MEDICAL GENERALISM, NOW!

RECLAIMING THE KNOWLEDGE WORK OF MODERN PRACTICE

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CHAPTER 1: PRINCIPLES OF WHOLE PERSON MEDICINE

Medical generalism is the expertise and practice of whole person medicine (RCGP). It stands in contrast to the expertise of a specialist medicine focus on condition or organ-system specific medical care. In a wide ranging, and sometimes confusing literature on medical generalism, this distinction is perhaps the one common thread.

Despite this clear distinction between these two forms of clinical practice, it is interesting that the *roles* or *work* of medical generalism are often still defined with reference to specialist medicine. A generalist physician has been described as a "jack of all trades" (Griffiths). The generalist is seen as someone who knows a little bit about a lot (of medical specialties), and so can deliver many 'basic' aspects of care. The generalist GP, for example, is commonly seen as a readily accessible clinician able to coordinate multiple elements of (specialist) healthcare in the patient's own community context. The generalist role becomes defined as *managing* the 'easier' bits of specialist medicine, and *referring* on the more complex elements to specialists. The work of the generalist is seen as care coordination, navigating patients through healthcare.

All of these roles are important components in an effective integrated healthcare system. But as we will explore in this book, these accounts are a misunderstanding and misrepresentation of the scope of work of expert medical generalist practice in a modern healthcare system dealing with the growing challenge of complex healthcare needs. Drawing on twenty years of research and scholarship, this book will redefine the work of medical generalism for today's healthcare.

WHAT'S IN A NAME: GENERALISM, GP AND GENERAL PRACTICE

If we want generalist practice to be clearer, we need to start by clarifying some of the confusing terminology. These three terms – generalism, General Practitioner (GP), and general practice - all contain the word 'general'. Perhaps that is why people often use the words interchangeably, talking about general practice when they actually mean generalist practice for example. Each term refers to something different and distinct.

In the UK, GPs are the largest group of practising medical generalists, but GPs also deliver disease-specific (specialist) healthcare. General practice refers to a community healthcare setting providing primary medical care – a 'general range' (rather than a specific focus) of healthcare services that includes specialist and generalist care.

I have often thought that it would be helpful to find a different word instead of *general*ist. But since it is still a commonly used term in western healthcare, I start instead by clarifying the definitions of each of these terms as I will use them in this book.

General Practitioners are clinicians trained in the medical speciality which focuses on primary care medicine. The definitions of General Practice, or Family Medicine, are defined by the World Organisation of Family Doctors (WONCA), and in the UK by the Royal College of GPs. In this book I will refer to General Practitioners as GPs.

General practice is the community model of primary healthcare delivery in the UK. If I talk about general practice in this book, I am referring to the organisational unit. When talking about professional practice, I will refer to GPs.

Generalist practitioners are clinicians with expertise in the distinct knowledge work of whole person medicine.

GPs use both specialist and generalist skills depending on the problem presented to them. The GP meeting a patient overwhelmed by the number of different medicines they take for multiple long term conditions foregrounds their generalist skills to reassess and re-prescribe according to a tailored assessment of need (see TAILOR in chapter 5). A GP meeting a patient with crushing chest pain who is sweating switches on their specialist skills to assess the need for urgent cardiology care. The expertise of the GP is the ability to *oscillate* between these two forms of clinical practice (Hjorleifsson, personal communication).

In this first chapter, I want to set the scene for the detailed discussions that follow by outlining 5 principles for understanding whole-person, generalist medicine.

1. The purpose for generalist, whole person medicine – creating a whole person understanding of illness
2. The focus for whole person medicine - understanding the self who we care for
3. The goal of whole person medicine - enhancing health as a resource people need for daily living
4. The work of whole person medicine - the wisdom of understanding in context
5. The context in which generalist medicine happens – delivering a complex intervention n a healthcare setting designed to support this work

1.1 THE PURPOSE FOR MEDICAL GENERALISM: creating whole person understanding

I opened this chapter by stating that medical generalism is the expertise and practice of whole person medicine, but I also recognised that there is much confusion attached to discussions of generalism. So let's start by clearing the pathway to our exploration of generalist knowledge work by clarifying what medical generalism *isn't*.

I have been studying generalist medicine for over 20 years. I have heard many accounts of what the generalist is, and does. I want to start by challenging three common stories offered about generalist practice. All relate to the way that generalist practice works, what it does. But each has lost touch with the defining purpose of medical generalism.

Not 'soft' skills, but the skills to deliver tailored care

Medical generalists look after the whole person, and so it is perhaps unsurprising that people often conflate generalist practice with the idea of person-centred care. But person-centred care is neither distinct to generalist practice, nor sufficient for effective generalist practice. Let me explain why.

Harden (2017) recognises the person-centred approach to mean putting people, families and communities at the core of the design and delivery of healthcare. As she discusses, there are many elements to the delivery of person-centred care. In UK general practice over recent years, emphasis has often focused on the importance of interpersonal skills including empathic practice, consultation skills and relationship-based care – sometimes described as the 'soft skills' of practice. But specialist clinicians would, rightly, reject an assertion that person-centred care is the exclusive domain of generalist medicine. A cardiologist may focus on clinical decisions about the management of an individual's heart problem, but they will be engaged in conversations with a whole-person about their goals, preferences and concerns. The clinical skills of communication, empathy, listening are not exclusive to generalist practice, and so do not define the expertise of the medical generalist. Generalist medicine and person-centred care are not synonymous.

Yet these patient-centred skills matter – my own research and clinical experience confirm the therapeutic benefit of relationship based care. But a patient in one of my previous research studies shows us why relationships and soft skills are not enough (Reeve et al. 2012).

Helen was a young woman in her 50s dying from breast cancer. Before her diagnosis, Helen was a busy wife, mum, working woman. Terminal cancer had turned her life upside down. Helen spoke movingly about her relationships with her clinical team. She described the empathic care she received from the range of health professionals involved in her care. Staff laughed with her, cried with her and offered her comfort. They were able to sign post her to help for the range of problems she faced as a result of her illness – the impact on her finances, her mobility, her everyday activities. Helen received great *personal* care.

But Helen was also very critical that she didn't receive *personalised* healthcare. The problems related to medical decisions about her treatment. Here, Helen had a very different story to tell. The same staff who had offered great personal care were also responsible for her medical care. Helen had decided that she didn't want to have any more active medical treatment, preferring to spend the time she had left with her family and friends – doing her everyday things. But she reported that staff repeatedly offered 'evidence-based' justifications for clinical decisions, repeatedly asked her to consent to further treatment (palliative chemotherapy). Helen described that her clinical team seemed unable , or unwilling, to tailor care despite being so familiar with her personal circumstances. Helen described that, in these clinical conversations, she felt like she was "stuck on a conveyor belt". All of the personal care was forgotten, lost. The impact was that healthcare conversations became a drain on her health for daily living, not a support.

Helen highlighted that person-centred (so-called 'soft') skills are important but insufficient for generalist, whole person, care. Instead, a generalist clinician must be able to *tailor* care (including the use of 'evidence') to the context of an individual. We will look in more detail at what this involves in chapter 2.

No jack of all trades, but expert knowledge worker

When I started researching generalist care, I asked a group of GPs, 'how would you describe a generalist?'. They almost all told me that a generalist is

someone who knows a little about a lot of things. This allows them to deliver first line care for the range of problems that patients present to them. They described themselves as a 'jack of all trades'.

This label has shaped perceptions of the generalist role, especially GPs, for some time. There is a common mis-conception that GPs work simply to filter and sort patients, dealing with the easier problems, and passing on the more difficult elements to specialist clinicians. The perceived skills needed to do this 'sifting and sorting role' focus on the tasks done (multi-tasking); the knowledge needed (a little bit about a lot); the interpersonal skills (empathy, communication, relationship based care); and the values of the practitioner (empathy, advocacy, ethics). All of which has shaped the vocational training of so-called generalist GPs. Now, as GP numbers in the UK have diminished, the service has started to train up other professionals including Advanced Clinical Practitioners, Advanced Nurse Practitioners, and Physician Associates in these same tasks.

But the reality of the work of whole-person, tailored healthcare is much more complex. As patients live, and present, with ever more complex healthcare needs, staff trained for a 'jack of all trades' role find themselves unsupported to provide the care needed by individuals. Consider, for example, a frail elderly person living with multiple long term conditions. The jack of all trades generalist can try and coordinate the delivery of multiple disease-focused guidelines of care. Digital technology may aim to help them work more efficiently. But as I will discuss shortly, these approaches are leaving patients overburdened by healthcare, and staff burnt out in trying to deal with the disconnect between the job described by healthcare systems and the need described by their patients. Yet if provided with the resources and support to use their distinct expertise, the medical generalist can do so much more. The expert generalist physician is able to create, deliver and review and revise a tailored management of healthcare that optimises the health of this frail elderly person so that they can maintain their daily living. This is the distinct knowledge work of advanced medical generalist practice and it is the work I will champion through this book.

Not better integration but new design

The primary purpose of generalist medicine is to create, a whole person understanding of illness so as to inform, shape and evaluate the healthcare that follows. Which means that whole person medicine is much more than the efficient integration of specialist medicine (Lewis 2013). We need to rethink our approach to healthcare delivery.

My research has highlighted a number of contextual barriers to delivery of whole-person, generalist health care. These studies have consistently highlighted four: a failure to value, prioritise, enable, and sustain the complex work involved in delivering tailored healthcare. As we hear repeated calls from health service leaders for changes in the culture of modern healthcare, we need to redesign our healthcare systems to address those barriers. This book outlines how we can.

1.2 THE FOCUS FOR WHOLE PERSON CARE: THE CREATIVE SELF

It is common to hear people talking about 'person-centred' care in many settings, but what actually do we mean by person-centred? I said there were multiple, often confusing, accounts of generalism – and the same is true of person-centred care.

In 2018, Professor Chris Dowrick led the publication of a new book on Person-Centred Primary Care. He argued the need to recover a 'sense of self' for both patients and professionals if we are to undertake genuinely person-centred care in everyday practice. The book looks at why concepts of the self matter not only to philosophers and academics, but to managing the practical challenges facing clinicians everyday. These include mismanagement in clinical practice, dealing with technology in the consultation, and addressing the epistemic disadvantage (experience of not being heard) faced by patients such as Helen.

My contribution to that book was a chapter on the role of primary care, generalist practice in unlocking the Creative Capacity of the self. This work was developed from Harvi Carel's writing. Carel is a professor of philosophy living with a life limiting long-term illness. In her writing, she invites us to recognise what she calls the creative capacity of every individual. Her work describes the innate capacity of every one of us to respond to the ups and downs of daily life, including the adversity of illness. She invites us to consider the resources available to a person to do that work. For me, her writing sparked a recognition that as a healthcare practitioner, my job is to ensure that the care I offer enhances, perhaps even optimises, that capacity – but certainly doesn't undermine it.

Carel's writing challenges us to think differently, and more broadly, about what we – as healthcare professionals – are trying to do. The generalist clinician, seeking to deliver whole person care, needs to think not only about the disease(s) that an individual has, but also the resources that they have for daily living with those diseases (including those which could be enhanced). Carel reminds us that medicine is only one (often small) part of healing, improving health. Carel reminds us that we should start our conversations, our consultations, with a curiosity about this person *in the context of their daily life*. We need to be curious not just about the illness, but also the resources and context that shape their experience of illness and its management.

Just as Helen described, a person who is ill is also a person living their daily lives. They are working to keep a roof over their head and food on the table, looking after family and friends, managing the work they do for an employer and for society. This so-called work of daily living goes further than those practical everyday tasks. Maslow described the many additional layers of work that people do every day – for example, in building and maintaining their self-esteem, their confidence, and their sense of place and identity (Maslow 1943). A person who is dealing with illness is also dealing with all of the context and work of daily life. Illness happens in context – and that context shapes not only the experience of illness but also the resources that someone has and needs to deal with illness.

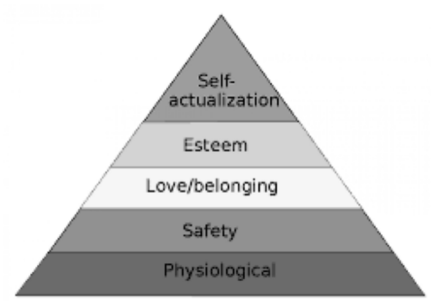


Figure: Maslow's hierarchy of needs

There is a rich body of research describing the workpeople do in to manage their daily lives whilst living with chronic illness. Clinicians reading this book will likely have been introduced to some of this work when you were an undergraduate in courses on health and society, social medicine and the behavioural sciences. These courses can introduce us to the 'whole person' experience' of illness, although often with limited discussion of how those perspectives can be integrated into daily medical practice and decision making. I will return to this point when I consider Iona Heath's work in chapter 3.

One of the most influential areas of that work was started by a sociologist called Michael Bury. His research looked at how a new diagnosis of a chronic illness, in this case rheumatoid arthritis, impacted on a person's story of their daily life -their biography. Bury (1984) described the disruption to everyday living caused by the effects of the illness, the treatments – medication and engagement with health care. He also recognised the impact of the diagnosis on an individual's identity and sense of self. Bury described the work that

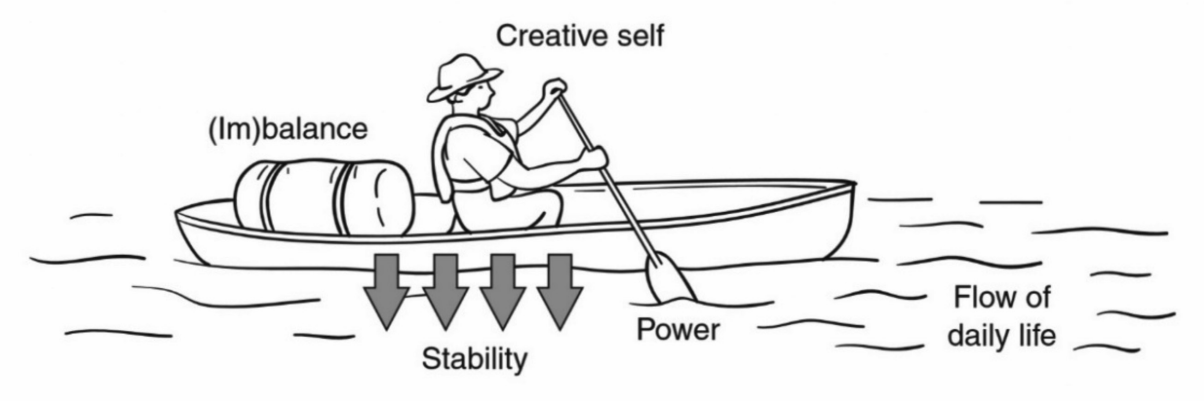
people do to adjust to now being ‘ill’, no longer healthy, possibly disabled with a new sense of their personal identity.

Other research followed looking at experiences in other communities and for other conditions. Some of these authors challenged Bury’s account of the impact of illness (for example Faircloth, Williams G, Williams S) . They noted that a diagnosis of chronic illness wasn’t necessarily disruptive to daily living. These studies described how some people can adapt successfully to the new element in their daily life that comes with an illness diagnosis. Faircloth described this ability to restore and maintain their daily life as maintaining biographical flow. Later studies even described how illness can even bring positive change to daily living (Williams G). I saw one example of this in my research for my PhD (Reeve 2010). I was looking at people’s experience of distress when living with a terminal diagnosis of cancer. One participant in my study was a young woman dying from ovarian cancer. Whilst she was fully aware that her cancer diagnosis was terminal, she spoke movingly about how being ‘terminally ill’ and transformed her from being an overworked undervalued housewife to someone who ‘mattered’. A devastating (and highly disruptive) new diagnosis had also bought additional help in her work of daily living.

Understanding how and why illness impacts differently on individuals daily living has significant implications for making healthcare decisions. The aspects of care that we prioritise, along with the elements of care that we put to one side, will be shaped by these personal lived experiences. These experiences shape the “ideas, concerns and expectations” that consultation models such as the Calgary-Cambridge model ask us to explore with our patient . And indeed, we can simply ask people directly, what are you most worried about? Or, what would you like me to do today?

Personally, I have rarely found these very helpful questions in a clinical consultation. Asked directly, they often elicit a response on the lines of ‘I want to know what’s wrong with me’ or ‘you’re the doctor…’.Neither takes us much further forward in our exploration of an illness problem. But if I have first explored the everyday work that my patient is juggling, whilst also managing their health concerns, ideas about concerns and expectations become part of a discussion – the exploration – rather than a direct question. “There’s a lot going on there…how are you managing to juggle all of this, deal with your hip problem along with everything else…”

In person-centred primary care, I bring together Carel's work on the creative self, this body of research on the work of being ill, and my own clinical experience of working with people living with chronic illness to develop and describe an account of the creative capacity of the individual self. In my account of the Creative Self, I recognise 5 elements that influence our ability to deal with potential disruption to daily living created by adversity including illness. These are the Creative Self, the energy to Power the work of everyday life, the factors which offer Stability and which create Imbalance, all taking place within the context of a more or less turbulent Flow of Daily Life (see Box). The chapter offers a series of case studies to explore how as a clinician, we can make use of these elements to shape our consultations with patients.



Box: CREATIVE CAPACITY (from Reeve 2018)

The Creative Self refers to the innate capacity of every human being to respond and adapt to a stimulus. It is the intellectual, emotional, physical and spiritual essence of ourselves that enables us to make sense of, and enact, daily life. Faced with illness, the goal for health care is therefore to enable patient and clinician together to optimise the capacity of each creative self.

Each creative self needs resources to Power the work of everyday life. As described by Maslow, these resources are varied – whether the basics of shelter, food, warmth, and the complex social activities of being with family, friends, in work. All can be both drained and restocked by the activities we do – including the health and healthcare work. Resources can be enhanced through partnerships – including partnerships with healthcare professionals. This doesn't mean healthcare professionals taking on extra roles and responsibilities; but it may involve professionals in reducing the healthcare work 'required' from an individual whose resources are depleted.

illness, and of managing daily healthcare routines, all occur in the context of the flow of daily life. For some, this may be relatively calm; for others, and at other times, this may be turbulent. Any healthcare work we ask of an individual needs to recognise, and fit with, the broader flow of daily living.

Our daily task to navigate through the flow of daily life will be made easier or harder by the (Im)balance of resources and demands on an individual and their creative self. In Unlocking the creative self, I introduce John and George. John lives with Type 2 Diabetes Mellitus and some significant complications arising from that. But he also describes strong social networks, together with a strong personal understanding of his priorities and values, all of which help him to juggle the many healthcare related demands on him. George has fewer biomedical complications from his diabetes but also fewer supportive resources to call on. George was at greater risk of being overwhelmed by the burden of his illness than John, even though his biomedical risks were less.

Finally, the creative self recognises that the things which matter to us as individuals provide important Anchors or Ballast in managing the turbulence of daily life. Often these reflect our sense of identity, our values. A strong faith may be an important anchor; as may a strong sense of my role as a wife, friend, member of a group. Anything that disrupts those anchors may undermine an individual's creative capacity to continue to navigate the choppy waters.

More discussion on these can be found in Reeve 2018

In daily practice, these elements offer me a series of pointers to explore in a conversation with the person who has come to see me about their illness. How steady, or indeed turbulent, is their everyday life just at the moment? What are the factors that act as 'anchors' or 'ballast' in this potentially choppy ride – perhaps the support of family or friends, the aspirations and goals that provide motivation even in the dark times, the beliefs and values that provide comfort? Indeed when my conversation with a patient reveals that they recognise few or none of these, this will be ringing a warning bell in my head. I may go on to explore, what factors are unsettling things at the moment – making it harder. Often these are losses – loss of family and friends, work, home, safety. I explore where my patient's energy levels are at – "you sound exhausted" often opens up a frank discussion about how much 'power' is left at the moment. And through all of this, I am asking myself – and ultimately my patient – does this

person recognise (feel) how much they are already doing in managing this illness problem.

When I discuss this concept with fellow clinicians, they have often questioned whether it is appropriate for clinicians to open up these wider conversations. They ask if there is a risk that by exploring these wider social and societal issues that we may unintentionally be taking on responsibility for issues that are beyond the remit of medicine and healthcare; inappropriately extending the medical gaze further. I usually respond by suggesting that instead, this concept of the creative self helps me to be clearer about boundaries and what is not my role. By understanding the context and capacity of the creative self that is my patient, I am better able to understand if and when medicine may have something to offer *or not* for the problems they are presenting. These conversations help in recognising when medicalisation of illness problems (including, for example, investigation and referral) may not be appropriate - unlikely to benefit the individual, and being more likely to burden or harm.

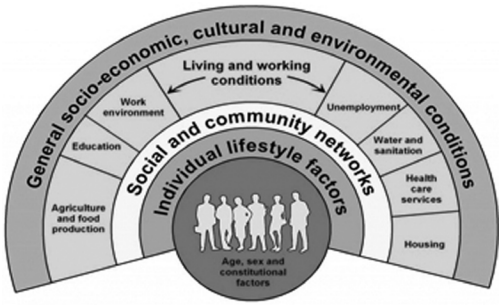
I find the concept of a creative self a useful way to highlight an understanding of the purpose of health as being to support everyday living – a means to an end, and not an end in itself. So let's look at that idea a little more.

1.3 THE GOAL OF HEALTHCARE: ENHANCING HEALTH FOR DAILY LIVING

The purpose of generalist healthcare is to understand the health and healthcare needs of an individual with creative capacity, enabling them to manage illness related disruption to daily living. This frames the goal of generalist healthcare - to enhance health for daily living.

The World Health Organisation (WHO) have long advocated for an understanding of health in the context of daily living. Their asset model of health described that "health is a resource for everyday life. Not the object of living. It is a positive concept emphasising social and personal resources as well as physical capabilities". Williamson and Carr developed this idea further in recognising health as a societal resource – a form of social capital that enable people to participate in society. When people have good health, they can participate in and give to society. Both the individual and the collective community benefit from investment in health capital. The authors intention in recognising health as a form of capital was to encourage investment in a societal resource to be valued and nurtured for the public good. Indeed the Public Health Agency of Canada describes health a " a positive concept that emphasises social and personal resources, as well as physical capabilities". So how do these discussions help us understand the goals of healthcare, and especially generalist (whole person) medical care?

Firstly these definitions flag up that health is dependent on much more than biomedical factors. You will probably be already familiar with the public health model describing the social determinants of health (see Figure). I have already discussed Carel's work highlighting the (important but) limited contribution of healthcare to health and wellbeing. Dahlgren and Whitehead's model reinforces that understanding. Both perspectives highlight the limited role of medicine in shaping the health of individuals and populations. Any medical decision has to be made in the context of this wider understanding of health.



Dahlgren & Whitehead: social determinants of health

As I have described, being aware of these wider determinants of health for daily living is not intended to extend the responsibility or reach of medical practice; but rather the opposite. In 1973, Illich warned about the dangers of overmedicalisation of (all aspects) of health. He described the iatrogenic harm that could result from using medicine and medical practice to try and control ever wider determinants of health. Today, we see a growing literature on the harms to individuals being created by too much medicine – too much screening, too much testing, overextension of medical diagnosis to describe wider societal problems. Optimising medical care has become the end point of healthcare. We strive to see people, diagnose people, start treatment – all as quickly as we can; and with limited reference to a broader end point of health for daily living. Medicine has become an end in itself; rather than a means to an end – communities better able to manage health for daily living. Just as Illich predicted, medicine is becoming part of the problem - contributing to the tsunami of health care needs facing today's patients and healthcare systems.

The World Health Organisation have described this approach within western medicine as the command and control of disease. Whilst a potentially appropriate and valuable approach for managing acute illness such as outbreaks of infection, authors have challenged its usefulness in managing the newly emerging problems of chronic illness and multimorbidity (see Tinetti & Fried). Within a command and control approach, for an individual living with multiple long term conditions, best care is achieved by efficient, coordinated management of each of those individual diseases. But Hughes and colleagues highlighted the limitations of this approach in a critique of guideline care published in 2013. They used an example of a fictitious patient, Alice, living with five common long term conditions (diabetes, cardiovascular disease, osteoarthritis, depression and chronic obstructive pulmonary disease). They listed what Alice's 'best' care would look like if each of the guidelines for these conditions was optimally applied. Alice ends up on over 11 medicines a day,

attending ten follow up appointments, being asked to do nine self care activities, all on top of her usual daily routines. Medical care may improve the control of her diseases, but may also come at the cost of reducing her capacity for daily living. In this scenario, medicine has become an end in itself, rather than a means to a broader end. This problem is replicated in communities and healthcare settings across the world.

In the last couple of decades a number of authors have started to describe, define and challenge the burden placed on patients by treatment plans focused on optimising disease care. In her work on living after a stroke, Gallagher argues that we need to focus more on the everyday work experienced by people living with long term conditions. This work includes the pre-existing everyday work a person does to keep a roof over their head, food on the table, to support family and friends. Add to that the work of living with an illness, for example, disability following a stroke; as well as the treatment work created by healthcare, on the lines described for Alice. From all of this, we start to see quite a different view of the 'value' of healthcare.

In 2009, May and colleagues proposed that we need to recognise a new approach for health care - what they described as Minimally Disruptive Medicine. Since then, they have described the Burden of Treatment Theory – shining a light on the work that patients do to manage everyday illness and associated healthcare in order to inform new ways of thinking about healthcare. From this, they have described and tested a tool to measure Treatment Burden, to help health care professionals recognise, address and monitor this important impact of care (Tran). Other teams have developed and validated tools for use in specific circumstances, for example multimorbidity (Duncan). This body of work serves to recognise and highlight the significance of a previously underrecognised impact of condition-focused (specialist) healthcare and so highlight the need to strengthen whole-person generalist approaches.

So we need to reset the goals of healthcare. By shifting our focus from optimising disease control, to optimising the work of daily living, we recognise that healthcare happens in the context of people's daily lives. And this needs to be factored in to the way we describe and set goals for health care. Our goals for health care need to focus on the work that people do, rather than just the disease process they have. This needs fundamental changes in the focus,

priorities and actions of healthcare delivery, including in how we recognise and judge good care. So how do we do that in practice? Let’s take a look…

1.4. THE WORK OF WHOLE PERSON HEALTHCARE: CREATING UNDERSTANDING IN CONTEXT

Achieving a goal of supporting health for daily living relies on us understanding an individual in context, so that we can consider the potential value and harm of medical care in supporting health for daily living. Creating tailored, individualised understanding of illness and the value or place of medicalisation of illness in context is the distinct work of the advanced medical generalist. This work uses skills to critically explore, explain and evaluate individual illness experience. Guidelines inform each stage of the work, but they do not dictate the outcome. The generalist practitioner uses the knowledge of guidelines but goes further to create new understanding of illness for this individual in their context. This work to tailor care to the individual and context is the knowledge work of advanced generalist practice. It is a distinct and different way of doing medical practice.

I therefore recognise generalist practitioners as knowledge workers – people who "think for a living" (Drucker). Knowledge workers can be found in many different work settings, not just healthcare. In most industries, they are valued for their abilities to undertake "non-routine problem solving"; using an "abstract knowledge base to [creatively] complete tasks, [adapting] the specific response to the context". Knowledge workers therefore need to use both "divergent [creative] and convergent [deductive] thinking" (Okkonen); and to be able to learn from what they do (Anon.). Knowledge workers are defined not by what they know, but how they use what they know to get results (Wenzel).

Applied EBM is also a form of knowledge work. EBM applied the principles of hypothetico-deductive reasoning and the knowledge derived from biomedical research to describe the probability that a patient has a named condition (generate a diagnosis) and would therefore benefit from treatment (describe a treatment plan). Advanced generalist practice is grounded in scientific knowledge practice, but uses a different model of clinical reasoning and an extended evidence base in order to generate an understanding of whole person illness to support a management plan (Reeve Interpretive Medicine). Yet it uses a form of scientific reasoning that is not routinely taught in health professional training. If we want to deliver whole person healthcare, we will need to address that gap. This will be the focus of my discussion in chapter 2.

1.5 THE CONTEXT OF WHOLE PERSON HEALTHCARE: COMPLEX INTERVENTIONS

My fifth principle for understanding whole person, generalist care recognises that all of this work doesn't happen in a vacuum. The generalist physician who seeks to understand their patient in context – the individual and their illness – does so in the context of a healthcare system which shapes and drives the work they do.

My research has repeatedly highlighted that health professionals experience a number of barriers to delivering whole-person tailored care in their everyday work place. This include a perceived lack of permission to tailor care; a failure to prioritise this complex work in the array of competing pressures on healthcare professionals; a lack of skills, confidence and resources to support the work; and a lack of feedback to support continuing practice. These are significant blocks that must be addressed if we are to deliver whole person, generalist care, now. Meaning we must not only change the training of professionals but also the contexts in which they work.

Tailoring healthcare to individual circumstances is an example of what is described as a 'wicked problem'. A wicked problem is one that can't be 'solved' or 'fixed' because there is no one single solution, and because the situation is constantly changing. Here, wicked doesn't mean 'bad' but instead refers to a problem that resists a simple or straightforward solution. Making individually tailored decisions about healthcare needs can be seen as a wicked problem. Understanding whole person illness requires us to consider the interplay of illness and pathology, in the context of a creative self supported (or otherwise) by multiple factors, and living their daily life in the context of many interacting elements. All of these elements interact and shape the individual experience of illness, and so the tailored intervention needed to help. We therefore need a healthcare system which can be flexible, adapting to context in making decisions about what to do, and what outcomes can be expected. Yet our current disease focused model of healthcare is a more linear model – describing pathways for assessment, diagnosis, management and monitoring of healthcare. To support generalist healthcare, we need to shift to a model that supports 'complex interventions'.

A complex intervention has multiple component parts, giving it the flexibility to adapt to variation in individuals and contexts. But a complex intervention is not a 'free for all'. It will have defined constant elements that make the model of

care distinct, and also variable elements that make it flexible for context (McPherson). In generalist healthcare, the constant component is the knowledge work of whole-person-medicine – the distinct element that contrasts the approach with specialist disease-focused care. The variable components will depend on circumstances and context. They may include the data available to support decision making, the skills and make up of clinical teams available to assess individual needs, and the community resources including social prescribing, available to support management.

I'll go into all of this in more detail in the next chapter, but let me briefly illustrate with an (fictitious) case example. Imran is a husband and grandfather who also has a busy role as a member of his local community group and who has developed memory loss and diabetes. If we just focus on his medical conditions, dementia and diabetes, there are clear rules and paths of care to follow that tell us about his diagnosis and his medical management. But if we factor in the issues we have discussed in this chapter, then things change. The dementia and diabetes are two elements in the broader work of daily living for Imran. Thinking about Imran's creative capacity, there are some stable elements supporting this daily work (the input from his family and family roles) but also some variable elements (the struggle with maintaining support for his local community group). Factoring in some new 'work' – managing his medical conditions – puts additional pressure on this delicate balance. And then Imran's wife dies unexpectedly. Even in this simplified case, it is clear that there is no one clear definition of best care for Imran. Tailored, generalist care, will require negotiating and creating a best understanding in context for Imran now. We will need to follow up and review how the plan is working for Imran, and potentially change it if it's not helping his health for daily living. And when life throws up something unexpected we will need to be ready to review and revise everything. Tailored care to manage wicked problems needs to be flexible and adaptable in its delivery – requiring the knowledge work expertise of clinicians trained in expert generalist practice. Wicked problems need to be managed in complex healthcare systems. Disease focused healthcare systems are designed to offer linear pathways of care for a patient. I will discuss the implications for redesign of our healthcare systems in later chapters.

1.6 SUMMARY

In this chapter I have outlined the 5 principles of expert generalist practice.

1. The purpose for generalist, whole person medicine – creating a whole person understanding of illness
2. The focus for whole person medicine - understanding the person we care for
3. The goal of whole person medicine - enhancing health as a resource people need for daily living
4. The work of whole person medicine - the wisdom of understanding in context
5. The context in which generalist medicine happens – delivering a complex intervention in a healthcare setting designed to support this work

The golden thread through these principles is the individual. The clinical professions have long recognised that our patients – the individuals we work with – drive *why* we do the work we do. Now, we must recognise that the person needs to define *how* we work too.

The task of whole-person medicine is being to enable and enhance the creative capacity of that individual to live their daily life. This task to explore, explain and evaluate tailored interpretations of illness, is a task that requires the skills of the distinct knowledge work of advanced generalist practice. In this chapter I have outlined why we need to shift the understanding of our professional role from a focus on what we know, to a new focus on how we use what we know to support our patients (Wenzel).

This is the work of the advanced generalist practitioner to create, use and critique new understanding (or knowledge-in-context) about a complex problem. It is a form of scientific knowledge work that goes beyond the traditional descriptions of medical practice described by condition-specific specialist healthcare. In the next chapter, I will explore in more depth how we do this work.

REFERENCES

Anon. (2018)What is a knowledge worker. www.panopto.com/blog/what-is-a-knowledge-worker/

Bury M. (1982). Chronic illness as Biographical Disruption. *Sociology of Health & Illness*, 4(2), pp. 167-182.

Carel H. (2008). Illness (The Art of Living). Oxon: Routledge.

Dahlgren G, Whitehead M. 1991. Policies and Strategies to Promote Social Equity in Health. Stockholm, Sweden: Institute for Futures Studies.

Dowrick C (Ed). (2019) Person-Centred Primary Care. Searching for the Self. Oxon: Routledge

Duncan P et al. Development and validation of the Multimorbidity Treatment Burden Questionnaire (MTBQ). BMJ Open *2018;* **8***,* 4*,* e019413*.*

Drucker P. (1959) The landmarks of tomorrow. London: Routledge.

Faircloth C.A., Boylstein, C., Rittman, M., Young, M.E. and Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. Sociology of Health & Illness, 26(2), pp. 242-261.

Griffiths J. Choosing to be a jack of all trades. https://drjongriffiths.wordpress.com/choosing-to-be-a-jack-of-all-trades/

Harden B. Person-centred approaches: empowering people in their lives and communities to enable an upgrade in prevention, wellbeing, health care and support. Health Education England, 2017.

Hughes L, McMurdo MET, Guthrie B. Guidelines for people not diseases: the challenges of applying UK clinical guidelines to people with multimorbidity. Age Aging 2013; 42:62-69.

Gallacher K et al. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative literature. PLoS Med 2013; 10:e1001473

Illich, I. (1973). Limits to medicine: medical nemesis – the expropriation of health. Penguin Books

Lewis S. The two faces of generalism. Journal of Health Services Policy and Research 2013; 19: 1-2.

May CR et al. We need minimally disruptive medicine. BMJ 2009; 339:b2803

May CR et al. Rethinking the patient: using the Burden of Treatment Theory to understand the changing dynamics of illness. BMC Health Services Research 2014; 14: 281

Maslow AH. A theory of human motivation. Psychological review 1943; 50: 370-396

McPherson H, Schroer S: Acupuncture as a complex intervention for depression: a consensus method to develop a standardised treatment protocol

for a randomised controlled trial. Complementary Therapies in Medicine. 2007, 15: 92-100.
Okkonen J. (2004) The use of performance measurement in knowledge work context. Tampere University of Technology, Tampere
Reeve J. (2006) *Understanding distress in people with terminal cancer: The role of the general practitioner. PhD thesis,* University of Liverpool, Liverpool.
Reeve J. Interpretive medicine: supporting generalism in a changing primary care world. Occasional Paper Series Royal College of General Practitioners 2010; 88: 1-20
Reeve, J., Lynch, T., Lloyd-Williams, M. and Payne, S. (2012). From personal challenge to technical fix: the risks of depersonalised care. Health and Social Care in the Community, 20(2), pp. 145-154.
Reeve J. Unlocking the creative capacity of the self. In Dowrick C (Ed). (2019) Person-Centred Primary Care. Searching for the Self. Oxon: Routledge
Howe A. (2012) Medical Generalism. Why expertise in whole person medicine matters. Royal College of General Practitioners.
Stewart M et al. (2003) Patient-centered Medicine, Transforming the Clinical Method (2nd edition). Radcliffe Medical Press.
Tinetti ME, Fried T. The end of a disease era. American Journal of Medicine 2004; 116:179-185.
Tran VT et al. Development and description of measurement properties of an instrument to assess treatment burden among patients with multiple chronic conditions. BMC Medicine 2012; **10**, 68.
Wenzel RP. Medical education in an era of alternative facts. New England Journal of Medicine 2017; 377: 607-609.
Williams, G. (1984). The genesis of chronic illness: narrative reconstruction. *Sociology of Health & Illness*, 6(2), pp. 175-200.
Williams, S.J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & illness*, 22(1), pp. 40-67.
Williamson DL, Carr J. Health as a resource for everyday life: advancing the conceptualisation. Critical Public Health 2009: 19: 107-122.
World Health Organisation(1986). Ottawa Charter for Health Promotion. World Health Organisation