to patients. A specially designed telephone was available for patients with disabilities but staff routinely intervened and operated the telephone for patients. The fittings and furnishings of the entrance area were very pleasant but the effect was marred by less-than-welcoming receptionists and a patronising orderly whose duty it was to meet new arrivals.

It was the author's general impression that patients freedom of movement though controlled was less intensely so and verbal recriminations were also less intense than those at centres B and C (refer the case histories of patients N and Z, chapter eight).

The senior therapist was re-allocated every six months and the basic grade therapist every three months, hence they were hampered in developing knowledge and experience in this area. This also hampered their liaison with other staff at the centre, e.g. prosthetists and medical officers. Those who knew most about the patients daily lives were the orderlies who were not re-allocated and who spent more time chatting to patients, e.g. in waiting areas. The practice for orderlies to wear navy blue 'sisters' uniforms gave weight to misinformed and often depersonalising chatter.

Attendance patterns were unsatisfactory. The spread of arrival and departure times was equally as great as noted elsewhere.

H. In Conclusion

This investigation is designed to establish broad trends and answer general questions in an area where no similar research is available. The results of the ethological data fulfill this aim. They are not obscure, marginal or abstruse. Encouragement of rehabilitation proper is not found in a reasonable or small amount that might be argued to be sufficient. Its incidence in these 'rehabilitation' classes is 0.16% and is clearly insufficient. Minor and incidental activity is at least five times greater than therapy activities. Unplanned acts, though similarly difficult to categorise, are also five times more in evidence than the planned programme. Staff dominate nearly a half of their patients activities and have complete control in a fifth of the total activity. In these walking training classes they carry out as much walking for their patients as they allow patients to carry out for themselves. pite methodological difficulties of many sorts these findings break down the assumption that physiotherapy is necessarily beneficial. The idea that rehabilitation practice is not effectively rehabilitative or even counter-rehabilitative is clearly worth pursuing.

Chapter Eight

Case History Results: Centres B and C and Reference to Centre E.

Introduction

In this chapter description of the day to day process of physiotherapy continues with a review of the case history material. This develops the ethological framework layed down in chapter seven, putting it in its human context and looking more closely at the problems. Diary notes again assist discussion. Finally a comparison is made with Centre E.

The case histories are those of the 19 patients at centres B and C who were the subjects of the ethograms. The patients are identified Mr. and Mrs. F to Z (omitting I and 0).

A. Biographical Outline

Fig. 1. The 19 patients from centres B and C who are the subjects of the ethological records.

Sex	4 female 15 male
age range	48 to 77 years
mean age	67.3 years
cause of amp.	18 peripheral vascular disease
	(6 in assoc. with diabetes)
	l trauma
unilat./bilat.	16 unilateral and
	3 bilateral.

Fig. 2. The 19 patients: their amputated limbs

no. of amp. limbs	22
right and left	15 right and 7 left
below and above knee	ll below and ll above knee
other	none

Fig. 3. The 19 patients: a comparison with national statistics

description	centres B and C	DHSS 1980	
% pat. 60 years and over	89•5	73	
% vascular disease	94•7	88	
% men (women)	78.9	67.7	
% Ak limbs (to Bk)	50	59	
% unilateral (to bilat.)	84.2	89•5	

We see from the above that these patients were not dissimilar from those found nationally. Though they were for the most part elderly vascular patients none may be described as very elderly or as particularly weak or frail or confused. As discussed in chapter 5 the method of choosing the patient sample mitigates against inclusion of the very ill and, at the other end of the spectrum, the young patient. One 48 year old patient with rta injuries can be categorised as a young amputee (Nichols 1976).

Fig. 4. The 19 patients: their prostheses at walking training.

stage of treatment	start of data collection	end of data collection	
pre-amputation	0	0	
post-amp, no prosthesis	0	1 0 15	
pneumatic limb (PPAMA)	4		
pylon or temporary limb	141		
cosmetic or definitive limb	1	3	
	19	19	

^{1:} This figure includes one bilateral amputee, Mr. M, who had a pylon and a definitive limb but walking training was for the purpose of teaching him to use his new pylon.

All 19 patients were learning to walk with prostheses and the four who began on pneumatic limbs had pylons by the end of the period of study. Seventeen of the patients were progressing towards definitive limbs but one reverted from a definitive limb to a pylon and one from a pylon to having no limb.

Fig. 5. The 19 patients: their surgical procedures

description	no. of procedures	
pre-amputation surgery	35	
toes, part foot, Symes	15	
major amputation Bk	16	
Tk	1	
Ak	11	
other, debridgement, re-amputation	14	
	92	

Figure 5 is of special interest. In the course of their becoming amputees these 19 patients had had to date 92 surgical operations: range 1 to 17, mean 4.8. Amputation is indeed characterised by a great deal of surgery. A number are known to have had further surgery since the period of study and mean totals would be significantly higher if the group were followed to the end of their careers as amputees. The rta patient had marginally the greatest number of operations.

The implications of this are profound. This high incidence of surgery is contrary to the single ablative procedure model which is certainly the lay understanding of amputation but furthermore, it is the implicit model underlying most of the literature on amputation as was shown in chapters one and two. The rationale of all that is known on amputation is undermined where the conceptual framework of 'the amputee' is incorrect. This level of surgery lends

support to a 'continuous process' model of amputation with the necessity for subsequent revision of theory and practice in many areas; for example; the patterns of stress related to loss of a limb, the implications for the patients' will to walk and prosthetic replacement schedules.

Figure 5 suffers some inaccuracies however. Neither staff nor patients were entirely clear on the subject of surgery and documentary evidence could not be relied upon to complete the picture. In practice, as at centre C, therapists compiled a physiotherapy case history and were empowered to draw upon any relevant documents but made limited use of this facility and so they worked from sketchy knowledge of the patients background. (Conversations with medical secretaries revealed immense scope for investigation into the role of patients records in patient care. Amputees have separate sets of notes for surgery and limb fitting.) The results given in figure 5 are not thought to be exaggerated nor their breakdown substantially inaccurate and it is felt that they provide a sufficient pointer for future research. Investigation is needed to validate surgical methods and policies and to record the careers of patients over long periods of time. On one hand one patient had no further surgery for 14 years following femoral popliteal bypass and 5 patients had had only one procedure per stump. While one patient underwent 16 reconstructive procedures only to be faced at a late and debilitated stage with eventual loss of the limb. Another could recall fifteen procedures but was uncertain beyond that. The three bilateral amputees had lost limbs in 2, 7 and 9 stages respectively.

Figure 6 has been drawn up along the lines of charts and tables in other studies which give social and domestic information (Van de Ven 1973, Weaver and Marshal 1973, Kegel et al 1978, Finch 1980). It serves the purpose of establishing for the reader further characteristics of those under investigation. But its inclusion here serves another purpose for it emphasises the shortcomings of presenting this sort of information in this form. To give

Fig. 6. The 19 patients: their social circumstances

Social o	class (by occupa	ation)				
II	III		,	IA	•	ν.
Out pati	lents					In-patients
•						
Own home	•	counci	l or tenant		_	none
	,				ş	
Ground f	floor accommoda	tion	two	storey, st	eps or lifts	3
,						
					•	
Living v	with family		8.	heltered		alone
	- T			· · · · · · · · · · · · · · · · · · ·		
Some for	rm of outdoor m	obility			confined	to home
		- 1 - 1 - 1 - 1 - 1 - 1 - 1 - 1 - 1 - 1				

examples. The range of social class misrepresents the homogeneity and comaraderie amongst the two groups of patients. The fairly low figure for those living alone disguises the loneliness of those living with their families. A high incidence of rehousing into ground floor accommodation masks its unsuitability. Outdoor mobility was especially problematic whereas this is concealed. In order to pursue the human issues which are the special feature of this investigation we turn instead to case history material.

B. The Case Histories

Rather than using selected histories, case notes on all 19 patients follow because it is particularly relevant to see the situation in its entirety. As discussed elsewhere the material had many sources. It is problem-orientated and focuses on rehabilitation and the mechanisms whereby it succeeds or fails. Each history is given using the following structure:

- (i) introduction
- (ii) walking training
- (iii) rehabilitation
- (iv) other issues

As stated in chapter three physiotherapy is to be investigated at two levels: to see whether it succeeds or fails in its own terms, using Humm 1977 as a guide to walking training procedure, and secondly whether physiotherapy provides a sufficient basis for patients in terms of rehabilitation proper, as defined in this thesis. Thus throughout the following case notes the two issues are discussed separately.

1. Mr. F. R Bk ptb pylon

- (i) This man seemed older than 69 years. He was thin and frail, partially blind and possibly a little confused. Below knee amputation had taken place 12 months previously. There had been very slow healing of a denuded and infected stump and recurrent general ill health.
- (ii) Six weeks post-operatively a pneumatic or PPAM Aid had been used with success to aid healing and 2 months post-operatively the patient took delivery of an Ak/Bk pylon. He found this too heavy, his walking training was interrupted by illness and he abandoned the limb which he could not manoeuvre. Against hospital advice he used under-arm crutches rather than a wheelchair thus avoiding being chairbound and bedfast. Eleven and a half months post-

operatively he was supplied with a lighter ptb pylon. On delivery of this limb the patient bought walking sticks which he cut to size. He was observed at this stage, during a six week period of walking training. He quickly became very mobile.

The patient's gait was unusual and walking training consisted of retraining in a more conventional gait which involved confiscating the patient's own walking sticks and replacing them at each class with a hospital pair which were 2 inches longer. The patient objected but was over-ruled. Training was ineffective since the patient was discharged still using his original gait.

Latterly the new pylon was causing concern. Mr. F repeatedly described pressure points and mis-alignment but was not referred back to the prosthetist. Mr. F was imprecise and partially incoherent and it seemed to the observer that the therapists did not have the necessary communication skills to understand and act upon his badly worded complaints.

(iii) Following from these poor beginnings the patient's rehabilitation was excellent. He was the only patient to claim to have used public transport and the only one to manage household shopping by means of walking and carrying, i.e. without a car. He prepared meals, helped with household chores, looked after a more elderly wife, babysat for a daughter in exchange for outings, and, considering his poor health, was a active and useful as any man of his age.

It is difficult to conclude that this patient's rehabilitation success was consequent upon effective treatment. For although walking training provided a safe and private environment in which to practise walking, the skills that this patient required in his daily life were not taught, e.g. use of public footpaths, stepping onto a bus, carrying groceries. And a compromise was never reached between the patient's and therapist's view of suitable mobility. A wheelchair was provided but returned by the patient because it was unusable in his ground floor flat. Bath aids ordered a year previously had not been del-

ivered. An occupational therapist included this patient in weekly screening checks but enquiries were superficial (possibly because of Mr. F's unclear form of speech) and no help was given. For example the therapist never ascertained that the patient did not have bath aids, that he cooked meals and so forth. Assessment of safe use of a kitchen might have been very useful. Despite their ready and costly availability, services were not given as effectively or efficiently as they might have been. Individual need was not assessed and met.

(iv) There had been two incidents of damage to the stump and leg. A stump bandage had been applied too tightly by a district nurse and the knee knocked during an ambulance journey. Both required treatment. It seemed to the observer that recurrent ill health was not an entirely satisfactory explanation for the long period of time this patient spent without a suitable replacement limb.

2. Mr. G. L A/k pylon

- (i) This patient was learning to walk on his first limb, a pylon delivered 8 weeks after above knee amputation. Mr. G was well liked, was in comparative good health and enjoyed the general good humour of the class. He was a single man.
- (ii) Walking training, as described by Humm 1977, took place daily for 3 weeks and the patient made rapid progress towards functional activities climbing stairs, walking around obstacles and over rough ground, getting up from having fallen. Both staff and patient were pleased with the speed and success of training. Neither stated fears for the future. The ethograms show this patient to walk more than 20 times in a session.
- (iii) Walking training and referral to occupational therapy had not however met domestic and recreational needs. There had been personal care assessment (bathing) but no training in the kitchen, at home or on public transport.

The patient's housework, shopping, cooking and gardening were each done by relatives and neighbours, and although the patient walked to a pub, he complained to other patients that he could not get onto buses. Staff enquiries did not reveal the extent of the patient's many daily incapacities. This degree of dependency on friends and relatives was partially known to the staff but perhaps it was not seen as unusual because no direct steps were taken to decrease it.

Vocational and economic aspects of rehabilitation were also overlooked. Mr. G was below the retiring age and intended to return to his still vacant job as a cellarman. The staff did not know of these intentions - routine enquiries on economic topics covered supplementary benefit payments but not the possibility of wage earning - and there had been no discussion as to the feasibility of this kind of work.

This history illustrates that even where walking training itself is highly satisfactory in its own terms it may still be inadequate to meet the patient's rehabilitation needs. With reference to models introduced in chapter two this suggests that the walking training regime or curriculum does not meet the needs of its more able pupils.

(iv) It seemed to the observer that Mr. G was insufficiently aware of the need to take special care of his remaining limb though at an earlier stage its eventual probable loss may have been explained to him. Some reinforcement of this advice may have been useful at the walking training stage but staff did not discuss its loss or examine the leg. Yet there is a relentless increase over time in contralateral amputation (Ebskov and Josephsen 1980). The patient was overweight and smoked fairly heavily and had in the contralateral limb a history of rest pain, lumbar sympathectomy and amputation of toes. Much could have been done at this stage of comparative health and mobility to avoid or prepare for bilateral amputation. In separate discussions

staff seemed resigned to this loss.

It is of interest that although Mr. G was measured for a pylon within a month of major amputation, of the subsequent 39 days awaiting delivery 26 days elapsed as a result of bureaucratic procedures and only 13 in manufacture. The A.L.A.C. operated a 14 day delay between the limb being ready and the patients being sent to take delivery. After delivery of the manufactured limb it was returned to store for a further 12 days until Mr. G was notified to commence walking training. In answer to questions raised in chapter three there seemed no sense of urgency to unite patient and limb. These latter points have undertones of low expectations and disabled living.

There had been a stump injury involving staff on the fifth post-operative day.

- 3. Mr. H. R A/k PPAMA to pylon
- (i) Mr. H, an in-patient for $3\frac{1}{2}$ months, was rehoused in ground floor sheltered accommodation in readiness for his discharge from hospital. Social workers and occupational therapists had been diligent in solving the problems that kept him in hospital and there was twice daily walking training.
- (ii) Three weeks post-operatively walking training began with a PPAM Aid and 2 months post-operatively a pylon was delivered. Mr. H was observed for most of his $2\frac{1}{2}$ months of walking training. During this period an important theme arose in the career of Mr. H, one that had many guises but was common to all 19 of these patients. This patient lacked information about all that is consequent upon loss of a leg. For example, whether he had been told or not, Mr. H was unable to offer in advance any description of the artificial limb he could expect to receive and his estimate of walking training was many months longer than the therapists. This lack of knowledge had serious consequences. An immediate effect was that Mr. H was unable to play a full and useful role in early limb wearing. He was unable to judge between the discom-

forts of limb wearing and unacceptable pain, and between the unusual but correct style of prosthetic locomotion for an above knee amputee and incorrect and laborious styles. A knowledgeable and experienced therapist bridges much of this gap but such therapists were not common and Mr. H was unfortunate in that his PPAMA was most often fitted by an inexpert therapist who fitted the limb at an adducted angle and who did not respond to complaints of pain. Also when first delivered the socket of the pylon was too loose. So walking training began on badly fitting limbs. What is unacceptable is that it continued in this vein. The patient continued to co-operate despite his disappointments, believing this to be the best he could expect. He blamed bad design of limbs and turned, like others, to the unfounded belief that all would be well when he had his definitive limb. Vehement complaints took place during coffee breaks when staff were not present but it seemed that conversation became progressively more guarded in answer to staff queries.

(iii) The role of the ward environment in rehabilitation was of interest. Those in charge stated that Mr. H was 'just a social case' and overlooked his needs in favour of what they described as their 'real' work, caring for the acutely ill. As observed through formal and informal visits and questions to all who could throw light on the issue, the ward staff did not play a part in the programme of gradual fitness and independence training which would have ensured that the patient would be all the more quickly able to leave the overcrowded ward. Mr. H was not encouraged to wear his limb while on the ward or even his clothes and was being shaved by a nurse during one of the observer's visits. Twice daily he was wheeled by a porter - rather than walking accompanied by a therapist, aide or nurse - across a courtyard to the walking school, then wheeled back, remaining in the wheelchair for the rest of the day on the ward. Thus dependency and inertia preceded and succeeded each session of independence training. Here was evidence of the institutional precursors of the need to rehabilitate over and above the clinical imperative of loss

of a limb (refer chapter three). Many opportunities were lost in the ward environment to develop walking skills for daily use in minor tasks.

4. Mr. J. R A/k pylon

- (i) Here was a second patient hospitalised awaiting suitable accommodation. His stay was seven months. He was at present homeless and, despite considerable efforts on the part of a social worker and occupational therapists, had no immediate prospects of getting somewhere to live. Hostel accommodation had been refused by the warden who saw Mr. J as necessarily disabled. He gave the excuse that Mr. J would not manage the stairs but he patently could climb many flights of stairs and walk great distances as evinced by the day he truanted from the ward and walked into the city.
- In normal circumstances Mr. J would have been discharged from walking training some months previously. He was observed at a time when his actual training was successfully completed and he attended twice daily in order to maintain fitness and counter the limbless dependency of ward life. For like Mr. H, Mr. J was wheelchair bound on the ward. He attended classes wearing dishevelled clothes over pyjamas and was pushed in a wheelchair to all appointments in the hospital. Again this was suggestive of the unsuitability of the general surgery ward where the needs of the lower limb amputee are seen in terms of ablation and not replacement: the immediate post-surgical period being successfully completed the focus of nursing care did not appear to shift towards replacement, locomotion and rehabilitation. Whereas, if the ward staff together with the physiotherapists had devised a fitness programme for Mr. J, his place at the walking training school could have been taken by others from the waiting list. It is of interest that Mr. J was observed on some days to do almost no walking at the school despite ability and ample opportunity. Ward exercise developed around minor daily tasks might have been more stimulating and interesting and hence more successful.

(iii) This patient received more occupational therapy than any other of the 19 patients. It included all aspects of personal and domestic care and some outdoor mobility. Mr. J was the only patient to be taken out of the hospital grounds by a therapist and accompanied briefly on public pavements.

Though 10 years under the retiring age there was no discussion on employment and no referral to the D.R.O.

5. Mrs. K. L B/k ptb pylon

- (i) Amputation was seen by this patient as a cure for the pain caused by intermittent claudication and had been requested by the patient for some time prior to its taking place. Mrs. K was pleased with the outcome and felt more comfortable and more mobile than previously. So, even though there was only one surgical procedure there was no element of sudden or shocking loss. The patient died a year later without further surgery.
- (ii) The patient was observed throughout a two week period of daily training. Her amputation had taken place 7 months previously and she had been using an Ak/Bk pylon for 5 months prior to recent delivery of a ptb pylon. Mrs. K employed an arduous limping gait, her eyes firmly at her feet. The therapists did not think that this was acceptable in a single leg below knee amputee but the patient was a difficult subject to teach and none of the staff managed to overcome this and improve her gait. One therapist eventually ignored the problem, another shouted commands. Whether or not the limb fitted comfortably was not fully established. Whether or not the gait was consequent upon previous use of the heavier long leg pylon the staff did not comment. She completed the full programme of training (re Humm 1977) and was discharged

^{1: &#}x27;without further surgery' was stated at follow up by the senior therapist. Usually two or more sources support the information of the case histories.

with very positive expectations from all concerned.

- (iii) A small incident exactly typifies the dichotomy between physiotherapy and rehabilitation. This lady could not walk and carry a cup and saucer. She reported to the observer that, living alone, she had her drinks standing up in the kitchen and not as was her stated preference sitting in the living room in front of the television. Yet a cup of tea was handed to Mrs. K at least twice daily during the three weeks of her walking training without her being taught this skill or even having the opportunity to return the empty cup. The staff were not aware of this type of small domestic difficulty. They did not in any case see the teaching of such activities falling within the scope of walking training. Patients managing ostensibly as well as Mrs. K were not generally referred to occupational therapy where this deficiency might have been noted but such a referral would be costly and unnecessary when the opportunity to teach this skill daily presented itself in the walking training environment. Meanwhile patients were discharged unable to perform these small functions which add much to the comfort of the elderly.
- 6. Mr. L B/k Ak/Bk pylon discarded.
- (i) This man was short tempered, he was thin and frail and had chronic lung disease. His amputation, a single procedure, had taken place seven months previously. Since then he had been without a limb. This was due to industrial action by ambulance drivers which had prevented Mr. L attending A.L.A.C. appointments. Three months after surgery a prosthetist made a domicilliary visit to take the necessary measurements and manufacture of an Ak/Bk pylon went ahead. It was a further three months before the industrial action ended and the backlog of work cleared and Mr. L could attend for delivery of this limb which was then put into store for a further month before a walking training place was available. When patient and limb were united it was immediately apparent that the socket of the pylon was by that time too loose. Also the

patient was too weak to manage its weight. Within a few days the therapist referred Mr. L to the medical officer, the limb was condemned and measurements taken for a ptb pylon - the latter against the advice of the prosthetist. The M.O. and therapist suggested to Mr. L that he abandon plans to use a prosthesis in favour of wheelchair mobility but were willing to continue when the patient insisted he wanted a limb. They saw him as too weak to use a limb rather than in greater need of a limb because of his weakness.

- (ii) The senior therapist was sensitive and sympathetic in her dealing with Mr. L but problems beyond her control defeated any progress in this patient's unhappy circumstances. After 4 days walking training was stopped until a suitable limb was manufactured.
- (iv) Mr. L had been at home for 7 months without satisfactory means of locomotion. He was without a limb. He was unable to use a Zimmer frame and hop because of the breathlessness caused by this exertion and the poor condition of the contralateral foot. His wheelchair was unsuitable for use at home. His wife was elderly and uncooperative. It was likely that he would remain in this state until a second limb was ready because a routine check by an occupational therapist took place prior to his pylon being condemned and this was not followed up when circumstances changed. It seemed to the author that this state of affairs typified a lack of care; a failure to identify problems and at the very least alleviate their worst effects; and failure above all to meet the patient's urgent need for a limb. Measures could have been taken. Industrial dispute was not uncommon and this dispute left prosthetists and therapists without work and with time in which a more vigorous domicilliary service could have been given. In-patient care may have been appropriate for this patient, providing not only care but access to the Limb Centre. The Social Services might have intervened to greater effect.

We see here how unsatisfactory the circumstances of an elderly amputee may be.

who is discharged from hospital to await an artificial limb. At home Mr. L had to choose between immobility or unsafe, inelegant and laborious forms of mobility. One can only guess the effects on general health and temper and the health of the remaining limb.

In the patient's documents were complaints from one hospital to another regarding lack of communication.

- 7. Mr. M. bilateral Bk L cosmetic limb R long leg pylon
- (i) Mr. M was well liked and eager to participate. There had been below knee amputation to the left leg 2 years previously and below knee amputation to the right leg 1 year previously. He was observed throughout one month's training in use of his newly delivered long leg pylon (right leg) in conjunction with a recently delivered cosmetic limb (left leg).
- (ii) The patient made satisfactory progress in walking training and was beginning functional activities for bilateral amputees (Humm 1977) when he was discharged. The senior therapist was absent and condemned this decision. It seemed to the observer that Mr. M was unsteady in open spaces and unsafe on stairs and that discharge had been premature.

Walking training had been greatly interrupted in the 2 years since the patient's first amputation. There had been infection and delayed healing of both stumps. Amputation of the second limb had interrupted delivery of the cosmetic prosthesis for the first limb. Industrial dispute and the backlog of work this created added many more months of delay. There was low exercise tolerance. There had been no domicilliary therapy during this period.

In conversation Mr. M and a fellow bilateral amputee, Mr. N, realised that neither were able to rise from a chair without the aid of parallel bars or similar support and so decided to teach themselves to stand up unaided. Mr. M

eventually succeeded but was not taught by the staff who on one occasion stopped this activity when they misinterpreted what was taking place.

- (iii) Walking training was not geared to meet domestic or social and recreational needs. Occupational therapy dealt only with personal care once the therapist had established that the patient had a wife and daughter to look after him. The implications were that it was acceptable for a person who has artificial limbs to be heavily dependent on others. Though the lost limbs had been replaced it would appear that training was geared to the diminished daily round of disabled living (Battye 1966) and not approximation of normal living. This was particularly striking in this case, the patient being discharged prior to mastering even the limited functional activities offered in the training schedules.
- (iv) Small incidents typify lack of co-ordination of services and their failure to be used effectively to meet the needs of the patient. For example, social service alterations were made to a door in the patient's home but later his wheelchair was changed and this solved the problem. The documents include complaints from the G.P. regarding lack of information.

By chance Mr. M remained for the most part outside the general comaraderie of the department. This was the result of the poor acoustics of the room, the patient's slight hearing defect and his being placed at a far corner of the room in order to use the parallel bars. This limited his opportunities to talk to other patients. There were other sets of parallel bars and if he had been wheeled to these from time to time - or been helped to walk into the department and to choose his own seat - the problem would have been overcome. Staff tended to place patients in the same spot. This was related to walking training requirements and not, as occasionally was observed to be important, with reference to the dynamics of the group.

- 8. Mr. N. bilateral Ak/Bk definitive limbs
- (i) The case of Mr. N is different from the others. Mr. N was the class failure. When therapists were asked to put a figure on the amount of failure or underachievement in amputee rehabilitation Mr. N's was the sort of case that was cited: the 1:10 in any group who underachieves compared to the others. Mrs. Z was just such a patient at the other centre.

Mr. N had seven surgical operations at regular intervals over a four year period and had one above knee stump and one below - considered by some to be the most disabling combination for a bilateral amputee (Murdoch 1967, Clarke-Williams 1969). Further, the below knee procedure, the most recent, had been performed below an existing injury to the knee. The remaining knee had a 10° flexion deformity and since amputation both hips had developed similar deformity. Mobility training had been interrupted by repeated surgery and industrial dispute. Mr. N was a diabetic, he had difficulty in keeping awake and was overweight. He said he wanted to learn to walk though he anticipated further surgery. He was observed throughout his 8 week period of walking training.

(ii) Mr. N's first attempt to climb stairs came after the longest walk he had ever been required to make and some minutes of standing and waiting while the therapists talked to each other. In a state of near collapse his subsequent stumbling on the stairs confirmed the staff in their belief that he would not succeed: an example of the self-fulfilling prophesy investigated by Hargreaves 1967 and Lacey 1970. So where help was most needed staff failed to provide it and appeared insensitive.

It seemed to the observer that Mr. N was not making such very poor progress as he was said by the staff to be making. His progress seemed slower than others but sensitive encouragement might have shown results. He initiated only half as many walks as the other bilateral amputee but he progressed to

walk unaided across the open room before he was discharged because of lack of progress. He initiated many more journeys which were to the toilet usually to smoke but the staff did not bring these moves into the walking programme. They insisted that he went to the toilet in a wheelchair and tried to curtail the number of visits with negative comments ("Are you doing any work today!"

"Is there something the matter with your bowels!"). He also received only a negative response to his holiday plans - 8 days at the seaside with his family - whereas this could have been put to use towards his proper rehabilitation.

With Mr. M this patient attempted to learn how to rise from a chair without the aid of the parallel bars but unlike Mr. M he failed to do so and was discharged still unable to do this. At home he reported being unable to rise from an armchair without the considerable efforts of his wife who also put on his limbs.

Mr. N was said to have 'the wrong attitude'. This was the reason put forward for his seeming lack of success. To the observer it seemed that treatment was not sufficiently sensitive; not sufficiently pupil-centred or patient-centred. Mr. N was not without motivation but there were many clinical problems and the walking training regime might have profitably been tailored to meet his circumstances as one of its less able pupils.

(iii) As previously (Mr. L) this third section which is reserved for comments on rehabilitation proper is not required, except to note that no direct moves were made towards the patient's rehabilitation. Personal and domestic activities were carried out only with assistance from the spouse. Social and recreational activities and outdoor mobility (by car only) were dependent upon the goodwill of relatives. Occupational therapy intervention had resulted in the supply of aids such as a chair lift but had not tackled these issues. The patient was discharged before he was competent in the functional activities described by Humm.

(iv) An incident was observed of Mr. N being left unattended for over one hour in a wheelchair with no brakes, at the top of a long ramp.

9. Mr. P. R A/k PPAMA to pylon

- (i) The patient, a cheerful and fairly fit 65 year old batchelor, was reported to be well motivated and making good progress. He was observed throughout his two week period of training. At another centre he had previously walked with a PPAMA.
- (ii) As with other such patients the staff systematically covered all the aspects of locomotion layed down by Humm 1977. Early walking began in the parallel bars and the patient walked unaided in the open room, over stairs and obstacles and outside on rough and sloping ground before he was discharged. There were group lessons on how to stand up correctly and sit down and to get up from having fallen. The patient was daily able to see his progress.

The patient's pylon, already a month late in delivery due to industrial dispute, had been in store for a further 19 days at the walking training centre in readiness for the patient to attend. More days were lost before patient and limb were united because - in the absence of the senior therapist - walking training began with a pneumatic limb (PPAMA) and not the pylon until the mistake was noticed.

(iii) Walking training, though satisfactory in itself, did not have direct bearing on rehabilitation. Organised around the schedules described by Humm 1977 it fell short and did not meet the locomotor needs of the individual patient. At discharge Mr. P did very little for himself. A friend cleared the garden, a home help cleaned the house, a nurse bathed him, a niece did his shopping, he went out only in a taxi and so on. Aids ordered by a previous hospital were useful, but erratic ambulance journeys caused Mr. P to miss routine o.t. screening at this centre. There was no point at which walking

training focused on the patient's own home circumstances and gave him direct help in becoming more independent. Nor was it suggested by the physical or occupational therapists that the patient should attempt more of these personal and domestic activities for himself now that his limb had been replaced.

- (iv) There were a number of worrying incidents which might have had the most serious consequences. First, this man had more than usual transport problems. On his first day of walking training, from being ready at home from 8 a.m. he did not arrive until 11.55 a.m. His first walk was at 1.30 p.m. He was not returned home until 6 p.m. By 7 p.m. he had developed chest pains, did not eat and was too frightened to sleep. The following day the therapist sought medical assistance before treatment could continue. Second, during three months between surgery and walking training the patient had been mobile on the ward and then at home by means of a Zimmer frame and hopping. With a history of vascular gangrene and surgery to the contralateral leg and the patient's own reports of pain in this leg associated with hopping, once again we can only guess as to its effects. Third, the PPAMA was not used correctly. At this centre only one member of staff was competent in its fitting technique. Misalignment in this the patient's first limb, we must assume creates poor walking habits and gives the patient a poor impression of walking capability. Mr. P reported to the observer that at the previous hospital there was injury to the stump while using the PPAMA. Fourth, delivery of the pylon was delayed, as explained. According to the patient it did not fit well. The therapist did not refer the patient back to the prosthetist but made frequent random adjustments to the suspension, asking the observer how the limb should fit.
- 10. Mr. Q. L Ak pylon to definitive prosthesis
- (i) Mr. Q, at 70, still worked full time and he drove his own car. He was disliked by other patients and his successes were resented. This man, whose amputations arose from peripheral vascular disease, had had 15 surgical proce-

dures over 9 years which, rather than weakening his resilience, contributed to his being portrayed as a heroic figure. He appeared to be the inmate convert (Goffman 1961). He accepted patronage from the staff and displayed patronages towards fellow patients which were antagonistic to the prevailing inmate ethos which was the opportunistic combination of adjustments Goffman terms 'playing it cool'.

- (ii) Mr. Q was observed while attending the classes once each week awaiting delivery of his definitive limb. Walking training schedules were successfully completed but he continued to attend for a two month period when others would have been discharged. He was articulate and well-liked by the staff. The senior therapist said that she continued to allow him to attend a) because he did not require NHS transport and b) as an example to other patients. Like Mr. J whose attendance had also been extended though for quite different reasons, Mr. Q walked 50% less often than similarly able patients.
- (iii) All aspects of Mr. Q's rehabilitation were excellent. He was fully employed, had a busy social life and so forth. This was in part due to his lifestyle prior to amputation which he was able to continue. He had his own business which was managed from home and employed many staff.
- (iv) A small incident was indicative of the tendency on the part of amputees to play the part of 'the disabled' while in the hospital precincts. The only time Mr. Q used a walking stick was in the physiotherapy class. It otherwise remained in his car in readiness for his next visit.

Delivery of the definitive limb was delayed for six weeks due to its being manufactured incorrectly. There was no advice from the therapist on care of the contralateral leg despite amputation of toes for vascular gangrene. There

^{1:} E. Goffman Asylums Pelican 1961 part VI p.64.

was some evidence that pre-amputation treatment by the patient's G.P. was not sufficiently aggressive.

11. Mrs. R. R Bk Ak/Bk pylon

(i) The prospect of below knee amputation did not alarm this patient coming as it did after two years of reconstructive surgery to a crushed limb, though her husband collapsed when he received this news. She wished it had taken place much earlier. Five months after amputation the stump was unhealed and the patient weak from this long period of invalidism.

Prosthetic replacement had not increased or improved the patient's mobility. Because of the weakness of the stump an Ak/Bk pylon was issued and this very large and ugly limb dominated the patient's physique. She found it too heavy to walk with, too bulky to sit in or to disguise and too offensive to use out of doors. It hampered her on stairs and using the toilet, weight bearing made her feel sick and she was embarrassed to wear the limb in front of her husband and children. So she did her housework before putting it on and went out without it. For a few hours each day she wore the limb 'to practise in' and walked around the house and a few paces out of doors. She had two hours of walking training each week which seemed too little and she was not progressing satisfactorily. This created a vicious circle when her lack of progress prevented her from being supplied with a lighter, less dominating and less ugly ptb pylon.

(ii) There were difficult clinical decisions here on which the author is not qualified to comment. What this case illustrated was that the present provision of a) a replacement limb and b) walking training did not necessarily meet the needs of a lower limb amputee, nor provide sufficient basis for rehabilitation. We have seen that provision of a pylon can have many shortcomings. So too walking training may have many shortcomings as illustrated here. For Mrs. R was observed for a 4 month period during which time this comparatively

young patient made few gains. Like others she had her own unique set of problems - general debility, lack of confidence, dislike of her limb, incapacity at home, nausea and so forth - and the walking training regime was not tailored to meet these. Half of her walking training time was spent without a limb playing team games.

To look more closely at one aspect of this problem. Training included walking on sloping and rough ground on the paths outside the department and around obstacles arranged on the floor. But walking, accompanied, in the safe and private hospital environment did not adequately prepare this patient for mobility outside the home. This was because in the first place very many natural barriers were not included in training (e.g. uneven paving, windy days, narrow steps, walking and carrying, quicker pace). Second, walking was more secure because it was accompanied and did not tackle lack of confidence in outdoor mobility. Third, while it occurred within the hospital grounds it was private, that is, it was part of what Goffman delineates as a back stage place and does not take into account the stigma attached to walking in a public place. Mrs. R reported very limited outdoor mobility for all three reasons. In part natural barriers presented difficulties. Most important to gain confidence in the initial stages she wanted to walk on the paths around her home accompanied by a therapist but this was not granted. Also she was very conscious of being in a public place when stepping into the street. As with other patients use of the family car was a means of avoiding this public-ness.

(iii) We can see from the above that there was a gap between training and rehabilitation which was not bridged by the staff or as yet by the patient.

There was no area of her normal daily activity which Mrs. R had regained since limb replacement. It was not even possible for her to wear her usual clothes

^{1:} E. Goffman Stigma: The Management of a Spoiled Identity Pelican 1967 London Ch.2.

because her choice of style did not fit over the waist band and bulky thigh corset of her pylon.

(iv) It is a criticism of therapists that they knew too little of the lives of their patients, but in Mrs. R one saw the distance at which patients frequently held themselves from the staff. After her early cues were brushed aside, Mrs. R turned to the inmate culture and conversation with staff was observed to become progressively more superficial. Walking training became a lively diversion from the patient's problems not a place where problems were solved. In the classes Mrs. R was cheerful and talkative while at home she reported to the observer that she was depressed to the point of suicide and rejected by her husband.

Consequent upon her lack of information on amputation there was loss of self-determination. Neither Mrs. R nor her family had plans for her future. She waited on the decisions of the staff; indeed in a vague way she understood walking training to continue for life. This information came from Mr. X who in common with most patients had only the sketchiest idea of treatment and did not distinguish physiotherapy from prosthetic aspects.

- 12. Mr. S. R Bk ptb pylon to definitive limb.
- (i) Mr. S, the oldest of the 19 patients, enjoyed comparative good health, he was cheerful and popular, his gait was excellent and, like patients P and Q, was seen by the staff as one of their successes.
- (ii) Mr. S mastered each stage of the walking training programme (Humm 1977). He attended twice weekly for 6 months, the latter 7 weeks with his definitive limb. He was observed for the latter 4 months.
- (iii) The training regime did not meet the needs of the patient. Indeed the staff did not know those needs. This was aggravated by lack of domicilliary

assessment for by chance Mr. S lived outside the geographic limits of such visits and was not included. Assessment or training in domestic activities would not have been especially appropriate because the patient's wife carried out all cooking and household work and would not let her husband be involved in these. But there were personal and recreational needs that were not met. For example, Mr. S was bathed by a district nurse. This arrangement began a year previously when he was seriously ill but now that the patient was much fitter, and although it was brought to the attention of the therapist by the patient, the situation was not reassessed. Also Mr. S was a life-long gardener. Since illness a year previously he had neglected this work. Although his health was now improved and his diseased limb replaced no advice or encouragement was given to help him to return to gardening or to take up any other recreational pursuit.

(iv) Mr. S had a single below knee amputation but there had been 5 surgical procedures - vascular reconstruction, amputation of toes, below knee amputation and debridement. Limb fitting was delayed for 6 months because of stump infection. There was an incident of staff involvement in damage to the stump. This was on the seventh post-operative day and the stump required restitching.

13. Mr. T. R Ak pylon

- (i) This patient was last and slowest in all group activities. It seemed to the author that as a result he was a figure of fun to the staff and patients and was spared from being a figure of abuse only by the presence of Mrs. Z who occupied the lowest place in the group hierarchy. Mr. T seemed to enter into the spirit of the many jokes and the class may have been for him a period of light relief. Privately he was intensely sad. To the observer he commented with some feeling 'I'm done for now since I lost my leg'. 'I don't know what I'd do without the wife'.
- (ii) Attempts to walk were defeated by pain. There was stump pain (described

as tight, pulling and nauseous when weight bearing), groin pain (at a point where the pylon dug into the body), and moderate phantom pain (with ineffective use of barbiturates). The senior therapist responded conscientiously. She listened. She examined both stump and prosthesis. She referred the patient to both surgeon and medical officer. But events that followed illustrated how the subjectivity of pain and the convenient myths that are built up around this complex issue blocked adequate treatment and the patient appeared to become labelled as a malingerer. X-rays revealed no abnormality and the medical officer said that sitting was a contributory factor. Failing tangible evidence the staff either disbelieved the complaint or saw idleness as the cause and walking as the cure. In nursing theory a model has been developed of how this occurs (McCaffery 1979). Prosthetic mobility did not improve in the following three months. The patient remained in pain. He also remained 'the failure', 'the malingerer'. An incident of pain in the contralateral limb caused the therapist to seek direct advice from the prosthetist who immediately requested refitting the prosthesis.

(iii) A domicilliary visit had taken place but the information had not been used to adapt in any way the walking training routines in order to overcome the many domestic difficulties of the patient. Mr. T had returned a wheel-chair because he was not able to manoeuvre it in his new ground floor flat or use it to leave the flat. There were narrow corridors with right angle corners, badly placed doors which opened one onto the other, lintel ridges at each interior door and external steps, front and back, which were too narrow to be negotiated safely by the patient. To the observer it seemed that Mr. T could have benefitted considerably from domicilliary therapy geared directly to overcoming the architectural barriers within the patient's own home. For example following on training in climbing steps and stairs in the department he could have had training in stepping over the lintel ridges at home and the narrow external steps thus developing his re-emerging mobility skills in ways

that were applicable to his needs. And if modern ground floor accommodation presents such barriers presumably domicilliary therapy must be considered for a wider role.

- (iv) On the subject of the patients' lack of information, Mr. T was one of three patients at this centre who did not have the correct or sufficient number of stump socks. If stump hygiene had been taught as Humm recommends this would have been discovered by the staff. For over a month after delivery of his limb this patient had only one stump sock which is a dangerous deficiency. Also, since delivery he had padded the socket of the pylon with folded cloth to alleviage pain at pressure points. By chance he found out from Mr. V about supply of socks though Mr. V was one of the three who had problems in this area, which illustrates the inadequacies of patient to patient information. (This also illustrates the strengths of the observational method which uncovers these new and unexpected problem areas.) He wore the pylon for three months before his padding of the socket was discussed with a prosthetist. The naivety of all nineteen of these patients on matters concerning amputation cannot be overemphasised and some of the information they did not have was very simple indeed.
- Mr. T had contracture deformity of the right hip. He reported that as an inpatient he had been nursed with a rolled sheet under the stump.
- 14. Mr. U. bilateral Ak short leg pylons
- (i) This 60 year old man lived in the family home with a son and daughter. He was observed for 4 months which included delivery of his first limbs. He was well liked by staff and patients.
- (ii) Within the parameters of the walking training programme progress was excellent. Mr. U had vigorously undertaken pre-prosthetic exercises. The staff had become very keen to see him succeed. He had begun to walk unaided outside the parallel bars on short pylons. His slightly preferential treat-

ment had the popular support of the group.

The mobility programme was desparately slow. (At Centre A bilateral amputees had attended walking training for up to two years). From delivery of the pylons it was five days before Mr. U's next scheduled physiotherapy appointment. Thereafter he attended for one hour twice weekly. On this basis it was a further three months before he was allowed to take his limbs home and use them more often. Mr. U walked between two and six times each session so that his actual walking time was not more than half an hour twice each week. Given that bilateral amputees must progress to long leg pylons before definitive limbs a much more intensive programme is called for if patients are to remain both fit and keen.

Mr. U is in that group of patients for whom rehabilitation is not auspicious i.e. the elderly vascular bilateral amputee (Van de Ven 1973, 1981) and here in the treatment of the most successful of such patients were clues as to why this is often the case. In the first place we have seen that the schedules were very slow. In the second, as with the other patients, walking training did not have direct bearing on rehabilitation. Many minor tasks and all the walking associated with these tasks was done for Mr. U by the staff. Staff walked for the patient double and treble the number of times he walked for himself. It was possible that the unplanned affect of this was that he was being conditioned to be passive and dependent. Also there had been no occupational therapy and no domicilliary assessment so the training did not meet personal and domestic needs. To give an example. Mr. U was not mobile outof-doors despite his great popularity and many offers of transport to local pubs and clubs. These were refused because Mr. U could not go unaided to the toilet and did not feel he could ask friends and relatives to help. The problems could have been tackled within walking training. Instead vital recreational stimulation was given up. We can conjecture that over a sufficient period of time offers of outings would diminish and the idea of going out would become disproportionally eventful and difficult in the patient's mind. Here again are the ingredients of the shrinking horizons, the diminished daily round of the disabled (Battye 1966).

- (iv) Ambulance transport was unreasonably arduous. This man lived fairly close to the centre but there was a tendency to collect him first and return him last. For this one hour class between 2 to 3 p.m. he might travel between the hours of 12.30 p.m. and 7.30 p.m. Single journeys were as long as three hours and forty minutes. He did not always arrive in time to take part in the training. This represented a large disruption of daily living and could not physically have been tolerated by a less fit man.
- 15. Mr. V. R Bk ptb pylon to definitive limb
- (i) Treatment moved swiftly from amputation of toes, part foot to below knee and then from PPAMA to definitive limb within five months. As with other patients who receive ptb limbs the patient was very pleased with the result.

 Mr. V was 62 years and lived in the family home with his wife and children.
- (ii) Mr. V progressed satisfactorily through each stage of the walking training programme. This lasted for 6 months and he was observed for the latter 4 months which included delivery of the definitive limb.
- (iii) The isolation and lack of understanding mentioned by most of these patients was particularly acute in the case of Mr. V. He disliked the use made of Mr. Q as an example to others. His family cited Douglas Bader: his friends cited the case of a well-known local man. Outside the inmate clique Mr. V felt the difficulties and discomforts were not appreciated. Hence, possibly because he felt stigmatised, possibly because he felt bereaved, despite his capabilities he was inclined to stay indoors and to do too little. Neither his good progress in walking training nor his obvious pleasure in his cosmetic

limb had, at the point of his being discharged, countered the effects of the limb he had lost.

In common with the other patients Mr. V disliked the random nature of the ambulance journeys yet he owned a car which he did not use because he was unsure of both his capabilities and the legal requirements since loss of his leg. Help and advice here would have been useful.

(iv) The socket of the definitive limb was not a good fit. Despite good discussion the therapist did not refer Mr. V to the prosthetist. He wore the limb loosely and tightly on alternate days. With one wool sock skin abrasions tended to result from a piston action. With two wool socks the stump was squeezed and became oedematous. Both are undesirable in the vascular patient and may precipitate further surgery. The patient did not know there were other socks available, e.g. one thin cotton sock worn over one wool sock may have been the answer, and the therapist did not give this advice. Neither patient or therapist made sufficient use of the prosthetist's greater expertise.

16. Mrs. W. R Bk PPAMA to Ak/Bk pylon

- (i) This elderly widow lived in sheltered accommodation, attended the walking class twice a week and a day centre three times a week. Domestic help was given by a home help, a neighbour and a daughter. There was every indication of a lifetime of class-related disadvantage.
- (ii) Mrs. W was praised and encouraged despite, what appeared to the observer, to be an unpromising start to walking training. But when Mrs. W was assertive when ill she contacted her G.P. with a view to his cancelling her transport for one day in order to save its cost the sanctions were intense and only when she was crying and the staff were able to comfort her were their respective roles re-established. That she had been ill was not in dispute only that she had ventured to play a part in the department's jurisdiction over transport.

Following questions raised in chapter two, this incident suggests that dependent roles are upheld or reinforced.

Walking training was not complete when observations ended. The patient continued to make slow but satisfactory progress.

(iv) The suitability of ground floor accommodation has been questioned. Its provision may not greatly contribute to mobility. Similarly the suitability of sheltered accommodation is questioned because in the case of Mrs. W it did not afford the protection or guardianship one might reasonably expect. For example, Mrs. W did not feel secure and fear of vandalism and burglary created insomnia. Duties one would associate with the work of a warden were done by neighbours. A neighbour locked and unlocked the front door night and morning. Although she rang for assistance, a neighbour eventually rescued Mrs. W when she fell in the bathroom. The warden did not collect a prescription or post a letter.

The view that ground floor sheltered accommodation is both enabling and protective may have contributed to the early discharge of Mrs. W from the hospital ward against the advice of the physiotherapist. When discharged her exercise tolerance was very low, she had no prosthesis and had no suitable means of moving around her home. A month later a pylon was delivered to her by post. She attended the next walking class carrying the limb and a month later still carried the limb to her twice weekly sessions. Again, there are undertones of lack of planning around the needs of individual patients, and failure to urgently unite patient and limb.

17. Mr. X. R Ak pylon

(i) Mr. X was a batchelor living alone in a ground floor flat. He had 5 months of twice weekly walking training, reduced to once per week awaiting delivery of the definitive limb. He was observed for 4 months of twice weekly

training with a pylon. Despite satisfactory progress through the walking training schedules the career of Mr. X provides a particularly clear illustration of their inappropriateness.

In the first instance the staff knew very little about Mr. X's day to day life. Neither were they aware that he had had 7 surgical procedures. There was no occupational therapy and as yet no domicilliary visit. And they were unaware how little Mr. X knew about the business of being an amputee.

- (ii) Mr. X particularly disliked the team games. These occupied one of two sessions each week. Their inappropriateness has been criticised elsewhere (refer chapters 6 and 7). A particular rehabilitation problem of this patient was failure to wear his limb when attempting domestic activities. Yet he spent half of his walking training time with his limb removed in order to play these games. This was a costly waste of resources and an insensitive response both to his stated wishes and his needs.
- (iii) It did not seem to the observer that walking training and limb wearing had brought day to day benefits. Mr. X undertook all his own housework as he had done throughout his life but he had developed hopping and shuffling habits during a long period of surgery and limblessness. Hence he only wore his pylon when the work was finished, finding even such tasks as climbing ladders to wash upper windows easier without a limb. Again, intervention was needed to bridge the gap between mobility training and its daily applications. Discussion alone might have greatly increased use of the prosthesis, e.g. the therapist could have stressed the role of the prosthesis in preserving the remaining limb. Or direct domicilliary therapy might have been the answer. For example, the patient had plans to become more mobile and daily attempted to walk to the home of a neighbour. With a therapist to help him in the initial stages it is likely that he would have succeeded. Instead rapid deterioration

of the remaining leg superseded and at follow up the patient was about to under-

go surgery.

- 18. Mr. Y. R Bk definitive limb to pylon
- (i) This patient was outstandingly popular, enthusiastic about his walking training to a point of recklessness and played an important role in the general good humour of the classes. Privately he was unhappy with his treatment and unhappy with his circumstances and slept badly. He was one of two patients to be referred to by a pet name. It seemed to the author that staff and patients portrayed this patient as a hero and that Mr. Y adopted this role in public which made such problems such as grief and anger all the more difficult to express.
- (ii) Five months after amputation Mr. Y took delivery of a definitive limb but over and above fitting problems its probably excessive use too soon damaged the stump and it was condemned as unsuitable by the vascular surgeon. Mr. Y described long outdoor walks immediately after taking delivery of this limb, possibly because this was expected of him. Returning to the pylon it broke and the patient sustained a Potts fracture of the left ankle. This took two months to heal. The definitive limb had been remodelled twice but so far unsuccessfully. So walking training had been interrupted and prolonged by prosthetic problems and Mr. Y almost daily presented some new fitting problem.

At this centre the senior therapist had worked to improve A.L.A.C. liaison and telephoned the prosthetist for advice concerning Mr. Y's fitting problems. Yet on the whole the Protestant Ethic prevailed and Mr. Y pushed on with walking training. To the observer it did not seem that the novice limb wearer or even the physiotherapists were an adequate judge of these issues and much closer contact with a prosthetist would have been desirable here. For example the presence of a prosthetist in the walking training class might have been invaluable. This patient had continual limb problems and the burden on the senior therapist was unreasonable.

Alternating between a ptb limb and an Ak/Bk pylon, Mr. Y did not change to the appropriate stump sock. This was not detected by the staff.

(iii) Again there were daily skills important to the patient which were overlooked in walking training. Mr. Y could not walk and carry. So he relied on neighbours for shopping despite good out-door mobility. Since amputation he had neglected an allottment he had kept for forty years. Encouragement here would have been beneficial. Generally staff did not know which occupations and passtimes were suitable for limb wearers and this may have made them reluctant to comment or advise. They seemed not to see usual and daily activities such as shopping or gardening as automatically suitable. There was no occupational therapy and as yet no domicilliary visit.

19. Mrs. Z. R Ak PPAMA to pylon

- (i) Mrs. Z was described by the staff at this centre as 'the class failure', as Mr. N had been 'the failure' at the other centre. She was a 73 year old widow living alone in an old-fashioned family house. She had had a cardio-vascular accident three years previously. There was arthritis and lordosis. A history of leg ulcers and poor circulation resulted in above knee amputation of the right leg since which there had been rehospitalisation and three procedures to the left leg, femoral popliteal bypass and skin grafting to the heel. Some of her ward treatment was positive the ward staff helped the patient into her pylon and assisted with walking practice in the day room. Some of her ward treatment was insensitive. Mrs. Z felt unwanted as a result of her bed being used for a day case. She was discharged against the therapist's advice without a limb and without satisfactory means of locomotion to live alone Her pylon was delivered by post. Support from two married daughters seemed poor.
- (ii) Walking training was observed daily while Mrs. Z was an in-patient using a PPAMA, twice weekly as an out-patient using a PPAMA and later a pylon

and again as an in-patient. During this latter period the patient was observed for one week without a limb. In complete contradiction to everything one seeks to achieve in amputee rehabilitation the patient's limb was confiscated for one week by the physiotherapist. This was shortly after skin grafting to the left heel and hopping exercises on this left leg replaced walking exercises for the week. Whatever the tenuous rationale behind this treatment, the therapist told the patient that her artificial limb was being taken from her as punishment for not making sufficient use of it.

Her first steps with a pylon were not in the parallel bars on even across a clear floor but over and around the obstacle course of mats, sticks and steps arranged for much more able patients, those about to be discharged. Subsequent poor performance confirmed the staff in their opinion that she would not walk well with her new limb. In answer to questions raised in chapter two, here was evidence of the detrimental effects of labelling patients as poor material.

- (iii) It is difficult to comment favourably on any aspect of this patient's physiotherapy or rehabilitation proper except adjustments to furniture made by the senior therapist during a domicilliary visit which made mobility easier in the patient's home. There was no occupational therapy except a single occasion when Mrs. Z made mince pies for the ward freezer for Christmas, yet she was greatly incapacitated at home.
- (iv) The pylon was dropped and broken by ambulance personnel. It was also dropped by a porter and it broke at the same point. The wheelchair which was supplied to the patient for use at home was returned because it was unsuitable for her home. The staff were negative and sarcastic. When the patient failed to attend for one day because of illness she was assumed to be shirking whereas this information would have been believed of others. Complaints of pain were not investigated. Passive exercise was carried out until the patient screamed with pain.

20. Summary

What the case history material shows is that the walking training regime for those who have lost limbs does not have direct bearing on the patients rehabilitation needs. What it further shows is that the shortcomings are not those of 'the rapacious doctor or the negligent nurse' (Illich 1977) but are part of the fabric of the regime itself. As such they effect to an intense degree the treatment of every patient from the most successful to the least.

Two main themes emerge. First, the walking training programme did not in practice give the priority one would expect to its first task that of uniting patient and limb. This was a surprising conclusion not envisaged from review of the literature except in so far as using Goffman's model on stigma (1963) one looked for expectations of less-than-normal living and there was speculation that amputation may be seen by professional workers as more disabling than is necessary. But such a clear indicator of disabled status was not anticipated. The second task, that of the walking training itself, was carried out with reasonable efficiency but had little impact on the needs of the patients. This supports the author's view that the literature shows the thinking on rehabilitation - and indeed, on physiotherapy - to be unclear and justifies the need to clarify rehabilitation theory as in chapter three.

There were other themes. The in-patient environment did not meet the needs of lower limb amputees. In chapter one nursing models on amputation were shown to be inaccurate and unhelpful. Circumstances for those discharged prior to delivery of a limb were unsatisfactory. Patients knew too little about the consequences of loss of a leg. This made their treatment less effective and contributed towards loss of self-determination. There were many indications of the patients low status, also of the staff's low expectations of them and

^{1:} Il Illich et al <u>Disabling Professions</u> Marion Boyars 1977 London p.14.

too ready acceptance of disability and of slow and problematic treatment. There was evidence that failure was compounded for those who were failing. As noted in education theory (Goodman 1962, Hargreaves 1967, Lacey 1970, Reimer 1971) staff appeared to teach the most teachable, those with the least problems whose success might be said to be assured, but to make little impact where professional skills were most needed. Further, underachievement (in limb wearing and rehabilitation) characterised even the careers of those who were most successful in walking training terms. There was no patient whose treatment was unproblematic. What we see here were not problems and failures in terms of normal distribution but affecting all. The author never felt convinced that the physiotherapists had confidence in artificial limbs, and promotion of the benefits of limb wearing were missing from their speech with patients. Equally the author was not convinced that the therapists! work with amputee patients was part of a serious attempt to return these people to near normal living. Over and above the particular failings that have been outlined here, a general enthusiasm was missing.

The problems were not due to shortage of equipment or of staff. Quite the reverse. Rather the evidence suggests that costly resources were available but wasted for lack of attention to detail and attention to the individual: that some major deficiencies could have been resolved almost without cost: that some could have been remedied at less cost than was already entailed.

C. Attendance, Ambulance Journey and Absenteeism

1. Attendance and Ambulances

With the active assistance of the staff it was possible at centre B to compile a complete and detailed record of attendance, times of arrival and departure and so forth. The results are given in figs. 7 and 8.

The spread of arrival and departure times was very great indeed. The net

Fig. 7. The times of arrival of patients booked to attend walking training commencing at 9 a.m. (centre B).

time	% of pat.	description
before 9 a.m.	•75	earliest 8.40 a.m.
9 to 10 a.m.	42	mean 10.10 a.m.
10 to 11 a.m.	43.25	(range 3 hrs 20 mins)
ll to 12.00 a.m.	14	latest 12.00 noon
	100%	

Fig. 8. The times of departure of patients attending walking training for a full day (centre B).

time	% of pat.	description
before 2 p.m.	6	earliest dept. 1.30 p.m.
2 to 3 p.m.	35	mean 3.20 p.m.
3 to 4 p.m.	35	(range 4 hrs 30 mins)
4 to 6 p.m.	24	latest 6.00 p.m.
	100%	

^{1:} Transport arrived at 11.30 a.m. to collect one patient booked to attend for a full day but was turned away.

result was that <u>any</u> patient on <u>any</u> day may arrive or depart at <u>any</u> time.

The problems of this cannot be lightly dismissed. It is surprising that such a wholely unsatisfactory system for uniting patient and therapist has been allowed to continue for so long. The transport arrangements exhausted patients. They disrupted plans made by staff. They served to emphasise the low status of

patients and confirmed their disabled role. They disrupted daily living and increased immobility.

The effects on one patient are worth recording. On his first day Mr. A waited at home from 8 a.m. but did not arrive until 10.35. The other patients had finished their break but a late cup of coffee was made for Mr. A. He was left until 11.10 a.m. until the therapist had an opportunity to see to him. He walked only briefly before lunch. He then waited until nearly 2 p.m. until he was returned to the parallel bars and he began to walk. This was quickly interrupted when his transport arrived. He protested, the staff responded unsympathetically and he was taken home annoyed and frustrated and without his limb. He had expected to do much more walking and also to go home wearing his new leg. He felt the day was wasted. Seven hours of the patient's day and three and a half hours in the department produced only minutes of walking training. This in itself was not an isolated incident and shows how patients can only wait despite their will to act. But there was a more subtle consequence. Over the week that followed the patient's language became less eager and more accepting. He took on the staff view that there is an inevitable slowness in the amputee's estate. He changed from blaming the organisation to blaming and regretting the condition of being an amputee.

The random nature of ambulance journeys resulted at centre C in a policy of not accepting late arrivals. Some narrowing down of the spread of journey times was reported together with an increase in those unable to attend when ambulances inevitably arrived late. For a one hour class patients spent up to four hours in the department and up to seven hours away from home.

2. Absenteeism

Atcentre B non-attendance was 36.5% (68.5:188) of a five day week. A half of this was the result of staff absence, i.e. staff holidays and a one day conference. Of the remainder, there were three main causes. One, patients had

other NHS, DHSS or Social Service commitments. Two, patients were ill or had stump or prosthetic problems. Three, there were organisational difficulties, e.g. failure to notify transport or patient. There were almost no grounds from which to conclude that non-attendance was due to the patients lack of interest or co-operation. Mr. N was absent for six walking training sessions because of family holiday and at another centre a patient was absent for one half day each week on a regular family shopping outing. Both of these absences were seen by the therapists as indicative of the wrong attitude.

At centre C absenteeism was much higher and impossible to calculate due to a different system of attendance whereby patients attended for much longer periods with more open access to classes, remaining on the register throughout intervals of ill health. Some patients, e.g. Mr. Q, were able to negotiate attendance to suit their requirements. Again absenteeism related to departmental holidays, ill health and limb fitting difficulties, and other legitimate commitments. Organisation errors and industrial dispute were not a feature during the observational period.

Particular investigation was made of Mrs. R and Mrs. Z who failed to attend two classes and one class respectively. Staff reported this as lack of co-operation. If one is sympathetic to the tensions of being an amputee and the special difficulties of the home circumstances of both of these patients then both had been legitimately absent. Mrs. R was absent once due to migraine headache - treated by her G.P. - and once because of acute depression following arguments with her husband who disliked seeing her wearing her artificial limb. Mrs. Z was absent the day after her discharge from hospital - which the therapist agreed had been premature - because she 'felt too messed about'.

It is of interest that the physiological basis of physiotherapy is bound to the socially determined five day week.

D. Centre E: Checking the Results

In order to see whether or not this pattern of results might be more generally applicable a further centre, E, was observed for a short period. It was chosen because, being an accident and emergency hospital, a half of the walking training patients were not elderly vascular patients but young amputees whose rehabilitation is described as less problematic (Nichols 1976). Cause of amputation included cancer, trauma and deformity. The age range of those observed was 20 to 69 years with a mean of 54 years. The centre was also chosen because amputee training did not take place in a separate environment but amongst those with often only slight or temporary disabilities and where attitudes might be more positive. There were no indications that trends in the careers of patients at centre E were dis-similar to those at centres B and C. Biographies of two patients are given in Appendix IV. The case of Mr. B represents treatment at its most problematic. The case of Mr. C was particularly satisfactory and successful.

More so than at any other centre, mobility training at centre E was divorced from the activities of serious living. This was manifest in many ways.

For example, none of the training took place outside the gymnasium. The therapists knew less than at other centres about their patients circumstances. They were openly scornful of liaison with the occupational therapy department and there was no domicilliary follow-up. Here was an exceptionally narrow focus on the prescribed exercise.

There seemed no benefits for those who had lost limbs in their attending these mixed classes. Therapists had less specialist knowledge on the treatment of amputees, denying knowledge of basic textbooks. Also amputee patients were treated as more disabled than the other patients, e.g. non-amputees were subject to an almost army discipline which amputees were for the most part excused, while more minor tasks were done for amputees than for non-amputees. There

were no A.L.A.C. facilities at hand and amputee patients had less opportunity to meet others with whom they could share experiences.

E. Conclusion

Although by its nature the case history material is not as well-defined as the ethological material, it equally shows that rehabilitation is not properly represented in the care plan of each of these patients. The argument has many interwoven themes. The models given by Goffman are applicable to many. The hypothesis that rehabilitation practice is not effectively rehabilitative or even anti-rehabilitative continues to be upheld.

Chapter Nine

Discussion of Results

Introduction

Physiotherapy does not emerge well from this investigation. In this chapter results will be discussed in relation to some of the medical sociological literature which may help in their interpretation.

Within the sociology and socio-psychology of medicine there are many frames of reference which could be used to assist explanation of the results of this study. Many have been introduced already. Theorisation on professional power (e.g. Friedson 1970) and the organisational structure of the hospital (e.g. Robinson 1973) will be used here. So too the more personalised or eye witness accounts of Goffman 1961 and Preston 1979: Goffman working within a sociological dramatists view; Preston placing his observations within a framework of existential philosophy (the work of Kafka). The literature reveals social pressures on staff to conform to impersonal standards (e.g. Tuckett 1976) and psychological pressures on staff to distance themselves from their patients (e.g. Menzies 1969). What we do not have are studies based on the working lives of physiotherapists or the lives of amputee out-patients attending rehabilitation classes with which this study could be compared directly. But, given that the great majority of the literature relates to either doctors or nurses, the shortcomings of modern medical practice are already well documented.

In this chapter discussion will be subdivided by those issues which observation showed to be the most important. Authorities are cited where they can shed light on an issue. The purpose is to place the results into a more theoretical context, also, as will emerge, to emphasise the dilemmas of therapists which contribute to their seemingly poor performance.

A. The Goal of Rehabilitation

In modern Britain the rehabilitation of those who have lost limbs takes place within hospital organisations. These organisations, as defined by Etzioni

1964, are 'social units deliberately constructed to seek specific goals'. The specific goal following limb amputation is rehabilitation, though it could be described in a variety of ways - in terms of cure, the maximisation of health and wholeness, the minimisation of disability and disease. The results of this study showed clearly that rehabilitation of the lower limb amputee was not taking place. Encouragement of rehabilitation proper represented a mere 0.16% of the total activity observed during walking training sessions. Physical therapy accounted for only 10% of each session. The case history data revealed that even patients who were most successful in the classes were incapacitated at home and that walking training was not having direct or useful bearing on the requirements of their daily lives. A clear contradiction was shown to exist between what we must assume is the purpose of the institution and what in practice occurred within its walls.

However, organisational goals are problematic (Robinson 1973). Goals may be multiple, misdirected and quite different in actuality than in theory. Middle grade staff are caught between conflicting goals of higher grade staff, and the fragmention of labour which typifies organisations gives rise to further conflicts of goals amongst the many grades of staff who will treat a single patient. Communication problems inherent in all large organisations prevent resolution of these conflicts. Each of these themes was seen to impinge upon the work of therapists and reduce the likelihood of successful rehabilitation.

First, therapists had a primary responsibility for the safety of patients, so their duties were custodial and restorative; duties which represent two conflicting goals. Custodial responsibilities were judged by the observer to be paramount because, while it may be permissable to fail to rehabilitate - this failure is in any case not easily measured and can be attributed to intangibles such as motivation and clinical condition - it is not permissable for a patient to be injured or to die during this process through any fault of the staff. There was evidence of staff restricting patients' movements, bodily

lifting them, reaching for items inadvertantly dropped, and so forth, each in the interests of safety, each part of established institutional routines, yet each contrary to the aim of independence training. (Safety considerations forestalled extending walking training to highways and public transport. Staff expressed the view that more intensive therapy which would have been rehabilitatively beneficial was too hazardous for those with cardio-vascular insufficiencies). So mobility training began in a safe and private environment, but, so too, it ended still in this safe and secluded environment, leaving patients unprepared for the rigours of daily living.

Second, physiotherapists were caught between the two authority structures of the modern hospital; the medical and administrative authorities whose goals conflict. Additionally, in the field of amputee rehabilitation, the medical goals were further fragmented into those of the hospital consultant and the A.L.A.C. medical officer and the prosthetist. (Frequent differences of opinion between medical officers and prosthetists caused the author to see these as separate rather than as a single entity, the A.L.A.C. team). Friedson 1972 and Robinson 1973 have described essential incompatibilities between bureaucratic and professional authorities. Physiotherapists were presented with patients for whom the consultant urged walking training whilst the A.L.A.C. medical officer judged them unfit for limb wearing reluctantly prescribing a limb that would not have been the choice of the prosthetist (e.g. patient L) and the bureaucratic schedules of the classes mitigated against the daily or individual treatments essential in such difficult circumstances. There were instances of artificial limbs rapidly assembled for patients but delivery being considerably delayed by the bureaucracy which is set up to ensure a fair rota of attention for each patient. Alternately, therapists were allotted facilities by administrative authorities for patients whom the medical authorities failed to treat sufficiently well for them to use fully.

Subdivision of labour is a prime characteristic of organisations (Etzioni 1964) and conflict arose here as well. The data showed that amputee patients were 'handled' by numerous members or grades of staff whose duties were frequently ill-coordinated or incompatible. One repeated example of this was incompatibilities in the roles of those within the physiotherapy department itself, i.e. the orderlies, porters, therapy aides and the therapists themselves. Essentially the duties of aides, porters, volunteers, etc., was to do things, quickly and efficiently, for patients. While basically the duty of the physiotherapists was to teach independence. In actuality therapists were frequently observed to carry out activities for patients rather than to teach or to stand back. Conversely the duties of aides included assisting mobility training and some ambulance personnel were observed to be especially willing to encourage patients to act independently. But on the whole this was a third area where conflict of goals made the therapists' work doubly difficult as patients were passed rapidly from staff with varying roles, duties and aims and where the work of all too few was essentially concerned with rehabilitation. find that almost any task that could be taken from a patient and done by a member of staff was taken away (refer chapter seven, discussion section D).

Inter-departmental subdivision of labour also brought problems. The treatment of patients H and J is a prime example. The ward staff saw their role
as the care of acutely sick patients and their rejection of these two patients
hindered the work of the physiotherapists, social workers and occupational
therapists. There were many other examples of this type of goal conflict
between departments. Case conferences were not in evidence at any of the many
centres visited during this study.

Fourth, what does not emerge in the hospital organisation are the legitimate goals of its clientele, the patients (Robinson 1973, Tuckett 1976). This showed clearly in the data. That is not to say that patients can be treated merely as objects, as are components in a factory, for their needs become part of the

complex negotiation of the hospital setting. Yet patients' goals were not found to be the prime targets of 'rehabilitation' activity. On the one hand patients' motivation was not harmassed: on the other, their needs and wishes not catered for. The treatment of patient R typifies both aspects. Her wish to have her leg amputated was rejected by the surgeon. In the event Mrs. R had 16 surgical operations over a 2 year period before amputation. Patient R specifically wanted a) to look normal, b) to wear her usual style of clothes, and c) to be independently mobile out-of-doors. Instead she was fitted with an artificial limb which because of its bulk, weight and ugliness prevented the first of these two goals, and she underwent standard mobility training which after many months had not achieved her third goal. Mrs. R was specifically labelled unco-operative (refer notes on absenteeism, chapter 8, section C2) though she undertook all tasks allotted to her in the department, including ball and team games which she disliked. While her own efforts at home and outof-doors were not supported by the staff. Goffman (1961) has shown that patients are labelled (in this instance as disabled) and therefore by definition in need of the treatment schedule which is seen by the staff as the route to rehabilitation. Patients' goals are presumed to be those of the staff or subsumed under those of the staff. We see from this study that patient and staff goals do not happily coincide and that therapists were not sufficiently alive to these differences. There seemed no evidence that they had been trained to recognise potential conflict in this area. Even had they been trained to see this. power structures cause staff to obey the surgeons wishes rather than those of the patient. Thus therapists busied patients in activities which were thought to be rehabilitative and which clearly were not, paying too little attention to what patients needed in the personal and domestic context and what patients were trying to do towards these ends. What is interesting is the degree to which patients complied, and complied increasingly over time, so that therapists were cushioned from the implications of this misguided activity by its victims.

Lastly, the results show the goals of walking training were misguided and inappropriate. This occurred at two levels, first within walking training itself and second in relation to rehabilitation.

First, the goal of walking training appears to have been satisfactory completion of walking training schedules as espoused by Humm 1977 but these had only incidental bearing on patients! daily lives and this appears to have been overlooked. The case history material provides very many examples of this. Mr. T negotiated stairs in the department but was unable to cope with smaller and narrower steps and ridges at home. Mr. U used the specially adapted toilets in the department but inability to use other toilets in a normal fashion greatly curtailed his social life. Training in outdoor mobility, climbing stairs and negotiating obstacles had not enabled Mr. G to use public transport. Despite satisfactory limb replacement and good walking training progress patients such as Mr. X still found it easier to undertake their daily round of chores before putting on their limb. The case history material showed the failure to integrate walking training with the domestic and social needs of the patients. The ethological material showed ways in which functional outcomes of walking training were actively prevented (refer chapter seven, fig. II). Unable to play their proper part in minor functional activities, patients were robbed of the opportunity to progress at exactly that point where physical therapy becomes rehabilitation, at the point where walking is given a purpose.

So we see that the schedules of walking training as exemplified by Humm 1977 fall short of what is required. To return to the question posed in chapter three 'are amputees taught the skills of mobility in such a way that they are encouraged - or at the very least not prevented - from generalising these mobility mechanisms towards their social and economic application?' The answer is no they are not, in any sense that is consistent, efficient or well-planned. One feels that intelligent identification with patients needs would have led therapists to see these shortcomings. Yet there is nothing in the present system

to encourage or reward such moves.

Second, here we see the consequences of the lack of research and lack of critical assessment in rehabilitation generally and physiotherapy in particular (Tumbridge 1972, McMillan 1973, Partridge 1982) and the tendency of the profession to be 'largely untheoretical' (Scrutton and Gilbertson 1975). Though the concept of rehabilitation proper follows naturally and logically both the spirit and the letter of the modern rehabilitation movement it has never previously been drawn out of the literature nor applied to rehabilitation practice. Consequently, because sound theory has not been available, the goals of rehabilitation have been inconsistent and unclear. The ethological data revealed that rehabilitation proper was only an incidental aspect of treatment regimes - incidence of its encouragement being a mere 0.16% of the total activity. Blame must be apportioned to the leaders of the therapy professions who have left therapists to continue to 'muddle through' on historical rather than scientific lines.

Summary and Recommendations

The goal of the hospital organisation and the needs of lower limb amputees would seem to be the same. Both seek health and wholeness or rehabilitation. In this section reasons why this seemingly obvious and mutual goal was not fulfilled have been discussed. Five areas of conflict were identified. Remedies depend first and foremost on recognising that these situations exist. Goal conflicts which result from custodial responsibilities, dual authorities and the subdivision of labour are inherent in the hospital organisation. Looking at them in the light of a specific condition, such as lower limb amputee rehabilitation, ways may be found to lessen their worse effects, e.g. by making therapists aware of the depersonalising effects of the duties they require of porters or by making surgeons, medical officers and administrators conscious of the need for close co-operation and common goals. Yet if problems

continue to be inherent in systems, permanent improvements along these lines seem unlikely. At best a fashion for upgrading amputee treatments may emerge which may wane as the plight of other groups are brought into focus. The logical alternative is to take amputee rehabilitation out of the hospital setting, i.e. into the patient's home. But absence of research prevents us from examining the pitfalls of this alternative. What it may do is, in effect, transfer institutional practices right into the patient's last refuge. A very sceptical researcher is needed to examine this possibly too plausible solution.

Where problems arise from failure to recognise the patients' goals the picture is more promising because of child-centred work which has long been established in education and patient-centred approaches which are being pioneered in nursing. It is possible to train teachers and nurses in such a way that they guide their pupils through an individually tailored programme which responds to the needs and motivations of the pupil without losing the advantages of professional authority. This study showed no evidence in physiotherapy practice of patient -centred physiotherapy training. It is recommended that the profession adopts an approach along the lines of the nursing process or, if such innovations are already present in training - though this seems unlikely - means must be found whereby they are not lost in practice. On the subject of misdirected goals it is naturally the author's view that the very word rehabilitation should come to have a different meaning, as elaborated in chapter three. Consequent upon this all aspects of care would need to be modified, and present goals re-examined.

B. Communication in the Rehabilitation Setting

Within an organisation achievement of goals depends upon good all-round communication. People have to agree to goals, and, as these are not static, they have to be continually re-negotiated. The results of this study show that there were many important failings in communication. This was true of staff

to staff communication, staff to patient communication and patient to staff communication. The picture varied however; positive and negative aspects having been discussed in chapter seven (refer especially section 2) and touched upon throughout the case histories. The net result was that poor communications added to the cost, the misery and the ineffectiveness of treatment. When there was apparent goodwill on all sides, why was this the case?

There is available in nursing a great deal of literature on this theme (e.g. Menzies 1961, Coser 1963, Cassee 1970, Preston 1979, Faulkner 1980, Gott 1982, McCleod Clark 1982). In this literature the hospital ward is typified as a place where personal contact between nurse and patient is kept to a minimum in order to reduce staff anxiety. Role distance operates for the nurse as a defense mechanism. Cassee and Preston have both commented on the ways in which patients contribute to this; distance themselves from staff and repress their emotions. Goffman 1961 cites, as a characteristic of institutions generally, that intimate contact with inmates is seen as dangerous by the staff. situation in which therapists are placed is more analogous with that of the nurse than the doctor in that they have daily and lengthy contact with patients. but Ley and Spelman 1967, Friedson 1970, Robinson 1973 and others have discussed the many ways in which barriers also exist in doctor/patient communication which serve purposes such as increasing the doctor's power over the naive patient, and again as a defense mechanism. Also there tends to be a narrow view of what is to be communicated.

This then is not a question of goodwill. Throughout the literature the hospital organisation is shown to be a setting where intimacy between staff and patients is an ever present danger, threatening the smooth running of the system and the emotional stability of the staff. This study shows similar patterns to exist in the physiotherapy out-patient department as on the ward. Staff restricted close contact with patients as patients did with staff. In terms

of how and why this happens in hospitals Cassee's account, 1970, is the most succinct and useful. In terms of explaining the daily psychological pressures on nurses, relatives and patients Preston's work, 1979, will be looked at more closely here.

Preston described weariness, frustration, impotence and indecision on the part of staff trying to cope with and maintain both high technical and humanitarian standards with disfigured, deformed, demanding and dying patients. Seeing the data from the staff point of view this can be said to describe much of the therapists work with amputees; patients who were in addition often immobile, cumbersome, heavy, presenting sore stumps and ill-fitting and ugly limbs.

Preston commented:

"If one followed a dedicated and competent nurse through the course of a busy shift, one would likely be impressed by how she meets the multiple demands of her work. The leg work alone seems ample inducement for varicose veins. Among the treatments, the charts, the basic physical patient care, the strains of staff relations, this nurse manages a kind word and an attentative ear for her patients, and a bit of jauntiness to cheer them up. On some days, that she manages this at all seems miraculous. If one gets a feeling for her work, one is not likely to question the focus of her effort. Ready explanation jumps to mind for any action that seems less than humanitarian. She seems hemmed in by imperatives. She is hardly to be blamed that she often does not hear what patients tell her or that she does not ponder their fates.

However, if one remains dispassionate and watches the nurse without attempting to rationalize her acts, one sees a somewhat different picture. The nurse seems engaged in an elaborate act, the production of which consumes much of her attention. Her behaviour denotes more a concern for her duties than for her patients. She seems to care for them, and yet also finds them tiring and aggravating. She keeps her distance."

Preston 1979¹

This too was the author's experience. It was possible to observe the therapist meeting the multiple demands of her work and, because of the way in which she was hemmed in by restrictions of all sorts, to quickly rationalise any short-

^{1:} R.P. Preston The Dilemmas of Care: Social and Nursing Adaptations to the Deformed, the Disabled and the Aged. Elsevier 1979 New York p.103.

comings. However, remaining dispassionate from such rationalisations the results do in fact show 'the elaborate act'; as evinced by the fact that a great deal of activity produced proportionally little actual therapy and virtually no rehabilitation. Behaviour was, as Preston noted, concerned with duties. On the one hand the ethological data showed a staggering list of duties performed by therapists for patients, many of which patients could have done for themselves, while the case history data showed the other side of this picture, failure to get to know patients and activity providing the means of avoiding finding out their needs and acting on them. A picture is built up of staff acting out duties but failing to be effective in terms of real change in the patient's state.

However, the medical and nursing literature shows many reasons why this situation occurs and these reasons are no less valid for therapists working with lower limb amputees. Given the social prejudice against such disfigurement as loss of a limb - prejudice which was shown in chapters one and two to be mirrored in the literature of the therapy professions - it is not surprising that physiotherapists, like nurses, respond to a need to distance themselves from the awful fate of many of their patients, seeking recompense and reward by doing their duty and thereby contributing to the smooth running of the organisation by compliance. One need look no further than Milgram's alarming study, 1974, to see how humanitarianism, which one understands is the prevailing social morality, can quickly disintegrate into incompassionate obedience to duty with the cruelest results. Seen in this light it is a tribute to therapists that they disputed with their medical superiors in order to give a more caring service and were observed privately to grieve the loss of patients.

But the present situation represents a costly impasse. Knowing the reasons why it exists does not make it less unpleasant. It may be argued that even though the system is less than perfect - and which system is not - at least every, patient has the opportunity to avail himself of a system of treatment, to receive a limb and undertake mobility training. Both limbs and training are, after all,

the product of many years of experience in these fields. When interviewed on the subject, Humm stated that there existed today a situation far better than pre-war days of limbs for only those who could afford them and training for almost no-one. But the argument is not as simple as that. Today there are more than 5,000 new amputees annually and the costs are correspondingly great. Yet there is no scientific evidence that present treatment patterns are, in rehabilitation terms, an improvement on the pre-war picture. And while what is available today seems more humane, more egalitarian, this study has revealed that for the client the system can be slow, humiliating and miserable, with very little success in terms of what patients themselves require.

Summary and Recommendations

The data revealed that communication between patients and staff was superficial and impersonal. The result of this was a system of treatment which revolved around organisational requirements rather than the needs of the patients. As such, success in real terms was not great. An obvious recommendation would be to improve communications at all levels but the literature shows that superficial communication serves many purposes, not least, allowing the system to operate more smoothly. Once again suggestions regarding changes are difficult in the face of problems which are inherent in system or integral to them. Using nursing as a model again, some modification of the system does seem possible along the lines of all that the nursing process seeks to innovate. Task-orientation can be attenuated. Communication can be more sensitive to cues from the patient. Care can be tailored to individual need. But in the same way that child-centred education offers scope for abuse so too do patient-centred approaches. In the hands of less efficient teachers and nurses less is achieved than under the old authoritarian task-orientated regimes. Communication becomes purposeless chatter and professional practice stands aside to let the patient 'do his own thing': staff lose respect and patients lose confidence and direction. While advising all those involved in work with amputees to move towards patient-centred patterns of

care, further investigation is urged to determine the degree at which this offers maximum benefit. Is this merely a question of therapists being more sensitive to what patients have to say or can there be no real improvement until patients control their own rehabilitation programmes?

C. Disfigurement, Disablement and Hopelessness.

Before going on to discuss in more depth bureaucratic management and professional power, there is an issue to be dealt with which arises from the previous section when reference was made to the work of Preston 1979. In the opening chapters of this thesis it was asked whether treatment schedules for lower limb amputees were characterised to any significant degree by a feeling of hopelessness. Physiotherapy literature depicts lower limb amputation, wrongly in the author's view, as a condition of irredeemable loss. Was this attitude borne out in practice?

Sadly the results show unequivocally that this was the case. The paramount example being that patients were not seen to be in urgent need of suitable replacement limbs. (The data revealed a host of factors which were allowed to intervene before the patient was united with the limb; therapists stored limbs, there were delays of many sorts, ugly, ill fitting and painful limbs were tolerated. Therapy involved removing limbs with patients taking part in limbless activities, there was a lack of positive comment on the part of therapists as to the value of these limbs, and so forth). Many other themes arise from the data to lend weight to the general impression of 'hopelessness' or certainly that treatment for lower limb amputees revolved around irreplaceable loss and permanent disability, of less-than-normal opportunity and less-than-normal living. (The stated aim of therapy was to enable patients to 'potter about a bit at home'. Therapy did not relate to serious living. Within the department far too much was done for patients, and so forth). Despite isolated

incidents there was no proper body of evidence to the contrary. With patients

who were seen as failures (patients N and Z, and to a lesser extent patients L and T) mobility training was clearly seen as pointless or hopeless or cruel. But what the author is especially concerned with in this section are aspects of 'hopelessness' in the treatment of the majority of patients; those who to a lesser or greater degree were seen by the staff to be making satisfactory progress. Therapists did not think of their work as a waste of time. What is at issue here are such aspects of hopelessness as underachievement and less-than-normal living, i.e. that training beyond a certain level was purposeless.

One need look no further than the work of Goffman 1959 and 1963 to see how profound is the effect of a person's being different from society's normative expectations and the prejudices which operate as a result. The work of Scott 1969 and 1970 showed that professional experts are just as susceptible to these expectations and prejudices as the lay man. Institutionalising a person confirms the staff in their belief that the person is what they label him and is in need of their services (Goffman 1961). The data yielded ample evidence to show that patients were treated as disabled with all that that entailed and discharged without treatment for many probably redeemable disabilities. has noted, 1970, that it is typical of rehabilitation programmes in Britain for 'centres to be constructed around good-naturedness and cheerfulness in the face of adversity; where 'agencies take the view that the level of independence and self-sufficiency possible for most disabled people is very slight!. This seems indeed to be what the results of this study have shown. In centre C in particular the prevailing ambience was one of cheeriness, games and goodwill but with little emphasis on mobility skills and less on rehabilitation proper. Superficially patients and staff appeared to be hard at work with walking training. Classification of the activities from the ethological data showed this was not the case.

In view of normal social prejudices the results are perhaps not surprising.

Preston's contribution to this topic, 1979, helps us to understand the invidious

position of the staff. He showed the effect of human abnormality on the normative witness. We must bear in mind that all amputee patients have been mutilated, many are dying, their replacement limbs are for the most part repulsive. Preston stated:

"The dignity of man is a humanitarian concept that refers to a coherent and positive human identity. Disease is the ultimate nemesis of this "dignity". "Death with "dignity" entails an inherent contradiction. "Debility with dignity" is a difficult proposition - more difficult as the debility is greater"...

"In practice, humanitarianism is a feeble means of assuagement; therefore, humanitarian effort is more alloyed towards more ambiguous men, or it becomes a tortuous exercise. Since sociability is largely impossible with patients whose personalities are greatly defective, the humanitarian effort is generally slackened for these patients. Nurses may feel the greatest humanitarian strain with patients whose extreme debilities are bodily since the intact personalities of such patients elicit humanitarian regard."

Preston 1979¹

As things are at present nurses and therapists have no reason to be unduly hopeful about the fate of those who lose limbs, especially those who are elderly and for whom loss of a limb is a postponement in the dying process, or to see their life chances on a par with their contemporaries. Further, they infrequently see patients walking well with cosmetic limbs and almost never have the opportunity to see amputees taking a normal part in society. Instead their work consists of never ending contact with the grotesque new recruits to the ranks of the limbless, in the face of which they largely maintain cheerful and good-natured care. Insensitivities may be attributed to the inherent strain of this work and the difficulties for any normative witness in facing the fact — if it be true — that real human beings accompany the disfigurements, disease and probably dying bodies that they daily see before them.

^{1:} R.P. Preston The Dilemmas of Care: Social and Nursing Adaptations to the Deformed, the Disabled and the Aged. Elsevier 1979 New York pp. 152 and 153.

Certainly there was evidence of insensitive care. There were overt instances as with patients W and Z. There existed also a continuous theme of insensitivity to the normal or fully-human needs of even the most successful of patients. Comments by Tuckett, 1976, shed further light on the difficult position in which nurses and therapists are placed partly by their medical and administrative superiors who can to some extent avoid the unpleasantness of prolonged contact with individual human abnormality. As discussed in chapter two, walking training can come at a late and debilitated stage for the patient. Staff may feel failure (or death) to be imminent or inevitable but the inevitability of the treatment process is underway. The real consequences of disease are avoided by the staff who expect patients to do likewise, and each co-operate in exhausting procedures despite their pointlessness. The observed failure to discuss the fate of the contralateral leg may be an example of this avoidance of unpleasantness.

Summary and Recommendations

The evidence showed that despite the care taken by physiotherapists with those who had lost limbs, even their obvious affection for many of these patients, treatment patterns did not constitute a serious attempt at rehabilitation.

For amputees, normal or near-normal living was not the goal. The work of Goffman Scott and Preston was used to help in understanding why this situation exists.

Loss of a limb epitomises disability, and throughout chapter two it was shown that the fate of amputees can be extremely bleak. Their rehabilitation compared unfavourably to that of the most seriously ill (Forer et al 1980). This being the case, one would expect no less than the prejudices described by Goffman and Scott nor the resultant strains and insensitivities portrayed by Preston for those working with amputees. 'Centres constructed around goodnaturedness and cheerfulness in the face of adversity' appear as a tribute to modern humanitarianism.

However, as was strongly argued in chapter two, in twentieth century Britain limb ablation is a redeemable condition. While loss of a leg rightly epitomises disability, a leg amputated nowadays can be <u>replaced</u> and many of these replacement limbs for varying levels of amputation allow the limb wearer a proper degree of rehabilitation. Consequent upon this the whole picture changes. The future need not be bleak. Gross prejudice need not operate. Sheltered environments need not be appropriate. These latter are the consequence of ugly and inadequate replacement, or failure to replace the limb at all, and of the disease process rather than the amputation itself.

Obvious recommendations are a change of attitudes, a vigorous approach to amputation, an earlier decision to amputate and speedier replacement, closer liaison of surgical and prosthetic teams, the abolition of all limbs that are not cosmetically acceptable and so forth. But these recommendations have been made before (e.g. Nichols 1971), though possibly the handicap of non-cosmetic limbs has not been adequately researched. Why should they be effective now when they have not been in the past? Society has deeply-rooted reasons for rejecting ideas that those who have lost limbs can be 'as-normal'. Perhaps change could be brought about if the focus for these ideas was physiotherapy and the para-medical professions, i.e. if instead of recommending from the top downwards, change came from the middle outwards, from patients and staff at the crucial walking training stage. Otherwise the situation will remain bleak, as noted previously, so bleak that 'reconstructive procedures should be considered even where there is little hope of saving the limb' (Huston 1980).

D. Bureaucracy

"In hospitals, and, indeed, in medical practice generally, the essence of managing patients is the routinisation of care. Hospitals are organised to help patients with particular diseases and problems, and standard rules and procedures have been developed to ensure that each patient obtains the appropriate treatment by doctors and nurses trained to carry these out.

Patients are diagnosed and they are placed in a category of people for whom a particular course of management is prescribed".

Tuckett 19761

This, in essence, describes hospital organisation. The term bureaucracy is common in this context. The term is frequently used in a pejorative sense but in Tuckett's description the usefulness of bureaucratic management of people is also apparent. It is egalitarian - each person is diagnosed and given appropriate treatment. It is intended to be efficient and cohesive - routines are established and a large labour force combine their many skills. But Tuckett has also shown many pitfalls, for 'no individual is ever likely to fall perfectly into any one category, thus tensions arise'.

"The goal of treating the whole patient, and ministering to all the needs, physical, psychological, and social, that bear on his medical problem, is often lost within the restricted aims and authority of the specialist departments which share responsibility for the patient, and do not take up sole responsibility. The fragmentation of authority has been much criticised (Lancet 1959 for example) and has caused many doctors, particularly those working in departments of social and community medicine to put forward ideas that emphasise 'human medicine' and the 'whole patient'."

Tuckett 1976²

Perhaps what the results of this study showed more than anything else was the way in which lower limb amputees were caught up in a bureaucracy that did not meet their needs and from which they could not legitimately escape. Within their physiotherapy there was negligible evidence of 'human medicine' or care of the 'whole patient'. The conclusion one is forced to draw is that the attempt, on the part of the NHS, to give a full and fair service to all those who lose limbs has resulted in a system which fails to give appropriate service

^{1:} D. Tuckett An Introduction to Medical Sociology Tavistock Publications 1976 London p.193.

^{2:} Ibid p.231.

to any. Let us examine some main points of the evidence, for this is an extremely sweeping conclusion.

The ideal time schedule from limb ablation to full cosmetic replacement was found to be five months. This may be judged to be reasonable (though it does not compare well with Malone's series who had full cosmetic replacement on average at 31 days, Malone et al, 1979, USA). But rarely was this schedule maintained and the case histories showed that the delays were not the unavoidable consequences of the clinical determinant. Most often delay in limb replacement was organisational, i.e. it was caused by tardy appointment schedules and training routines which effectively withheld limbs from patients. Where cosmetic replacement was accomplished in under 6 months, e.g. patients G and V, rehabilitation was unsatisfactory at the end of training, and re-amputation likely aggravated by lack of information on care of the contralateral leg and use of the wrong stump socks. It was found that temporary limbs could not be used as a measure of adequate limb replacement because they were unacceptable to normal society and disliked by patients who consequently made limited use of them.

Regarding mobility training, in many different ways the routines were shown to be unsatisfactory. Training may be given for as much as five full days each week or for as little as one hour per week. No optimum is known and schedules varied primarily upon hospital policy and staff availability and not individual need. The training provided for patient U exemplified a particularly lengthy and unsuitable regime which was eroding the patient's intense motivation to succeed. Arrangements for both in and out patient attendance were found to be unsatisfactory and particular criticism was levelled against the way in which ambulance transport was organised for out-patient attendance. It was costly, time-consuming, exhausting and depersonalising for patients and unduly disruptive both of the patient's day and the therapist's intended programme.

Ethological investigation of the organisation of the walking training classes themselves revealed proportionally little therapy - physical therapy represented around 10% of the total activity - whilst a great deal of anti-rehabilitative activity took place, e.g. 46% of the patients total activity was done by staff or controlled by staff on the patients' behalf. This situation was especially aggravated by the fragmentation of labour and routines had been established which blocked patient initiative at the point where mobility training became purposeful, the point at which it became rehabilitation (refer chapter seven, fig. II).

Routines, duties, institutional or organisational practices, fragmentation of labour, impersonal bureaucracy - call it what you will - these were seen to take precedence over individual need and consequently over rehabilitation proper which is intrinsically tied to the needs of the individual. Thus the ethological data revealed that the incidence of rehabilitation proper in the schedules was less than 1% of the total activity. This finding was supported by the case history data which revealed that neither was it apparent in the lives of the patients; a paradox in an organisation set up for the purpose of rehabilitation.

There is a substantial literature which shows how nurses become cogs in the huge machinery of the hospital organisation. This has many parallels with the work of physiotherapists and their aides and orderlies. Training socialises them into its routines (Coser 1963, Davis 1966), tasks gradually become focused upon duties to be done rather than on people to be helped and staff become alienated from their work and turn to extrinsic rewards such as pay, bonuses, job status, etc. (Saunders 1954, Tuckett 1976, Preston 1979). Apathy can be conveyed to patients who are treated as objects (Brown 1973), 'The common decencies and rituals of everyday life are ignored or performed in so perfunctory a manner as largely to negate them'. 'Minor aspects of the tasks

tend to dominate. 'There is insufficient involvement for any kind of genuine appreciation of the person's needs'. Brown's comments referred to mentally ill patients but are not without relevance to the descriptions of the treatment of lower limb amputees.

One cannot envisage the chaos that would ensue if staff were not to operate within given boundaries but the literature shows the frustrations and tensions which this gives rise to. Goffman, 1961, noted that staff genuinely concerned with rehabilitation often felt they had to leave the 'rehabilitation' institution in order to practise their skills effectively and to the full.

Summary and Recommendations

The hospital organisation which has been established for the purpose of the rehabilitation of lower limb amputees was found to comprise little that was rehabilitative and that organisational practices were themselves a chief factor in the failure to rehabilitate. Therapists did not or were unable to effect change.

The primary recommendation for change is that those concerned should be aware that this unsatisfactory situation exists. At present the term physiotherapy is equated with rehabilitation. This study has shown that this is not the case either in theory or practice.

Working within the present organisation many beneficial changes now begin to be possible. The approach of Burgess and Malone (USA) and Hutton and Rothnie (England) points the way to more rapid and intensive regimes which could be tried, even if on modified lines. There should be urgent discussion on the advisability of discharging patients from the ward prior to delivery of at least a temporary limb, for at present patients are discharged prior to replacement procedures which were the raison d'etre of the ablative procedure. With evidence of the high levels of activity done by staff for patients, a conscious

effort could be made to redress this situation. Minor functional activity could be included in the treatment plan and given equal prominence with mobility training. Therapists could examine the ways in which their aides and orderlies undermine their efforts. More attention could be given to patients queries on social and domestic matters. And so forth. The organisational structure could be attenuated in very many ways.

Other changes could not be brought about within the present system and the question of a domicilliary service again comes to mind, and, again, new ways of organising rehabilitation services are blocked by lack of supporting research, thus making it premature to suggest a radical new basis for future treatment.

E. Power

Professional power is another major theme in the sociology of medical practice (e.g. Mechanic 1968, Friedson 1970, Robinson 1973, Cox and Mead 1975, Tuckett 1976, Illich et al 1977). Texts most often refer to the doctor/patient relationship but when discussing professionalism in a broader context (e.g. Robinson 1973) we can see how similar themes apply in the nurse/patient relationship and, though not specifically mentioned, the therapist/patient relationship.

At all stages in the treatment of those who lose limbs decisions have to be made and negotiation must take place. But 'what happens in the bargaining process will often be influenced by power: by the relative ability of each participant to apply rewards and sanctions to each other! (Tuckett 1976). The medical and para-medical professional workers have all the knowledge and authority of their professions to call upon while the patient has only negative sanctions, he can refuse to co-operate, refuse to be cured and drop out of treatment. Even the patient's free choices, e.g. of consultant, adds to professional power because if the patient questions any aspect of treatment he can be reminded that as he came voluntarily so too he may leave (Friedson 1970).

An important finding of this study, which the author only gradually came to realise, was the extreme naivety of these patients. This made them all the more easily manipulated by the staff, for staff power is greater where patients are ill-informed (Robinson 1973). Thus there were patients who appeared to have undergone far too many surgical procedures, who walked daily with limbs they detested, patients who used a transport system they heartily disliked, participated in games which were equally disliked, who were treated as less-than-adult and so on, and yet continued to co-operate to an extreme degree in the belief that what they had to undergo was inevitable and that 'they know what they're doing', 'they know best'.

The author is not an advocate of self-help schemes as alternatives to professional help for this would seem to abandon centuries of accumulated knowledge and leave every patient to arduously seek solutions to problems which are already known and quickly taught. Nor does the author advocate policies whereby each patient be thoroughly schooled in 'amputeeism'. Quantities of information would be supplied which would be surplus to requirements, which few patients sought or wanted, preferring - though possibly expecting - to remain in ignorance. But what the data showed was that a) patients were supplied with less information than they needed and requested and b) lack of this information had costly consequences. The right balance was not struck and professional power was unreasonably guarded.

Professional power was unreasonable in other ways. Therapists (doctors and others) are not only authorities of their subjects and parted with too little information, in addition they were often observed to be too authoritarian in their attitudes and practices. Patients were forced to be unduly subordinate and this seemed at odds with the goal of rehabilitation which is closely allied to such ideas as independence and autonomy. Many instances revealed patients treated as children even as objects. Too often their moves were blocked rather

than harnessed and developed. Again, too much use of professional power was counter-productive and it could have been slackened without loss of status. There is no reason for example why patients should not return cups to a trolley without fear of a reprimand or why they should have to ask permission to go to the toilet.

With regard to the relative position of the senior therapists this issue is not a simple one. In effect they were less authoritarian than either their superiors or their subordinates. Senior therapists were at times observed to enter into most useful negotiation with patients, to discuss in depth such topics as limb wearing, climbing stairs at home and so forth. As has been discussed elsewhere the focus on these discussions was frequently too narrow. They also failed to supply much important information or advice but often this was the result of their being too busy, to common habits of task orientation and because they were unaware of the extent of the patients' ignorance - this latter being due to communication barriers which have already been discussed. Also, their authoritarian stance, again as has been discussed, arose from the pressures of custodial responsibilities. Basic grade therapists on the other hand, other less senior staff and students, quite clearly a) rarely knew the answer to patients! queries and b) were defensively authoritarian as a result of their own inadequacies and insecurities in their professional role. Auxilliary and ancilliary staff were effectively the most authoritarian towards patients. The frequent insensitivity of their approach may have reflected their lack of professional training but was also a consequence of the way in which their immediate superiors defined their work as a series of tasks, e.g. collect x number of patients, lift heavy patients, carry artificial limbs, walk x numbers of patients every 20 minutes, etc. So, it was usual for them to approach a patient as an object to be handled or transported, as a job to be done.

Summary and Recommendations

As bureaucracy mitigates against rehabilitation so too does professional power. Each exists in theory to help the patient towards recovery yet in reality each hindered recovery in quite specific ways where bureaucracy or professionalism was too dominant. Senior therapists were less domineering than other staff, though at no point was the situation satisfactory.

To the author it has always seemed that (over and above sound and extensive knowledge), the hallmark of true professionalism is in being able to recognise one's fallability, to dare to be uncertain, to be prepared to listen and learn, and to recognise the need to co-operate with the skills that others have to offer. It was this type of professionalism that was so rarely apparent, at any level, in the treatment of those who were the subjects of this study. If it had been much more in evidence those dealing with amputees would have known more, would have been more sensitive and more willing to learn. The patients' needs would have then become apparent, the patients' efforts could have been harnessed and the staff could have guided them through a much more full rehabilitation programme. Fewer authoritarian aspects of professionalism would have been obvious.

It is strongly recommended that therapists be much more highly trained and basic grade therapists better supervised. The costs of this could be met by dispensing with many auxilliary and orderly staff who are presently engaged in tasks that, in a rehabilitation setting, patients should be learning from therapists to do for themselves. Also a more rapid turnover in patients is envisaged as a result of much more professional patient-centred approach, thus cutting costs further.

F. Conclusion

The results of this study were discouraging, both in terms of the therapy

professions and the fate of those who lose limbs. From discussions in this chapter the impressions that spring to mind are those of the invidious position of those who work daily with amputees and the inevitability of the poor results. Such recommendations as have been touched upon seem to be of the nature of negative or pessimistic possibilities rather than hopeful probabilities.

However, it is the author's opinion that this unhappy picture could be greatly changed. For the reasons for failure are not narrowly concerned with limb amputation as such, nor necessarily its attendant illness, but have been discovered to be significantly the result of institutional practices and prejudicial attitudes, which are in turn the product of unsound theory. In this chapter those very institutional and prejudicial causes of these unhappy results seem inherent in the treatment systems and likely to prevent real change. But recognition of these factors already begins the process of modifying and attenuating them. Further, through this investigation three quite new areas of thought are opened up - in rehabilitation theory, in physiotherapy practice and in an improved understanding of lower limb amputation. Thus rehabilitation could be put on a new course. Recognising the inadequacies of present thinking on rehabilitation and employing the author's redefinition of these subjects new treatment systems would result. There are possibilities for the future to explore ways for changing things for the better.

At present unsound thinking prevents those involved from seeing where the problems and failures lie. Indeed most patients are mistakenly seen to be succeeding. The value of the author's review and redefinition of these subjects is that it enables the truly rehabilitative themes to be distinguished from other aspects of treatment so providing for the first time sound criteria for identifying problems and failures and opening the way for new and effective forms of treatment to be researched and developed.

Chapter Ten

Conclusion

Introduction

In this final chapter the conclusions of this study are listed. Critical assess ment is made of the value of the study and there are suggestions for further work.

A. Conclusions

The aim of this investigation was to find out whether the rehabilitation process of those who lose (lower) limbs embodied serious contradictions which limited its effectiveness. The means of examining rehabilitation was through an investigation of the process of physiotherapy from the perspective of the lower limb amputee undergoing walking training. The conclusions take two main forms. First, large and important components of physiotherapy were not truly rehabilitative to the extent that they undermined the whole process. Secondly, at discharge from walking training patients were not rehabilitated and further help that might have continued the rehabilitation process was not forthcoming. In the following these points are elaborated.

Review of the literature on rehabilitation did not inspire confidence. It was found to be an impoverished area of medicine lacking a sound and scientific basis. Such statements of definition and intention as could be identified would not bear the weight of the discipline which has been based upon them. Organisation and practice were also criticised. Sociological texts suggested inherent contradictions in hospital rehabilitation and government reports testified to its unsatisfactory state (Tunbridge 1972). Regarding lower limb amputee rehabilitation the literature of nursing and physiotherapy was disturbing. Examining this topic more closely in chapter two it was found that loss of a limb was needlessly viewed as a most grave or irredeemable condition. Research into amputee rehabilitation was patchy and incomplete. The impression was however that its success was very low. A certain hopelessness surrounded

the treatment of amputees. Surgery was delayed and patients became unnecessarily debilitated. They underwent a great many surgical procedures. The numbers of these procedures and their frequent failure to provide a good stump were severely criticised. Mortality and morbidity were high and amputation was associated with 'a marked lack of volition' (Harris et al 1974.) Some studies suggested that a much more positive approach could produce much happier results (Hutton and Rothnie 1977, Malone et al 1979), but there were few grounds for optimism in the present situation.

Two imperatives arose: a) the need for a sound theoretical basis for rehabilitation and b) the need for research into rehabilitation practice to find out what actually occurs and what is its present state.

In chapter three the concept of rehabilitation was examined. The logical, reasonable and humanitarian conclusion of this was a redefinition of rehabilitation. It was called rehabilitation proper to distinguish it from previous terms and ideas. Rehabilitation proper is the restoration of a person to a proper condition, which is a social condition. It was found to have three boundaries. It was distinct and separate from clinical treatment. It was equally distinct from physical therapy. Nor was it found possible to include the grosser forms of handicap. Rehabilitation proper is personal, domestic, economic and recreational restoration, relative to daily living. Mobility training does not become rehabilitative until it has these components.

A descriptive enquiry using two distinct methods - ethological and case history - was found to be the best method with which to investigate rehabilitation practice. Experimental methods, questionnaire surveys and so forth were found to be inappropriate and the rich data produced by descriptive observation supports this choice.

In the light of the revised view of rehabilitation, the conclusions of this

investigation are as follows:

- 1. The rehabilitationists physiotherapists and remedial gymnasts contributed very little indeed to lower limb amputee rehabilitation. The incidence of their encouragement of rehabilitation proper formed a mere 0.16% of their activities with patients, and patients were discharged unprepared and unable to cope with personal, domestic, economic and recreational aspects of their lives. For example, nearly half the patients were housebound and those who went out of doors relied for the most part on the motor transport of relatives or taxis. Yet none had been taken into a public street by the walking training therapist in order to learn these skills. What was taught within the department was not generalisable to 'outside' conditions. The staff did not sufficiently enhance wholeness and usefulness.
- 2. While rehabilitation proper could be argued to be outside the province of physiotherapy; more serious than the failure to teach rehabilitation proper was the tendency to block its natural development. The ability to perform minor and routine tasks within the walking training environment was seen as a first step on the rehabilitation ladder. Yet 30.7% of these minor tasks were done entirely by staff for patients. As the proportion of minor tasks to physical therapy was 5:1 so the proportion of these tasks carried out entirely by staff for patients was greater than the total therapy, 3:2. For the most part these tasks could have been done by patients. Where patients were unable to do them, in a rehabilitation setting they should have been taught. The incidence of minor tasks that were taught was only 7.3%. So patients only incidentially improved their skills in these areas, and walking training took place in an environment that fostered disproportionate elements of waiting and dependency. Over and above failure to enhance wholeness and usefulness, the

staff were engaged in activities which compounded disability.

Further evidence supports this conclusion that physiotherapists did not teach physical therapy in a way that enhances the rehabilitation of those who have lost limbs. The prime evidence comes from actual walking training where therapists carried out as many walks for patients as they allowed patients to carry out for themselves. What is of special note is that while patients engaged in walking exercise, staff were engaged in walking for the purpose of carrying out the <u>patients!</u> minor tasks. Staff undertook tasks for patients at a rate whereby almost any routine activity which could be taken from a patient and done by staff was taken away. Thus staff robbed the patient of the initiative in daily activities exactly at the point where emerging mobility skills become useful to the patient; exactly at the point where physical therapy becomes rehabilitation.

3. A surprising conclusion is that there was very little actual therapy. Physical therapy comprised only 12.14% of the total activity of these physiotherapy classes; walking training sometimes occupying mere minutes within a week. Also staff failed to teach safe and correct mobility skills to a large proportion of patients. (A figure of 26.3% may be derived from the data at centres B and C, patients F, K, N, T, Z, 5:19). Up to 25% of this therapy comprised the entirely inappropriate and much criticised team games and ball games. So, therapy was not sufficiently intensive, not sufficiently successful and not sufficiently appropriate to rehabilitation.

In addition the therapy may be criticised for not being sufficiently extensive. For though the staff taught a number of applications of locomotor skills, e.g. climbing stairs, walking on rough ground, etc., in practice application outside the department was very limited indeed. The safety and privacy of the depart-

^{1: 12.14%} is the largest figure that may be derived from the data whereas a figure of around 10% may more truly reflect the proportion of physical therapy to the total activity.

ment did not prepare patients for the real world, for therapists did not follow up what was usually sound initial instruction with domicilliary or out-of-door therapy. Nor was there sound occupational therapy. Patients were discharged unable to perform the simplest daily tasks such as carrying a cup of tea (Mrs. K), stepping out of the house (Mr. T) or rising from a chair (Mr. N).

- 4. The walking training department was found to be heavily characterised by the elements of institutional life described by Goffman 1961. Comparing the total institution and out-patient amputee departments it can be concluded that there was an underlying similarity in organisational approach if not the same intensity of attributes. In view of this, the failure to rehabilitate is less surprising, being a characteristic of institutions. Depersonalising practices and an irrelevance to serious living are also characteristic.
- 5. Prejudicial attitudes operated to a significant degree within treatment settings against the interests of the rehabilitation of the amputee client.

 There was clear evidence that patients who had lost limbs were seen as disabled, treated as disabled and as a result became 'disabled people'. Many of the behaviour traits which characterise normal reaction to stigma (Goffman 1963) were present in staff reaction to patients. In particular expectations were low and the 'nine steps mentality' went unchallenged. (Indeed the criteria at centre B was four steps). Patients were assumed to be incapable and 20% of their potential activities were done entirely by staff, who directly controlled 46% of patient activity. The way in which cosmesis was completely overlooked and that patients were not seen to be in urgent need of replacement limbs shows that the system does not see the patient as having normal wants. The unsightliness and lack of substance of NHS temporary limbs speaks volumes of what society feels is suitable for 'the disabled'.

None of these characteristics are likely to contribute to rehabilitation in the way it has been defined in this study. Each operates against the patients!

chances of normal living and a return to a proper condition in society. At the level at which these attitudes were observed to take place they governed the walking training environment. The effects were profound. Case notes on patients H, L and R show how difficult and different is the life of the lower limb amputee. Patients were left in far more disabling states than need have been, and indeed may even have been positively encouraged into disablement. It must be concluded from the evidence that the view of amputation manifest in rehabilitation is one of permanent and severe disability.

Whether or not therapists saw loss of a limb as a sudden or shocking procedure or as a continuous process it is not possible to determine from the limited evidence of informal interview. They did not for example console patients or discuss psychological sequelae. In answer to questions raised in chapter two, there was good evidence however that they reinforced stereotypes, e.g. the 'hero', patients Q and Y, the 'failure' patients N and Z, the 'dependent' patient W.

6. Certainly the most surprising conclusion of this study is that patients were not treated as being in urgent and real need of their replacement limbs. There are indeed factors which mitigate against early and immediate fitting and problems of many sorts necessitate delays but over and above these were inexcusable organisational delays and inexplicable physiotherapy practices. These included prolonged storage of the limbs of patients attending walking training to outright confiscation of limbs as a punishment for poor performance. While one's first impression of a walking training class is one of patients learning to walk, a second glance reveals a row of sound artificial limbs stored in a rack at one side of the room, their owners elsewhere, waiting to walk. The data is littered with examples of the many ways in which patient and limb were separated. When the patient was united with his limb it was often unhappil and uncomfortably, and the undoubted expertise of one or two therapists was insufficient to alter the general picture. The flexibility of the observation-

al method allowed many new themes to emerge on this topic.

Thus it must be concluded that the staff of the walking training department and the larger bureaucracy of which they were a part, failed in their first duty to the limbless patient. They failed to replace the missing limb in a way that inspired confidence or ensured maximum use. Patients did not have essential knowledge and essential equipment and were prevented in a variety of ways from seeing their replacement limb as an integral part of their bodies and their daily lives. The foundation of poor and non-use of artificial limbs is here.

7. The question of whether 'a certain hopelessness' characterised patient or staff attitudes or practices was raised in chapter two. It was found that a degree of hopelessness infiltrated treatments at many levels. A further finding of this study was the private unhappiness of many patients. 42% (8:19) of patients talked privately to the author and to other patients in very negative terms about their predicament and future. Thoughts of suicide were not uncommon. Where patients were confident and optimistic their optimism was often ill-founded and unlikely to stand the test of time. It seemed to the author that both hopelessness and euphoria were sustained by lack of information, lack of informed advice, lack of the means to formulate questions and thus to find solutions to problems. As discussed, patients co-operated despite misgivings.

Staff stated that treatment was hopeless in relation to the few patients overtly seen as lacking motivation or in poor physical condition. Covertly, their practices suggested more generally a lack of urgency and low criteria of success and patients left in states far more disabling than need have been. In education such traits have been associated with lower stream schooling (refer chapter two) where an ethos has been found to prevail that there is no urgency to teach those who are felt to be going nowhere.

This topic is one of the least tangible aspects of amputee rehabilitation, though it was on just such topics that it was hoped this study would shed light. In has yielded clear evidence that some very negative attitudes prevail.

- 8. There was unexpected evidence of lack of care. Care was not under investigation. Yet there were indications at all phases of treatment that patients were not properly looked after. For example, there was a 26% (5:19) incidence of stump injury involving staff, artificial limbs were broken by staff, patients waited for up to four hours for ambulance transport and had to endure journeys of up to 3 hours and 20 minutes duration, in-patients were dirty and badly dressed, there was unacceptable verbal abuse, and so forth. From a broader perspective both ground floor and sheltered accommodation failed to provide an environment for mobility. There were as many and more examples of adequate even exceptional care, but one must conclude that standards were not as high as they should be.
- 9. The author's views that amputation of a leg is in itself both a less shocking and more redeemable condition than it is generally held to be are substantiated. We see sufficient evidence in this study that things could be different. Over and above illness and limblessness the foundations of handicap are inherent in the system that treats it. Clinical and prosthetic factors were not more problematic than organisational practices, prejudicial attitudes and psycho-social factors. Furthermore, clinical factors were aggravated by a seemingly very high incidence of surgery (19 patients had to date undergone 92 ablative or pre-ablative procedures). Also too high an incidence of discomfort or pain were tolerated. Prosthetic factors were aggravated by the too lengthy process of replacement and the insufficient knowledge of many of those who were involved. Subsequent revision of theory and practice must now become a serious consideration. And as the model of sudden and shocking loss loses ground, the model of loss of a limb as a continuous process must be given more

credence.

10. At the present time rehabilitation failure was found to be governed by two myths. The first is that it depends first and foremost on the clinical determinant. The second is that it is dependent on the patient's motivation - the 'some patients have it and some don't' approach. (This has an exact parallel in education where the literature dictates that home background is the largest single determinant of success or failure in school, while, in the staff room, pupils are divided into dull and bright, the ones who don't have 'it' or who do.) We have seen that the clinical determinant exists, that it places the recipient into the rehabilitation setting, but whether or not its influence is paramount is unlikely - at best unproven and uncertain. What is clear is that the innate and immutable motivational determinant view can be dismissed.

Given the evidence that these patients were for the most part stripped of the usual rewards and stimulii of daily living, substantial evidence that they were unmotivated or anti-motivated independently of environmental determinants was missing. On the contrary they co-operated to an intense degree, despite misgivings, often in hopeless circumstances. Some of the least able patients and those labelled by the staff as 'poor material', attempted the highest levels of activity, e.g. patients F and BJ. More able patients, bored with prolonged training did much less, patients J, Q and Y. Neither was lack of motivation the prime factor where the staff had specifically labelled this to be the cause of failure, patients N, T and Z.

On a general note where poor motivation is present it must be borne in mind that it is first and foremost a measure of staff failure. A therapist is a teacher and the role of any teacher is to use and develop the intrinsic motivation of the pupil through such means as setting interesting and attainable goals. Lack of motivation must be laid first and foremost at the door of poor teaching skills.

Conclusion

This was intended as an introductory rather than definitive study of rehabilitation, specifically physiotherapy and lower limb amputee rehabilitation. Here it establishes sufficient evidence to question the rationale of both theory and practice.

B. A Critique of the Study

As stated this is not a definitive study. It is an introductory study which challenges medical rehabilitation - its concepts, theory and practice - and presents a new view from which debate and research can develop in new areas.

The weaknesses of this study are that, first, it is the work of one person and reflects one view. This increases subjectivity. However, the views, models and biases are made overt so others are able to assess their influence on the results. Second, are the intrinsic weaknesses of social science methods. These have been discussed throughout and their effects estimated. Third, this is too vast a subject to have been studied at sufficient depth. Superficiality is its major weakness. Any one of its main themes might have become the basis for a major work in its own right, but the state of rehabilitation was felt to mitigate against too detailed an inspection of any one aspect of this topic at this stage.

At the present time rehabilitation lacks ground theory. What this work does do is to point out this dearth of theory and begin the task of filling this gap.

Also rehabilitation suffers a lack of appropriate research method. It is hoped that this work illustrates the value of description and observation. The method used here has two distinct aspects and each have infinitely variable possibilities for use in further research in this field.

A further attribute of this study is that it breaks the mold of previous thinking in this field. Physiotherapy is seen in a different light. The thinking on amputation is reviewed and revised. New perspectives are shown to have value, and this should have an enlivening effect on these subjects.

On the subject of the patient-bias, this investigation has not been patientcentred in the sense of all research in medicine, i.e. that patients are its The approach has centred on the patient in a much more fundamental sense. The literature was reviewed from the point of view of the inmate, the client, the recipient of care. The proper condition of the patient became part of the ensuing definition of rehabilitation. The method was developed and was used to focus upon the patient through sustained and intimate contact with patients. This had the effect of producing a much more realistic account of theory and practice from the point of view of the patient. The reason for this is that this perspective is free of the implicit bias of the modern rehabilitation movement which incorporates the prejudices of modern society and whose perspectives are all too often too cosy and optimistic. The raison d'etre of medicine is the existence and well-being of the patient and when the patient is properly placed at the centre of a study higher standards are set and the consequences of failure are more honestly recognised.

It was intended at the outset that this thesis should have general application to physical medicine rather than being solely relevant to amputee rehabilitation. It is felt that this has been achieved. Though the data on those who have lost limbs is unique to these patients, wider implications are evident. In the first place, the revised theory of rehabilitation given in chapter three is not in any way tied to amputee treatments but is written in the context of any physical impairment. Also the research methods have application to many other therapy settings. The settings used in this study reflect usual physiotherapy practice; the techniques, staff and facilities could be or were used

on other occasions by a wide range of other patients. It is not credible that physiotherapy carried out in the manner depicted here was, moments later, carried out on a completely different basis with other patients. Indeed observation of hemiplegia patients at centre A and rta and sports injury patients at centre E suggested not dissimilar patterns in operation. Yet amputation may be seen as more disabling than other conditions. We wait to see what results other research may bring to light.

C. Suggestions for the Future

Recommendations were discussed in chapter nine. Most often points were mentioned in order to prevent others from using this evidence to draw false conclusions. Repeatedly it was shown to be inappropriate or premature to move towards such obvious steps as domicilliary therapy, self-help, increased communication and so forth. There is clearly too little supporting research. The paramount recommendation is for further research. Suggestions for further work have been touched on throughout this study.

Firm recommendations emerged however. Rehabilitation could become much more patient centred and something akin to the nursing process could profitably be introduced into physiotherapy. Some pitfalls were discussed in chapter nine but clearly a more sensitive approach to patients needs is called for. Second, contrary to the recommendation of the McMillan Report, 1973, orderly and clerical staff should not be proportionally increased. It is not 'wasteful use of professional skills' for therapists to be involved in such activities as portering. Currently, it is a contradiction of their skills that they teach patients to move independently while neither allowing or teaching a purpose for this movement.

From this enquiry it ought to be possible for those working in amputee rehabilitation to give firmer guidelines on frequency and duration of mobility treatment, and changes are needed in policies which separate the amputation patient from the prosthetic limb. Where possible, short daily sessions are recommended by the author, that is, on a seven day week basis. When the limb is not used or worn it should be with the wearer. Present travel arrangements have nothing to recommend them and cannot meet these proposals. Only in-patient or domicilliary therapy could meet these needs but again progress is blocked by lack of research. The increased role of occupational therapy in lower limb treatment also needs to be investigated. So too, policies governing surgical procedures and supply of prostheses.

It is suggested that no hasty changes - indeed no hasty recriminations - be made in physiotherapy practice in the light of this work. Rather each new topic should be tested and retested by others. The findings show that further work would be worthwhile. However because of the weakness of present theories it is urged that the philosophy of rehabilitation proper be given due consideration by the rehabilitation movement with an urgent view to the development of a much more sound and scientific basis for this subject.

Conclusion

An artificial leg is always preferable to the diseased and deformed leg or the certainty of death which it replaces and the prosthetic industry is advancing sufficiently to allow many who lose limbs a replacement to provide activity on a par with normal living. But rehabilitation is not taking place. Failure or underachievement are almost total. Where failure has been recognised in the past it has been largely attributed to clinical causes or vague motivational causes. In this thesis the wealth of situational difficulties shows it to be unnecessary to suggest lack of motivation on the patients part to explain lack of progress. These situational causes are not less significant than the clinical determinants. Most notable are contradictory and prejudicial attitudes

and practices generated within the staff world and in which rehabilitation is enmeshed. Rehabilitationists were shown to fail to have an impact on rehabilitation, to alleviate misery, to build confidence, to utilise resources and to get to know their patients at a personal level in order to assess the problems of each and tackle these problems. At the present time the outlook for those who lose limbs is unnecessarily very bleak indeed.

END

APPENDICES

I to IV

Appendix I

Derivision of the Five Groups of Activities from the Twenty-Eight Categories

The five groups of activities, introduced in chapter 4, divide and classify the ethological data and are used as a means to handle and interpret it. They are derived from the twenty-eight categories thus. Refer fig. 1.

Categorising and grouping is problematic in respect of all human activity but three of the groups were less so than the remaining two. The first of these three were the four categories of major functional activities which were added to the ethogram as a group - a deviation from usual ethological practice discussed in chapter four - to test directly for evidence of rehabilitation proper in a physiotherapy setting. Second were the clinical activities or those specific to the condition of lower limb amputation. Third, there was conversation other than that which was integral with gross activity and recorded elsewhere.

The two groups, minor functional activities and physical therapy activities, presented more problems. Some confusion may arise from use of the term 'physiotherapy' which includes both physical and functional activities, and from the author's use of the term 'functional' which differs from that of Humm 1977 and extends the term to areas he ignores, e.g. tea and coat. The distinction here between these two groups is thus. Physical therapy activities were concerned with the parts of the body, with mobility and exercise. (This has been discussed in chapter three.) Minor functional activities were concerned with the man as a whole, in giving physical acts a purpose which was relevant to daily living. The breakdown of these two derived from lengthy observation and this form of grouping did not bias the results to the detriment of the therapists. Rather it allowed the teaching of the most minor tasks to be recorded as therapy involvement in the first rung of the rehabilitation ladder. Thus the grouping is biased in favour of the therapists.

Fig. 1. Derivision of the Five Groups from the Twenty-Eight Categories

	major function		minor function	
Page one	(the activities of rehabilitation proper)	home	(minor or routine task necessary entail- ments of attending physiotherapy)	to dept.
Ca	major function	neighb	minor function	coat
	· · · · · · · · · · · · · · · · · · ·	neighbourhood	"	
-	major function	н	minor function	
	11	recreation	11	dressing
	major function		minor function	-
	II .	work	ıı .	tea
	clinical		minor function	- r
key	"	cosmesis	· · · · · · · · · · · · · · · · · · ·	return cup
mir	clinical	- b	minor function	
minor functional	11	prosthesis	11	
onal	clinical		minor function	adL
	≤u =	stump	11	I (in dept)

conversation major functional

Fig. 1. (page two)

	minor function	walking - ven surfaces	physical therapy (posture)	standing
100	minor function minor function	rs (No.) wal	physical therapy minor function	walking
	minor function	stairs	minor function	wa
200 200	physical therapy	lower body exercise	minor function	stand up
233	physical therapy	9 1	minor function	
12.60 13.00 04 13.00	physical therapy	upper body exercise	minor function	sit down
	physical therapy	e u	minor function	and a second
	minor function	transfers	physical therapy	walking aids
	minor function		minor function	W
two	minor function	falling	minor function	furniture
Page	minor function		minor function	

Appendix II

The Ethological Results: A Comparison of Centres B and C

Throughout chapter seven the ethological data is interpreted as one unit. This is because there were sufficient similarities in the results of centres B and C to allow this to be done. Here these results are separated so that the reader can judge the similarities. Refer figs. 2 to 6.

Distributed by the five groups of activities (refer fig. 4) we find the pattern of results from centres B and C is remarkably similar. In each case around 60% of the activity is minor and routine. Conversation, physical therapy and clinical activities, each in that order, comprise between 10% and 15% of the remainder of the activity. And at both centres there is very little of the major functional activities of rehabilitation proper.

Activities at centre C were more intensive. Walking training was concentrated into one hour rather than spread over a whole day as at centre B. Also at centre C the more intensive group exercises and team games were used as a main method of teaching mobility. This is reflected in the slightly higher proportion of physical therapy at centre C (refer fig. 4). Distributed by taught and non-taught activities (refer fig. 5) again the pattern of results is similar with a slightly higher proportion of taught activities at centre C for the above reasons.

Distributed by columns, i.e. by patient and staff initiative and control of activities (refer fig. 6), though the pattern is similar again, we find at centre B patients act alone a little more often. This is <u>not</u> because there were fewer staff. Indeed there were more staff per patient at centre B and

there was less auxilliary assistance at centre B and proportionally more trained staff (refer chapter 7). Again the more intensive, even hurried, activity at centre C accounts for this.

At no point do the patterns of results diverge in such a way to yield results which differ from those given in chapter seven.

Centre B
1 Results,
Ethological 1
Fig. 2.

ambulance to dept.	coat	dressing	tea	return cup	toilet	adl (in dept.)
1234	1234	1234	I 2 3 4	1234	1234	1234
3 4 42	24 14 10 23	21 4 13 10	40 12 50 69			6 42 12 21
Total 53 NIL	71 NIL	48 NIL	171 NIL	70 NIL	28 NTL	81 NIL
home	neighbourhood	recreation	work	cosmesis	prosthesis	stump
1234	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
0 0						
	0 0			0 0	21	2 0 0
Total 0 7 7 NIL NIL	~0	NIL	1 1		222 86 61 51 NIL 54 21	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$

	furniture	walking aids	sit down	stand up	walking	standing	conversation 1 2
	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1234	1234	1 2 3 4
317.	1 7 4 84	146 30 43 22 0 0 1 0	147 59 - 0 0 7 5	$ \begin{array}{c c} $	31 11 11 197 165 83 61 4	11 16 0 . 0 1 4	29 - 304 5 5 - 99 - 5
	Total 96 NIL	241	238		250	103	338
	falling	transfers	upper body exercises	lower body exercises	stairs (No.)	walking - uneven surface	walking - out of dept.
	1 2 3 4	1 2 3 4:	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
	3 3 3 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	16 16 1		0 0 0 0 0	5 4 4 1	1 0 0 0 14 24 9 0	0 0 3 0 , 2 4 5 0
2	Total 9 4 4	36 NIL	NIL NIL	1	11	47	11
Fig.	Page two Centre	В	.4				

The Ethological Results, Centre C.

ambulance to dept.	coat	dressing	tea	return cup	toilet	adl (in dept.)
1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1234	1 2 3 4
29	25	-18	21	1 13	0 0	25
Total 100 24 20 NIL	56 7 NIL	74 14 14 NIL	58 <u>3</u>	22 3 3 NIL 5	NIL	5 5 2
home	neighbourhood	recreation	work	cosmesis	prosthesis	stump
1 2 3 4	1 2 3 4	1 2 3 4	1234	1234	1 2 3 4	1 2 3 4
5 1	5 0		1 1 1	1 2 0 0	71 87 34	18 23 4
Total 13 NIL	IO	NIL NIL	NIL	A NIL	238 NTL	51 NIL

Page one Centre C.

	furniture	walking aids	sit down	stand up	walking	standing	conversation 1 2
	11234	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
319•			62 39 11 - 0 14 9	57 38 39 0 1 15 25 4	22 11 5 200 47 42 49 3	14 4 4 0 7 0 0	2 211 8 0 93 6
	Totals 65 falling	96 OI transfers	upper body	lower body	stairs (No.)	walking -	walking - out of dept.
			exercise	exercise		uneven surfaces	1 2 3 4
	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1234	1 2 3 4
e two)	11s 2 0 0 0 (7 4 4	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	22 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	$\frac{5}{5}$ $\frac{1}{2}$ $\frac{0}{1}$ $\frac{3}{5}$
Fig.	page two centre	e C.	<u> </u>	<u> </u>			

same

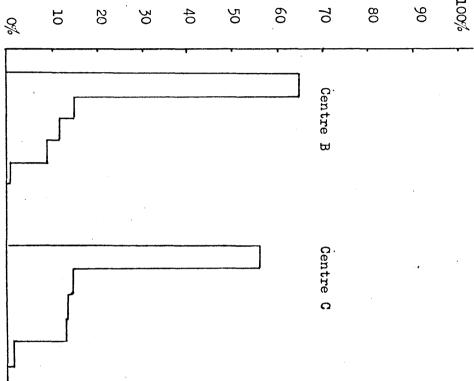
pattern

for centres B and C.

100% 90 60 80 40 50 70

minor f. 64.2 (1883:2932) converst.15.1 (443:2932) phys.th. 11 (321:2932) clinical 9.1 267:2932) major f. 0.6 18:2932) 100%

minor f. 56.85 (1236:2174) converst 14.7 (320:2174) phys.th. 13.75 (299:2174) clinical 13.5 (293:2174) 26:2174) major f. 1.2 100%



percentage of total activity

Fig. 5. Results distributed by taught and non taught activities,

Centre B and Centre C.

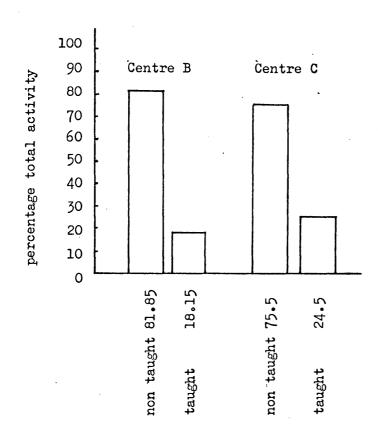
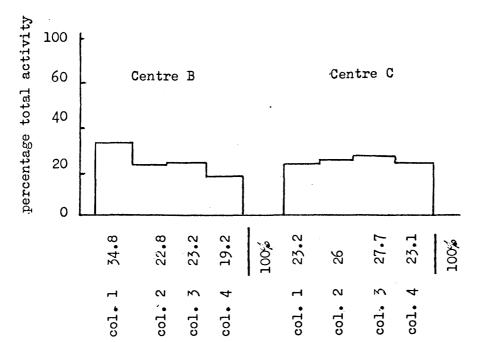


Fig. 6. Results distributed by columns, Centre B and Centre C (i.e. distributed by initiative and control of events).



key
col. 1: patient
col. 2: patient
leads
staff

col. 3: staff lead patient

col. 4: staff act for patient

Appendix III

Results: Centre D

The results from centre D take the form of diary notes or descriptive observations based on the twenty-eight categories. These are as follows. They show a similar pattern of results emerging as those of centres B and C.

Centre D

- 1. <u>ambulance to department</u>. Modern architecture greatly facilitated mobility but did not lessen staff control. All wheel chairs could be hand-propelled but patients in wheelchairs were most often pushed by ancilliary staff.
- 2. coat. As at centres B and C, the hooks were too high for wheelchair patients and inconveniently in a corner. Physiotherapists routinely hung up patients' coats and those patients who did this for themselves tended to be those the staff had missed. Staff removed and put on the coats of wheelchair patients.
- 3. <u>dressing</u>. Patient-initiative was not discouraged and screens were almost always used. But for those who could not manage staff <u>did</u> rather than <u>taught</u> the activity. There was uninvited adjustment of clothes and for wheelchair patients especially there was unrequested help with clothes.
- 4. <u>tea</u>. As at centres B and C, control was with the staff. A therapist took the orders, collected the money (sometimes out of patients' pockets), collected the refreshments from the patients' self-service bar, handed out the cups and so forth. There was general amusement when one patient pretended to fetch his own drink.
- 5. cup. Collecting cups was staff work. As crockery was not used the opportunity to teach patients to balance a cup and saucer did not present itself.

The plastic beakers with lids seemed to the observer to be a very institutional form of equipment but staff and patients did not comment adversely on their use.

- 6. <u>toilet</u>. Ancilliary staff escorted and assisted the less able but did not teach. The more able were not subject to staff control. As with other minor tasks systematic assessment of problems did not take place and teaching opportunities were lost. Relegation of minor tasks to ancilliary staff contributed to this situation as with point 1 but as in the case of points 2, 3, 4 and 5, therapists themselves contributed to this unsatisfactory state of affairs.
- 7. <u>adl</u> (in dept). Patient initiative was high because of the insignificant nature of many of these minor acts but, as at centres B and C, would have been higher if it had not been the <u>duty</u> of ancilliary staff to do things for patients. Draw strings would have allowed patients to operate the screen curtains.
- 8. <a href="https://www.not.gen.com/homes.com/
- 9. community. Out-of-door mobility requirements were not met. Walking training did not extend beyond the safe and private and indeed, indoor environment of the walking room and had only incidental bearing on social requirements.
- 10. <u>recreation</u>. Interest, encouragement or advice in patients leisure activities barely featured in staff conversation.
- 11. work. Vocational and economic activities none observed.
- 12. cosmesis. This was not a feature though staff corrected ungainly sitting postures. Also, portage of artificial limbs in the reception areas was more discreet than at other centres.

- 13. prosthesis. Eight limbs were stored at the side of the walking training room. Their owners all out-patients did not attend daily but once, twice or three times per week. Much staff handling/control of limbs occurred when these 'owners' attended. Some good negotiation and teaching was also observed. Fitting problems could be immediately rectified by prosthetists at the centre but relations were impeded by the therapists' inexperience and frequent reallocation. Prosthetists were not invited into the walking training room to observe or screen patients for problems and referral was left to the less experienced therapy staff.
- 14. stump. Problems were referred to an experienced SRN at the centre.
- 15. <u>furniture</u>. As at centres B and C there was very high staff control of furniture, fittings and equipment in which all grades of staff participated and which considerably increased the proportion of tasks done by staff for patients. Once again the impression was one of lost opportunity to teach patients to handle, lift and carry bulky objects, such as chairs and pillows. We may conjecture that such objects will be moved by patients at home and instruction on how to do this safely would have been useful and important.
- 16. walking aids. Patient control was high but when aids were dropped or out of reach teaching opportunities were lost as items were picked up and passed to patients by staff rather than patients being shown a safe method of reaching for themselves.
- 17. sit down. This activity was not linked to the patients home environment where chairs would not be of the safe metal type. Wheelchair patients were not given the opportunity to choose where to sit.
- 18. stand up. Patients were taught how to rise from a chair but when this had a purpose, e.g. when it was time to stand up and leave, patients could be quickly hauled to their feet by a porter called in to assist. Patients were

only taught to rise from the stable metal chairs in the department and were not asked about use of other chairs, armchairs, etc., at home nor were other chairs available, so the activity was not related to serious living.

- 19. walking. Patients were expected to initiate much of their walking training and did so. Once again the walking associated with minor tasks was dominated by staff. However, it appeared to the observer that, for various reasons, staff control of minor activity and its associated walking was less intense and a little more open to negotiation at centre D than at centres B and C. The atmosphere was a little more relaxed. The more modern surroundings may have contributed to this and the less authoritarian or possibly less confident personalities of the two therapists. The staff had positioned a large desk in such a way as to effectively block what had been planned as a clear and open space in which patients could walk. As at centres B and C ambulance routines resulted in wasted attendances. For example, one patient, a bilateral amputee, attending only once each week and undertaking his first walk of the day, was hurriedly removed when his ambulance arrived to take him home. Late arrivals overlapped early departures. If training goals had been set these would have been impossible to maintain because of transport failures.
- 20. standing. There was good attention to posture. As at other centres patients paused during walking exercise to chat to other patients. This was not seen as malingering.
- 21a. conversation: chat. The conversation of one of the orderlies was patronising and often derisive. This had unfortunate effects as it was one of the duties of this orderly to meet new arrivals. Other reception staff were efficient but not welcoming. Otherwise the classes were a pleasant social occasion for the participants. When the exchange of pleasantries was used by patients to introduce more serious topics staff did not actively encourage its development.

- 21b. conversation: knowledge seeking exchanges. Inadequacies here reflected not so keenly low inmate status but the therapists' lack of knowledge and experience. The more experienced and knowledgeable SRN was, for many reasons, much less accessible to the patients so that her deep commitment to the patients' welfare had too little impact. (It is of interest that her office was sited for the convenience of the doctor and not the patients.)
- 22. falling. None observed.
- 23. <u>transfers</u>. Unnecessary bodily lifting of patients took place. Again depersonalising acts were especially associated with the work assigned to ancilliary staff. Lack of training caused some of this patient-handling to be exceedingly dangerous. The observer intervened to prevent accidents.
- 24. <u>upper body exercise</u>. Easy access to modern equipment allowed patients to control this activity.
- 25. <u>lower body exercise</u>. The inappropriate ball games and team games, condemned by the author at centres A and C, were again a feature but were not observed to involve removal of limbs.
- 26. <u>stairs</u>. Easy access and encouragement of patient initiative resulted in regular exercise on the safe wooden steps but this was not developed to relate to the steps, stairs and obstacles of serious living.
- 27. <u>uneven surfaces</u>. The skills required for this walking training routine were rudimentary compared to the mobility requirements of normal daily living where almost every surface presents obstructions.
- 28. walking out of the dept. There were instances of patients leaving the walking training room temporarily without permission, indicating far less tight institutional control than observed at other centres. No training took place outside this room or out-of-doors.

APPENDIX IV

Two Case Histories From Centre E

Observations at centres D and E are used to check the results of centres B and C. This check takes place in centres with the most modern resources and which were thought to be the most well-disposed towards amputee patients.

Observations at centre D support the ethological findings. The following case histories augment the case history data.

Patient BJ, Centre E.

Investigation of patient BJ took place one year after hip disarticulation amputation as a result of cancer, by which time the patient was attending walking training four times each week and had a definitive prosthesis for four months. He was an intelligent and articulate forty-five year old batchelor; social class III. This case exemplifies very many of the problems surrounding amputation.

In the first place pre-operative treatment was not prompt. There was a delay of six months during which time the patient reported considerable pain to his G.P. Turning to private medicine, a biopsy revealed cancer at the knee. Ablation and chemotherapy quickly followed. We are left to speculate whether earlier diagnosis may have saved the limb or greater length of limb.

On the subject of grief, here we see amputation accompanied by both sudden and shocking loss. What it is important to note is that grief had three distinct causes and the amputation itself was reported by the patient to be the least of these. First, grief followed knowledge of poor chance of survival and, a year later, the patient still keenly feared death. Second, grief followed loss of the limb but the patient described coming to terms with the loss,

deciding that if other people had learned to walk with artificial limbs then so could he. Third, he described the shock of losing his leg as secondary to the shock of seeing his first artificial leg and the dismay and depression which followed delivery of his definitive limb. This reaction had not subsided but was daily aggravated by hardship and limitation.

At every stage it seemed to the observer that the patient had lacked essential knowledge and support. For example, he had never known in advance what to expect of his prostheses, he had no satisfactory means to remedy pain, he had had only a brief chance meeting with an amputee with a similar condition, his otherwise supportive family had been unable to give emotional support, he was not told until eleven months after surgery that he was entitled to a mobility allowance and to rehousing, and so forth. These failures had in themselves caused unhappiness. They had also led the patient to make mistaken plans which, when dashed, added to his unhappiness. On the advice he was given he expected to receive a good modern artificial leg, to put it on, take ten minutes to learn to balance, then to walk and return to work. Whereas after eight months of limb wearing his mobility and functional independence were not improved.

At the present time the patient had no future plans; his normal self-determination appeared to be completely eroded. 'I live one day at a time'. 'I don't know about the future'.

The patient's full leg prosthesis was extremely heavy. That is, it was too heavy for the observer to lift comfortably with both arms. This definitive or cosmetic limb was also ugly. That is, the patient's gait and posture, particularly his sitting posture, were unsightly to the normal eye. The patient felt less embarrassed when limbless. He found sitting uncomfortable and walking painful and wearing the limb it did not improve his ability to perform minor and routine daily tasks. Though he could walk for up to one hour on the safe flat gymnasium floor he removed the limb at home because he could not work

or rest when wearing it, or sit or bend. He was limited by pain and discomfort and the limitations of the limb itself. Limbless, he used a variety of aids - wheelchair, crutches, Zimmer frame.

Leg pain, phantom pain, stump pain and the discomforts and embarrassments of limb wearing, each were a feature of this case. None were effectively dealt with.

Much additional discomfort was caused by the patient's journey to the outpatient clinic. He lived alone in an upstairs flat. Descending the stairs took him twenty minutes so in order not to keep fellow ambulance patients waiting he descended the stairs early and waited in the hall. This meant that four times each week he waited for up to one hour in a bare and often cold hallway. A chair placed there for him did not greatly ease the situation for patient BJ found sitting too uncomfortable and for the most part he had to stand. If while waiting he wanted to go to the toilet he had to return upstairs.

Walking training progressed in accordance with Humm 1977. Therapists taught toning and walking exercises and encouraged the patients to initiate and carry these out alone. They did not see their work in the wider context of the patients' daily needs and daily tasks. Up to the point at which observations were made mobility training had no immediate relevance to the patients' daily living. No occupational therapy was introduced and, at centre E, physiotherapists were dismissive as to its role in rehabilitation. The therapist had only the most vague idea of the patient's future. They expected the hip area would 'harden' and walking tolerance would increase. The observer's direct questions to them on goals and aims received non-committal replies. Direct comments on the patient's unenviable condition were answered in terms of hopelessness and resignation. Working on a 1:1 basis, the therapist had long conversations with the patient and listened to his many complaints and problems

but action was not taken as a result and the therapist was unable to give emotional support. Walking training was expected to continue for many months.

Patient CJ Centre E.

The patient was a sixty-one year old married man, social class II. He had a below knee amputation as a result of arthritis and saw the amputation as a cure to previous pain, deformity and immobility. He anticipated similar treatment to his other leg. Observations were made seven months after surgery. The patient had attended walking training throughout this period.

The question of delayed surgery again arises. Amputation had been discussed a year before it took place. During the intervening year the patient was housebound and walked with great pain and was therefore less fit when surgery eventually took place.

It seemed to the observer that the patient had gained a great deal from sound replacement of an unsound limb. He was pleased with the results of surgery and fortunate to have little phantom pain. Since being fitted with a temporary limb he had been mobile out-of-doors and returned to gardening. He expected to drive his car again, though he had has yet no information on the legal requirements.

Prosthetic replacement had been prompt. The patient walked with a pneumatic limb seven days post-operatively and took delivery of a temporary limb a month after surgery, though the stump was then still unhealed. The limb was at present very loose fitting and padded by the patient with cloth but delivery of a definitive limb was expected very shortly.

Walking training seemed at this stage to be too protracted. It had served its proper role of uniting patient and limb but the patient's rehabilitation - his return to the active pursuits of normal living- seemed to be consequent upon

factors in which the walking training routines played little part, for there had been no domicilliary visit and no referral to occupational therapy, no training out-of-doors and no training directly linked to the patient's social and domestic circumstances. Important factors in rehabilitation were the patients many interests, possibly his comparative wealth, his large and supportive family, his view that his treatment had been a cure, and not least the capability of any limb wearer who has a good ptb replacement. At the present time it seemed to the observer that no purpose was served by the patient's attendance at these classes. The limb was too loose for him to walk well and attendance was an undue disruption of daily living. It could have been halted until delivery of the definitive limb.

BIBLIOGRAPHY

Chapter One

- J.L. Baker Traumatic Sub-Total Amputation of the Right Hand <u>Nursing Times</u> (23 Feb. 1978) 323-325.
- L. Battye The Chatterley Syndrome (1966) from D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock in assoc. O.U. Press (1974) London Ch. 10 93-99.
- P.L. Berger Invitation to Sociology: A Humanistic Perspective Doubleday and Co. (1963) USA.
- J.A. Bitter Introduction to Rehabilitation C.V. Mosby Co. (1979) St. Louis.
- M. Blaxter Disability and Rehabilitation: Some Questions of Definition, from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier and MacMillan (1975) London Ch. 12 207-223.
- M. Blaxter The Meaning of Disability Heineman Ltd (1976) London.
- M.J. Bloor and G.W. Horobin Conflict and Conflict Resolution in Doctor/
 Patient Interactions (1970) from C. Cox and A. Mead (editors)

 A Sociology of Medical Practice Collier Macmillan (1975) London
 Ch. 16 271-284.
- D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock in assoc. O.U. Press (1974) London.
- A Brechin and P. Liddiard Look At It This Way: New Perspectives in Rehabilitation Hodder and Stoughton in assoc. O.U. Press (1981) Kent.
- E. Buchwald Physical Rehabilitation for Daily Living McGraw Hill (1952)

 New York.
- P. Buttenshaw, D. Dixey, C.M. Van de Ven, J. Jackson, M. Hallett Letter to the editor Physiotherapy (Sept. 1981) 67(9) 272.
- S. Callen A Modern Method of Stump Bandaging Physiotherapy (May 1981) 67(5) 137-138.
- F.F. Cartwright A Social History of Medicine Longman (1977) London.
- J. Cash (editor) A Textbook of Medical Conditions for Physiotherapists
 Faber and Faber (1976) (5th edition, original 1951) London.
- J. Cash (editor) Physiotherapy in some Surgical Conditions Faber and Faber (1977) (5th edition, original 1955) London.
- E.T. Cassee Therapeutic Behaviour, Hospital Culture and Communication (1970) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London Ch. 13 224-246.
- M.J. Clarke-Williams The Problems of the Lower Limb Amputee Practitioner (1978) Vol. 220 (1319) 703-707.
- J. Cleary Demands and Responses from D. Hall and M. Stacey <u>Beyond Separation</u>
 Routledge and Kegan Paul (1979) London.

- C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London.
- H. Crowther New Perspectives on Nursing Lower Limb Amputees <u>Jnl. Advanced</u>
 Nursing (1982) Vol. 7 453-460.
- J. Ditton The View from Goffman MacMillan (1980) London.
- C.A. Donahoo and J.H. Dimon Orthopaedic Nursing Little Brown and Co. (1977)
 Boston.
- C.D. Evans Rehabilitation after Severe Head Injury Churchill Livingstone (1981) London.
- P. Foot Moral Beliefs from A. Flew (editor) The Is/Ought Question MacMillan (1969) London Ch. XIX (reprint 1973) 196-213.
- E. Friedson Dilemmas In The Doctor/Patient Relationship (1962) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London Ch. 17 285-298.
- E. Friedson Disability as Social Deviance (1965) from M.B. Sussman (editor)

 Sociology and Rehabilitation American Sociol. Assoc. (1965)

 USA Ch. 4 71-100.
- E. Friedson Professional Dominance: The Social Structure of Medical Care
 Aldine (1970) Chicago.
- J. Garrad Impairment and Disability: The Measurement, Prevalence and Psychological Cost, from D. Lees and S. Shaw (editors) Impairment,

 Disability and Handicap Heinemann Ed. Bks (1974) London Ch. 8

 141-156.
- D.G. Gill The British National Health Service: Professional Determinants of Administrative Structure (1971) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) Ch. 9 155-169.
- G. Gingras Feet Was I To The Lame Souvenir Press Ltd (1975) London.
- R.E.A. Goble and P.J.R. Nichols The Rehabilitation of the Severely Disabled Vol. I Butterworth (1971) London.
- E. Goffman The Presentation of Self in Everyday Life Pelican (1959) London.
- E. Goffman Asylums Pelican (1961) G.B.
- E. Goffman Stigma: The Management of a Spoiled Identity Pelican (1963) London.
- H. Gowland and E. Joy Letter to the Editor Physiotherapy (July 1981) 67(7) 213.
- W.R. Grant Principle of Rehabilitation Livingstone (1963) Edinburgh.
- K. Grunewald The Guiding Environment: The Dynamic of Residential Living (1972) from D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock and O.U. Press (1974) London Part I, Ch. 2 10-15.

- E.A. Hamilton and P.J.R. Nichols Rehabilitation of the Elderly Lower Limb Amputee British Medical Jnl (1972(2)) 95-98.
- J.T. Hart The Inverse Care Law (1971) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London.
- M. Hawker Motivation in Old Age: The Physiotherapists' View Physiotherapy (June 1975) Vol. 61(8) 183-184.
- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindal (1977)

 (3rd edition) London.
- I.M. Hutton and N.G. Rothnie The Early Mobilisation of the Elderly Amputee

 <u>British Jnl Surgery</u> (1977) Vol. 64(4) 267-270.
- J. Ibbotson Motivation The Occupational Therapists Approach Physiotherapy (June 1975) Vol. 61(8) 189-191.
- I. Illich Limits to Medicine Pelican (1976) London.
- I. Illich, I.K. Zola, J. McNight, J. Caplan, H. Shaiken <u>Disabling Professions</u>
 Marion Boyers (1977) London.
- H.H. Kessler Rehabilitation of the Physically Handicapped Columbia Press (1953) New York.
- M.D. Kerstein, H. Zimmer, F.E. Dugdale, E. Lerner, The Delays in the Rehabilitation in Lower Extremity Amputees Connecticut Medicine (1977) Vol. 41(9) 549-551.
- S. Kitzinger Birth at Home Oxford University Press (1979).
- F.H. Krusen Physical Medicine W.B. Saunders Co. (1941) Philadelphia.
- F.H. Krusen Concepts in the Rehabilitation of the Physically Handicapped W.B. Saunders Co. (1964) Philadelphia.
- C.B. Larson and M. Gould Orthopaedic Nursing C.V. Mosby Co. (1943) St. Louis (8th edition 1974).
- A. MacBride, J. Rogers, B. Whylie, S.J.J. Freeman Psychological Factors in the Rehabilitation of Elderly Amputees Psychosomatics (1980) Vol. 21, 258-265.
- E.M. MacDonald Occupational Therapy in Rehabilitation Bailliere Tindall (1976) (4th edition, original 1960) London.
- M.S.A. MacInnes Bilateral Amputation of the Legs, Patient Care and Rehabilitation Nursing Times (1977) Vol. 73(27) 1033-1034.
- (The Mair Report) Medical Rehabilitation: A Pattern for the Future HMSO (1972) Edinburgh.
- C.H. May, M.C. McPhee, D.J. Pritchard An Amputee Visitor Programme as an Adjunct to Rehabilitation of the Lower Limb Amputee Mayo Clinic Proceedings (1979) Vol. 54 774-778.
- J. McFarland Basic Clinical Surgery Butterworths (1973) London (2nd edition 1980)

- (The McMillan Report) The Remedial Professions: A Report HMSO (1973) London.
- J. McNight Professionalised Service and Disabling Help, from I. Illich, I.K. Zola, J. McNight, J. Caplan, H. Shaiken <u>Disabling Professions</u>
 Marion Boyers (1977) London 69-91.
- D. Mechanic Medical Sociology: A Selective View Collier MacMillan (1968)
 London.
- J.B. Millard Measurement in Rehabilitation Rheumatology and Rehabilitation (1976) Vol. 15 199-200.
- N. Milio Values Social Class and Community Health Services (1967) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London Ch. 2 49-61.
- J. Moroney Surgery for Nurses E.S. Livingstone (1950) Edinburgh (13th edition 1975).
- S. Mountford <u>Introduction to Occupational Therapy</u> E.S. Livingstone (1971) Edinburgh.
- D.F.E. Nash The Principles and Practice of Surgery for Nurses and Allied Professions Edward Arnold (1955) London (7th reprint 1980).
- P.J.R. Nichols Rehabilitation of the Severely Disabled Vol. II Butterworth (1971) London.
- P.J.R. Nichols Rehabilitation Medicine Butterworth (1976) London.
- P.J.R. Nichols Training in Rehabilitation: Basic Needs and Considerations

 International Journal of Rehabilitation Research (1979) Vol. 2(1)

 21-31.
- G. O'Gorman Anti-Motivation Physiotherapy (June 1975) Vol. 61(8) 176-179.
- Open University Health and Social Welfare Courses P 251, 252 and 253.
- S.E. Orem Sharing: A Time for Trust Nursing (1977) Vol. 7(12) 8.
- J. Øvretveit, W. Kinston, J. Richardson Organisational Problèms of High Level Clinical Physiotherapists Physiotherapy (Jan. 1982) Vol. 68(1) 10-12.
- T. Parsons The Social Structure Routledge and Kegan Paul (1951) London.
- C.J. Partridge The Effectiveness of Physiotherapy Physiotherapy (May 1980) Vol. 66(5) 153-155.
- C.J. Partridge 1982(a) Letter to the Editor Physiotherapy (March 1982) Vol. 68(3) 91.
- C.J. Partridge 1982(b) The Myth of the Medical Model Physiotherapy (October 1982) Vol. 68(10) 329.
- (The Piercy Report) Report of the Committee of Enquiry on the Rehabilitation

 Training and Resettlement of Disabled Persons HMSO (1956)

 London.

- M. Powell Orthopaedic Nursing Churchill Livingstone (1951) Edinburgh (7th edition 1976).
- D.K. Rapier, M.J. Koch, L.P. Moran, J.R. Geronsin, G.E. Phelps <u>Practical Nursing</u> Henry Kimpton (1958) USA (4th edition G.B. 1970).
- E. Reimer School Is Dead Penguin (1971) G.B.
- L. Reinstein Rehabilitation of the Lower Extremity Cancer Amputee <u>Maryland</u> State Medical Journal (1980) Vol. 29 85-87.
- D. Ritchie Stroke Faber and Faber (1960) London.
- D. Robinson The Process of Becoming Ill Routledge and Kegan Paul (1971)
 London.
- D. Robinson Patients Practitioner and Medical Care William Heinemann Medical Bks (1973) London.
- H.A. Rusk and E.J. Taylor New Hope for the Handicapped: The Rehabilitation of the Disabled from Bed to Job Harper Bros (1949) New York.
- H.A. Rusk Rehabilitation Medicine C.V. Mosby Co. (1971) (3rd edition, original 1958) New York.
- R.A. Scott The Making of Blind Men: A Study in Adult Socialisation Russell Sage Foundation (1969) New York.
- R.A. Scott The Construction of Stigma by Professional Experts (1970) from
 D.M. Boswell and J.M. Wingrove The Handicapped Person in the
 Community Tavistock and O.U. Press (1974) London Part 3, Ch. 12
 108-121.
- D. Scrutton and M. Gilbertson Physiotherapy in Paediatric Practice
 Butterworth (1975) London.
- R. Shepherd Physiotherapy in Paediatrics William Heinemann Medical Bks (1980) (2nd edition, original 1974) London.
- A. Shopland Refer to Occupational Therapy Churchill Livingstone (1979)

 London.
- J.H. Siegel and P. Chodoff The Aged and High Risk Surgical Patient Gryne and Stratton (1976) New York and London.
- R. Strauss Social Change and the Rehabilitation Concept, from M.B. Sussman (editor) Sociology and Rehabilitation American Sociology Association (1965) USA Ch. 1 1-34.
- R.P. Stryker Rehabilitation Aspects of Acute and Chronic Nursing Care W.B. Saunders Co. (1972) Philadelphia.
- S. Taylor Principles of Surgery and Surgical Nursing Hodder and Stoughton (1961) London (3rd edition 1977).
- M. Thompson Relationships Between Physiotherapists and Doctors, Physiotherapy (June 1979) Vol. 65(6) 176-178.

- (The Tunbridge Report) Rehabilitation: Report of a Sub-Committee of the Standing Medical Advisory Committee HMSO (1972) London.
- C.M.C. Van de Ven A Pilot Survey of Elderly Bilateral Lower Limb Amputees Physiotherapy (1973) Vol. 59(10) 316-320.
- M. Wallace and M. Robson On Giants Shoulders Times Bks (1976) London.
- A.W.M. Ward, B.T. Williams, R.A. Dixon Physiotherapy: Its Prescription and Implementation for Orthopaedic Out-Patients Rehabilitation (1978) Vol. 17 14-21.
- H.S. Willard and C.S. Spackman Occupational Therapy Pitman Medical Publishing Co. (1963) London.
- World Health Organisation First Report of the Expert Committee on Medical Rehabilitation (1958) Technical Report Series.
- G.N. Wright Total Rehabilitation Little Brown and Co. (1980) Boston.
- I.K. Zola Medicine as an Institution of Social Control (1971) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Chl. 10 170-185.
- I.K. Zola Healthism and Disabling Medicalisation from I. Illich, I.K. Zola, J. McNight, J. Caplan, H. Shaiken <u>Disabling Professions</u> Marion Boyars (1977) London 41-67.

Chapter Two

- M.K. Adler, M.D.D. Hamaty, M.D.C.C. Brown, H. Potts Evaluation of Rehabilitation Efforts in an Amputee Population Connecticut Medicine (1977) Vol. 41 (10) 614-617.
- D. Bader Reach for the Sky Collins (1954) London.
- R.S. Berardi and Y. Keonin Amputations in Peripheral Vascular Occlusive Disease American Jnl. Surgery (1978) Vol. 135 231-234.
- M. Blaxter Disability and Rehabilitation: Some Questions of Definition from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London.
- M. Blaxter The Meaning of Disability Heinemann Ltd (1976) London.
- I.A.O.D. Brodie Lower Limb Amputation British Jnl Hospital Medicine (Nov. 1970) 596-604.
- B. Buck and A.D. Lee Amputation: Two Views Nursing Clinics of North America (1976) Vol. 11(4) 641-657.
- E.M. Burgess, R.L. Romano The Management of Lower Extremity Amputees using Immediate Postsurgical Prostheses Clin. Orthop. (1968) Vol. 57 137-146.

- E.M. Burgess, R.L. Romano, J.H. Zettl, C.P. and R.D. Schrock Amputations of the Leg for Peripheral Vascular Insufficiency <u>Jnl Bone and Joint Surgery</u> (1971) Vol. 53(A) 874-890.
- D. Caine Psychological Considerations Affecting Rehabilitation after Amputation Medical Jnl Australia (1973) Vol. 2 818-821.
- H.C. Chadderton Prostheses Pain and Sequelae of Amputation as seen by the Amputee Prosthetics and Orthotics International (1978) Vol. 2(1) 12-14.
- M.A. Chamberlain, G. Thornley and V. Wright Evaluation of Aids and Equipment for Bath and Toilet Rheumatology and Rehabilitation (1978) Vol. 17(3) 187-193.
- A.S. Chilvers, J. Briggs, N.L. Browse and J.B. Kinmonth Below and Through
 Knee Amputations in Ischaemic Disease British Jnl Surgery (1971)
 Vol. 58(11).
- A.S. Chilvers and N.L. Browse The Social Fate of the Amputee Lancet (Nov. 27, 1971).
- M.J. Clarke-Williams The Problems of the Lower Limb Amputee Practitioner (1978) Vol. 220(1319) 703-707.
- B. Coard How the West Indian Child is made Educationally Subnormal in the British Schools System New Beacon Books (1971) London.
- N.P. Couch, J.K. David, N.L. Tilney, C. Crane Natural History of the Leg Amputee American Jnl Surgery (1977) Vol. 133(4) 469-473.
- N. Croucher High Hopes Hodder and Stroughton (1976) London.
- The Crowther Report A Report of the Central Advisory Council for Education (England) HMSO (1959) London.
- B. Davis Amputations Ch. 12 294-311 J. Cash (editor) Physiotherapy in Some Surgical Conditions Faber and Faber (1977) (5th edition) London.
- Department of Health and Social Security <u>Amputation Statistics 1980</u> HMSO (1980) London.
- M.B. Devas Early Walking of Geriatric Amputees <u>British Medical Jnl</u> (1971) 1 394-396.
- B. Ebskov and P. Josephsen Incidence of Reamputation and Death after Gangrene of the Lower Extremity (1980) Vol. 4 77-80.
- D.R.A. Finch, M. MacDougal, D.J. Tibbs, P.J. Morris Amputation for Vascular Disease: The Experience of a Peripheral Vascular Unit British Jnl Surgery (1980) Vol. 67(4) 233-237.
- F.W. Fleurant and J. Alexander Below Knee Amputation and Rehabilitation of Amputees Surg. Gynae. & Obst. (1980) Vol. 515(1) 41-44.
- P. Foot Moral Beliefs (1958) from W.D. Hudson (editor) The Is/Ought Question MacMillan (1969) London Paper XIX.

- S.K. Forer, M.A. Lawrence, S. Miller Rehabilitation Outcome: Comparative Analysis of Different Patient Types Archives Physical Med. Rehab. (1980) Vol. 61(8) 359-365.
- J. Garrad Impairment and Disability: Their Measurement, Prevalence and Psychological Cost Ch. 8 141-156 D. Lees and S. Shaw (editors)

 Impairment Disability and Handicap Heinemann Ed. Books (1974)
 London.
- H.W. Glattly A Statistical Study of 12000 New Amputees Southern Medical Jnl (1964) Vol. 57 1373-1378.
- R.E.A. Goble and P.J.R. Nichols Rehabilitation of the Severely Disabled Vol. I, Butterworth (1971) London.
- I. Goldie, A. Jerndahl, M. Nordin, P. Renstrom The Walking Training School
 A Rehabilitation Centre for Leg Amputees <u>Lakartidningen</u> (1978)
 Vol. 75 (30-31) 2712-2716.
- P.W.B. Green, S. Hawkins, W.T. Irvine, C.W. Jamieson An Assessment of Above and Through Knee Amputations <u>British Jnl Surgery</u> (1972) Vol. 59 (11) 873-875.
- B. Greenspun A Unique Amputee Archives Physical Med. Rehab. (1977) Vol. 58(6) 273-274.
- J.M.T. Griffiths Surgical Policy in the Over Seventies Geront. Clin. (Basel) (1972) Vol. 14 282-296.
- C.I. Gryfe Reasonable Expectations in Geriatric Rehabilitation <u>Jnl of the</u>
 American Geriatrics Society (1979) Vol. 27(5) 237-238.
- R. Hall and H.S. Shucksmith The Above Knee Amputation for Ischaemia <u>British</u>
 Jnl Surgery (1971) Vol. 58(9) 656-659.
- A. Hamilton The Rehabilitation of the Geriatric Amputee Rehabilitation (1973) Vol. 87 5-11.
- E.A. Hamilton and P.J.R. Nichols Rehabilitation of the Elderly Lower Limb Amputee British Medical Jnl (1972) 2, 95-98.
- D.H. Hargreaves Social Relations in a Secondary School Routledge and Kegan Paul (1967) London.
- A.I. Harris The Handicapped and Impaired in Great Britain HMSO (1971) London.
- P.L. Harris, F. Read, A. Eardley, D. Charlesworth, J. Wakefield, R.A. Sellwood The Fate of the Elderly Amputee <u>British Jnl Surgery</u> (1974) Vol. 61 665-668.
- R.J. Haworth and E.M. Hollings Are Hospital Assessments of Daily Living Activities Valid? <u>Int. Rehab. Med.</u> (1979) Vol. 1 59-62.
- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindall (1977)

 (3rd edition) London.

- G.A. Hunter and J.P. Waddell Management of the Patient Requiring Leg Amputation for Peripheral Vascular Disease <u>Canadian Medical Association Jnl</u> (1976) Vol. 115(7) 634-638.
- G.A. Hunter and P. Holliday Review of Function in Bilateral Lower Limb Amputees

 <u>Canadian Jnl Surgery</u> (1978) Vol. 21(2) 176-178.
- C.S. Huston, B.A. Divins, C.B. Ernst, W.O. Griffin Morbid Implications of Above Knee Amputation Archives of Surgery (1980) Vol. 115(2) 165-167.
- I.M. Hutton and N.G. Rothnie The Early Mobilisation of the Elderly Amputee

 <u>British Jnl Surgery</u> (1977) Vol. 64(4) 267-270.
- B. Jackson and D. Marsden Education and the Working Class Pelican (1968) (3rd reprint) G.B.
- R.F. Jones Amputee Rehabilitation: Basic Principles in Prosthetic Assessment and Fitting Medical Jnl Australia (1977) Vol. 11(9) 290-293.
- B. Kegel, M.L. Carpenter, E.M. Burgess A Survey of Lower Limb Amputees:

 Prostheses, Phantom Sensations and Psychological Aspects <u>Bulletin</u>

 Prosthetic Research (1977) Vol. 10(27) 43-60.
- B. Kegel, M.L. Carpenter, E.M. Burgess Functional Capabilities of Lower Extremity Amputees Archives Physical Medical Rehab. (1978) Vol. 59 109-119.
- B. Kegel, M.L. Carpenter, E.M. Burgess Recreational Activities of Lower Extremity Amputees: A Survey <u>Archives Physical Med. Rehab</u>. (1980) Vol. 61 258-264.
- M.D. Kerstein, H. Zimmer, F.E. Dugdale, E. Lerner The Delays in the Rehabilitation in Lower Extremity Amputees Connecticut Medicine (1977)
 Vol. 41(9) 549-551.
- R.B. Kihn, R. Warren, G.W. Beebe The Geriatric Amputee Annals of Surgery (1972) Vol. 176 305-314.
- V. Kolind-Sorensen Follow up of Lower Limb Amputees Acta. Orthop. Scand. (1974) Vol. 45 97-104.
- C. Lacey Hightown Grammar Manchester University Press (1970) Manchester.
- H.I. Lippmann, F. Clippinger, B.R. Friz, R.L. Romano Hospital Resources for a Quality Amputation Programme <u>Circulation</u> (1972) Vol. 46
 A292-A304.
- A. MacBridge, J. Rogers, B. Whylie, S.J.J. Freeman Psychosocial Factors in the Rehabilitation of Elderly Amputees <u>Psychosomatics</u> (1980) Vol. 21(3) 258-265.
- J.M. Malone, W.S. Moore, J. Goldstone, S.J. Malone The Therapeutic and Economic Impact of a Modern Amputation Programme Annals Surgery (1979)
 Vol. 189(6) 798-802.
- G. Murdoch (editor) Prosthetic and Orthotic Practice Edward Arnold Ltd (1970)
 London.

- P.J.R. Nichols Rehabilitation of the Severely Disabled Vol. II Butterworth (1971) London.
- P.J.R. Nichols Rehabilitation Medicine Butterworth (1976) London.
- P.J.R. Nichols Rehabilitation Services and Responsibilities Asian Medical

 Jnl (1977) Vol. 20(3) 147-159.
- C.M. Parkes and M.M. Napier Psychiatric Sequelae of Amputation <u>British Jnl Hospital Medicine</u> (1970, Nov.) 610-614.
- C.M. Parkes Bereavement: Studies in Grief in Adult Life Penguin (1972)
 London.
- C.M. Parkes Psycho-social Transitions: Comparison between Reactions to Loss of a Limb and Loss of a Spouse <u>British Jnl Psychiatry</u> (1975) Vol. 127 204-210.
- C.J. Partridge The Effectiveness of Physiotherapy Physiotherapy (1980)
 Vol. 66(5) 153-155.
- H.E. Pedersen The Problem of the Geriatric Amputee Artificial Limbs (1968)
 Vol. 12 i-iii.
- J.R. Potts, J.R. Wendelken, R.C. Elkins, M.D. Peyton Lower Extremity Amputation:
 Review of 110 Cases American Jnl Surgery (1979) Vol. 138(9)
 924-927.
- L. Reinstein Rehabilitation of the Lower Extremity Cancer Amputee Maryland State Medical Jnl (1980) Vol. 29(5) 85-87.
- A.J. Roon, W.S. Moore, J. Goldstone Below Knee Amputation A Modern Approach

 American Jnl Surgery (1977) Vol. 134 153-158.
- A.S. Russek Management of Lower Extremity Amputees Archives Physical Medicine (1961) Vol. 42 687-703.
- W.R. Russell Neurological Sequelae of Amputation <u>British Jnl of Hospital</u> Medicine (1970 Nov.) 607-609.
- W.M. Schultz Rehabilitation of the Lower Extremity Amputee in a Larger General Hospital New York State Jnl of Medicine (1950) Vol. 50(17) 2061-2066.
- J.P. Smith In What Sports Can Patients with Amputations and other Handicaps Successfully and Actively Participate? Physical Therapy (1978) Vol. 50 121-126.
- O. Sneppen, T. Johansen, J. Heerfordt, I. Dissing, O. Petersen Hemipelvectomy Acta. Orthop. Scand. (1978) Vol. 49 175-179.
- P.H. Stern and P.A. Skudder Amputee Rehabilitation New York State Jnl of Medicine (1977) Vol. 77(9) 1436-1440.
- Therapy (1981) Vol. 8(10) 12 (A. Kennedy Tells of the Real Heroes). .
- Therapy (1981) Vol. 8(11) 1 (Climbing Literary Heights).

- D. Thompson Social Work Support for Amputees Is It Adequate? Unpublished (1977).
- I.M. Troup and M.A. Wood Total Care of the Lower Limb Amputee Pitman (1982)
 London.
- (The Tunbridge Report) Rehabilitation: Report of a Sub Committee of the Standing Medical Advisory Committee HMSO (1972) London.
- C.M.C. Van de Ven A Pilot Survey of Elderly Bilateral Lower Limb Amputees

 Physiotherapy (1973) Vol. 59(10) 316-320.
- C.M.C. Van de Ven An Investigation into the Management of Bilateral Leg Amputees

 British Medical Jnl (1981) Vol. 283 707-710.
- R. Warren Early Rehabilitation of the Elderly Lower Extremity Amputee
 Surgical Clinics North America (1968) Vol. 48 807-816.
- P.C. Weaver and S.A. Marshall A Functional and Social Review of Lower Limb Amputees British Jnl Surgery (1973) Vol. 60 732-737.
- D.C. Welch and R. Helsby An Analysis of the Physical and Social Conditions of Elderly Lower Limb Amputees Rehabilitation (1973) Vol. 87 9-11.

Chapter Three

- L. Battye The Chatterley Syndrome (1966) in D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock and O.U. Press (1974) London.
- P.L. Berger <u>Invitation to Sociology: A Humanistic Perspective</u> Doubleday and Co. (1963) USA.
- P.L. Berger and T. Luckmann The Social Construction of Reality: A Treatise in the Sociology of Knowledge Allen Lane (1967) London.
- J.A. Bitter Introduction to Rehabilitation C.V. Mosby Co. (1979) USA.
- E.M. Burgess and R.L. Romano The Management of Lower Extremity Amputees Using Immediate Post Surgical Prostheses Clin. Orthop. (1968) Vol. 57 137-146.
- J. Cleary Demands and Responses in D. Hall and M. Stacey (editors) <u>Demands</u> and <u>Responses</u> Routledge and Kegan Paul (1979) London.
- M.B. Devas Early Walking of Geriatric Amputees British Medical Jnl (1971) (1) 394-396.
- E. Durkheim Elementary Forms of the Religious Life George Allen and Unwin Ltd (1971) London 1st published in French 1912.
- J. Garrad Impairment and Disability: Their Measurement, Prevalence and Psychological Cost in D. Lees and S. Shaw (editors) Impairment,

 <u>Disability and Handicap</u> Heinemann Ed Bks (1974) London.

- E. Goffman The Presentation of Self in Everyday Life Pelican (1959) London.
- E. Goffman Stigma: Notes on the Management of a Spoiled Identity Pelican (1963) London.
- R.M. Goldenson Disability and Rehabilitation Handbook McGraw Hill (1978) USA.
- W.R. Grant Principle of Rehabilitation Livingstone (1963) Edinburgh.
- R.E.A. Goble and P.J.R. Nichols Rehabilitation of the Severely Disabled
 Butterworth (1971) London Vol. I Evaluation of a Disabled
 Living Unit.
- J. Hayward Information: A Prescription Against Pain RCN (1975) London.
- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindall (1977)

 London (3rd edition).
- I.M. Hutton and N.G. Rothnie The Early Mobilisation of the Elderly Amputee

 Br. Jnl Surg. (1977) Vol. 64(4) 267-270.
- I. Illich, I.K. Zola, J. McNight, J. Caplan, H. Shaiken <u>Disabling Professions</u>
 Marion Boyers (1977) London.
- W. Jaehnig Seeking Out The Disabled (1972) from D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock and O.U. Press (1974) London 441-449.
- F.H. Krusen Concepts in the Rehabilitation of the Handicapped W.B. Saunders Co. (1964) Philadelphia.
- F.H. Krusen Handbook of Physical Medicine and Rehabilitation W.B. Saunders Co. (1971) Philadelphia (2nd edition).
- (The Mair Report) Medical Rehabilitation: A Pattern for the Future HMSO (1972) Edinburgh.
- J.M. Malone, W.S. Moore, J. Goldstone, S.J. Malone The Therapeutic and Economic Impact of a Modern Amputation Programme Annals Surgery (1979)

 Vol. 189(6) 798-802.
- S. Mattingly (editor) Rehabilitation Today Update Books (1977) London.
- G.H. Mead Mind, Self and Society University Chicago Press (1934) Chicago.
- I.E.P. Menzies A Case Study in the Function of Social Systems as a Defence against Anxiety: A Report on a Study of Nursing Services of a General Hospital (1961) <u>Human Relations</u> 13 95-121 (1970)
- P.J.R. Nichols Rehabilitation of the Severely Disabled Butterworth (1971)
 London Vol. II Management.
- P.J.R. Nichols Rehabilitation Medicine Butterworth (1976) London.
- P.J.R. Nichols Rehabilitation Services and Responsibilities Asian Medical Journal (1977) Vol. 20(3) 147-159.
- P.J.R. Nichols Training in Rehabilitation: Basic Needs and Considerations Int. Jnl. Rehab. Research (1979) Vol. 2(1) 21-21

- The Oxford Dictionary (The Shorter Oxford English ...) Vol. I and II Clarendon Press (1933) Oxford.
- Roget's International Thesaurus Collins (1963) London (3rd edition 1977).
- H.A. Rusk Rehabilitation Medicine C.V. Mosby Co. (1958) New York (3rd edition 1971).
- R.A. Scott The Making of Blind Men: A Study in Adult Socialisation Russell Sage Foundation (1969) New York.
- F. Stockwell The Unpopular Patient RCN (1973) London.
- K. Thompson and J. Tunstall (editors) <u>Sociological Perspectives</u> Penguin (1971) England.
- (The Tunbridge Report) Rehabilitation: A Report of a Sub Committee of the Standing Medical Advisory Committee HMSO (1972) London.
- G.N. Wright Total Rehabilitation Little Brown and Co. (1980) Boston.
- I.K. Zola Medicine as an Institution of Social Control (1971) in C. Cox and

 A. Mead (editors) A Sociology of Medical Practice Collier MacMillan
 (1975) London.

Chapter Four

- N. Blurton-Jones (editor) Ethological Studies of Child Behaviour Cambridge Univ. Press (1972) Cambridge.
- K.J. Connolly Ethological Techniques and the Direct Observation of Behaviour from P. Mittler (editor) Assessment for Learning in the Mentally Handicapped Churchill Livingstone (1973) 219-241.
- B. Davis Amputation from J. Cash (editor) Physiotherapy in some Surgical Conditions Faber and Faber (1955) (5th edition 1977) London Ch. 12 294-311.
- J.P. Dean, R.L. Eichorn, L.R. Dean Fruitful Informants for Intensive Interviewing from G.J. McCall and J.L. Simmons (editors) Issues in Participant Observation Addison-Wesley (1969) Mass. Ch. 5 142-144.
- N.K. Denzin The Research Act Aldine Publ. Co. (1970) Chicago.
- J.D. Douglas <u>Investigative Social Research</u> Vol. 29 Sage Library of Social Research Sage Publications (1976) USA.
- E. Goffman Asylums Pelican (1961) London.
- E.C. Grant An Ethological Description of Non-Verbal Behaviour During Interviews Brit. Jnl Med. Psych. (1968) Vol. 41 177-184.
- D.J. Hargreaves Social Relations in a Secondary School Routledge and Kegan Paul (1967) London.

- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindall (1965)

 (3rd edition 1977) London.
- S.J. Hutt and C. Hutt Direct Observation and Measurement of Behaviour Charles C. Thomas (1970) Illinois.
- C. Lacey Hightown Grammar Man. Univ. Press (1970) Manchester.
- E.J. Mash and G. Makohoniuk The Effects of Prior Information and Behaviour Predictability on Observer Accuracy Child Dev. (1975) Vol. 46 513-519.
- E.J. Mash and J.D. McElwee Situational Effect on Observer Accuracy: Behaviour Predictability, Prior Experience and Complexity of Coding Categories Child Dev. (1974) Vol. 45 367-377.
- G.J. McCall and J.L. Simmons (editors) <u>Issues in Participant Observation</u>
 Addison-Wesley (1969) Massachusetts.
- M. Mead Growing Up In New Guinea Harmondsworth (1942) Middlesex.
- M. Mead Coming of Age In Samoa Harmondsworth (1943) Middlesex.
- R.A. Scott The Making of Blind Men: A Study in Adult Socialisation Russell Sage Foundation (1969) New York.
- M.D. Shipman The Limitations of Social Science Longman (1972) London.
- I.M. Troup and M.A. Wood <u>Total Care of the Lower Limb Amputee</u> Pitman (1982) London.
- W.F. Whyte Street Corner Society Univ. Chicago Press (1955) Chicago.

Chapter Five

- M. Argyle Social Interaction Tavistock and Methuen (1969) London.
- J.D. Douglas <u>Investigative Social Research</u> Vol. 29 Sage Library of Social Research Sage Publications (1976) USA.
- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindall (3rd edition 1977) London.
- S.J. Hutt and C. Hutt Direct Observation and Measurement of Behaviour Charles C. Thomas (1970) Illinois.
- C.J. Partridge (1982(a)) Letter To The Editor Physiotherapy (March 1982) Vol. 68(3) 91.
- J.B. Reid Reliability Assessment of Observation Data: A Possible Methodological Problem Child Development (1970) Vol. 41 1143-1150.
- A.W.M. Ward, B.T. Williams, R.A. Dixon Physiotherapy: Its Prescription and Implementation for Orthopaedic Out-Patients Rheumatology and Rehabilitation (1978) Vol. 17 14-21.

H.F. Wright Recording and Analysing Child Behaviour Harper (1967) New York.

Chapter Six

- B. Davis Amputations in J. Cash (editor) Physiotherapy in Some Surgical Conditions Faber and Faber (1977) (5th edition) London Ch. 12.
- Department of Health and Social Services <u>Amputation Statistics 1980</u> HMSO (1980) London.
- J.D. Douglas Investigative Social Research Vol. 29 Sage Library of Social Research Sage Publications (1976) Beverley Hills London.
- E. Goffman Asylums Pelican (1961) G.B.
- E. Goffman Stigma: Notes on the Management of Spoiled Identity Pelican (1963)
 London.
- M. Gott Learning Nursing: A Study of the Effectiveness and Relevance of

 Teaching Provided During Student Nurse Introductory Course (1982)

 Unpublished Thesis University of Hull.
- D.H. Hargreaves Social Relations in a Secondary School Routledge and Kegan Paul (1967) London.
- H.R. Harre and P.F. Secord The Explanation of Social Behaviour Blackwell (1972) Oxford.
- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindall (1977)

 (3rd edition) London.
- C. Lacey Hightown Grammar Manchester University Press (1970) Manchester.
- G.J. McCall and J.L. Simmons (editors) <u>Issues in Participant Observation</u>
 Addison Wesley Pub. Co. (1969) Massachussets.
- R.W. Revans Standards for Morale, Cause and Effect in Hospitals Nuffield Provincial Hospital Trust, Oxford University Press (1964) Oxford.
- A. Ryan The Philosophy of the Social Sciences MacMillan (1970) London.
- L. Saunders The Changing Role of the Nurse American Journal of Nursing (Sept. 1954) 1094-1098.
- C.M.C. Van de Ven A Pilot Study of Elderly Bilateral Lower Limb Amputees

 Physiotherapy (1973) 59(10) 316-320.
- D.C. Welch and R.C. Helsby An Analysis of the Physical and Social Conditions of Elderly Lower Limb Amputees Rehabilitation (1973) 87 9-11.

Chapter Seven

- L. Battye The Chatterley Syndrome (1966) from D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock and O.U. Press (1974) London Ch. 10 93-999.
- A. Faulkner The Student Nurse's Role in Giving Patients Information Unpublished Thesis (M.Sc) (1980) University of Aberdeen.
- E. Goffman Asylums Pelican (1961) G.B.
- E. Goffman Stigma: The Management of a Spoiled Identity Pelican (1963)
- M. Gott Learning Nursing: A Study of the Effectiveness and Relevance of

 Teaching Provided During Student Nurse Introductory Courses

 Unpublished Thesis (Ph.d) (1982) University of Hull.
- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindall (1977)
- J. McCleod Clark Nurse Patient Verbal Interaction: An Analysis of Recorded Conversations on Surgical Wards Unpublished thesis (Ph.d)

 (1982) University of London.
- D. Ritchie Stroke Faber and Faber (1960) London.
- D.C. Welch and R. Helsby An Analysis of the Physical and Social Conditions of Elderly Lower Limb Amputees Rehabilitation (Oct/Dec 1973)

 Vol. 87 9-12.

Chapter Eight

- L. Battye The Chatterley Syndrome (1966) from D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock and O.U. Press (1974) London Ch. 10 93-99.
- M.J. Clarke-Williams The Elderly Double Amputee Gerontology Clinic (Basel) Vol. 11 (1969) 183-192.
- Department of Health and Social Security Amputation Statistics HMSO (1980) London.
- B. Ebskov and P. Josephson Incidence of Reamputation and Death After Gangrene of the Lower Extremity (1980) Vol. 4 77-80.
- D.R.A. Finch, M. MacDougal, D.J. Tibbs, P.J. Morris Amputation for Vascular Disease: The Experience of a Peripheral Vascular Unit British Jnl Surgery (1980) Vol. 67(4) 233-237.
- E. Goffman Asylums Pelican (1961) G.B.
- E. Goffman Stigma: The Management of a Spoiled Identity Pelican (1963)
 London.

- P. Goodman Compulsory Miseducation Horizon Press (1962) USA.
- D.H. Hargreaves Social Relations in a Secondary School Routledge and Kegan Paul (1967) London.
- W. Humm Rehabilitation of the Lower Limb Amputee Bailliere Tindall (1977) London (3rd and revised edition).
- I. Illich, I.K. Zola, J. McNight, J. Caplan, H. Shaiken Disabling Professions
 Marion Boyers (1977) London.
- C. Lacey Hightown Grammar Manchester University Press (1970) Manchester.
- B. Kegel, M.L. Carpenter, E.M. Burgess Functional Capabilities of Lower Extremity Amputees <u>Archives Physical Medical Rehabilitation</u> (1978) Vol. 59 109-119.
- M. McCaffery Nursing the Patient in Pain (1979) (1st pub. UK 1983) Harper and Row Inc.
- G. Murdoch Level of Amputation and Limiting Factors Annals Royal College Surgeons (England) (1967) Vol. 204-216.
- P.J.R. Nichols Rehabilitation Medicine Butterworth (1976) London.
- E. Reimer School is Dead Penguin (1971) England.
- C.M.C. Van de Ven A Pilot Survey of Elderly Bilateral Lower Limb Amputees
 Physiotherapy (1973) Vol. 59(10) 316-320.
- C.M.C. Van de Ven An Investigation into the Management of Bilateral Leg Amputees British Medical Jnl (1981) Vol. 283 707-710.
- P.C. Weaver and S.A. Marshall A Functional and Social Review of Lower Limb Amputees British Jnl Surgery (1973) Vol. 60 732-737.

Chapter Nine

- L. Battye The Chatterley Syndrome (1966) from D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person in the Community Tavistock and O.U. Press (1974) London.
- G.W. Brown The Mental Hospital as an Institution Soc. Sc. and Med. (1973) 7
- E.T. Cassee Therapeutic Behaviour, Hospital Culture and Communication (1970) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London.
- R. Coser Alienation and the Social Structure: A Case Analysis of a Hospital (1963) from E. Friedson (editor) The Hospital in Modern Society Free Press (1963) New York.
- C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London.

- F. Davis Professional Socialisation as Subjective Experience: The Process of Doctrinal Conversion Amongst Student Nurses (1966) from C. Cox and A. Mead (editors) A Sociology of Medical Practice Collier MacMillan (1975) London.
- A. Etzioni Modern Organisations Prentice-Hall (1964) New Jersey.
- A. Faulkner The Student Nurse's Role in Giving Patients Information Unpublished Thesis (Mc.Sc) (1980) University of Aberdeen.
- S.K. Forer, M.A. Lawrence, S. Miller Rehabilitation Outcome: Comparative Analysis of Different Patient Types Archives Physical Med. Rehab. (1980) Vol. 61(8) 359-365.
- E. Friedson Professional Dominance: The Structure of Medical Care Aldine Pub. Co. (1970) Chicago.
- E. Friedson Profession of Medicine: A Study of the Sociology of Applied Knowledge Dodd Mead (1972) New York.
- E. Goffman The Presentation of Self in Everyday Life Pelican (1959) London.
- E. Goffman Asylums Pelican (1961) G.B.
- E. Goffman Stigma: The Management of a Spoiled Identity Pelican (1963)
 London.
- M. Gott Learning Nursing: A Study of the Effectiveness and Relevance of

 Teaching Provided during Student Nurse Introductory Course
 Unpublished Thesis (Ph.d) (1982) University of Hull.
- C.S. Huston, B.A. Divins, C.B. Ernst, W.O. Griffen Morbid Implications of Above Knee Amputation Archives of Surgery (1980) Vol. 115(2) 165-167.
- I. Illich, I.K. Zola, J. McNight, J. Caplan, H. Shaiken <u>Disabling Professions</u>
 Marion Boyers (1977) London.
- P. Ley and M.S. Spelmann <u>Communicating with a Patient</u> Staple Press (1967) London.
- J.M. Malone, W.S. Moore, J. Goldstone, S.J. Malone. The Therapeutic and Economic Impact of a Modern Amputation Programme Annals Surgery (1979) Vol. 189(6) 798-802.
- J. McCleod-Clark Nurse Patient Verbal Interaction: An Analysis of Recorded Conversations on Surgical Wards Unpublished Thesis (Ph.d)

 (1982) University of London.
- (The McMillan Report) The Remedial Professions: A Report HMSO (1973) London.
- D. Mechanic Medical Sociology: A Selective View Collier MacMillan (1968)
 London.
- I.E.P. Menzies A Case Study in the Function of Social Systems as a Defence Against Anxiety: A Report on a Study of Nursing Services of a General Hospital (1961) Human Relations (1970) 13 95-121.

- S. Milgram Obedience to Authority Tavistock (1974) London.
- P.J.R. Nichols Rehabilitation of the Severely Disabled Vol. II Butterworth (1971) London.
- C.J. Partridge Letter to the Editor Physiotherapy (March 1982) Vol. 68(3)
- R.P. Preston The Dilemmas of Care: Social and Nursing Adaptations to the Deformed, The Disabled and The Aged Elsevier (1979) New York.
- D. Robinson Patients, Practitioners and Medical Care William Heinemann (1973)
- L. Saunders The Changing Role of the Nurse American Jnl of Nursing (Sept. 1954) 1094-1098.
- R.A. Scott The Making of Blind Men: A Study in Adult Socialisation Russell Sage Foundation (1969) New York.
- R.A. Scott The Construction of Stigma by Professional Experts (1970) from

 D.M. Boswell and J.M. Wingrove (editors) The Handicapped Person
 in the Community Tavistock and O.U. Press (1974) London.
- D. Scrutton and M. Gilbertson Physiotherapy in Paediatric Practice Butterworth (1975) London.
- D. Tuckett An Introduction to Medical Sociology Tavistock Publications (1976) London.
- (The Tunbridge Report) Rehabilitation: Report of a Sub-Committee of the Standing Medical Advisory Committee HMSO (1972) London.

Chapter Ten

- E. Goffman Asylums Pelican (1961) G.B.
- E. Goffman Stigma: Notes on the Management of a Spoiled Identity Pelican (1963) London.
- P.L. Harris, F. Read, A. Eardley, D. Charlesworth, J. Wakefield, R.A. Sellwood The Fate of the Elderly Amputee British Jnl Surgery (1974) Vol. 61 665-668.
- I.M. Hutton and N.G. Rothnie The Early Mobilisation of the Elderly Amputee British Jnl Surgery (1977) Vol. 64 267-270.
- J.M. Malone, W.S. Moore, J. Goldstone, S.J. Malone Therapeutic and Economic Impact of a Modern Amputee Programme Annals Surgery (June 1979) Vol. 189(6) 798-802.
- (The McMillan Report) The Remedial Professions: A Report HMSO (1973) London.
- (The Tunbridge Report) Rehabilitation: A Report of a Sub-Committee of the Standing Medical Advisory Committee HMSO (1972) London.