

The University of Hull

Effects of compulsive hoarding and the search for
help as experienced by one family member and one
researcher

Being a thesis submitted for the degree of PhD in the
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By

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For Sarah, Peggy and Ted

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Like this piece of writing and those featured in it, I am a composite of eclectic parts. Some of these elements come from the diligent nurturing of parents who displayed a love of learning and an enthusiasm for facilitating the development of others in the most selfless way. Mum and Dad, thankyou for starting me off so well and for not losing hope or patience when I really tested you so many times over so many years. And thankyou to Angie, my mother in law who has provided so much help in so many ways which has made completing this work a possibility.

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Abstract

This thesis reports a shared journey within a personal one. I intended to understand help-seeking motivation in family members of compulsive hoarders. I learned something about myself. An integrative review of family experience of hoarding revealed themes of quality of life; shattered families; rallying around and lack of support, which was the central theme. This begged the question:

What sources of help do family members of compulsive hoarders seek and why?

A family-group collaborative design was proposed but developments in recruitment produced a situation of recruiting and being recruited simultaneously by a co-researcher expert by experience engaged in help-seeking. Negotiations around the collaborative workings of the project produced a cycle of action and reflection similar to co-operative inquiry. Analysis consisted of a free association exercise conducted by both co-researchers and dialogical narrative analysis by me alone. Results were triangulated with field notes including reports of interviews with other family members. Findings from these exercises included a focus on my co-researcher's role within the family and within the research team; identity; relationships within and outwith the family and tolerance of uncertainty.

My co-researcher's prolonged and wide-ranging help-seeking led to her discovering that hoarding had been included in the fifth edition of Diagnostic and Statistical Manual of the American Psychiatric Association (APA) (DSM-5), and this opened the possibility of treatment. Initially stating she preferred to focus on large scale projects as a way of avoiding her family situation, exploration of the experience from a different perspective unexpectedly allowed for a re-appraisal of the situation and its effects despite little change in circumstances. "The answer is in the exploration", as Tracy put it during analysis.

At the end of this project, I found myself not ready to let go. I also found myself unsure about my own identity. I explore why through autoethnographic writing, examining how the same processes which inadvertently benefited my co-researcher helped me to develop a new story for myself in relation to my status as a registered mental health nurse transitioning from psychosocial practitioner to mental health nurse academic.

Building on our work together, this work has produced further arguments for the use of autoethnographic methods in mental health research and has made a case for flattened structures and slow approaches in research relationships and by extension in other mental health work. In addition, we have uncovered a helpful bespoke response to compulsive hoarding in a relative which employs aspects of research and therapy.

In considering these issues I suggest a model for mental health nurse practice, education and research which understands evidence-based practice as a situated, narrative exercise with a broad range of influences from other disciplines and a requirement to proceed from a critical standpoint.

Foreword

Perhaps what you are reading here is “a blend of observation with participation and rationality with altered states of consciousness”? That would make it Gonzo ethnography, according to Tedlock (2011). Of course, if I sat down and said to myself (and then wrote on my ethics application) “I propose to explore family experience of compulsive hoarding through Gonzo ethnography” it would be ludicrous. Whilst the form appears to me to be a great means to achieve reflexivity, engagement and evocative accounts, how could it possibly be decided prior to commencing the study that this was the most appropriate way of doing this? I knew I wanted people to feel something when they read or saw my work on hoarding but the “how” part was a combination of intuition and co-operation. The participants and the data shaped this. The experience dictated it.

This text recalls the development, evolution or emergence of a method through the twists and turns of a doctorate the initial intent of which was to explore the experience of family members of compulsive hoarders. What was initially intended as a particular type of collaborative project went through developments which retained the collaborative element but ended in an autoethnographic reading of events. It recalls the development of a researcher, a collaborator (or participant, if you prefer), a family and a problem. As such, it employs stories to give its accounts. What makes a story? Characterisation, plot, a beginning, middle and end? Using story enables development of a common language and accessibility of the text to a greater audience, principles of performative social science (Jones, 2010). It also creates an evocative account which aims at producing verisimilitude for the reader. Not “the Truth”, but true-to-life. Plausible.

In talking about the development of characters or phenomena, Gergen (1991) identifies the interdependent and contingent nature of these concepts. The researcher, the participant, the phenomenon of interest are all contextually and relationally derived (Steier, 1991). From this social constructionist point of view, objectivity is unachievable and uncertainty is a continual presence. The tolerance of uncertainty is something which will return again and again in this thesis. The development of this tolerance is essential to the progression of the thesis. Certainty is not sought here. I couldn't have said that at the outset but I can say it now and in saying it I can understand better some of the trials of the earlier stages (for instance, ethics). Relational ethics have loomed larger as the writing up has progressed. Certain things may have to remain unsaid as not everyone shares the desire to be included in this book and not everyone will want my portrayal of them.

Autoethnography employs the experience of the individual in pursuing understanding of sociological concepts and phenomena. In exploring my own becoming I am examining concepts of mental health, academic practice and research. The use of reflexive writing was an essential feature of the process throughout, which became more marked and significant as the project developed. Reflexivity refers to a process of examining and acknowledging one's position within and interaction with the research. The researcher (co-researchers) influences the research (and each other) and vice versa.

“Do not store up for yourselves treasures on earth where moth and rust destroy, and where thieves break in and steal”

Matthew 7:19

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Abbreviations

APA	American Psychiatric Association
APDO	Association of Professional Declutterers and Organisers
CBT	Cognitive Behaviour Therapy
CCG	Clinical Commissioning Group
DSM-5	Diagnostic and Statistical manual of the American Psychiatric Association, fifth edition
HD	Hoarding Disorder
ICD	Institute for Challenging Disorganisation
ICD-10/11	World Health Organisation International Classification of Diseases, tenth/eleventh edition
IOCDF	International Obsessive Compulsive Disorder Foundation
NMC	Nursing and Midwifery Council
OCD	Obsessive Compulsive Disorder
OCDIGNO Orleans	Obsessive Compulsive Disorder Institute of Greater New Orleans
OCPD	Obsessive Compulsive Personality Disorder
SCID	Structured Clinical Interview for Diagnosis
WHO	World Health Organisation

General Introduction

The words written here are the result of numerous interactions with clinical and academic colleagues, family members, friends and strangers in a wide variety of settings. Only a few of these are acknowledged here. Many have been forgotten but the need to acknowledge that what is produced is the result of interactions is essential to the collaborative philosophy at the core of this thesis. I can write what I like but I am only able to do this by dint of my shared experiences. The person who submitted a research proposal in 2013 would not be able to produce this work. Or at best he was completely unaware of his capability to do so. Likewise, I can already imagine my future-self cringing at these efforts.

In the paragraphs below and elsewhere in this thesis, I have allowed my feelings in all of their naivety to be reported as they happened. This is an attempt to allow the reader to chart my journey more accurately. I aim to show the mess and the struggle involved in the process to allow you to make links between the researcher and the research – how each influences the other. Rather than tell you what this did to me or what I did because of that, I intend to show you.

This thesis is about two personal narratives intersecting and therefore I should say something about the structure of this (thesis). As Laurel Richardson (1994) mentions, time does not proceed in a linear fashion for human beings but can in fact be experienced differently depending upon the circumstances. The narrative form allows us to reflect this, whilst offering an ordered series of events

For the most part, I have tried to provide a linear narrative for ease of use of the reader but at times this does not lend itself to the representation of the process which often felt more circular. This came as no surprise as I had already submitted this timeline (fig. 1) for the interim viva which attempted to convey the uncertainty and circularity of the process (albeit rather naively) of gathering and analysing data. From this distance, it seems obvious to me that as I influence the research as much as it influences me, there will be a circularity to most of it – a period of rumination which inevitably creates tensions (Grant et al, 2013).

The focus of this thesis moves inwards as it progresses. It shifts to accommodate changes in circumstance in need and in people (especially me). Four years is a long time and most people experience a fair degree of change or some significant life events in a period of time that long. For some this requires a degree of professionalism reflected in the production of a piece of work and perhaps a public self which does not

betray the change – which stands apart from it as a piece of perfected scientific writing. For others the acknowledgement and demonstration of how the work and the life are mutually influential through an audit trail candidly and carefully reported is what is required (Etherington, 2004). These modes of writing are not mutually exclusive, it has been argued (Richardson, 1990).

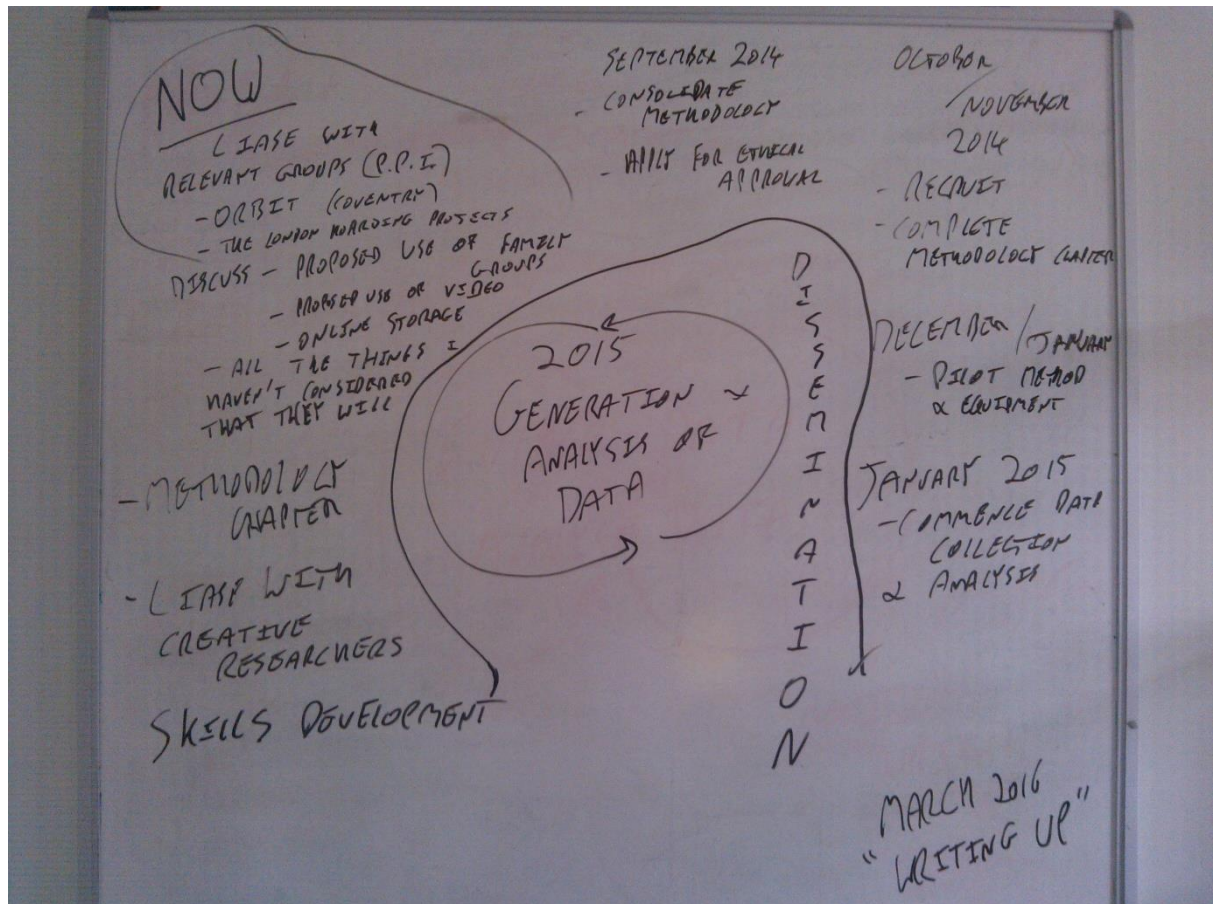


Figure 1 - timeline for thesis, June 2014

At the end of this introductory material, I have given a potted (hi)story of me up to the point of beginning this PhD. Much of what is contained in this account can be seen to have a bearing on what and how I chose to study. This material was written whilst I was tussling with completing the later chapters and as such is influenced by struggles I was having to express something which made me uncomfortable. I have put this at the beginning to offer a point of origin for this researcher and give a reflexive statement which allows for theorising, discussion and engagement. It is not there to overshadow the collaborative research or the narrative experience of my co-researcher, whose story is perhaps the real point of origin for this “origins story”.

Chapter one presents a background to compulsive hoarding and the development of theory into a diagnosis of hoarding disorder. It also describes the contributing voices which helped shape the clinical and public understanding of compulsive hoarding, its

causes and effects and how it can be “treated”. There has been significant overlap between key clinical figures and reality television shows focusing on “extreme hoarders”, producing a powerful narrative of mental illness which is available to a vast number of people. In the wake of this, an industry of therapeutic interventions and lifestyle managers has emerged, offering cure or management of this affliction. I suggest some possible alternative ways of looking at this phenomenon as offered by other disciplines.

Chapter two is a report of a literature review first conducted in 2012 and updated in 2017, using an integrative review methodology. Initial emergent themes were quality of life, shattered families, rallying around and lack of support. The re-iteration of the review offered the opportunity to examine the development of lines of inquiry in the research literature. It emerged that families were burdened by their relatives hoarding behaviour but were able to bear this burden more easily when they had an explanation for it. As a reply or adjunct to this review, I include a discussion of memoirs of people who grew up or spent time as a child in houses where the number of possessions made living a “normal” life difficult. Some of these people were still involved with the relatives responsible for the accumulation and now had caring responsibilities for them. I attempt to synthesise the themes of these memoirs with those of the academic literature in an exercise of triangulation.

Chapter three describes the methodological journey taken by the research in response to the needs of the project. It is presented in three acts which take their inspiration from Valerie Janesick’s (1994) chapter on the dance of qualitative research design. There are events which influence methodological direction. There is the theoretical justification for these developments and there is reflection on the process and its effects on the research as a whole and its direction. By way of illustration, I have included diagrams devised during and after the process to try to make sense of events for myself. Excerpts from research diaries and reflexive commentary are included with the aim of providing transparency for the reader, allowing them to see the inescapable relationship between researcher and research (Ellis, 1991).

In act one, the difficult recruitment process which ended in a set of circumstances more akin to conscription or a commissioning is described. The original proposed research design proved unworkable for potential participants, despite the stipulation that this was only intended to be a preliminary and temporary framework on which to base a co-designed project. A person searching for help with a problem arising from compulsive hoarding in their family was searching for a local source of help as I was searching for a local person interested in exploring their experience of compulsive hoarding. Through a mutual acquaintance (one among a great many both of us made along the

way), I was introduced to Tracy, who agreed eventually to be a co-researcher. We had begun to talk about a project together when it became evident that we were embarking on a potential research project.

Act two describes how, in working together with my co-researcher, Tracy, we employed a model similar to co-operative inquiry (Reason, 1994; Heron, 1996). A cycle of action and reflection was sparked by her plan to seek funding for a hoarding awareness and training project. I began this believing I would act as a passive chronicler of this experience but came to understand through negotiations around project design, that this would not be sufficient. An ethical imperative to help if possible took hold, both at the behest of Tracy and in response to something internal. I became more involved in planning the prospective intervention and supporting Tracy (with others) through the process. We met to discuss the project and the reasons for doing it and our conversations were recorded. Members of Tracy's family were involved in these at times, too.

Our bid for funding was unsuccessful but rather than becoming despondent we took time to take stock and in act three I describe the process of analysis we undertook in this reflective period. Initially sending the transcripts of our reflective conversations to Tracy for her examination, we met and conducted a free-association exercise (Hollway and Jefferson, 2000) on a whiteboard. I used the results of this to guide me in identifying stories for a dialogical narrative analysis I conducted later.

Chapter four reports the narrative typology I developed through the analysis and examines how they interact with each other in the stories we shared. Ultimately, four types are offered: the campaigners, who seek to raise public awareness of an unmet need; the carers, who experience a sense of entrapment and fear about their narrow role and its challenging responsibilities; the curators, who make aesthetic judgements about material objects and want to celebrate them; and the experts, who synthesise these narratives into a new story of appreciation for a hoarding family member whilst also holding some worry about her.

In chapter five I discuss the implications of our discoveries about the power of narratives in understanding Tracy's mum's hoarding behaviour and how the increased resources for re-storying this experience allowed for a new way of engaging with it. This is not to suggest that there is an answer to hoarding or responses to hoarding here. This new story is offered as a resource for others struggling with similar problems in the hopes that they will find resonance within it. The resolution offered is more of an acceptance and a perspectival change. The hoarding is still a feature of Tracy's life but does not define her or her mum.

Chapter 6 describes and explores what happened at this point which normally would mark the end of a project but for me did not. Why had I continued the research project with Tracy after the original CCG funding bid had failed? It transpired that I had unfinished business. That business related to wider ideas and problems arising from the experience of researching a new mental health diagnosis and being a registered mental health nurse; a part of the “system”. My reaction to this growing revelation led to further development in the methodology with a greater emphasis on the effects of the research on me and me on the research, moving beyond the reflexivity of earlier chapters to an awareness of the need to write autoethnographically. This creates new ethical issues and demands I confront some things which I have felt for a long time but which have gone unsaid. These ethical developments are discussed at the end of this chapter.

Chapter 7 attempts to find a resolution to this dilemma and effectively leads me to the same place Tracy and I were led to in chapter five. Tolerance of uncertainty: As a person in transition (when is a person ever not in transition) from psychosocial practitioner to academic, I question what my research meant for me and how I could maintain the focus and message of my practice as an educator of mental health nurses. I was rapidly coming to the conclusion that this was a position fraught with difficulty, given the demands of the NMC and provider services which seem so different to the expectations and hopes I had for promoting a critical stance to medicalisation in my students (one which I believe many mental health nurses hold). I had been keeping this to myself, or trying to express it somehow in my work with Tracy but what I needed to do was tell the story. I believe it will resonate as I have found evidence of others struggling with similar problems in mental health nurse education. This has given me heart and offered me the resources to tell myself about myself as a researcher and academic.

Style of the text

Barone (2018) identifies the purpose of a piece of writing as signified by its label – fiction or nonfiction. As he and Laurel Richardson (1990) have both observed, these labels are in fact not as distinct as they might appear and both employ a performative function. The purpose of this piece of writing is for the award of a doctorate. There are conventions to be followed. Requirements to be met. People have employed numerous different ways to achieve this but the vast majority have followed a particular and prescribed format for reporting scientific experimentation. As there was no such

experimentation involved in this enterprise I hope the slight deviation will be forgiven and welcomed.

I am not trying to claim to be some great innovator here. People have undertaken creative doctoral writing in the field of nursing before now (Short et al, 2013; Short, 2010; Turner, 2012). Barone (2018) identifies the development of scientific writing as distinct from creative writing developed in the 17th century as a way of distinguishing fact from fiction. He relates that after Eisner (Barone and Eisner, 2012) in particular, academics were more interested in experimenting with evocative styles of writing. Latterly, Jones (2014) has called for a “neo-emotivism” deliberately engaging audiences of academic outputs in an emotional way in order to effect change. In an age of emotional arguments about whether emotion or evidence is the most important or convincing, bringing together the evocative and the analytic would perhaps offer the best way of promoting engagement and impact. Whilst this thesis is a very modest step in this direction, I hope it marks the beginning of a developing style for me.

Our influences in writing style are not limited to the author guidelines for whatever journal we fancy, anyway. As I have mentioned below, I have a strong liking for certain authors and their influence is inescapable. Striking a balance between requirements for certain formatting standards whilst retaining the essence of the writing has been difficult and the subject of much discussion. Many of the above sources of inspiration were also sources of guidance in this respect. This text is messy. This is intentional. The person writing it is messy. The subject matter is messy and the research process was messy. Messy texts have been acknowledged as effective in engaging readers in complex academic arguments and ideas. Marcus (1994) suggests:

“once we know, or analytically fix by naming, that we are writing about violence, migration, the body, memory or whatever, we have already circumscribed the space and dimensions of the object of study...the object of study always exceeds its analytic circumscription...there remains the surplus of difference beyond, and perhaps because of, our circumscription.” (p.567)

The term “hoarder”, as discussed elsewhere in this thesis, has been identified by some people as an offensive one. The term “hoarding disorder”, as discussed below, is at least for me, a highly contentious one. However, attempts to produce a suitable alternative for the former have not progressed far and in lieu of a better signifier, I have let it stand where it feels necessary, with a slight disclaimer that I see no benefit to calling people such .this text hopefully makes the case for turning away from such attempts to categorise people by their alleged non-conformity to social norms.

By uttering or writing “hoarding” a perimeter is erected in the mind of the reader and the writer. For a long time, I struggled with other ways of talking about “people who have a lot of possessions in their home” (this is as loaded as any other phrase in some respects) or “people with hoarding tendencies” (not mine – coined by a hoarding officer for a housing association). The purpose of the messy text is to allow the phenomenon as experienced to emerge in the writing, rather than reduce it to pre-defined shorthand which precludes much of what is experienced:

1. Confronting the remarkable space/time compression that defines the conditions of peoples and culture globally. How to contest this in relating local experience which is seen as not sufficient object for study
2. Wrestle with the loss of credible holism – “The territory that defines the object of study is mapped by the ethnographer who is within its landscape, moving and acting within it, rather than drawn from a transcendent, detached point.”
3. Messy texts are messy because they insist on open-endedness, an incompleteness, and an uncertainty about how to draw a text/analysis to a close. Such open-endedness often marks a concern with an ethics of dialogue and partial knowledge that a work is incomplete without critical, and differently positioned, responses to it by its (one hopes) varied readers.

(Marcus, 1994, p.567)

So, it’s about how it ends (openly), how it uses concepts (hesitantly) but this does not constitute a prescription for writing “messy”. Marcus (1994) sees texts like this as symptomatic of the struggle to represent experience using existing means. When in chapter three of this thesis, Arthur Frank’s (2012) ideas about endings and findings become apparent, it will be clear why this idea is so important. I have tried to reduce the number of headings in an attempt to undermine the apparent solidity of certain constructions.

I have used pictures and links to other materials within the text. Something I carried over from my interim viva report. Many autoethnographic accounts contain different media and in particular pictures (e.g. Short, 2013; Turner, 2012). In this text, these pictures are sometimes pictures of a process, sometimes emblematic of a concept or sometimes there to convey a sense of me. They also break up the text. The links, too are there as diversions, offering a place to let the mind wander. I hope they slow you down. I hope this gives an impression of how my mind works. And how this research project has worked at times. I also hope they are interesting.

Etherington (2004 p.84-85) talks about the efforts of Lather and Smithies (1997) to show parallel voices on a split page with a very mixed reaction (and not a favourable

one from participants). Etherington (ibid) has tried other methods such as different fonts and layouts. This chimes completely with my struggles to set out reflexive writing, chronology and methodological development. Throughout this thesis, the narrative is in Ariel 11, as required by the institution, with journal entries in italics. Transcript excerpts are in Times New Roman as they arrived from the transcription service.

In describing a farewell message recorded by one participant in an autoethnographic writing class, Etherington (2004) notes

“...it lacks the full power of hearing Mel’s voice, her inflections and pauses, the lilt of her musical accent and the fast pace of her speech. The written words are not everything.” (p.137)

This is how I feel about our transcripts which are seen as “data” derived from conversations I guess, but to me are also a partial record of a performance (Denzin, 2003; Zeeman et al, 2014). Like a photograph of a play, or a book review, the emotive components are somehow diluted. And my writing this is doing the same to those texts. However, the method of analysis demands that the analysis is ongoing and is added to by each and every reader of the text (Frank, 2010; 2012), each reader will make of it what they will as they deconstruct this deconstruction (Derrida, 1976)

Etherington’s (2004) student describes personal growth and discovery with a compulsion to look deeper within herself in her research. She asks “How did I get where I am today?” (p.138). For me, it is the search for a personal identity called into question by experience which provides the common ground, the drive to look within, backwards and forwards and across to the other. See below from Ellis and Bochner (2000):

“As they zoom backward and forward, inward and outward, distinctions between the personal and the cultural become blurred, sometimes beyond distinct recognition. Usually written in the first-person voice, autoethnographic texts appear in a variety of forms – short stories, poetry, fiction, novels, photographic essays, personal essays, journals, fragmented and layered writing, and social science prose. In these texts, concrete action, dialogue, emotion, embodiment, spirituality and self-consciousness is featured, appearing as relational and institutional stories affected by our history, social structure, and culture, which themselves are dialectically revealed *through action, feeling, thought and language.*” (p.739)

It might seem to some that this sounds like I am describing two separate pieces of work: a thesis and a piece of autoethnographic work about completing it. But this work requires both of these elements because it is about the ability of stories and possibility

to transform individuals' self-perception. It seems disingenuous to offer the thesis as a report in isolation of the effects it had. It is also an essential development in the plot of the story that I gained a position in academia during the course of this thesis which changed my accessible resources for storytelling and story hearing (Frank, 2012). As I continue to write this thesis to its conclusion, I start to see the expanded possibilities offered by this increased repository of materials. The possibility for a richer, fuller story. Not a scientific report nor a literary work of art (Ellis et al, 2011). A crafted text.

Situation of self – me before thesis (TBBT)

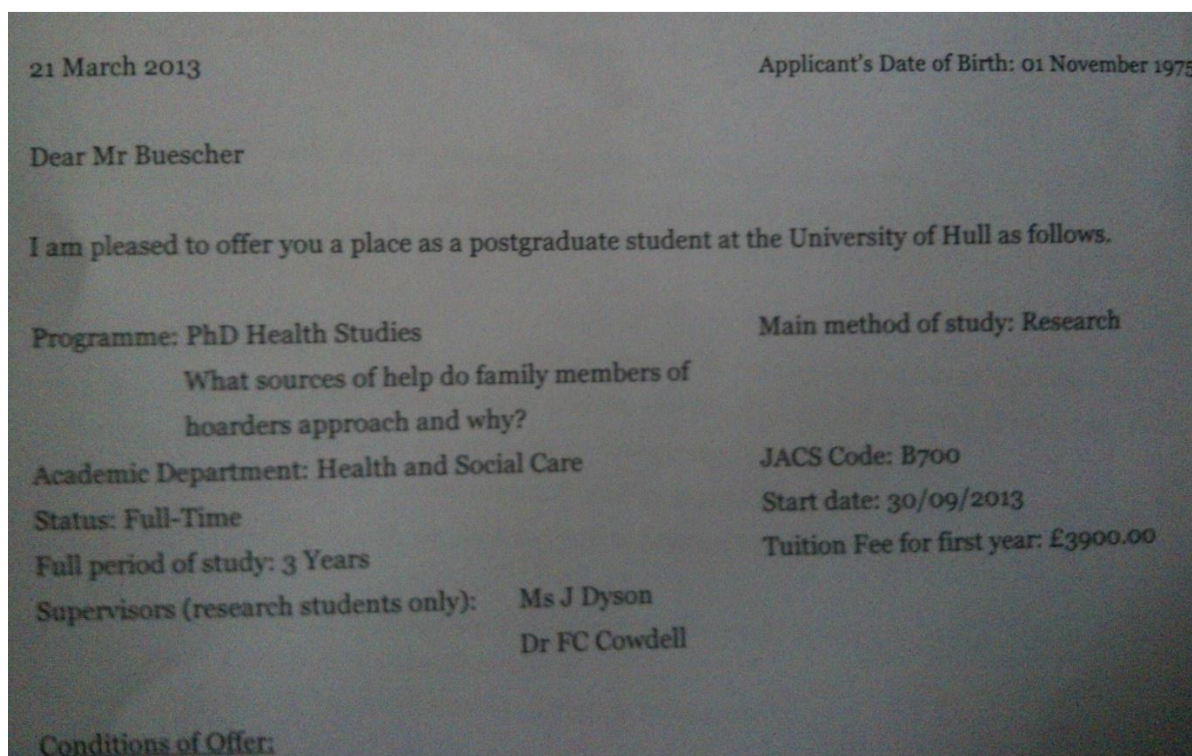


Figure 2 - Acceptance letter for a PhD in Health studies, 2013

This section is here to provide readers with an account of how I came to be a PhD student and some of the events and encounters which have shaped my approach, if that doesn't sound too pompous for an early career researcher. In relation to later developments in the research, I felt that the autoethnographic aspect of the work needed to be established early on to provide continuity and provide the sense of a journey taken within a journey.

Many people in my field who undertake a doctorate do so after a long period of clinical service and a long academic tenure (at my university, in my Faculty, at least). At this point, they may well have formed a strong sense of their own clinical values and academic position. In my case, I came to this straight off the back of an undergraduate degree completed in my mid-thirties after a string of unsatisfactory employments. I saw a way to make good out of a redundancy and it culminated in a scholarship. I had formed ideas about the world and my values but in terms of clinical and academic development, I had not made connections. Consequently, I have been finding my place and myself whilst completing this work. This has a significant bearing on the resulting thesis. The idea of the constructed self is one which Holloway and Freshwater (2007) identify as essential to nursing and nursing research. They cite Gergen and Gergen (1987) in suggesting that the constructed self is both stable and changing. In the

construction of this text, I have tried to reflect this idea as it applies to my co-researcher and me through the exploration of narrative resources (Frank, 2012).

At the end of the literature review I made a brief diary entry which recorded my dismay and even anger at the approach taken to the phenomenon of hoarding (this can be seen at the end of chapter two on page ninety). Hoarding disorder, too, is a social construction and, I believe, an unhelpful one. The problematizing and in particular the medicalisation of something which has its roots in the very culture we inhabit. An expression of grief, loss, loneliness and wanting to belong, worry about uncertainty and attempts to prepare for whatever may befall us. The papers I was looking at seemed to point to the individual as being at fault in some way, or to families as accomplices in their accommodation of this deviant behaviour. This began a journey of self-examination in relation to my professional role and the research I was embarking upon. I don't see this phenomenon as a manifestation of some human deficit. Nor do I see psychosis or depression in this way. Furthermore, I have never seen families as needing to be set against their relatives as a means to help them.

The influence of Social Constructionism can be traced throughout this project. When we look at the interpretation of its influence on research, we can see how narrative research, action research and collaborative research all have attracted the interest of Gergen (1999), who has also explored performative social science (Gergen and Gergen, 2012). The challenge that this mode of thought poses to established forms of power and knowledge is what first attracted me to it. I say it as if there were a tangible thing called social constructionism but it's pretty hard to pin down. More of a mindset than a manual. In the mix are Foucault, Kuhn and Derrida. Zeeman, Aranda and Grant (2014) argue that constructionism aims to take up a position of neutrality, however, I find some evidence in Gergen that this is not the case when it comes to mental health (e.g. Gergen and Warhus, 2001; Gergen, 2014).

In this text you will also see theoretical influences from narrative research (Arthur Frank and Carl Leggo and Laurel Richardson), autoethnography (Carolyn Ellis and Alec Grant and Kim Etherington), performative social science (Norman Denzin and Kip Jones) and collaborative approaches (John Heron and Christopher Reason), all of which share constructionist roots. Other influences are those artists who I admire such as the music of Captain Beefheart and the Magic Band, the films of Werner Herzog and the storytelling of Kurt Vonnegut, Neil Gaiman and Geoff Johns. This hopefully gives you a sense of my aesthetic sensibilities. A reflexive footnote of sorts. After the suggestion of Arthur Frank, that we must read more to become better narrative analysts, I believe it is worth noting the other sources of influence that affect this text you are reading now.

Stories. I am writing about stories. Here are some of mine.

It was 1998 but the cracks had become significant late 1997. I was living in Aberdeen on a diet of cannabis and Pernod. I had stopped going outside. My job at Spar was doomed and so was the likelihood of my completing my degree in theology. I had spent less and less time out of the flat and then out of bed. I had clipped pictures from newspapers and stuck them all over the walls of the room. Hundreds of them. They all pulled for my attention but there was a part of me which sought to produce a balanced account of world events in the images. I had attached a long piece of green fabric to the lampshade which hung to the floor where it was sort of gathered together, forming an enormous chili and offering quite a dim light. There were a lot of books accumulating in the room. Religious, philosophical and literary texts. Nothing frivolous. The idea kept popping into my mind that I was destined to be an anachronism. That is pretty much true for everyone at points during their life but this was so overwhelming in its presence, I couldn't find the means to counter it. At this point, I would smoke some more weed.

If I went out (to see friends, for instance) I would often fall asleep from excess in their living room (this pattern of behaviour carried on for some years). On occasion, I would arrange to go out and then shy away at the last minute. I was usually forgiven with a light finger-wagging but any chance of romance or belonging was damaged by this reliable unreliability, I believed. It didn't occur to me to test this hypothesis. In the end even my wonderful friends could not maintain my sense of purpose and I ran away – from whence I came. Not exactly.

I came from a home bounded by simple loving understanding. We understood that Jesus was Lord and love of him came first always. We understood that we were loved by him who died to save us from the consequences of our sins and accept the punishment of his father on our behalf. This required us to be eternally gratefully and observant of rules which were enshrined in and derived from scripture to make us acceptable to God. God was in charge. There was a devil and a hell but these could be overcome by sticking with God and following the rules. There were right things and wrong things and the whys and wherefores of these were not really our concern. God knew what he was doing and if something looked fishy (starving millions, sectarian warfare – it was the eighties) we didn't know as much as he did and he had a reason for it. He was all-powerful and omniscient and we were taking up a seriously generous offer he had made to be on his team and have everlasting life in heaven (which I still can't picture – always struggled with that).

There were lots of benefits to the rules of God. For one thing, they were about being good. And that is good. Being good to each other is good. And you always knew where you were with things. There was no moral ambiguity. Things were yes or no. Do or don't.

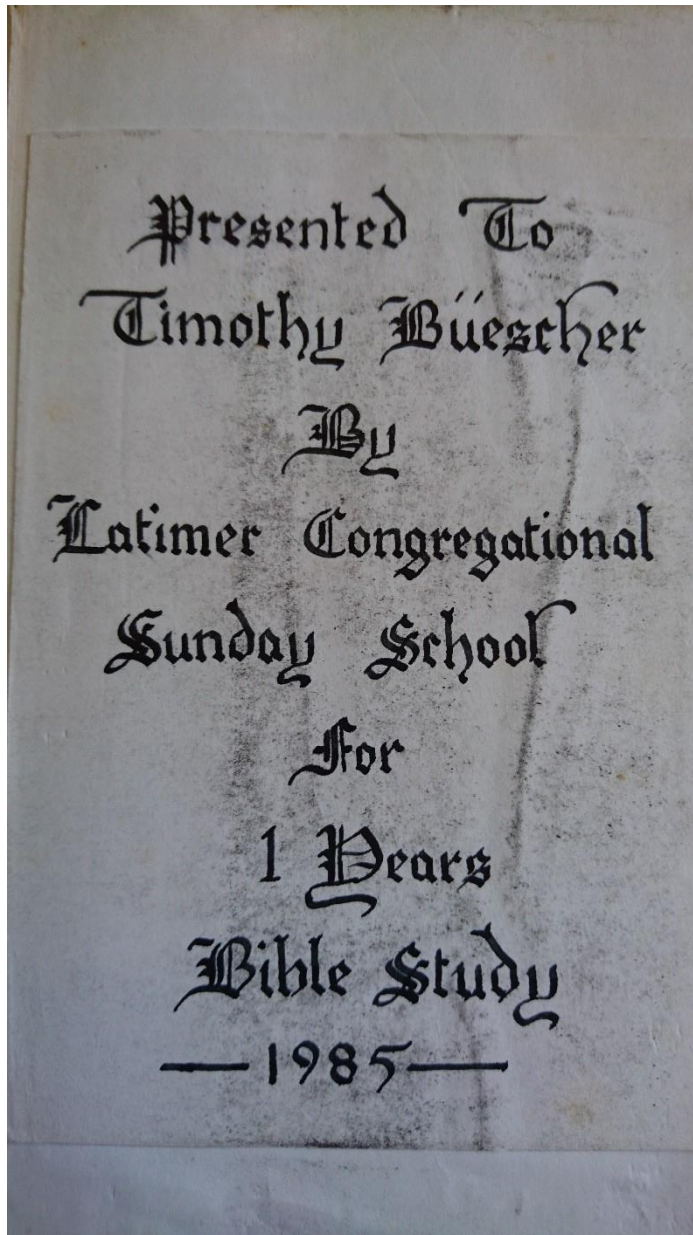


Figure 3 - Early literary influence and sense of self

In 1998 this wasn't the case for me. I knew by the time I left for Aberdeen in 1994 that things just weren't like that. I had found things I liked to do which were not things which were liked by God. We were falling out. Things came to a head in 1995 when I attended a sermon at Easter which I found nothing short of offensive. I did not hold the belief that people of other faiths would be condemned to hell at the last judgement whilst us good ones (the ones who got it right) were taken up to heaven in a blaze of glory (I had found this hard to swallow since I was about 12). In a late-night conversation in a house in Aberdeen, I was continuing to hold on to the last vestiges of faith (despite my dislike of many of the views I came across back in my childhood

second home I still had this) when a friend said something. I don't remember what it was and if I asked him now I doubt he would remember that conversation with any degree of significance. Nobody else was there to hear it as it was one of our late-night jabbering (I miss those). Anyway, something was said which allowed or clicked or persuaded or permitted or verified or clarified or crystallised or emboldened. And I was done with it. No more of that God business. I was out of it and I knew I wasn't going back.

What I hadn't reckoned with was that the God bit would be out of me. And the rules, which I had bent for so long, were not there. I was rootless and there was no Jesus in my heart. Who was I? Where did I get my guidance? Previous sources of inspiration were almost exclusively dead rock stars from the 1960s. But these ideas had been held somewhat in check by Jesus. Now there was no check. But I wasn't Jim Morrison or Keith Moon. They were talented and popular. I was a fuck up. And the forgiving God who I used to turn to wasn't there. Wasn't real. And that's about when I lost my shit, I think. So, I had a few adventures. I was looking for answers – looking for me, I think- this new one who didn't need that old God bit. Anyway, I made a lot of wrong turns and ended up in the pickle described above. I left Aberdeen and severed all ties. I avoided people on the phone. I missed a wedding. I disappeared up my own arse.

I found myself back in my parents' house but that is what it was and how it felt. I was not the me that was expected in that house. The rules now seemed incomprehensible and unnecessary. I was unreasonable, unstable and clearly off my face regularly. I was unsure about everything from my sexuality to my fashion preferences. There were just too many choices on offer. I had a lot of jobs, tried a few courses, and spent a lot of time in the pub. I couldn't hack it. Who the hell was I? What was I?

Why did I become a mental health worker?

Accident. Redundancy. Witnessing my friend's supervised and organised decline. My own experiences. Curiosity. Opportunity. The chip on my shoulder. I came into this line of work through my struggles to keep my shit together. I lost it ("what, again?"). I had had enough and I threw the cakes across the restaurant and went to the office in tears. I knew I was leaving. I had only the previous week or so spoken out at a regional meeting about the disappointment I felt with the lack of ambition and creativity at my new workplace and the frustration I felt at not being listened to. The reception I got suggested that this might not be an appropriate forum for these comments. In Plymouth, I had been going places. Now I felt like I was an inconvenience. The company had found me a place, were funding my development too, but I had a feeling. Like I was being humoured. This feeling got worse and I had to get out.

I took a new job with the local mental health trust as a housekeeper. I worked in my town and I saw people I knew. Once, I bumped into someone in town who told me that her son was in the unit and he would like a visitor. I already knew (small town. I didn't work there anymore but gossip keeps a market town going and no-one went to "cracker factory" without a report being issued from the local intelligence bureau). We didn't have a very friendly history at all and I couldn't envisage any way of having a friendly chat with him. I remembered him sneering at me when he threw half a brick at my

head after school one time. How was my presence going to help? I gave it a miss. Fast forward a few weeks and he's on the news. The chance had passed.

I don't think this was in my mind when I went to see about secondment into nurse education. I just saw the chance to get a degree after all these years. To make up for something in that sense. But once I got out and saw a bit more of what was going on in practice. Once I got a flavour for how people were living and what futures were expected for them, I think those other events took on more significance. Especially when I got to working with young people and met others who had had similar experiences to me and were being prescribed stuff and had all these people in their lives to "help" in a very prescribed sense. It had taken me over a decade, some very patient and caring people and a fair amount of good luck to get myself into some form of serviceable shape and start making decisions about my life with some sense of purpose again, rather than just survival.

I brought this experience into my practice working with people who were having it rough. Time. I couldn't offer them ten years and more of patient attendance through all their stumblings but I could tap into my knowledge of my own journey. Mental health nurses have reference to their own experience in being present with those with whom they work (Grant, 2016). Alec Grant and others have suggested that this is the only worthwhile method of research into mental health nursing. I brought this with me into research. Because it is a part of my practice and a part of my mind-set. Journeying is what we are doing. Together. And that is what happened here. Inevitably. It looks serendipitous at first glance but actually, no. Inevitable.

What does all this have to do with research, you ask. Well, that journey in search of me continues. There were many other waypoints and chances, time and much unconditional love through some incredible difficulty and meanness. Through an amazing relationship, I got my shit together again. Through an apparent misfortune, I got another chance at studying. I was older, wiser and we had a mortgage. So, I did a good job of it and it got me to this point – writing a thesis. This thesis is about journeying. It is about looking for answers to questions of selfhood whilst holding your own (Frank, 2010), beset by anxieties (Hollway and Jefferson, 2000). It describes scenes from the window of a moving train which left Aberdeen 20 years ago and it tells of one fellow traveller in particular. Other people are glimpsed as the train passes but this one got on for a while. She too was struggling with events that had raised questions about identity. Glimpsed as we passed, her mother seemed to have similar themes buzzing around her. A later conversation with my fellow-traveller's brother seemed to confirm this. Some of the things we talked about diminished for the talking.

This was true for both of us. This story will hopefully tell how sharing stories and honesty can be a valuable part of the relationship between people looking for answers.

Chapter 1 A hoarding (hi)story – some background

Foreword

The beginnings of my involvement with research into hoarding were as an undergraduate following a family discussion in front of the television about a new series which was airing and how this bore some familiarity with issues we were grappling with as a family at the time. Mills (1959) states that research proceeds from personal interest and in this case, something in me responded to this topic

A diary entry from 2014/15 reflects on this family situation:

A member of my family has a problem with organising and saving things. She is impulsive and stubborn in relation to these tendencies in turn. This problem severely affects the quality of life of someone I love. It has threatened to invade our life at times and has produced turbulence in familial relationships. (I am unused to the level of encryption and find it difficult).

I have seen this behaviour creep in with other family members but not to this extent. It appears to be inherited in some way (behavioural or genetic). It frustrates most of us at one time or another and has put serious strain on family. It does not seem to be managed easily or made to go away is frustrating and embarrassing but it is also a fact. We must learn how to live with it without it becoming as monstrous as it was before.

“Here, more than elsewhere, I saw multitudes
to every side of me; their howls were loud
while, wheeling weights, they used their chests
to push.

They struck against each other; at that point,
each turned around and, wheeling back those
weights,
cried out: Why do you hoard? Why do you
squander?”

(Aligheri, D. (tr. Mandelbaum) 2014)

In 1993, Frost and Gross published a paper that was to mark the beginning of the work which would develop into cognitive behaviour therapy (CBT) formulation (Frost and Hartl, 1996) and treatment (Frost and Steketee, 1999) of the phenomenon of hoarding. This culminated in the diagnosis of hoarding disorder in the fifth edition of the diagnostic and statistical manual (DSM-5) of the American psychiatric association (APA, 2013) recognizing it as a distinct mental disorder. At the same time, another text

on the same subject which encapsulated many of the traits later described by further academic studies was published. *The Woman Who Saved Things* (1993) by Phyllis Krasilovsky is an illustrated children's book describing the habits of a woman who compulsively acquires, struggles to discard and worries that her family will not be able to stay in her house with her when they come to visit. The family find a way to appreciate their mother/grandmother and her eye for useful things whilst helping her to manage her situation. The story is told in a very even-handed way, neither apportioning blame nor wallowing in pity. It does not propose a solution to the woman's hoarding as it does not frame it as a crippling problem, rather as something which requires family support but which the woman enjoys. The family begrudge but eventually come to value this tendency to collect things as they re-appraise their family member for her creativity and resourcefulness. This may be a unique text in the warmth it shows towards its protagonist and the audience for which it is written, but it may also be ahead of its time in proposing a collaborative family approach based on acceptance and patience. Or it may be just that this bore a resemblance to our family response, which appeared to have been successful for improving everyone's experience and relationships.

Background

The current formulation of hoarding disorder (APA, 2013) has grown out of ideas of hoarding as illness which has retrospectively identified a development in understanding, pulling in theories and accounts from many avenues. The cross-pollination of people and ideas between clinical work and media representations necessitates the inclusion of a diverse selection of strands to produce the whole story of the development of the hoarding disorder diagnosis as reported (from a psychology standpoint) by Penzel (2014) and (from a sociological/queer theory standpoint) Herring (2014). Orr et al (2017) have offered an alternative reading of the development of knowledge about compulsive hoarding from a social care perspective. The following is an attempt to bring together the various strands in a continuous history in the hope that the different possible readings of these events and developments can be seen.

The popular narrative

In Britain and other Western cultures people are familiar with the idea of the hoarder or “pack rat”, and in the cultural language of Japan, the term “Gomi yashiki” – garbage houses - is used to refer to hoarded houses (Frost and Steketee, 2011), which are seen to be an increasing problem (Rufus, 2014). In Russia and other places, there is a recognisable “hoarder” figure (Frost and Steketee, 2014). References to hoarding or behaviour which could be described as hoarding in individuals can be found in the literature of Dante (2014, tr. Mandelbaum), Dickens (1861) and Gogol (1842 tr. Rayfield, 2008) but there is a current increase in new fiction and real-life accounts of people who have lived with or “through” hoarding (Riggle, 2013; Sholl, 2011). These newer accounts draw on a familiar narrative which could be seen as deriving from Gogol’s character Plyushkin, who picks up at random any piece of detritus that catches his eye and adds it to the mound which sits in his house and is arguably the first incidence of hoarding being depicted as debilitating (Penzel, 2014).

“What, one might wonder, did Pliuhskin want with such a mountain of manufactured goods of this kind? A whole lifetime would not suffice to use them, even with two estates the size of his: but this was, to his mind, not nearly enough. Not satisfied by what he had, he would walk every day through the alleys of his village, looking under culverts, under planks across ditches, and dragging home and piling in the heap that Chichikov had seen in the corner of the room everything that he caught sight of: the sole of an old boot, a woman’s rag, an iron nail, a shard of pottery...Indoors, he would pick up off the floor anything he saw – a piece of sealing wax, a scrap of paper, a feather – and put it on the desk or on the windowsill. “

Plyushkin's family, property and land are decaying around him whilst he obsesses over trivialities. The explanation for this retreat into a world made up of worthless possessions is the loss of his wife and subsequently his children, something which sounds familiar when one has heard the stories of hoarders through the reports of clinicians (e.g. Kellett et al, 2010) or the media (for instance "The hoarder next door" (Twenty Twenty, 2012-14)).

The word "hoard" derives from old English and refers to a (usually secret) store or stock of something valuable, such as money (Oxford English Dictionaries, 2017). Hoards of treasure have been excavated by archaeological digs such as the caches of silver amassed and buried by Vikings and Picts found in various parts of Britain. This image of a hoard as a heap of riches can be found throughout ancient and medieval literature to *The Hobbit* (Tolkien, 1978) and present-day archaeology. In fact, the topic of the hoarding of international financial reserves has received much attention in the business literature (Aizenman and Lee, 2008), in addition to other valuable assets such as land (Overman, 2013). Hoarding commodities describes when an investor accumulates a large reserve of a particular commodity to reduce supply and force up the price, increasing the value of their own stock. These issues (in particular land hoarding) have received much political and press attention and the tone has been one of outrage in these reports (e.g. Dunn and Warnes, 2017).

Through the middle ages into the renaissance, the figure of the miser became common in the arts as a signifier for the sin of avarice, evolving into comic caricatures in the writing of Dickens and later in the popular television characters of Albert Steptoe and Rigsby. Perhaps a lingering moral judgement is being attached to people who hoard objects due to this portrayal of miserly and greedy characters in historical literature (Lepselter, 2011). An examination of some recent news and editorial items provides contemporary evidence of this in China (Beijing Review, 2007) and the United States (Kristof, 2013). The word "hoard" can be used directly as a term for something unhealthy in contrast to the more acceptable and even admirable notion of the "collection" in the current work of the team at King's College (Mataix-Cols et al., 2013; Nordsletten et al., 2013; Drury et al., 2014) but also in the popular press (Rider, 2012). Rider may or may not have applied the term correctly as defined by Mataix-cols et al. but its use in connection with valuable cars reflects the cultural shift in the understanding of what constitutes a hoard versus an orderly and presented collection where there previously was no apparent distinction. Herring (2013) illustrates an

important turning point here with the advent of “antiques”, although there is a hint that such a phenomenon existed in the nineteenth century in the form of “bibliomania”, the obsessive collecting of books (Penzel, 2014). Penzel offers this as an early example of a pathology but other reports suggest that to declare oneself a bibliomaniac was a term of pride amongst the well-to-do young men who collected these expensive items (Berry, 2017). This is echoed in the reported “information hoarding” and newspaper saving in many well-reported cases such as Langley Collyer (Lidz, 2003) and Richard Wallace (Trumble, 2011), neither of whom were regarded as “collectors”. The perhaps comparable phenomenon of “digital hoarding” (e.g. emails, photos.) has been commented on in the popular and business media (Beck, 2012). Perhaps the issue of comparative value between books and newspapers (or emails) is being used as a criteria for discernment.

Lidz (2003) reports that “Human packrats” was a term used by one reporter to describe the Collyer brothers (the first hoarding case to appear in mass media, in 1947). A pack rat is a member of the rodent genus *Neotoma* which exhibits the behaviour of collecting items to build its nest or “middens” from a large radius around it and cements these items with urine which crystallises as it dries. The pack rat also is attracted to shiny objects and stores these and food in its midden. The term is commonly used in the US to describe people who hold on to a lot of possessions. In Germany, the term “messies” has been a popular term of reference (Mueller et al, 2009). It is easy to see why Steketee and Frost (2007) have reported the dislike of being described in these terms by many people who receive treatment from them, instead preferring to talk about “saving” or “collecting” rather than “hoarding”. “Cleanliness is next to Godliness” perhaps still infiltrates the imaginations of many people, giving the phenomenon a moral taint (Herring, 2013). The suggestion from the above description is that there is attendant squalor in most cases of the hoarding of possessions but these have been found to be separate problems (Snowdon et al, 2012). Diogenes or Plyushkin (or Havisham) syndrome (now more commonly referred to as severe domestic squalor), often described in relation to dementia, may not necessarily be a discrete diagnosis but Norberg and Snowdon (2014) suggest that there is a significant area of overlap between severe domestic squalor and hoarding. Occurrence of the two problems together accounts for one third of hoarding cases and one third of squalor cases (Norberg and Snowdon, 2014).

The notion of hoarding as illness rather than eccentricity may be said to begin with William James (1893), claims Penzel (2014). Freud’s 1908 treatise on the anal character further suggests a personality orientation, linking the “anal triad” of orderliness, parsimony (defined by Oxford dictionary online (2012) as “an extreme

unwillingness to part with money or use resources”) and obstinacy with an inability to mature as an individual past the infant stage of faecal retention. Jones (1913) added the suggestion that parsimony may be expressed in the hoarding of possessions. Fromm (1990) describes hoarding as marked by stubbornness, miserliness and a lack of imagination with a tendency to see all as possessions or potential possessions, including people. In addition to this, a tendency towards perfectionism to the point of destruction is described.

The first specific incidence of hoarding individuals coming to the attention of mass media was the case of Homer and Langley Collyer of New York, reported in the New York press in 1947 (the same year as the publication of Fromm’s *Man for Himself*). In fact, even before the events described below, Langley had featured in a collection of journalistic essays as part of a parade of eccentrics (Erskine, 1953). The elderly brothers were found dead in the huge brownstone building which had been their family home and which they had filled, after the deaths of their parents, with all manner of objects, including an x-ray machine and a grand piano. The weight of material removed from the home is said to be over 140 tons. Langley had suffered heart failure and died amongst the clutter whilst Homer, blind, crippled and dependent on Langley for his survival, had then starved to death. The attention of the press and public was drawn by the grand family origins of the brothers, the tragic circumstances of their deaths and the sheer scale of the hoarding (Lidz, 2003). Lidz (2003) relates from contemporary records that crowds of up to 2000 people gathered to watch the building being emptied and that it was sixteen days after the body of Homer was found that workers were able to find the body Langley. Whilst the interdisciplinary working of the fire, police, sanitation and housing workers represents the first public record of this collaborative approach to dealing with a hoarding problem, the fact that Homer was buried in a sealed coffin due to fears around contamination demonstrates the level of suspicion and mystery surrounding hoarding at that time. This idea of contamination, as mentioned above, appears to linger in the public imagination. The story has been re-imagined as a novel (Doctorow, 2009) and a play (Greenberg, 2003), resurfacing in contemporary press articles in the wake of the increasing interest in hoarding (McQueeney, 2012). According to Frost and Steketee (2011) the New York fire department still use the term a “Collyer House” to refer to a hoarded property.

At the time of these events, theories put forth to explain the Collyers’ behaviour included catholic recriminations about greed, Marxist warnings about materialistic society, and psychoanalytic theories about regressive personalities. Lidz (2003) suggests that the loss of love may be to blame for Langley’s retreat and saving behaviour. This may seem a somewhat romantic notion from a man with no clinical

background but as can be seen from case studies and accounts of those working with people who hoard, loss may play a role in the development or escalation of hoarding (e.g. Villaverde et al, 2017; Paxton, 2011). The story bears this detailed telling here because it forms the beginning of the widely available resources for stories about hoarding. It marks for many people the first occasion they had heard such a tale and it forms a means to re-examine existing experiences “of this type”.

The award-winning documentary film *Grey gardens* (Maysles and Maysles, 1975) is referenced as a “resource” in some of the reference books on hoarding (e.g. Bratiosis et al, 2011). Whether the film shows an example of compulsive hoarding as described in the literature is debatable, as the picture appears to be more one of decline and neglect. In fact, in 1975, nobody would have had the narrative or clinical resources to describe what was on the screen as hoarding, but it would have perhaps have seemed similar to the Collyers case for those who were familiar with it, especially the “eccentric recluse” aspect of press reports. This strand is evident in the cases of Edmund Trebus (BBC, 1999) and Richard Wallace (Trumble, 2011) and other cases (Zig Zag Productions, 2007), which are reported with a degree of humanity and curiosity with a sense of seeking resolution for the people and their families. They give us the opportunity to see the positives of the lifestyle they have, as unpalatable as that may be to many people. Mr Trebus, the subject of two episodes of the BBC documentary series “A Life of Grime” (1999) (about public health workers), captured the interest of many people. In particular his interesting history, feisty character and the sad denouement of his story when he was taken to a residential home where he had almost nothing.

In the US, meanwhile, a different approach was developing to the presentation of the same problems on television. A format in which the problem was approached by a team of regular experts (a psychologist and professional cleaners) who gave interventions to the person and removed items from the home (Discovery Studios, 2010- present; Screaming Flea Productions 2009-13; Twenty Twenty Ltd., 2012). The scale of the problem was portrayed as almost competitive; a spectacle; and the successful resolution at the end of the treatment period was the important culmination of the programme.

The purpose of these shows has been called into question and an examination of the style of reporting adopted in the press around the now-frequent hoarding horror stories (often online stories and often taken from non-news sources) appears to confirm suspicions that this is a form of entertainment grounded in the misery of others in order to make the watcher/reader feel superior in some way. This recalls the morality message attached to hoarding in the form of the “miser” or as an aspect of

“uncleanliness”. In these series, we are made to feel sorry for, but also frequently frustrated with, the people with hoarding problems. The therapists, organisers and “extreme cleaners” are firmly established as the “good guys” coming to the rescue. Family members often portrayed as victims or reprimanded for not standing up to their relatives.

Recent public interest in “fixing” the hoarding “problem” is further demonstrated through the publication of self-help guides for the decluttering of your home and the organising of your life taking in advice from psychologists (Tolin et al, 2007a; Neziroglu, 2004; Zasio, 2012) and “organisers”. The number of books offering advice on decluttering and organising (in particular eBook editions) are too numerous to list here, running into the tens and possibly even hundreds and none of them published more than three or four years ago. In fact, there is a great deal of overlap between the professional and the entertainment/media aspects of hoarding in some quarters such as the output of Neziroglu, a psychologist who experienced living with a parent with hoarding behaviour and who is now an expert on the TV show “Hoarding: Buried Alive” (Discovery Studios, 2010) and the author of two self-help guides, one for hoarders (2004) and one for their families (Neziroglu and Donnelly, 2013). She has also contributed to the International Obsessive-Compulsive Disorder Foundation (IOCDF) website resource (Neziroglu et al, 2013).

Much of the momentum behind the recent increase in hoarding research and treatment development owes something to this gathering media attention focussed on it although as pointed out by psychologist Simon Rago (Robehmed, 2011), this also brings significant negative ideas about the problem by focussing on the most extreme cases and simplifying and shortening reports in order to fit the requirements of entertainment programming. Some documentary makers have taken different approaches.

Cynthia Lester (2008) filmed her own experience of trying to help her hoarder mother along with her brothers in order to evade the enforced eviction of her mother from her home. This film (*My Mother's Garden*) is one of two films made by the family members of hoarders, the other being Kris Britt's *Packrat* which currently has no distribution in this country. Lester's film describes the significant suffering experienced by all of the children growing up and shows the intense difficulty they experience in having to revisit the scene of their childhood distress but ultimately offers a hopeful message. Mike Hampton's 2009 independent short film *Possessed* shows four members of a peer support group for compulsive hoarders in their home environments apparently demonstrating a range of problems in which the relation to possessions is different in each case and the problem seemingly more emotionally painful. Problems range from

an obsessive collection of films to an obsessive buying of gadgets to what appears to be self-neglect occasioned by grief.

The relationship between the increased profile of the hoarding of possessions and the ever-increasing materialism of modern society was arguably first touched upon by Fromm in *To Have or To Be?* (1976) in which he distinguished between the “having” mode—defined by what one possesses of existence and the “being” mode which is defined by one’s experience. Furby (1978) described the need for control over one’s environment and take one’s identity from the things one possesses. Winnicott (2016) first established the theory of the transitional object (adopted by a developing infant in the process of becoming semi-independent from its mother as a defence against anxiety).

The bestselling book *Affluenza* (de Graaf et al, 2005) depicts overconsumption as a diseased cycle anxiety and isolation fed by seeking comfort in shopping and was published following two successful television documentaries on the subject (PBS, 2014). Originally finding its first public airing in 1984 in a New York Times article by Daniel Goleman, this idea of excess as disease was clearly introduced to the general public consciousness at this point, with *affluenza* entering the dictionary (Oxford University Press, 2014). Further books, most notably by Oliver James (2007; 2008), were published on the subject of how to deal with the problem. What makes this notable is how the conversation around over-consumption appears to have moved away from reducing buying towards orderly throwing-out. Denniss (2017) offers a distinction between consumerism (a culture based on buying) and materialism (a culture based on the love of things).

Lepselter (2013) has identified the trends underlying media portrayal of hoarding cases in such a way as to facilitate the medicalisation of hoarding in order to then develop treatments to produce normalised behaviour in the disordered individuals. The links between leading therapists in the field connected to the IOCDF and the US television shows mentioned above is hard to ignore. I comment further on this in chapter two. Eddy (2014) continues on this theme, looking at the way that in the wake of the financial crisis, individuals are held up as examples of unhealthy consumption on the TV show “Hoarders” due to their inability to discard “waste”. Boland (2012) examines this further, suggesting that media portrayals reflect a model of consumption in which the whole family is held responsible for responsible stewardship of possessions and the management of “waste”.

The medical narrative – hoarding disorder

Initial clinical studies into the distinct features of compulsive hoarding were carried out using samples recruited from a college campus (Frost and Gross, 1993; Frost and Hartl, 1996). Other studies into hoarding in specific conditions such as populations with anorexia (Frankenburg, 1984), dementia (Hwang et al., 1998), anxiety (Tolin et al, 2011), schizophrenia (Luchins et al., 1992), autism (Greenberg et al., 1990), post-traumatic stress disorder (Hartl et al, 2005), Gille de la Tourette's syndrome (Zhang et al, 2002) and brain injury (Eslinger and Damasio, 1985) have also been carried out. Older studies employed measures for Obsessive Compulsive Disorder (OCD) symptoms which included hoarding and/or definitions of hoarding which do not reflect current understanding of hoarding for example Yale Brief Obsessive-Compulsive Scale (Goodman et al, 1989). They therefore lack the definition of the structured clinical interview for hoarding disorder. Frost et al (2012b) state that they should no longer be used in the assessment of hoarding on these grounds. The World Health Organisation (WHO, 2016) describe OCD as marked by distressing and intrusive thoughts, images or urges (obsessions) and behaviours which are intended to reduce the distress caused by these (compulsions).

Frost and Steketee (2014) cite Iervolino et al (2009; UK), Mueller et al (2009; Germany), Timpano et al (2011; Germany) and Bulli (2014; Italy) as providing the most reliable attempts to describe prevalence due to their employment of up-to-date definitions of hoarding (although only the last two utilised a formal set of criteria for defining hoarding disorder). A range of 2-6% is produced when these studies are taken together, although there are still inconsistencies in the application of threshold within the instruments employed and use of different scales in any case. Furthermore, Grisham and Williams (2014) identify acknowledged problems with insight in cases of hoarding as potentially affecting results in studies using self-report scales (Iervolino, 2009; Mueller, 2009; and Bulli, 2014). Steketee and Frost (2014) suggest that psychopathological interviews conducted in the home environment provide the most accurate assessment of clinical severity. None of the studies offer evidence of visual confirmation of hoarding severity. Nordsletten et al (2013) employed clinician administered interviews conducted in respondents' homes as well as self-report measures and found a lower prevalence rate (1.5%) – still a higher rate than schizophrenia.

Hoarding behaviour is not bound by social circumstances it seems, with reports of hoarding occurring in equal measure in men and women across various ethnic backgrounds and economic circumstances (Tolin et al, 2008b). The Collyer brothers

themselves were from a particularly privileged background (Lidz, 2003) and Frost and Steketee (2011) give a very engaging account of another set of twin brothers who compulsively hoard luxurious objects to the extent that they rent extra hotel suites for their possessions. They also, along with Paxton (2011), offer examples from a range of different social and economic backgrounds.

Suggestions have been made that the tendency to hoard may be the result of an early life of deprivation (Samuels et al, 2008) however, Greenberg (1987) produced evidence to the contrary which has been added to by numerous studies since (e.g. Landau et al, 2011). Hartl et al (2005), Cromer et al (2007) and Tolin et al (2010d) demonstrated a possible link between trauma and hoarding, suggesting that experience of violence or loss provokes or aggravates the hoarding tendency. Iervolino (2009; 2011) conducted twin studies which indicate that 50% of the hoarding variance may be genetically derived. Family studies (e.g. Samuels et al, 2007) have demonstrated significant levels of hoarding behaviour in first degree relatives of people who hoard possessions. Steketee et al (2015) interviewed 443 participants regarding familial hoarding behaviour along with hoarding clinical scales and found that hoarding is more common in people with a first-degree relative who hoards. They also found that in their hoarding disorder participants (there were also control and OCD-diagnosed participants), there was no demographic indicator regards gender.

Compulsive hoarding has been cited as beginning at around age 11-15 (Grisham et al, 2006) but developing over the life course of an individual. It has been suggested that adverse childhood incidents (Samuels, 2008) and traumatic life events (Landau et al, 2011) can provoke a hoarding response as can the loss of a regulatory influence such as a partner or children (Tolin et al, 2010a). It has been suggested that as average lifespan has increased, so has the likelihood of more people accumulating more possessions.

In 2008, Pertusa et al published evidence to suggest that compulsive hoarding was not necessarily a symptom of OCD or obsessive-compulsive personality disorder (defined by the APA (2017) as “a pattern of pre-occupation with orderliness perfectionism and control” marked by inflexibility), as had previously been believed. This prepared the ground for the further publication by Mataix-Cols et al (2010) making the case for the new diagnosis of hoarding disorder as an obsessive-compulsive spectrum disorder. Following the London open field trial for hoarding disorder (Mataix-cols et al, 2013), DSM-5 (APA, 2013) was published, including the hoarding disorder diagnosis which differs little from Frost and Hartl’s original 1996 model (see figure 4 on page 39). The hoarder compulsively acquires and cannot discard items which are of little perceived value to the observer to the degree that their living space is unusable and even

dangerous, causing distress or impairment (APA, 2013). This hoarding behaviour must not be attributable to any other clinical cause (such as those suggested by Pertusa and Fonseca, 2014).

Where diagnosis is based on the World Health Organisation International Classification of Diseases tenth edition (ICD-10), compulsive hoarding is only found listed as a possible symptom of OCD, although recent research calls this singular listing into question (Pertusa et al, 2008; Mataix-Cols et al, 2010) and ICD-11 looks set to include hoarding as a compulsive spectrum condition (WHO, 2017). Furthermore, the diagnosis of obsessive-compulsive personality disorder under which hoarding is also mentioned in DSM is not listed in ICD. It's equivalent, anankastic personality disorder, does not feature hoarding as a symptom. A search of the current (2016) version of ICD-10 online revealed no results for the term "hoarding". Nevertheless, the same problems of compulsive hoarding arise in populations where mental disorders are classified and treated according to ICD-10.

Whilst there is now diagnostic clarification as to what constitutes hoarding disorder (see figure 4) it should be noted that research into this area using recruits who fit this set of criteria is in its infancy (Steketee and Frost, 2014b) and all of the various scales and interventions developed for working with this disorder were developed before the diagnosis itself. Efforts are underway to demonstrate the validity of these older scales (Tolin et al, 2018; Saxena et al, 2015). This leaves me with a difficult task here regards the use of language. Whilst talking about hoarding disorder, the literature often refers back to research written before this terminology was operationalised and this means that often the thing referred to is compulsive hoarding which is interpreted as fitting the 1996 description rather than a specifically defined hoarding disorder as evidenced by Structured Clinical Interview for DSM-5 (SCID). In the following discussion, this will inevitably have a bearing and where possible, unless there is a specific application relating to the diagnosis, I will use the term compulsive hoarding to remind me and readers that what we are writing and reading about is not a discovered truth but a social construction arrived at by committee and consensus.

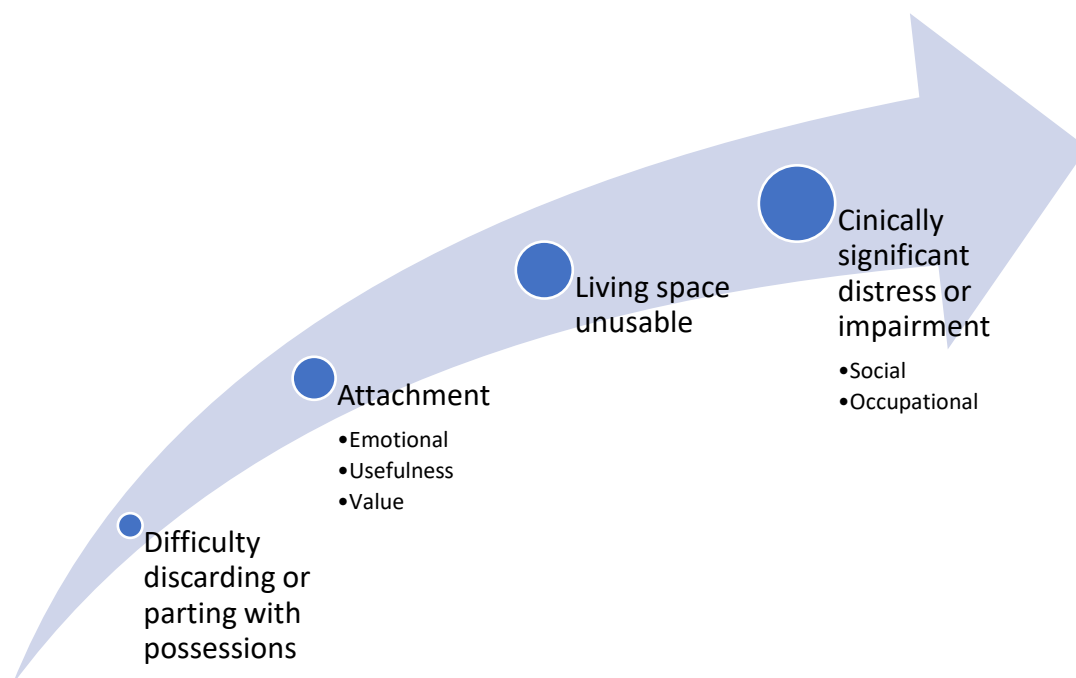


Figure 4 – Illustration of clinical features of hoarding disorder derived from Frost and Hartl’s (1996) model as found in DSM-5

1 – Acquisition

Frost et al (2011b) and Samuels et al (2007) have demonstrated a highly significant link (up to 80%) between hoarding and a further secondary impulse control disorder diagnosis. This impulsivity has been explored in the context of hoarding behaviour and found to be particularly notable with regard to acquiring (Timpano et al, 2013). Hoarding may have certain similarities with other impulse control disorders such as gambling, skin picking and trichotillomania. In reviewing the evidence to date (2012), Frost and Müller (2014) found a very varied picture. Correlations between hoarding and compulsive buying, acquisition of free things and kleptomania were found. Although the latter is cited as a problem for a minority of hoarders, at 7-10% this is rather significant and we cannot be certain that those respondents taking part in the relevant studies were comfortable with sharing such information, potentially under-representing the actual figure.

2 – Attachment

Frost and Steketee (1999) identify this emotional attachment as the major contributor to the difficulty in treating people with hoarding problems. Pertusa et al. (2008) found that people who hoard objects cited emotional attachment as a central reason for hoarding. Kellett and Holden (2014) conducted a review of literature which demonstrated

emotional attachment to be an important element of compulsive hoarding in a sample of 15 papers.

3 – Impairment to daily living

Frost and Gross (1993), Frost et al (2000), Wilbram et al (2008) and many other studies have found reported impairments to activities of daily living such as washing and cooking. In fact, these impairments form part of the measures for hoarding severity such as the hoarding rating scale (Tolin et al, 2010c) and the saving inventory (Frost et al, 2004). In a study by Steketee et al (2001) interviewing case workers of 62 older adults with hoarding problems, approximately 60% were unable to use their cooker whilst over 40% could not use their kitchen sink, fridge freezer or bath.

4.- The impairments cause clinically significant alarm or distress.

There is a high rate of comorbidity between hoarding disorder and anxiety disorders, depression and trauma (Frost et al, 2011a). In a sample of 217 people exhibiting compulsive hoarding, approximately 25% exhibited major depressive disorder, 10% generalised anxiety disorder, 10% attention deficit disorder, 10% social phobia. In fact, the rate of co-morbidity is so high that it calls into question the idea of hoarding as a discrete disorder. It is estimated that up to 30% of OCD cases exhibit compulsive hoarding and Samuels et al (2008) have demonstrated a link with personality disorders. Grisham et al (2006) and Landau et al (2011) have made connections between PTSD and hoarding

Poor concentration and memory (Steketee et al, 2003; Hartl et al, 2004) along with a lack of ability to categorise (Chan et al, 2008) were found to be typical traits of hoarders. Grisham et al (2010) also found significant impairments in categorisation, planning and decision-making. This drew parallels with attention deficit hyperactivity disorder (ADHD) and impaired impulse control (Frost et al, 2002), particularly in relation to the compulsion to acquire objects by either buying, “finding” or even stealing them (Frost and Müller, 2014). Tolin and Villavicencio (2011) have identified that most people with clinical levels of hoarding problems do not have diagnostic levels of ADHD symptoms, however. Timpano et al (2014) highlight the predominantly laboratory-based assessment of cognitive functioning in people exhibiting hoarding and suggest that this may miss factors associated with context which may play a part in those functions assessed. They also cite the complexity of hoarding and suggest that previous assessments have focused on individual aspects when it is the intersection of these aspects which form the neuropsychological model for hoarding. Sumner et al (2016) examined a sample of unmedicated HD patients and found no cognitive deficits

as described in earlier studies when compared to a control group, although they did identify a difference in learning.

Treatment

The approach to the hoarding problem before the pioneering work of Frost and Steketee was to remove the hoard immediately and completely (Frost and Steketee, 2011; 2014). Public health officials or environmental health officers would order the removal of the offending material in the interests of public health and safety once the problem affected more than those within the property. Very occasionally, the removal of vulnerable persons or animals would be necessary (Frost et al, 2000). Subsequent to the production of the CBT formulation model of compulsive hoarding and first set of diagnostic criteria (Frost and Hartl, 1996; Frost and Steketee, 1999), the notion of treatment (Steketee and Frost, 2007).

This model has included many variants such as group CBT (Muroff et al, 2014), online CBT (Muroff et al., 2010) and self-directed CBT (Tolin et al, 2007). The bespoke one-to-one CBT intervention for compulsive hoarding takes a year to deliver, making it costly and time-consuming and results for the group and self-directed hoarding interventions have shown promise (Muroff et al, 2011; Muroff, 2014). Comparisons have found little difference in the modest improvements made by these CBT variants (Thompson et al, 2017). Thompson et al (2017) also note that all treatments reviewed reported similar modest degrees of success and therefore alternatives to CBT are equally worthy of exploration.

Ale *et al* (2014) and Storch et al, (2011) report family-based behavioural treatment for children with hoarding problems of a similar nature. In both of these cases, whilst there was a very slight reduction in hoarding behaviour, other issues such as aggression, separation anxiety and boundary-setting are the areas in which the key changes seem to have been made, calling into question whether there was a hoarding problem in the first place, at least in the sense it is understood within the discourse around compulsive hoarding. They were conducted before a clearly defined set of criteria for diagnosis were available and therefore their credibility is diminished (Steketee and Frost, 2014). The two studies mentioned above considered a ten-year-old girl and a nine-year-old girl. As mentioned elsewhere here, age of onset for compulsive hoarding is thought to be a little older.

Saxena (2014) claims that despite the popular belief that drug treatments for compulsive hoarding using selective serotonin reuptake inhibitors have produced

uninspiring results, they are in fact as effective as CBT in treating hoarding. On closer inspection of his reported data, however, it is apparent that the participants which he describes as having the compulsive hoarding syndrome were included in that group even if they displayed other OCD symptoms. In effect then, this trial (Saxena et al, 2007) is examining two groups of OCD diagnosed patients, although attempts to screen participants using a scale developed by the researchers (University College Los Angeles hoarding severity scale; Saxena et al, 2007) and the Saving Inventory – Revised (SI-R, Frost et al, 2004) for the “compulsive hoarding syndrome” were made. More recently, Saxena and Sumner (2014) have conducted a trial of venlafaxine for hoarding disorder in which the participants in the target sample met the diagnostic criteria for hoarding disorder, in addition to meeting agreed scores on the UHSS and the SR-I. Saxena and Sumner (2014) report a 70% response rate to venlafaxine amongst participants with reduction in SI-R and UHSS scores. Saxena (2014) calls for more data from serotonergic drugs to be produced from studies specifically targeting people diagnosed with hoarding disorder.

Tompkins (2011) reported on the use of a harm reduction strategy for compulsive hoarding first published by Tompkins and Hartl in 2007 and reported on again in 2014 by the same authors. No study has been conducted comparing the effectiveness of this approach to other approaches so only the case studies and customer feedback reported by Tompkins and Hartl provide us with information as to its effectiveness. Support groups run by therapists or peers are a seemingly popular and valuable resource for hoarders and their families. Whilst research in this area is scarce (Holmes, 2014) the sheer number of groups in the US and their emergence in the UK suggest that people want these. Papers by Frost et al (2011; 2012) evaluating the “buried in treasures” workshops based on the self-directed CBT-based workbook by Tolin et al of the same name (2007) and facilitated by non-clinicians, indicated improvement in hoarding behaviour and beliefs in participants.

A review of treatments for hoarding disorder was conducted by Muroff, et al in 2011 (which is some time ago in terms of the rate of development of new treatments for what was then not a formal diagnosis). It found that hoarding treatments require an innovative approach. This message has been repeated by Thompson et al (2017), who reviewed all treatment approaches to hoarding. Conducting a review of alternative methods of CBT for hoarding disorder, Muroff (2014) found that group interventions and online versions were more effective, although Thompson et al (2017), state that this difference is very small and all the trials reported in their review failed to improve any participant’s problems to a non-clinical level. Inconsistent use of measures and cut-off scores dogged the studies they found and as mentioned earlier here, many

populations would not meet the criteria for a clinical hoarding problem by DSM standards.

Thompson et al (2017) found that only two trials of interventions for families have been conducted, both of which suffered from a lack of credibility. Chasson et al (2014) found improvements in the effects of hoarding on families during the intervention (psychoeducation and harm reduction training) but this did not last beyond the life of the study. Thompson et al (2016) found an improvement in wellbeing of family members after a psychoeducation programme. Both found increased knowledge about hoarding and Chasson et al (2014) reported improved coping strategies in family members.

Responses to hoarding

Most common responses reported by researchers (Frost et al 2000; Tolin et al, 2008a), hoarders and their relatives appear to consist of environmental health interventions to deal with the threat to public health/complaints of neighbours. In practice, examples have been cited by personal report of mental health act section being used to detain some hoarders in hospital whilst their houses are cleared out by local authorities with no consideration as to the reasons for the hoarding behaviour and no available “treatment”. The effects of the removal of possessions on the hoarder can be very extreme, causing stress reactions such as violence (Paxton and Zasio, 2011) and depression (Frost and Steketee, 2011). Neziroglu and Donnelly (2013) claim to have witnessed individuals so distressed as a result that they have attempted suicide. In addition, the “clear out” resulted in nothing other than a new collection being instigated, starting the whole process over again. It is only recently that attempts have been made to address underlying issues and direct interventions at the wellbeing of the individual rather than the consequences of their behaviour.

The cost to the public purse of dealing with the consequences of compulsive hoarding can be significant (Tolin et al, 2008b). National Housing Federation (2015) give an example estimate of £45,000 to resolve a case. Frost et al (2000) and Tolin et al (2008a) examined the effects upon and the cost to society of hoarding and discovered increased costs to employers, public health, local boards of health, fire departments, landlord, housing departments and social services raised by contracting in specialist cleaning services, dealing with the effects upon the hoarder’s physical health, legal costs etc.

Extreme cleaners are perhaps exemplified by Matt Paxton of the television show “Hoarding: Buried Alive” (Paxton and Zasio, 2011). They can come in and remove the

“mess” as perceived by neighbours, local authorities etc whilst in many cases being sympathetic to the needs of the owner of the possessions. The first UK conference on hoarding involved a professional cleaning and decluttering company (Cluttergone, 2014).

The Association of Professional Declutterers and Organisers UK has been in existence in the UK since 2004 (APDO UK website, 2014) and has a growing number of members. There are various equivalent organisations internationally such as the Institute for Challenging Disorganisation (ICD) and the Association of Professional Organisers in the USA (OCD Foundation website, 2014). Links between these bodies and hoarding and anxiety organisations, along with declutterers working alongside therapists on television series have helped to cement the role of the organiser in the current accepted approach to hoarding problems. The ICD is actively engaged in research on hoarding as can be found on its website (ICD, 2014). Other professional organisers have begun to be involved in research alongside clinicians (Kellett et al, 2015) and many hoarding services now offer a bespoke mix of clearance and therapeutic interventions.

Mental health services were not historically particularly evident in hoarding cases (Frost, Steketee and Williams, 2000; Frost and Steketee, 2014) and certainly not in response to the hoarding problem which was treated as a separate issue of public health and/or risk of danger to the hoarder and their family. Indeed, Frost and Steketee (2014) note that initially there was no way that their work could keep pace with the demand for information from many and varied sources. Whilst there are papers (although very few) dealing with the approach of community nurses when dealing with hoarding service users, the mental health literature appears to be focussed on the “treatment” angle. However, the publication of a report on a nurse-consultant led group intervention for hoarding (Singh and Jones, 2013) in a non-academic journal indicates that nurses are at least becoming involved and informed.

Beginning in 1999, various states in the US have established hoarding Task Forces to deal with the problem in a co-ordinated way (Bratiosis et al, 2011). These include representatives from boards of health, fire departments, environmental health and more although they are quite varied throughout the 85 existing groups (Bratiosis, 2013). It is now clear that such a multidisciplinary approach is being seriously explored in Britain as can be seen from the draft hoarding interagency proposal from Merton Borough Council (2014) and the Chief Fire Officers Association’s inaugural hoarding awareness week in 2014, which has been continued by others (National Fire Chiefs Council, 2018; Hoarding Awareness Week website, 2018).

Effects of hoarding

Examination of the effects of compulsive hoarding on individuals has revealed that they tend to be socially isolated both due to withdrawal from social life through shame and due to others avoiding them. They suffer with poorer physical health due to the poor quality of their living conditions and the higher incidence of infestations of pests as well as the inability to gain access to large portions of the house to clean it (Tolin et al, 2008a). Furthermore, the inability to use bathrooms and kitchens properly due to their being blocked by possessions (Steketee et al, 2001) means that individuals cannot attend to their personal hygiene adequately or eat a nutritious diet. The intervention of services in clearing objects from the home (often against the person's wishes) causes psychological harm (Bratiosis et al, 2011). The reactions of neighbours can be unsympathetic and even hostile and it may be the case that care providers refuse to enter properties if they feel that their health and safety is in danger. Where the hoarding is accompanied by compulsive buying, there may be significant personal debt. Isolation can be further enhanced by the individual's apparent preference for their possessions over their families, leading to conflict and eventually the retreat of the family members. Tolin et al (2008a) found a high incidence of divorced and unmarried people in a large sample of self-reported hoarders.

Families

The effects of growing up in a hoarded house are significant, as suggested by Frost et al (2008) and Tolin et al (2008b). This leads to the suggestion that the costs not only relate to the hoarder themselves and the environmental consequences of their hoarding, but that family members experience physical and mental ill-health as a result and this then places further burdens on the health and social care infrastructure.

In 2006, the internet-based support group "Children of Hoarders" was established (Children of Hoarders, 2014). The network has grown rapidly over the last 8 years to become a repository of knowledge as well as a place to share stories, seek understanding and provide and receive support. The group comes recommended by Frost, Steketee and Tolin in various books (Frost and Steketee, 2011; Tolin, Frost and Steketee, 2007; Bratiosis, Schmalisch and Steketee, 2011)

Little research has been conducted into the experience of family members of hoarders but what has been carried out has been synthesised into a review (Büscher et al, 2014) outlined and updated in chapter 2. Further published studies are equally scarce (Sampson, 2013a; Drury et al, 2014) and do not necessarily advance knowledge of the subject. In fact, it is the output of the family members themselves which is notable, not only in the higher profile projects such as Montag's (2004) and Lester's (2007) films or Sholl's (2011) account and Neziroglu's confessional interviews publicising her resource

book (2013) but even more noticeably in the plethora of blogs and online posts at the Children of Hoarders and Help for Hoarders websites.

A survey report by the Obsessive-Compulsive Disorder Institute of Greater New Orleans (OCDIGNO) was presented at the 14th Institute of Compulsive Hoarding and Cluttering of the Mental Health Association of San Francisco in 2012 (Chabaud and Garrett, 2012; see appendix 5). Chabaud was a consultant on the TV series "Hoarders" (A+E, 2012) and is in the process of affiliating the OCDIGNO into the IOCDF (OCDIGNO website, 2018). No published paper was found within the relevant databases relating to this survey, however. Even hoarders themselves are acutely aware of the discomfort and distress their actions cause to their families (Kellett et al, 2010) despite reports of low insight from some research (Tolin et al, 2010), yet sources of professional help targeted at hoarding behaviour and cognitions are scarce in the UK. It was the lack of information which prompted the revisiting of the inquiry:

What are the effects of having a hoarding family member?

Chapter 2 Review of literature

Introduction

As part of a previous course of study, a literature review into the effects of compulsive hoarding on families was conducted. This chapter will give an overview of that original review which marks the beginning of my interest in compulsive hoarding. An update of that review (with some minor modifications) was carried out for the interim viva examination for this doctoral programme. This update will be briefly mentioned below. At the culmination of this thesis, in June 2017, the review was updated a second time. Results incorporated those of the interim review and will be reported in detail. Thematic analysis of the resulting papers will be presented and a representation of the process employed to find other sources of information about family experience of hoarding (conducted at the time of the original review) will be offered. This will be followed by the findings and the research question. This review addresses the question “What are the effects of compulsive hoarding on families?”

Recap of original review

This chapter builds on a prior review of the literature, the themes developed from which can be seen on a poster from the RCN international research conference 2014 which can be found at appendix 1. That review was subsequently reworked for publication (Büscher et al 2014) and can be found at appendix 2.

Overview of scoping methods used in original review

At the outset of the original review a scoping strategy was employed to form a picture of the state of knowledge around compulsive hoarding. Scoping employs five stages: identifying the research question; identifying relevant studies; study selection; charting the data and collating, summarising, and reporting the results (Arksey and O'Malley, 2005). At this stage, all I knew was that I was interested in compulsive hoarding, so the question was broadly, “What do we know about compulsive hoarding?” As a starting point to identifying relevant studies, in 2012 a search of Cumulative Index to Nursing and Allied Health literature (CINAHL), Medical Literature Online (MEDLINE) and PsycINFO databases without parameters revealed only one hundred and thirty hits for articles with “hoarding” in the title (TI). The data revealed there may be a new diagnosis of Hoarding Disorder about to enter the DSM-5 in 2013. In addition to some

developing CBT approaches to treatment, much of the literature concentrated on the features and parameters of the proposed diagnosis (Pertusa et al, 2008; 2010; Mataix-Cols et al, 2010). Some examined the wider effects of hoarding on the hoarder and those around them (Frost et al, 2000; Tolin et al, 2008b; Tolin et al, 2010). Some papers related to hoarding behaviour in rodents. Hardly any of the papers reported on experience of hoarding in either family members or people with compulsive hoarding problems themselves (Tolin et al, 2008a; Wilbram et al, 2008; Kellett et al, 2010). To broaden my awareness of the experience of hoarders and those around them I ran citation searches of existing literature on the emerging diagnosis (Pertusa et al, 2010; Mataix-Cols et al, 2010; Tolin, 2011a, 2011b). I also looked at other sources of information, immersing myself in television, film, and true-life accounts. This meant initially scanning academic search premier and Google scholar to increase the number of databases covered by the scoping search and examining papers presented at past conferences on hoarding from the conferences' own sites, where available, inspired by suggestions from Arksey and O'Malley (2005), the aim being to capture a broad range of views and provide a fuller picture of the subject. The small number of papers resulting from this process and the broad sweep of the question meant that the selection of papers (step 3) was not a relevant step. All of the available information had to be included.

Several blogs by family members of hoarders identified from the children of hoarders WordPress site (e.g. The Hoarder's Daughter (2013), Hoarder's son (2013), Hev's blog (2013), Barbara Allen (2013)) were followed to pick up any references to ideas, themes, and areas of current study as well as information from the websites of the Institute for Chronic Disorganization (ICD) (2013) and the Association of Professional Declutterers and Organisers (APDO) (2013). RSS feeds (Really simple syndication - a means of receiving updates from websites) and social media enabled notification of new posts within these. The hoarding area of the International Obsessive-Compulsive Foundation (IOCDF) (2013) and the home site of Dr Suzanne Chabaud (2013) (a consultant on a hoarding television show and someone who has presented several times at conferences about children and families of hoarders) were also consulted as well as various support networks and organisations such as Children of Hoarders (2013), Help for Hoarders (2013) and OCD Action (2013). Creative sources of information such as documentary films (Lester, 2007), biographies (Lidz, 2003) and memoirs (Sholl, 2011; Allen, 2012; Miller, 2013) (identified through open searching on Google and recommendations from the web resources above) were also consulted for new ideas for focussed question formation and areas for research. A particularly valuable source of information and the starting point for many further questions and searches was key texts such as *The Hoarding Handbook* (Bratiosis, Schmalish and

Steketee, 2011), *Stuff: Compulsive Hoarding and the Meaning of Things* (Frost and Steketee, 2010) and a special issue of the *Journal of Clinical Psychology* on hoarding. These provided opportunity for further snowballing. Results of this entire process were mapped on a spider diagram (see appendix 3).

Search of academic databases

A methodical search of CINAHL, Medline and PSYCinfo using the terms outlined below (figure 5) returned sixty-three hits. At abstract review, removal of duplicates, book reviews, general interest articles, articles about hoarding as a symptom of another disorder and letters left twenty. Full texts were screened for direct study of family members in relation to the effects on them of their relative's hoarding behaviour. Four papers met criteria for inclusion in the final synthesis, comprising one case study (Tompkins, 2011), one interpretative phenomenological analysis (IPA) (Wilbram et al, 2008) and two cross sectional surveys (Tolin et al, 2008; 2010). The process is reported below at figure 6.

"Hoarding disorder" or hoarding (TI)	
And	
compulsive or disorder or extreme (TI)	
And	
Famil* or spouse* or children or parent* or carer* or partner* (TI)	

Figure 5- Search terms used in original review 2012

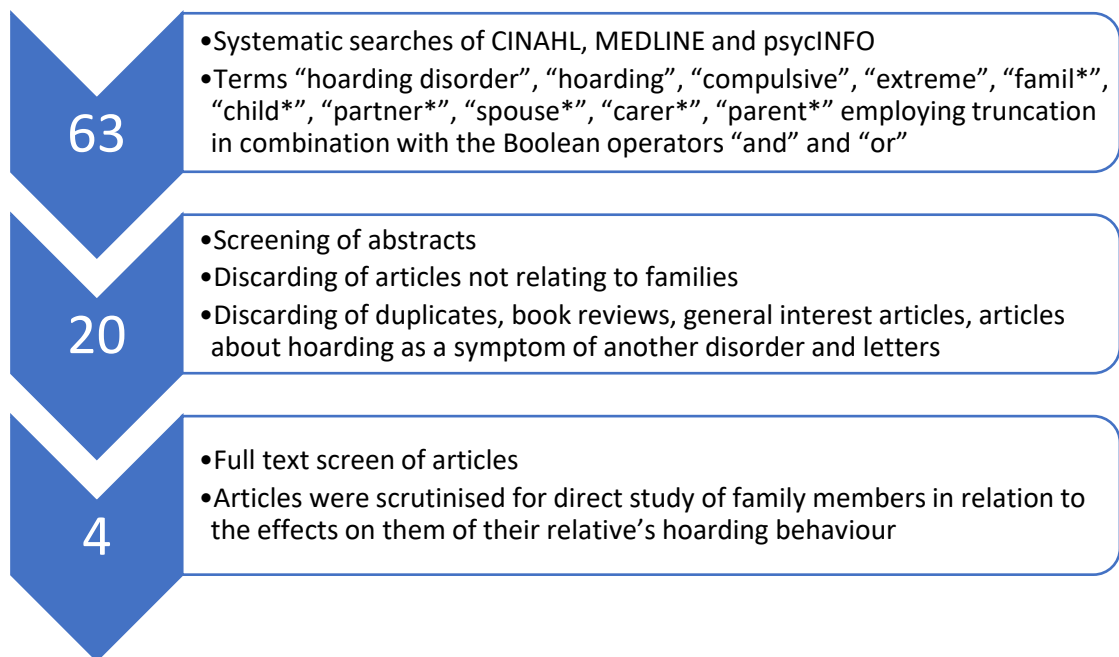


Figure 6 - Search strategy and results of original review 2012

Thematic Analysis

Braun and Clarke’s six-stage model (2006) was employed in conducting thematic analysis due to its effectiveness in dealing with mixed methodologies:

Phase 1 is familiarisation with the data, achieved through extensive reading and re-reading of papers and making copious notes both on the texts themselves as well as on a series of charts to capture the themes common to similar papers, which leads in to phase 2: generating initial codes through exploration of the texts in conjunction with a system of annotation (see appendix 4). Twenty-three codes emerged. Searching for themes (phase 3) involved moving back and forth between codes and texts to uncover emergent themes and subthemes, keeping note of these shifting ideas.

Phase 4 requires comparison between emergent themes and papers, reflected in the emergence of the unifying theme of the lack of support for family members of compulsive hoarders. Four themes developed in relation to the research question as a result of merging and grouping codes, continually checking back against the texts (as outlined by Braun and Clarke in phase 4). Effects on family members, effects on the family system and attempts to fix the problem and a lack of available support emerged as distinct themes, fulfilling Braun and Clarke’s requirement that themes are clearly defined as distinct entities (phase 5). Refining the themes enabled clarification of the

relationship between them and the distinct features of each as demonstrated in sub-themes. These were “quality of life”, “shattered families”, “rallying around” and “lack of support”.

Phase 6: producing the report

“...tell the complicated story of your data in a way which convinces the reader of the merit and validity of your analysis.”

(p.23)

The narrative of the review was published with embedded diagrams to demonstrate the processes involved. The published paper can be seen at appendix 2. This review has been cited several times, including in practice guidance from the British Psychological Society Division of Clinical Psychology (Holmes, 2015).

Update in preparation for interim viva

An update of this search was carried out for the interim viva examination in 2014 with a broader set of databases (as reported in the second update below) returned six papers. No new codes arose from this. Themes arising from thematic analysis (Braun and Clarke, 2006) were identical to those from the original review above. This update is due for publication in *Mental Health Today* (manuscript accepted July 2016). This update is encompassed by and was superseded by the one reported below from 2017 and will therefore not be reported on further.

Update of review June 2017

In June 2017 a second update of the review was performed as part of the writing up process. Elements of integrative review methodology as described by Whitemore and Knafl (2005) were employed in the interest of providing a framework for a more rigorous exploration of the literature, encompassing as broad a range of theoretical and empirical literature as possible. Close attention was paid to their recommendations as Hopia et al (2016) demonstrated that despite the popularity of the method, very few integrative reviews provide the level of rigour suggested by Whitemore and Knafl (2005). Hopia et al (2016) reported weaknesses (or absences) in reporting literature search strategy, data evaluation (critique), and data analysis. In response to this, for the 2017 update some enhancements (reported below) were made to deal with the greater number and range of methodologies represented. The stages of this review are reported using the titles offered by Whitemore and Knafl (2005)

Although there was no new scoping search, developing literature in hoarding was consulted as it emerged through the use of RSS alerts and developing networks of other academics and clinicians aware of the topic of interest as mentioned above. This created the possibility of greater inclusivity than the original search or its re-iteration had managed by allowing access to new information as it became available, potentially before publication.

Literature search strategy

Databases searched were PSYCHINFO, PSYCHARTICLES, PSYCHBOOKS, Medical literature analysis and retrieval system online (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), International Bibliography of the Social Sciences (IBSS), Journal Storage (JSTOR), ProQuest dissertations and theses (UK and Ireland site and US and world site) and Academic Search Premier. Author searches and citation searches were employed but did not produce any new papers. Broadening the range of databases was a response to suggestions from reading during the scoping phase which were not accessible through the clinical databases originally employed. As they returned no relevant papers despite the large numbers of titles screened, further social science databases were not searched. The inclusion of grey literature (unpublished work deemed to be of sufficient quality to be held by a library or repository (Farace and Schöpfel, 2010)) was an attempt to provide as much chance as possible of discovering anything not found in 2012 or 2014.

Search terms employed are shown below in figure 7. Terms were broadened for this update as a result of the development of my knowledge of the topic and growing experience in searching. Terms which proved unhelpful were removed and terms which were naively expressed in the original review were altered to improve the rigour of the search (e.g. hoarding which was refined to hoard* to allow for hoarder, hoarders, hoarding, hoarded and hoard. Similarly, carer* was altered to car* to allow a greater number of possible relevant results using the word “caring”).

“Compulsive hoarding” or “Hoarding disorder” or hoard* (TI)	
And	
Famil* or spous* or child* or paren* or car* or partner* (TI)	

Figure 7- search terms used in 2017 update

Inclusion and exclusion criteria

For this update, inclusion and exclusion criteria were refined to increase the potential number of relevant include papers. Family Interventions for compulsive hoarding were included for their contribution to the understanding of experience. One of these papers (Sampson, 2012) had been initially excluded from previous searches but due to alterations to inclusion criteria, was now included. Vorstenbosch et al (2015) met exclusion criteria for the assessment validation component of their work but were included for their exploration of accommodation in families with hoarding members, which was a second aim of their study. Accommodation is defined as family members participating in behaviour associated with obsessive compulsive disorder (Albert et al, 2010), including adherence to rules imposed on their relative by the OCD (Cooper, 1982) and is associated with poorer treatment outcomes (Chambless and Steketee, 1999).

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none">• Family impact• Hoarding as a discrete phenomenon/disorder in humans• Evaluation of family interventions• Peer reviewed• Grey literature• Whole text available	<ul style="list-style-type: none">• Authentication of impact measurement scales• Hoarding as a symptom of another disorder• Animal hoarding• Hoarding in children

Figure 8 - inclusion and exclusion criteria for 2017 update

The vast majority of returned results did not match the search terms accurately and re-runs of the same searches at different times produced fluctuating numbers of hits. The inconsistent nature of database search facilities has been commented upon previously (Whittemore and Knaf, 2005). Six hundred and sixty-eight of the records screened were removed due to focus on hoarding in animals, animal hoarding in humans, hoarding as a symptom of another disease, non-family focussed interventions for hoarding, economic use of the term hoarding (e.g. labour hoarding), literature reviews, book reviews and general information articles on hoarding.

Of the twenty-two remaining papers, ten were excluded at full text screen. Four of them proved to be theses already included in the results as journal articles and were therefore removed to avoid “double counting” of data which would skew the results of the analysis (Senn, 2009). One conference presentation offered insufficient detail to enable critique. Nordsletten et al (2013) reported validation of a scale for measurement of family impact of hoarding, meeting criteria for exclusion. The

remaining doctoral theses were only available as abstracts or samples, which rendered critique impossible. These excluded papers are reported separately for illustration below at appendix 5. The number of included papers is triple those in the original review (although numbers are still small) due perhaps to increased profile of hoarding disorder in the clinical and public awareness of the problem and its potential treatments as well as the alterations to the search terms and inclusion and exclusion criteria.

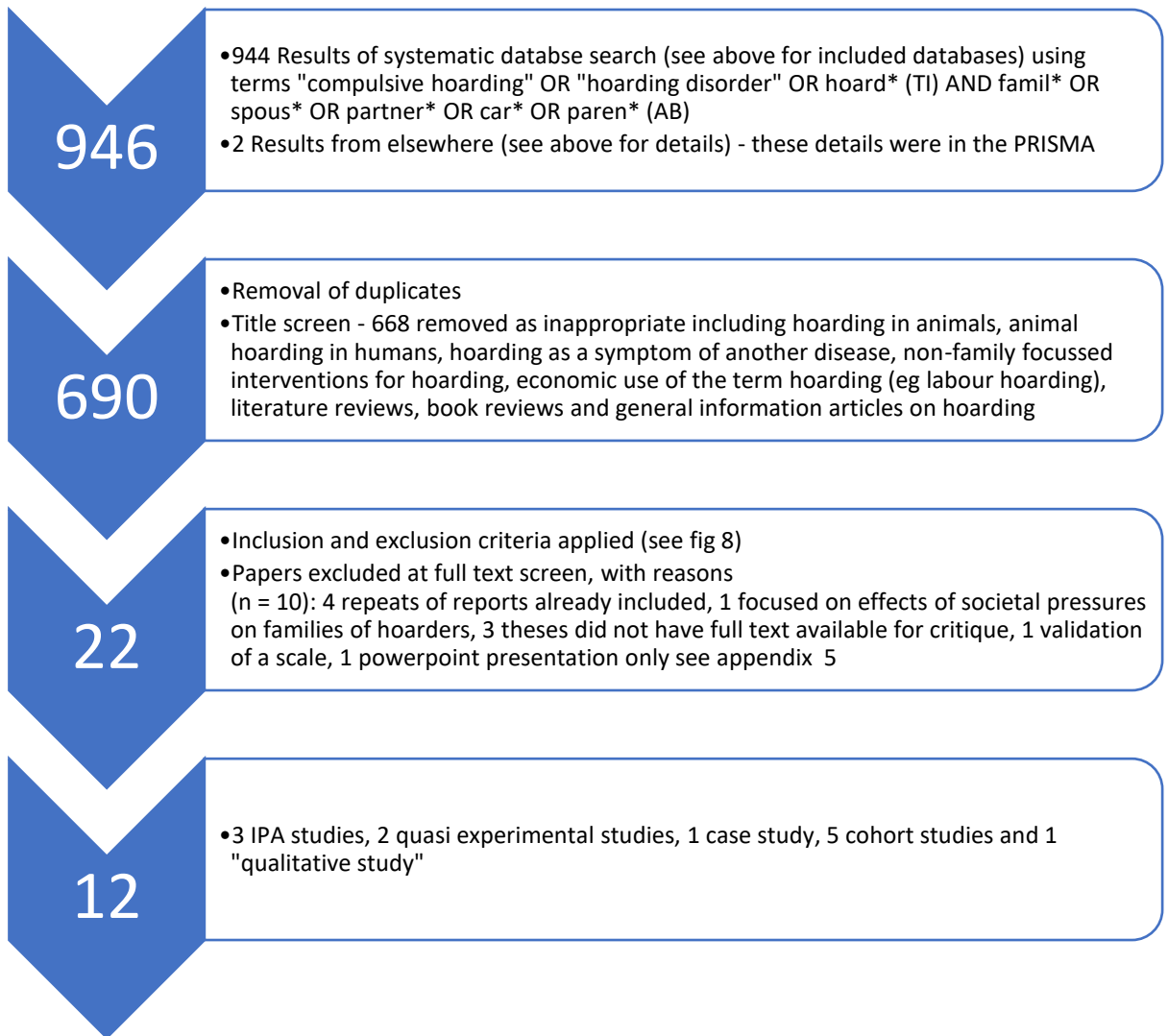


Figure 9 - Strategy and results of update 2017

Data evaluation

Hopia et al (2016) argue that Whitemore and Knafelz were clear that by being able to demonstrate the credibility of contributing papers, it is possible to see how much weight they add to thematic development. Suggestions have been made that papers could be assigned scores based on their quality and relevance (Whitemore and Knafelz, 2005) but concerns this could potentially lead to the marginalisation and potential dismissal of valuable outliers have led to the rejection of this approach. Therefore, quality of papers was not influential in including or excluding them from the final analysis for fear of losing vital information, but appraisal forms an essential element of analysis (Whitemore, 2007).

Papers (five cross-sectional surveys, two quasi-experimental, four qualitative and one case study) were subjected to critical appraisal using appropriate specific tools from the Joanna Briggs Institute (Tufanaru et al, 2017, Lockwood et al 2015, Moola et al, 2017). Criteria for appraisal included appropriateness of design, recruitment, instrument validity, comparator/control, randomisation (cross-sectional and quasi-experimental studies); epistemological integrity; ethical considerations; audit trail; credibility (qualitative studies). This allowed a rigorous approach to critique of a broad range of specific research designs. These tools were selected for their availability, clinical focus, and structure. It should be noted that tools for critical appraisal are not uniform in the criteria they apply (Katrak et al, 2004) but as a novice researcher, they can be beneficial in establishing uniformity of approach. Results have been incorporated into the table of included papers below (table 1). These results included the four papers found in the original review.

These findings spanned published qualitative and quantitative studies providing a broad picture of the family experience of hoarding. Unfortunately, there are various limitations to each of the papers. Survey data can give an impression of the size of the problems facing families, but only if the right questions are asked and therefore it would have possibly been helpful if Tolin et al (2008;2010) had allowed development of understanding of the phenomenon and consulted qualitative research first to identify areas to target. There was only Greenberg's seminal 1987 study to consult in this capacity, however. Other published work considered hoarding as a symptom of another disorder (see examples in previous chapter). The anonymised online design employed by Tolin et al (2008;2010) meant that false reporting by participants, duplication and people outside of the target population (for instance, people looking for help with their own hoarding problem) could not be screened out as it would be impossible to confirm participants met the inclusion criteria. Tomkins (2011) case studies are thin and whilst they are interesting they lack diagnostic information and clinical detail. Wilbram et al (2008) provided a very thorough and useful study but

recruitment was localised to a single group in a specific part of South Yorkshire in which the hoarding family member was already receiving some help. Data provided by Wilbram et al (2008) and Tolin et al (2008; 2010) is now rather dated and the public and professional awareness and understanding of hoarding has developed somewhat since then. Sampson et al (2013) confirm themes found by Wilbram et al (2008), extending the radius of people affected by the hoarding to those caring for hoarding relatives who do not share living space with their hoarding relative to say that more than one model can be applied to examining the situation of hoarding in families. Drury et al (2014) demonstrate specific areas of life in which family members are adversely affected by the hoarding. This still leaves a large gap in the qualitative investigation of the experiences of families of compulsive hoarders.

The sample used by Drury et al (2014) was self-selecting hoarders whereas the sample used by Tolin et al (2008; 2010) was self-selecting family members of hoarders. Hoarders who take part in studies about hoarding are more likely to be aware of their problems and those of their families whilst family members of hoarders taking part in a survey about hoarding are arguably more likely to be exasperated and looking for answers or at least somewhere to vent their frustrations.

Many of these studies asked people to rate their hoarding relatives using the Hoarding Rating Scale- Self Report (HRS-SR Tolin et al, 2008) which is not the scale's intended use. Drury et al (2015) conducted a small-scale study on the accuracy of hoarding reporting between self-report, informant-report and clinician-report measures. The sample included 24 dyads of people meeting clinical threshold for hoarding disorder and a relative n=24 pairs and 40 family informants whose hoarding relatives declined to take part (unable to verify they met diagnostic criteria). Over-reporting on the level of squalor was found in family informants but on other measures, reports of hoarding and non-hoarding family members were comparable. Hoarding family members with reported "low insight" proved hard to recruit, although a refusal to take part is not necessarily indicative of a lack of insight and could in fact be the result of embarrassment or shame due to awareness of the scale of the problem. The low insight is an assumption based on the reports of relatives and the unwillingness to take part. The accuracy of the lone family informants' responses is based on the 24 responses given by those paired with hoarding relative's accounts. As Drury et al (2015) observe, these people willingly took part together. This suggests a different relational dynamic which may influence the responses.

Table of papers

Table 1 - Included papers from literature review

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
Wilbram, 2008	Interpretative Phenomenological analysis of transcripts from semi-structured interviews (1 hour) conducted in participants' homes	To understand carer and family perspectives on the impact of hoarding on family members	10 relatives and friends of people with compulsive hoarding (4 male, 6 females; 1 daughter, 2 mothers, 1 brother and 6 partners) drawn from South Yorkshire, UK.	Emerging themes were: Loss of "normal" family life, the need for understanding, Coping, impact on relationships and marginalisation.	The process of thematic analysis employed in IPA is a subjective one. The area from which the sample was drawn was highly localised. Participants were recruited through a support group could indicate a bias towards those already engaged in a source of help.
Tolin, 2008	Cross-sectional Internet based survey employing a battery of tests	To quantify the rejection towards hoarding family members expressed by their relatives	665 family informants from USA with a relative with compulsive hoarding	Levels of rejection similar to family member with schizophrenia or bipolar disorder diagnosis. Rejection correlated with severity of hoarding, insight of hoarding family member, age at which the accommodation was shared and relationship of hoarder to informant.	Potential for recall bias and biases associated with self-report. Participants were help seekers only. New scales of hoarding severity validity/reliability uncertain Outcome measure (PRS) not validated for use with hoarding.

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
Sampson, 2013	Interpretative Phenomenological analysis of semi-structured interview data	To understand the impact of hoarding on family caregivers no longer sharing the home	12 family members (USA) (10 female, 2 male) 1 spouse, 1 nephew and 10 children of hoarders	Themes emerging: Negative feelings toward family member who hoards; Lack of understanding of hoarding behaviour; Experiences of loss; Internal barriers to seeking support; Internal conflicts	Recruitment via "Craigslis" Meeting in a public place could inhibit participants' responses variance in length of interview Participant representation biased towards one respondent (4 not represented) Screening by telephone according to behaviour which "seemed to meet" HRS-I criteria No mention of data saturation.
Tolin et al, 2010	Cross sectional Internet based survey employing a	To gauge family informants' perception of insight in hoarders	558 family informants (USA)	Hoarders of all levels (including subclinical) are reported by family members as having very poor levels of insight.	Impossible to verify whether participants met inclusion criteria. Exposure measures newly developed – questions validity/ reliability of measure. Informants estimated ratings for hoarding relatives and

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
	battery of measures			This greater the hoarding the greater the level of insight the hoarder is believed to have.	<p>ratings hoarding relatives would give themselves.</p> <p>Included data from participants who fulfilled criteria for a diagnosis of hoarding disorder on HRS-SR (approx. 10% of responses) despite citing this as an exclusion criterion</p> <p>Few potential confounders identified</p> <p>Effect sizes from statistical tests were noted as being very small.</p>
Tompkins, 2011	Case report	To describe the benefits of harm reduction (HR) as an intervention for hoarding	<p>2 families</p> <p>One consisting of a mother and her two daughters and one son (all adults)</p> <p>The other a mother and her two</p>	Families of hoarders can be essential to the therapeutic team.	<p>No report of adverse effects of treatment</p> <p>Clinical condition of patient reported on to a limited degree.</p>

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
			daughters (both adults). All from USA.		Lessons offered from the report not objective
Drury et al, 2014	Cross-sectional survey Screening by telephone followed by online battery of scales	To further explore the detrimental effects of having a hoarding relative	37 people meeting DSM-5 criteria for HD; 55 relatives of people meeting the same criteria; 51 self-identified collectors and 25 relatives of collectors all from London, UK.	Relatives of hoarders experience equivalent levels of detriment to hoarders themselves. Impairment to relationships, work, and daily functioning. The only predictor found to be significant for impairment to family member wellbeing was the Home Environment Index, a measure of domestic squalor.	Potential for recall bias and bias associated with caregiver stress. Recruitment was through a hoarding information and support website available to the public. Measure of exposure delivered by absence of visible proof of hoarding severity.
Park, 2014	Cross-sectional Online/telephone survey	To gauge Impact of parent's hoarding on	150 adult-aged children of hoarders in the USA (87% female) with a living	accommodation of hoarding increased	Uses a battery of scales of varying validity. Clinician rated scales delivered as self-report).

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
	Path model analysis	adult children	parent with clinically significant hoarding.	<p>Perceived lack of insight equated to increased conflict within the family.</p> <p>Family accommodation not associated with impairments to family functioning.</p> <p>Impairment to offspring was not found to mediate hoarding severity and relationship between parent and offspring.</p> <p>Increased hoarding severity produced reduced family functioning which negatively affected relationships between parents and offspring.</p>	<p>Absence of a diagnostic clinical interview</p> <p>Psychopathology of informants was not assessed.</p> <p>Authors question stability of some of the statistical models used in relation to low magnitude.</p>
Chasson et al, 2015 (USA)	Quasi-experimental Pre- and post-intervention assessment battery without	To assess effectiveness of training for family	9 adult family members of people with a hoarding tendency (7 female, 2 male)	The intervention did not reduce levels of emotional distress in participants but changes in coping strategy (reduction in self-blame) were observed as well as	High rate of attrition. Very small numbers for the number of statistical tests employed in analysis. Scales employed in measurement of family impact of hoarding are not validated

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
	control group- Regression Discontinuity design?	members of hoarders	3 adult children, 3 siblings, 2 spouses, 1 parent. All participants from USA. No report of inclusion criteria	increased hopefulness and reported reduced accommodation of hoarding behaviours (this occurred prior to a session on accommodation being delivered).	so using them together to produce convergent validity does not compute. Significance of all effects was small with mid- to post-training producing no significant effects. No power calculation. Recruitment was from first author's CBT group for OCD could produce bias
Sampson et al, 2012 (USA)	"qualitative study" – content analysis of Observational data and semi- structured interviews	To assess the effectiveness of a group intervention for family members of hoarders	8 US adult family members of compulsive hoarders	Themes: Loss of normal family experiences; Loss of childhood home; Support; Interruption to family relationships;	Aim of the research does not match the methodology The interview schedule indicates that questions were somewhat leading. No stated philosophical position – attempts to use qualitative methodology (no explicit methodology offered) to measure effectiveness of

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
				<p>Limited time spent with family;</p> <p>Loss of childhood home</p>	<p>an intervention. No explicit method of analysis offered</p> <p>No evidence of a reflexive statement of position of researcher.</p> <p>Researcher identified “topics of interest” and reported only data relating to these despite acknowledging that other topics were raised by participants. Little representation of participant voices. No indication of ethical process or approval.</p>
Vorstenbosch, 2015	<p>Cross sectional</p> <p>Online self-report with telephone interview</p>	Investigation of the construct of family accommodation in hoarding	<p>52 dyads (1 self-reported non-treatment seeking problem hoarder and close significant other) from Canada.</p> <p>CSO's included partners (56%),</p>	<p>Accommodation mediates distress and conflict in families with a member with hoarding tendencies.</p> <p>Severity of hoarding was not found to directly affect quality of relationship.</p>	<p>Measure of accommodation is untested.</p> <p>Model of family accommodation in OCD may not be transferrable to hoarding.</p> <p>Claims of convergent validity with the FRHS scale, validity</p>

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
		And Validation of Family accommodation index – hoarding	children (25%), parents (8%), siblings (8%) and 4% were cousins/nieces/nephews.	Symptom severity was positively associated with level of accommodation and family accommodation level was significantly related to conflict in relationship.	of which is unreported has not been subject to review \$40 reward for participants were “non-treatment seeking” raises questions about motivations for participation
Thompson et al, 2016	Quasi-experimental Pre- and post-intervention assessment – no control group - Regression Discontinuity design?	Assessing the effectiveness of group psychoeducation for carers of people with hoarding disorder	12 family members of people with hoarding disorder in two groups of six. (Nine adult children, one step-daughter, one parent, one nephew). All were resident in the UK.	Improvements in wellbeing, understanding of hoarding and positive caregiving experiences No reductions to carer stress, expressed emotion, or burden to caregivers. No change in coping style (avoidant).	verification of hoarding disorder (SIHD) delivered by telephone through a third party 3 participants declined follow-up. Five-minute speech sample (FMSS) conducted by telephone rather than face-to-face as recommended. No possibility of triangulation of ratings (inter or intra-rater) No power calculation. Very little information offered on statistical analysis used.

First author, year	Methods	Aim(s)	Population/Sample	Findings	quality appraisal
Rees et al, 2017	Interpretive Phenomenological Analysis of semi-structured interview data	To understand the continuing impact of parental hoarding on adult children and explore coping strategies	7 Australian adult children of hoarders (all female) with at least one parent with 20+ years hoarding problems. Participants must have cohabited with hoarding parent until at least age 15	Four emergent themes: Impact on relationships – Coping strategies – Perceptions of parental hoarding – Psychological and emotional outcomes –	Analysis verified by independent second rater. Researcher used reflexive journal. Three respondents' hoarding parent or parents were deceased – potential for recall bias. Screening used HRS-I rather than agreed diagnostic SIHD Not clear who conducted screening of participants

Data analysis

A recent review of integrative reviews (Hopia et al, 2016) has found sporadic and inconsistent reporting of analytic processes. Whittemore and Knaf's (2005) novel ideas about how to break down and then re-integrate analysis offered potential improvements to the process and transparency of this report. Whilst the approach to analysis in this exercise was a bespoke one, Whittemore's (2007, p.153) suggested use of creativity in displaying data to encourage a more thorough iterative process was a helpful starting point.

The qualitative nature of the research question invited the use of experiential inquiries as the starting point for synthesising the literature as these were the most closely aligned to it. For this update the results included four such studies (Wilbram, et al, 2008; Sampson et al, 2012; Sampson, 2013a and Rees et al, 2017) which I displayed in a table, enabling a comparison of their identified themes (see appendix 6). By examining these phenomenological papers together, it was possible to get a more detailed picture of how hoarding affects family members in different ways depending on roles historically and currently. This synthesis produced themes much the same as the original review (figure 10).

Following this exercise, the findings of the other eight papers, were mapped against these in a second table (appendix 7). These papers offered refinements to understanding of and



Figure 10- synthesis of themes from phenomenological papers

relationships between themes as can be seen from the resulting map (figure 11). The map was constructed using Inspiration tm software which allowed for the transposing of information from the two tables (appendices 6 and 7) onto a pictographic format during development. These have been subsequently removed for purposes of presentation.

Whittemore and Knafl (2005) suggest the creative representation of thematic development and relationships in the report to aid the reader’s understanding. Themes could be seen as locations on the map. The relationships between these factors were then further illustrated by the addition of the quantitative synthesis (the “roads” or “routes” connecting the locations).

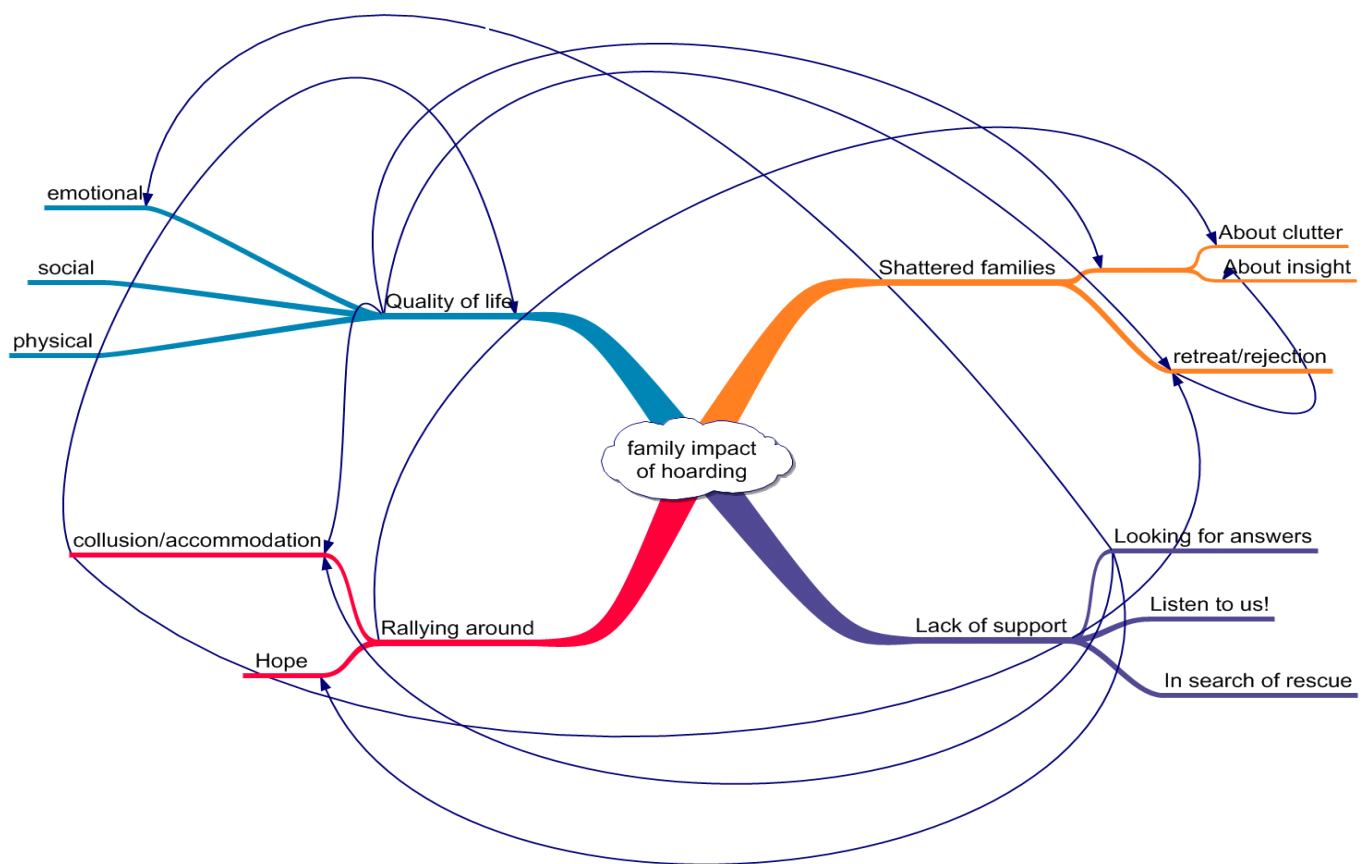


Figure 11 - map of themes following inclusion of all papers

Results of data analysis

Themes arising from data analysis were – quality of life (detrimental effects of hoarding on the day to day lives of family members); shattered families (tensions, conflict and disintegration of the family as a result of these detriments); rallying around (families' attempts to help with or manage the hoarding problem and preserve the integrity of the family) and lack of support (families' unmet need for answers and a sense of not being heard). In this section each theme, including its subthemes, will be introduced in turn followed by a synthesis of these results.

Quality of life

Impaired family life was discovered to be an emergent theme by Wilbram et al (2008), Sampson et al (2012), Sampson (2013a) and Rees et al (2017). Sampson (2013a) examines loss experienced by relatives of hoarders who have lost their relationships, sense of “home”, future opportunities and family rituals to an obsession and their home along with them. Furthermore, she also examines the role of unresolved events in creating the hoarding problem in the first place, these affecting the whole family. In a previous paper, Sampson et al (2012) found participants in a programme of intervention for family members of compulsive hoarders reported loss of living space, family life and time spent with the family. The effects on quality of life divide into three overlapping aspects– social life, domestic life and emotional life.

Social life

Many family members feel trapped by their claustrophobic domestic situation and cut off from the world behind the clutter. Lack of a social life, due to embarrassment and anxiety (Wilbram et al, 2008; Tolin et al, 2008, Drury et al, 2014; Rees 2017) and “limited socialisation within the home” due to tensions and constrictions(Rees et al, 2017 p.6) which is echoed in Wilbram et al (2008), Sampson et al (2012) and Sampson (2013a).

Tolin et al (2008) found a significant correlation between the level of clutter in the house and the avoidance of having visitors. One respondent to Wilbram et al (2008) reported avoiding making friends to avoid the embarrassment of inviting them home. Rees et al (2017) also report respondents' accounts of isolation in childhood and adolescence, avoiding friendship formation and inviting people home with examples from two respondents. Three respondents described continuing issues in this regard.

Sampson et al (2012) found emergent themes of loss of time spent with family and loss of

family rituals. Wilbram et al (2008) also found loss of normal family life to be an emergent theme. Rees et al (2017) found respondents also described avoiding the family home as children. Tompkins (2011) describes the loss of a family relationship between mother and daughter but also found a ready desire to be reunited with their hoarding family members and to help them.

Wilbram et al. (2008) note that their interviewees commented on the retreat of the family from the world. A husband describes “keeping [the world] out.” (p. 65). Tolin et al. (2008b) reported that there is a high incidence of social withdrawal in children of hoarders, especially those aged between 11-20 years for reasons of embarrassment about the condition of the home. Tompkins (2011) describes a case in which the individual hoarder is existing in solitude with very sparse contact with her family (once a year) and apparently no other social network. The model of ambiguous loss as defined by Boss (2006) and applied to hoarding experienced by family members in Sampson et al (2012;2013) describes a state where the person is still a physical presence but emotionally, there is an attitude of ambivalence towards them.

Domestic life

Wilbram et al (2008) and Sampson et al (2012; 2013) found reports of lack of living space and Drury et al (2014) demonstrate Home Environment Index (squalor) scores and time spent living with hoarder are predictors of worse outcome on Work and Social Adjustment Scale wellbeing, suggesting this has an enduring effect. Different ways of seeking sanctuary from the all-pervading clutter are reported by Rees et al (2017) and Wilbram et al (2008), who cite the example given by a mother of her son having erected a tiny Christmas tree in his bedroom as there is no room for the tree anywhere else in the house (p.64). She also recounts a visit from her daughter and her partner, who have to eat their dinner in her son’s room from trays on their knees owing to the lack of anywhere else to sit and eat together (p.64). Rees et al (2017) report that respondents had avoided the family home altogether when they were younger.

Emotional life

Drury et al (2014) demonstrate family members of hoarders report lower emotional wellbeing than those of collectors. The reluctance of people with hoarding family members to invite

people over correlates with the severity of the hoarding as does the embarrassment and shame of the family member (Tolin et al, 2008b). Wilbram et al (2008 p.69) reports a child bullied at school because of the hoarding behaviour of his brother.

The care proceedings threatened in the second case in Tompkins' (2011) study provoked family distress in estranged family members, underscoring Sampson's (2013a) reports of distress and confusion in non-caregiving family members of hoarders. Rees et al (2017) outline sources of worry for adult children of hoarders including fears for the safety of their relative. Worries that they would become hoarders themselves and negative emotional impacts, self-esteem difficulties, psychological strengths all emerged as themes for Rees et al (2017).

A psychoeducational group intervention for family members (Thompson et al 2016) produced no reduction in expressed emotion, carer stress or burden but did increase positive caregiving experiences. Similarly, a group intervention based around motivational interviewing (Chasson et al, 2014) was found not to improve the experiences of family but did produce changes in carer coping strategies.

Shattered families

Families in the papers appeared to be buckling under the pressure of trying to maintain a "normal" existence whilst dealing with the intrusions and interruptions of the hoard, creating conflict and driving members apart. This theme emerged as two distinct subthemes, one of which ("conflict") further divided into topics for conflict ("clutter" and "insight"). The second subtheme of "retreat/rejection" is a consequence of this conflict.

Conflict

Arguments are common in families with a member who has hoarding tendencies, especially between spouses and parents/children (Tolin et al, 2008; Rees, 2017; Wilbram et al, 2008). When hoarding behaviour affects family functioning, there is a significant effect on relationships (Park et al, 2014). "*Negative feelings towards the family member who hoards*" (p.393) is one of Sampson's (2013a) identified themes. Sampson (2013a) notes the long, detailed and emotionally charged descriptions of hoarding relatives' behaviour, with all respondents reporting frustration and bewilderment.

Conflict over clutter

Arguments about clutter, discarding and acquiring are common in families of hoarders (Tolin et al, 2008). Wilbram, et al (2008) reported verbal and possibly physical assault resulting from arguments about hoarding. Sampson (2013a) notes the high level of conflict over behaviour of hoarding family members. Park et al (2014) demonstrated a link between level of hoarding and family dysfunction which negatively impacted on the quality of relationships. Family function was demonstrated to mediate accommodation and conflict (Park et al, 2014). Tompkins (2011) and Wilbram et al (2008) both note unhelpful or non-inclusive strategies to reduce clutter such as discarding items when the family member with the hoarding problem was absent. This caused arguments. Following an intervention to educate family members about hoarding and develop their motivational skills to help their hoarding relatives, participants reported a reduction in conflict due to reduced rates of unhelpful behaviour (Chasson et al, 2014).

Conflict over insight

Perceived level of insight correlates strongly with rejection (Tolin, 2008) and conflict (Park et al, 2014) and informants perceive their relatives as lacking insight (Wilbram, 2008; Tolin et al, 2010; Drury et al, 2014; Rees, 2017). Drury et al (2014) found insight not to be a predictor of family burden, however. Arguments were common in these family groups (Tolin et al, 2008), particularly between spouses and between children and hoarding parents.

Retreat/rejection

Rees' (2017) respondents reported avoiding being in the house as children, consistent with Tolin et al (2008) reporting significant links between sharing hoarded accommodation as a child, shame about the house and avoiding inviting people over. Negative ideas about parents were found by Tolin et al (2008;2010) regardless of severity of hoarding or level of clutter or level of insight, with rejection highest for those who grew up living with hoarding parents (Tolin 2008). The highest levels of rejection were found in those who had shared living accommodation with a hoarding relative at age 10-19. Rees et al (2017) found respondents had tended to leave hoarded homes at a young age.

Tompkins (2011) reports of a woman who would not visit her mother at home anymore due to the extent of the hoarding and would only see her away from the house once a year. Memories of childhood events appear to gain strength to revolt and frustrate family members who leave the family home and come back. Sampson et al (2013) examines the feelings of family members who live away from the hoarded home and finds these feelings to still be riding as high as do Wilbram et al (2008). One of Wilbram's (2008) participants, however,

states that he sees his wife's hoarding as "*part of her*" (p?)

Rallying around

Family members described and implied many strategies for helping hoarders and themselves such as throwing out items covertly (Wilbram et al. 2008) which could cause arguing over possessions and even aggression (Wilbram et al., 2008; Tolin et al., 2008b). Tompkins (2011) provides illustrations of the pressure which can be felt by family members of hoarders in providing support (a son worried about taking in his mum and a mother who only wants to have her daughters in her HR support team). The subthemes of collusion/accommodation and hope show the different ways of trying to maintain the integrity of the family and the self.

Collusion/accommodation

There is some misalignment, perhaps, between the examination of "accommodation", explaining this as referring to the adjustment of family and individual routine to accommodate hoarding behaviour (Park et al 2014, Vorstenbosch et al 2015; Drury et al 2014; Chasson et al, 2015; Thompson et al, 2016) and "acceptance" (resigned or more positive) (Sampson et al 2012; 2013; Rees, 2017; Wilbram et al, 2008). Chasson et al (2014) and Thompson et al (2016) seemingly want to provide a therapeutic means of moving from one mode of thought to the other. However, accommodation prevention interventions including motivational interviewing and hoarding awareness provided by Chasson et al (2014) proved to be ineffective in reducing hoarding or accommodation.

Vorstenbosch (2015) found a significant relationship between increased accommodation and increased rejection leading to diminished relationship functioning. Severity of hoarding affected level of accommodation and conflict whilst accommodation moderated conflict. No significant link between accommodation and wellbeing of offspring was discovered (Vorstenbosch, 2015), although Park et al (2014) did find a link between accommodation and offspring impairment but not family functioning. Offspring impact did not mediate offspring relationship and hoarding severity (Park et al, 2014). Those who live further from their hoarding relative accommodate less (Vorstenbosch et al, 2015) but this does not mean that the hoarding no longer affects them, even if they do not have a "caretaker" role (Sampson, 2013). Tompkins (2011) reports of relatives who are aware of the problem but act as if it does not exist, whilst Wilbram et al (2008) report the expression "living with it" used by one interviewee. They also found two outlying themes relating to the organisation of

care and the identification of strengths (Wilbram et al, 2008).

Hope

Wilbram et al (2008) found positive reports of acceptance of hoarding behaviour and subthemes of organisation and support and protective positive qualities. This is developed further by Rees et al (2017) in their exploration of positive psychological outcomes. Family members of hoarders are often keen to help even if they haven't been in contact for years. Tompkins (2011), cites the example of a daughter long estranged from her mother who nevertheless was prepared to pay for an organiser to help with clearing out and therapy. Tompkins (2011) describes family members as team members and contactors of help – even the daughter who had not spoken to or heard from her mother for years paid for the professional organiser and made no demands in return. Wilbram et al. (2008) spoke to a sample entirely made up of “key carers” for hoarders, most of whom lived with the hoarder and had done so for many years. The main source of participants approached to take part in the studies by Tolin et al. (2008b; 2010c) was people who had contacted a source of help, indicating that someone believed things could get better. This help may have come at a considerable financial cost. However, Sampson reports that 11 out of 12 participants reported having "given up" trying to help. Hopefulness scores were inflated and use of positive reframing was increased following a psychoeducational intervention for relatives of hoarders which included motivational interviewing (Chasson et al, 2014).

Lack of support

What is common to all the above themes is the contributing factor of the lack of outside support for families. This puts stressful demands upon families, allows quality of life to decline (Wilbram et al, 2008) and both factors can contribute to family breakdown. Tompkins (2011) describes an exchange in which adult protective services contacts a family to tell them that their estranged relative needs help, with no mention of any suggested source of support or offer of assistance. Wilbram et al (2008) found complaints of a lack of help from statutory and non-statutory services. Interviewees expressed bewilderment at their family member's behaviour and a wish to have an explanation (Wilbram et al, 2008; Rees et al; 2017). Many made guesses at what the cause might be and how this could inform a cure (Wilbram et al, 2008; Rees et al, 2017). The second case study in Tompkins' (2011) paper was identified by an Adult Protective Services worker. There is no mention of this worker contacting any source of help for the client regarding interventions for hoarding or any

mental health concern, only the family. Two subthemes developed through the process of analysis; looking for answers and listen to us!

Looking for answers

The “lack of understanding of hoarding behaviour” inside and outside the family (Sampson, 2013a) and “the need for understanding” from service providers (Wilbram et al, 2008) inevitably produce “attempts to explain or understand” by family members (Rees et al, 2017). The inability to make sense of this behaviour would be one possible explanation for the high levels of rejection towards hoarding relatives and low evaluations of their perceived insight found by Tolin et al (2008; 2010) despite discovering that the worse the hoarding the better the reported insight of the hoarder (Tolin et al, 2010).

Worry about parental and own wellbeing (Rees et al, 2017) may be related to this deficit in knowledge about hoarding. Chasson et al (2014) found that hopefulness increased and self-blame, accommodation and negative impact decreased in family members despite quality of life scores remaining the same as pre-intervention, following psychoeducation about hoarding along with motivational interviewing and harm reduction training. Thompson et al (2016) found that their psychoeducational intervention improved levels of knowledge, wellbeing, and positive experiences but no reduction in stress, burden or expressed emotion. Their report highlights their intervention as the first to be aimed at carers without trying to involve them in treatment for the hoarding family member.

Listen to us!

Wilbram et al (2008), Tolin et al (2008; 2010) and Tompkins (2011) all reported aggression directed towards family members to some extent in relation to hoarding behaviour and the family’s response. In their 2008 study, Tolin et al found that a significant number of respondents believed their hoarding relative to fit the description “lacks insight/delusional”, a finding echoed by Drury et al (2014). Despite these indications of serious mental health concerns as well as domestic safety issues, respondents to Wilbram et al (2008) reported a lack of statutory support from mental health services and ultimately many described a resignation to their fate, echoed by the ambiguous loss of their family members described by Sampson’s (2013a) respondents. It may be argued that interventions are now available as evidenced in this review (Thompson, 2016; Chasson et al, 2015) but these are pilot studies with no reported follow-up yet and they are focused on different outcomes and do not show evidence of any great degree of consultation with families of hoarders in their development. Complaints by respondents of lack of help from all agencies, with no available explanation or

advice regarding their relatives' behaviour, were found by Wilbram et al (2008). Many had developed their own theories about what the underlying problem was and how to help. Tolin et al (2010) showed that family informants rated their hoarding relatives as having, overall, poor insight regardless of the severity of their hoarding but Drury et al (2014) found that insight was not in fact a predictor of greater family burden in families of hoarders and put forth the thought that caring for a relative with a hoarding problem with poor insight may cause increased levels of frustration as suggested by Tolin et al (2008). Reports of being ignored by health services appear in Wilbram et al. (2008). There is reported indifference and the need for someone to listen and understand the needs of family members and hoarders.

Summary of analysis

These papers present a set of themes which unite around the lack of available support, contributing to feelings of stress and tension within families as they try to deal with the effects of compulsive hoarding in their own ways whilst living in adverse circumstances, the effects of which may affect some family members for the rest of their lives. I found that there was a resource available for exploring this experience outside the research literature and next I want to give an overview of this and how I tried to use it to enhance the review and deepen my understanding. Whilst exploring this idea, I referred to these resources as "real voices"

Real voices

In 2012 there was little evidence to enable understanding of family members' experience of hoarding. Only Wilbram's (2005) thesis had explored this aspect of experience in a way which allowed the voices of those affected to be heard (subsequently published as Wilbram et al 2008). To enhance understanding of family members' experience I explored and exploited everything I could find. I gravitated towards narrative accounts as this is how I worked with and understood my clinical clients and their experience but also as that is all there was. There is a risk with such an exercise that the researcher is led by their preferences to materials which fit a preferred theory (Whittemore, 2007). In this instance, I took what there was and read it. The memoirs were well regarded by users of the children of hoarders website.

Frank (2012) advocates reading published memoirs to familiarise oneself with the current stock of stories available to people for their own use in representing their experience. He also highlights that stories are not just found in research interviews, but informally as well. In fact, memoirs are the exemplar of readability to which research reports should aspire to warrant publication. Acknowledgement of the fact that your research contributes to an existing body of literature generated by memoirists demonstrates “good scholarship and intellectual honesty” (p. 9).

These lines of inquiry provided a continuing source of rich information which provides illustration and a real-world setting for the issues described in the scant literature from researchers in the field. As time has moved on and research into family experience of hoarding has grown (very little, I might add), I have come to see the accounts of experience provided by non-academic experts by experience as essential in understanding their lives. They provide a source of potential triangulation for our research findings – a kind of virtual member check. They also have the potential to raise awareness of lines of inquiry not yet identified by research. The application of triangulation here may help to add the “rigour, breadth, complexity, richness and depth” suggested by Denzin and Lincoln, (2000 p.5) to the review, whilst acknowledging the inclusion of these texts may not add to the validity of the findings (Silverman, 2014).

In the original iteration of this search there had been very few studies into the lives of families of compulsive hoarders. There were, however, a few published autobiographical accounts of those who grew up in hoarded homes. Whilst above is a description of a formal review of the academic literature from the fields of social work, social science, psychology, medicine and nursing and the results thereof, further triangulating evidence for thematic development in this informal literature could be identified through use of these informal sources. This would fit with what Denzin (2009) has termed “data triangulation”, extending the ability to triangulate data produced by different methods offered by the integrative review process beyond academic sources altogether. It could also be viewed as an extension of the “interdisciplinary triangulation” suggested by Janesick (1994), in this case going beyond academic disciplines to include memoirs. Janesick describes how:

“By using other disciplines such as art, sociology, history, dance, architecture, and anthropology to inform our research processes, we may broaden our understanding of method and substance.” (p.215)

By having several accounts to compare there is an element of triangulation of reporters, too.

Selection of texts developed from the scoping review through use of the Children of Hoarders website and bookstore (set up on Amazon). Related titles were then searched

using the Amazon website and synopses examined for the inclusion criteria of first-person non-fiction accounts by family members of hoarders, to screen out fiction, and factual writing by family members of hoarders about other subjects. Self-help books, fiction titles and therapist manuals were excluded as they did not offer accounts of experience. Citations in blog posts and in reference sections of scholarly texts and self-help books were scrutinised for further examples. Reporting of the wider set of resources proved too difficult to report in any orderly way beyond the descriptions offered in the narrative. The report provided above in the description of the scoping review gives some degree of illustration, although it is acknowledged this is not perfect.

The literature in this category can be described as generated by the (adult) children of hoarders relating to their own experience of growing up in a hoarded house. Titles meeting the criteria were then entered book sites to look at related titles using the suggestions tool. A snowballing process in which these suggestions were examined for further titles which matched the criteria autobiographical accounts, written by family members of hoarders.

This process produced 5 titles:

Lidz, F. (2003) *Ghostly Men (Kindle edition)*

Allen, B. (2012) *Nice Children Stolen from Car (Kindle edition)*

Boudreaux, F. (2011) *Where the Sun Don't Shine and the Shadows Don't Play (Growing up with an Obsessive-Compulsive Hoarder) (Kindle edition) iUniverse*

Miller, K. (2013) *Coming Clean (Kindle edition) New Harvest*

Sholl, J. (2011) *Dirty Secret Gallery Books*

Details of these are available in appendix 8

Quality of non-research articles

A proven method of narrative analysis would offer findings of greater confidence than the process employed here, which consisted of reading the texts with reference to the developed themes and highlighting passages to the themes as they became apparent. Selected passages were then used to illustrate the themes in the interim viva report mentioned above.

Three of these titles (Boudreaux, 2011; Allen, 2012; Miller, 2013) appear to be self-published, could be the result of predatory practices and may not have been subject to the same level of editorial scrutiny as Sholl (2011) and Lidz (2008) have. Although, this may have allowed for a more frank report without the need for a focus on what "sells" to the same

degree. In addition, their focus is on reporting the experience of one member in one family, from their own point of view so triangulation application is limited as there has been none of the peer review employed in the research literature.

The emotional turbulence recalled in these memoirs may have served to produce an account prejudiced against those people and experiences described. Accounts by Allen (2012), Miller (2013) and Boudreaux (2011) are liable to recall bias whilst Sholl (2011) and Lidz (2008) are describing present difficulties in relation to past experiences and may well be emotionally affected. The temporal distance between the events and record opens up all of the accounts to varying degrees of recall bias. However, there is high degree of reflexivity in these accounts and efforts to create a balance of or come to terms with the dissonance caused by love and neglect experienced simultaneously in the lives of the writers are given depth not available in the research papers reviewed.

Had these accounts been pieces of research from academic journals, the need for reflexive statements of position and the application of ethical standards as well as measures of rigour as described elsewhere in this thesis would apply. Of course, given the context of these publications, these issues were not given consideration and as such the weight given to these accounts can, in this academic context, therefore be less.

Themes from real voices

Common to many of these is the idea that the problem is far more complex than the model of hoarding proposed by CBT (see chapter 1), which locates the problem within one person. It is played out in the emotional geography of the house (Davidson et al, 2005 p.4; Segrott and Doel, 2004) and in the relationships between family members. Emotional geography is defined as the effect a place can have on or be affected by the emotional life of a person or persons (Davidson et al, 2005). Reactions to the hoarding and interactions between family members coloured by this context could have systemic effects. In addition to confirming themes emerging from the above review, these books included the use and importance of imagination; the feeling of invisibility or attempts to become invisible; the desire for escape and the shock of seeing the conditions in which they had been living with the eyes of a stranger upon returning from living elsewhere. These are outlined in appendix 8

Synthesis of themes from academic and non-academic sources

The work of Tolin et al (2010) demonstrates that the ages of 10-19 are the most difficult and distressing to live in such conditions and the accounts of those who have written about their childhood experiences give painfully tangible examples of the problems of decreased privacy, lack of amenities for washing and eating and social isolation and stigma as well as the tense atmosphere of the house.

The physical deprivations caused to families by hoarding in terms of lack of privacy and facilities for activities of daily living are matched by the loss of the heart of the family (Sampson et al, 2012; Sampson, 2013a; Wilbram et al, 2008; Rees et al, 2017). The stress of this can fracture families and continue to cause emotional pain for family members even after they have made their escape. Continuing effects of living in a hoarded home as a child even as an adult away from the hoarded home demonstrated by Rees et al (2017), Tolin et al (2008), Chasson a et al (2015) and Thompson et al (2016). Park et al (2014), Drury et al (2014) and Sampson et al (2012) provide evidence that this may be due to continuing contact and support from children of hoarders as caregivers. Sampson et al (2013) also found non-caregiving relatives living away from the hoarding family member to experience negative effects.

A marked awareness of the difference between young people living in hoarded houses and their peers is evident from Tolin et al (2008) where the social isolation of 11-20-year olds is reported due to withdrawal over embarrassment regarding their living conditions. A mother reports that her son is being bullied at school and a husband expresses the feeling that his family are “keeping [the world] out” in the study by Wilbram et al (2008), who observe that the theme of retreat from the world is common with their participants. Rees et al (2017) also identify social isolation and avoidance of relationship-forming as childhood and adolescent traits of her adult participants. The overriding theme of this body of literature is the feeling of a lack support reported by the families of people who hoard objects. In particular, it is the adult children of these people who bear perhaps an emotional burden not only as caregivers for their hoarding parents (Park et al, 2014; Drury et al, 2014) but as people affected in their childhood by the same issue (Tolin et al, 2008; Rees et al 2017), leading to expressions of frustration and even anger (Rees et al, 2017). Sampson et al (2013) discusses the experiences of family members who do not live with their hoarding relative and Tompkins (2011) describes relatives who have retreated from the family home. Wilbram et al. (2008) surmise that both physical and psychological entrapment are very real for people who live with their hoarding family member. A son in the first case study of Tompkins’ paper fears that he will have to accommodate his mother at his home.

Drury et al (2014) identify, as does Sampson et al (2013), a need for family education and support to strengthen the family against the effects of hoarding. Attempts have been made to provide this with mixed results (Sampson et al, 2012; Chasson et al, 2015; Thompson et al, 2016). In the meantime, families argue, ignore, harangue and placate their hoarding relatives in attempts to keep the peace (Wilbram et al, 2008). Feelings of frustration and isolation were reported by respondents to early studies (Wilbram et al, 2008; Tolin et al, 2008) are confirmed by Sampson et al (2012), Thompson et al (2016) and Chasson et al (2014) who cite the group support format as potentially the most helpful element of their diverse interventions. Armed with knowledge about hoarding and a network of support long missing, the benefits are (very moderately) measurable (Chasson et al, 2014; Thompson et al, 2016). This perhaps demonstrates why the Children of Hoarders website, forum and network of resources has been so successful. Finding people who are experiencing the thing which you thought was your shameful family secret lends a degree of normalisation to the situation.

In the midst of this, the hoarding family member still appears to display little insight, as far as their relatives can judge (Tolin et al, 2010) only serving to fuel the negative emotions of guilt and frustration further (Tolin et al, 2008). There are examples of social withdrawal (Wilbram et al, 2008; Tolin et al, 2008; Sampson et al, 2013; Drury et al, 2014; Rees et al, 2017) and of stigmatisation (Wilbram et al, 2008; Rees et al, 2017). The combination of shifting perceptions in the media, the public and the medical consciousness will undoubtedly change the context in which hoarders and their families are seen (Herring, 2013; Boland, 2012). This may bring with it hope in the form of treatments and interventions (Chasson et al, 2015) and a sense of normalisation (Sampson et al, 2012).

Adult children (Park, 2014) and partners (Vorstenbosch, 2015) of hoarders' responses illustrate reasons for tensions described by earlier papers (Tompkins, 2011; Tolin et al, 2008) but also show the desire to help shown by Tompkins (2011) and Wilbram et al (2008). The difficulty of navigating the family ties and the carer stress and burden described by Drury et al (2014) is illustrated in *Dirty Secret* (Sholl, 2011), where Jesse struggles to remain at a distance from her mother due to worries about her safety (as discovered by Rees et al, 2017) but finds it equally challenging to maintain contact owing to all the problems associated with the effects of the hoarding behaviour and the stress this brings (Tolin et al (2008); Wilbram et al, 2008). Participants in studies by Park et al (2014) and Vorstenbosch et al (2015) showed continuing negative consequences to their own wellbeing and to family functioning through continued contact with their hoarding relative but this evidently has not prevented them from maintaining their relationship with that relative. The links between impairment and relationship quality are complex (Park et al, 2014; Vorstenbosch et al, 2015)

and it would appear that even when understanding of the hoarding behaviour is improved in family members, their levels of distress and impairment remain high (Thompson et al, 2016; Chasson et al, 2015).

Drury et al (2014), Park et al, (2014) and Vorstenbosch et al (2015) all deal with the subject of “family accommodation”, first suggested by Wilbram et al in their discussion. Wilbram et al, 2008 appear to offer positive and negative readings of family interactions before suggesting this line might be worth investigating. However, the subthemes from their research which suggest positive experience have not been pursued by later studies. Boland (2012) perhaps offers an explanation of this difference by way of media and cultural paradigms, describing the need for families to conform to a model of consumption which includes a certain demand for disposal. Families which are together working to put their family’s survival before this demand could be said to be “accommodating” a deviant behaviour or could be said to have different priorities to society at large. An acceptance of family obligation can be found in Sampson et al (2013) Wilbram et al (2008) and Tompkins’ (2011) papers. This is most vivid in the account of the son who dreads the day when he will be required to have his mother live with him in Tompkins’ account. A client in a second case study in this paper expresses a wish for her support team to comprise her two daughters and no-one else, indicating the level of pressure applied to the family bonds by some hoarders’ anxieties. Sampson et al (2013) demonstrates that even when family members no longer live with the hoarder and do not have a “caretaker” role, they share those same feelings of family duty and loyalty. Vorstenbosch et al (2015) described how respondents who live further from their hoarding relative accommodated less.

With the above indications regarding the poor insight of hoarders into their problems (Tolin et al, 2010) and therefore frequent possibility for conflict within households (Tolin et al, 2008; Wilbram et al, 2008), the very fact that so many relatives were engaged in all of these studies when they could have simply forgotten about their hoarding family members could indicate that there is an enduring hope that things can be better in some way. This is particularly vivid in the examples provided by Tompkins where close and estranged relatives are still keen to be involved with practical and financial support. Sampson et al (2013) on the other hand, notes that 11 of her 12 interviewees stated that they had “given up” attempting to help their hoarding relative despite the fact that their participation in her study may suggest otherwise.

Level of accommodation may be mediated by severity of hoarding and level of perceived insight (Vorstenbosch et al, 2015) but this does not address reasons for accommodation, which these findings suggest are lack of knowledge (Wilbram et al, 2008; Sampson et al,

2013; Rees et al, 2017; Chasson et al, 2015; Thompson et al, 2016) and lack of services to deal with this issue (Wilbram et al, 2008; Rees et al, 2017).

Family members do not know where to look for help, or even why their loved one is behaving in the way that they are, indicating a lack of information. There is a vast number of people who have sought independent expert advice specifically for hoarding problems (Tolin et al, 2008b;2010c). Tolin et al. (2008b; 2010c), who represented a small group of academic (and media) figures associated with compulsive hoarding at the time of recruitment show that thousands of people have contacted them for help. They were probably not their first port of call as they are expensive and difficult to get hold of. They are the authority on these issues globally so having to go to them indicates there is no lower level support structure.

What is common to all of the above themes is the contributing factor of the lack of outside support for families. This puts stressful demands upon families, allows quality of life to decline (Wilbram et al, 2008) and both of these factors can contribute to family breakdown. Tompkins (2011) found that families needed more help and the fact that people are seeking his expert help as well as that of Tolin, Frost and Steketee suggests that there is a lack of statutory support available.

Wilbram found complaints of a lack of help from statutory and non-statutory services.

Interviewees expressed bewilderment at their family member's behaviour and a wish to have an explanation. Many made guesses at what the cause might be and how this could inform a cure.

In all cases it is evident that family members are seeking answers from outside as well as within the family. The authors of the autobiographies put forward synopses of the current state of the scientific knowledge about hoarding in an attempt to explain and make sense of their relatives' behaviour (Sholl, 2011; Miller, 2013; Boudreaux, 2011). The participants in the research papers were volunteers recruited from people who had already sought help for their relatives from outside. The original number of participants looking to take part in the survey by Tolin et al (2008;2010) was in the thousands, illustrating the magnitude of the problem. Perhaps Thompson et al (2016) are indicating the direction interventions for family members of compulsive hoarders need to take – a focus on the person not the hoarding as suggested all along by Tolin, Frost, Steketee and other hoarding experts. However, this focus on the person should be applied to the non-hoarding family member as much as it should the person with a hoarding problem. Given the lasting effects of sharing hoarded accommodation as a child (Tolin et al, 2008; Rees et al, 2017; Sholl, 2011, Boudreaux, 2011), the continuing stress of living as an adult with a hoarding relative (Drury et al, 2014; Vorstenbosch, 2015) and the demands of caring for someone with a hoarding problem (Wilbram et al, 2008; Park et al, 2014; Sholl, 2011) an understanding of what these people

would benefit from and what they see as needed for their own wellbeing needs to be sought.

Discussion

Despite many objections to the additions and revisions made to DSM-5 (DCP, 2011; Allen, 2014; Society for Humanistic Psychology, 2013), the World Health Organisation (2018) is offering a set of classifications for hoarding disorder including a catchall “not otherwise specified” category, which gives greater weight to the clinical gaze. Yet, when looking at the body of research evidence around compulsive hoarding (or hoarding disorder as it became known around that time) one thing was immediately clear. There wasn’t much of it. And what there was, was pretty weak. How could it be that a diagnosis had been created seemingly before there had been any serious consideration given to the thing itself. Then one looks at the rest of DSM-5 and wonders what is going on. There has been outcry from most quarters about this tome but there it stands. The power resides within the words.

There are pre-existing narratives of hoarding found mainly in popular media and psychiatry/psychology research (e.g. Frost and Steketee/Hoarding: Buried Alive). Frank (2014) suggests that these stories are autonomous actors evoked by tellers in an act which they believe is the generation of a new story. In fact, older stories of illness and cure and of eccentricity and perhaps of the Collyer brothers’ untimely death (a restitution narrative), were being evoked in the pathologising of a complex problem.

Reading the opening chapters of the Oxford Handbook of Compulsive Hoarding and Acquiring (Frost and Steketee, 2014), the process of constructing the narrative of the clinical hoarding problem using existing narrative means becomes obvious. First, a piece of research identifies a set of students within a population who keep more things than other students within the same group (Frost and Gross, 1993). Then this exploration is expanded to the local populace (Frost and Hartl, 1996). Having discovered there are people in the public at large who also keep a lot of items, a suggestion as to why was produced using an existing psychological model (Frost and Hartl, 1996). Numerical data was then sought as to who, what, where and why (please see chapter 1 for examples). This went on for twenty years alongside strident efforts to “prove” that this was a discrete problem which was not attributable to previously identified causes and therefore required specialist attention (despite significant evidence produced by that very research that in fact this problem seldom if ever occurs in isolation – e.g. Frost et al, 2011). At the end of the twenty years, the story was formalised in the canon of cultural narratives known as the DSM-5. At the same time, a historical perspective was outlined (Penzel, 2014), synthesising historical figures, literary

fiction, religious imagery and the arts, creating a story not unlike that found in chapter 1 of this thesis. The past has been informed by the present and (one might argue) certain considerations of the future. In turn, the past has then been called forth to reply to the present by way of confirmation (albeit tenuously in some instances).

Richard Wallace's whole village ostracised him as a pariah who was ruining the image of their home until one person decided to engage with him at his own pace and work with him on tidying the place up (Trumble, 2011). Demonstration of the effectiveness of this approach and the acceptance offered to Richard by Andy Honey and his family produced a tidier village and lasting positive relationship. By changing the nature of the relationship between family members through introduction of education around hoarding, as demonstrated by Thompson et al (2016) and Chasson et al (2014), relationships can be strengthened.

The poststructural/postmodern posits the need to replace grand narratives which constitute our rules for understanding the world with smaller, locally situated and constituted little stories (Rolfe, 2000). Many voices can be represented rather than one unified set of facts. Foucault, it is argued by Burr (1995), suggests people have the ability to change and influence the discourse. This is contradictory to common criticisms that Foucault is neo-conservative or at least that he offers no hope for change (Alvesson and Sköldberg, 2009). In this research project, it is hoped new narratives will emerge which challenge this idea of a finished, formalised and "proved" narrative of hoarding as a disorder of the mind. The proliferation of experience of hoarding in wildly variant circumstances suggests that it would be highly unhelpful to treat this multifarious phenomenon as if it were a singular "problem" and even more so an "illness" which suggests a cure. As with other concepts from psychiatry (Szasz, 2010) such as schizophrenia (Bentall, 2004) and depression (Bentall and Pilgrim, 1999), empirical evidence for this disorder is at best tenuous.

Lyotard (1984) suggests that grand narratives such as the march of scientific progress following the enlightenment can be alienating and disempowering. Instead, localised accounts which resonate with audiences offer new ways of making sense of experience. The constant questioning of Boudreaux (2012) as to the cause of her mother's condition offers a clue, I think. What is required is an acceptable explanation which will provide mitigating circumstances for the hoarder, permitting the family to better tolerate their experience and interact with their relative without thinking of them as "hoarder". But the notion that my explanation will be as helpful/applicable to you or everyone in the same circumstance must be abandoned.

The development of knowledge around compulsive hoarding offers greater understanding to be offered to families and service providers struggling with this problem. Chasson et al

(2014) and Thompson et al (2016) have shown, however, that this does not mean that things will necessarily be easier in living and working with people who hoard objects. Rather, they have demonstrated that the burden can be better born if the bearer knows “why”. An attitude of informed, patient solidarity with the hoarder can reduce the conflict and other resultant injuries caused by attempts to cure, chastise, or in other ways “improve” the person with the hoarding tendency. This brings the discussion back to the book I mentioned at the beginning of this chapter, “The Woman Who Saved Things”. The awareness of the individual needs and character of this woman allows her family to interact with her and her possessions without conflict. They do not look to fix her or to outsource professional assistance. Illich (1976) has focused on the expropriation of health by medical institutions for their own purposes which has led to a diminished ability to suffer with meaning owing to the commodified nature of pain in a medicalised culture. This creates a distraction from the causes of suffering which are much larger. Focus on the individual circumstances and behaviour of people who hoard objects reduces tolerance of this distinct difference in family members and distracts our attention from the bigger issue of late capitalism and its celebration of excess, wasteful attitude to materials and people and its focus on the self above all else (Fromm, 1947, 1976; De Graaf et al, 2005; James, 2007; Dennis, 2017).

As a body of literature, what we have above largely looks on hoarding and family experience not with curiosity, patience and a sense of the person’s story but with a sense of homogeneity, impatience and urgency (Herring (2013) has referred to this as a moral panic after Cohen (2002). Development of interventions to cure a medical problem that affects up to 6% of the population and brings comorbid mental illnesses and physical and economic consequences for the individual and psychological and social ones for their families on a scale equivalent to serious mental disorders. But there are some generalisations involved in the development of this story and this story as with all stories, is being told for a particular audience and a particular effect. Derrida (1976) proposes that all texts are wholly contained within themselves and cannot signify some other (referent) external to themselves, outside of language. The construction of texts invites their deconstruction in a search for understanding of these and other factors which will illuminate the message of the text. This deconstruction is then an object for further deconstruction and this process can continue in perpetuity, a new text being generated at each approach (Freshwater and Rolfe, 2004). So begins my social constructionist research project. Firstly, deconstruction. Secondly, an acknowledgement of the relations of power involved. Thirdly, an attempt to create helpful new constructions, each one specific to the context and players involved.

As can be seen, we still know little about hoarding as a discrete phenomenon. Perhaps this is because it needs certain conditions to thrive. As mentioned in chapter one, certain family

factors (having a first degree relative with a hoarding problem), certain cognitive factors such as aging, certain life experiences, certain other mental health phenomena and a host of other factors may either together or in any combination or in isolation be connected to hoarding. Perhaps this offers a suggestion or two for those interested in improving the life experience of families affected. Further investigation may provide a set of different categories of hoarding (as presciently suggested by a professional declutterer in our telephone conversation) which may offer more specific interventions for particular hoarding types. Or, perhaps the hoarding should be seen as symptomatic of other issues given the high rates of comorbidity which, when addressed, may have beneficial effects on the hoarding. Or, the hoarding could be seen as something which could be managed without it becoming the focus for everyone's attention all of the time (in the way described by Park et al (2014) and Vorstenbosch et al (2015) – a long-term condition as Tompkins (2011;2015) suggests. But this is still only one way of examining such experience.

Information about hoarding is becoming more available but has its faults and the most available sources (e.g. Hoarder next door), despite doing some exploratory work and not taking things at face value, offer a promise of a quick fix which other literature reviewed here and peoples' real-life accounts suggest is not attainable in the majority of cases. Similarly, by presenting hoarding as a singular phenomenon which requires the development of a singular solution, the wide variation in presentations and origins of hoarding which can cause distress is overlooked. Respondents in some of these studies (e.g. Chasson et al, 2014) were equally distressed regardless of level of hoarding, so by developing measures which are designed to assign problem status to some but not others, we run the risk of developing a means to "screen out" some people from sources of help.

The development of the hoarding literature over the period of this study was significant and the narrative appeared to have turned by the time of the 2017 update. Interventions were being piloted and the concept of accommodation (e.g. Calvocoressi et al, 1995) had begun to be applied to hoarding in talking about families almost as a matter of course (hoarding disorder is listed under obsessive compulsive spectrum disorders in DSM-5). Most papers originated from the US where healthcare culture is different to the UK and the diagnostic system is also different. Ideas about hoarding have had longer to develop in that culture.

In Britain there is no standard response to many of the questions raised by the families of hoarders as statutory services have only just begun to address the issue. The inaugural UK Hoarding Awareness Week, organised by Chief Fire Officers Association (CFOA) in May 2014 (National Fire Chiefs Council, 2018) and involving professional declutterers, trainers of professionals working with hoarding, building services and health professionals may signal a

change in this respect. In particular, what stands out from the footage and documentation available (Chief Fire Officers Association, 2014) is that the focus is much more on an understanding approach to managing the behaviour and less about “treatment”. This initiative has been continued by a housing charity. HoardingUK is now the official charity for hoarding in the UK (HoardingUK, 2017). Initiatives to combine health and housing are still in their infancy despite the example given above from Liverpool Housing Trust.

The very act of seeking help from non-statutory agencies, such as those run by the authors of these papers, may indicate a lack of satisfaction with the response of statutory agencies to the problem of hoarding. Individuals taking part in these studies are by and large people who have already sought help from the researchers for family hoarding problems. However, it may be the case that as the majority of these cases are from the USA there is a different culture regarding help-seeking for such problems, and is there any need for a standard response when there is arguably no standard problem. The risks to health appear to be the same but the underlying problems and comorbidities are so varied.

We could also look at the adoption of non-statutory services as providers of support in cases of compulsive hoarding as being necessary, not due to the absence of statutory services but due to the inability to respond to complexity in a coherent way, through adaptable approaches and creative responses. The restrictions brought about by care pathways and packages as well as localised targets which set statutory services at odds with each other in a game of numbers do not serve to encourage engagement on uncertain terms, perhaps. There is no tolerance in the system for uncertainty. Or for prolonged engagement without rigid boundaries.

Only three of these studies were conducted in the UK and this indicates the lack of attention this issue has received in this country. With DSM-5 published, and ICD-11 reportedly intending to include a hoarding diagnosis along similar lines (World Health Organisation, 2017), it must be time for more research to be conducted in this area to formulate care strategies for service users affected by this problem and their families. Furthermore, this provides an opportunity to examine how families are involved in the care of their relatives with any chronic diagnosis and the role of children and its effects on them. All the papers, books, films etc. consulted used the views, memories, and insights of adult children of hoarders recalling their own childhoods. Nowhere is there any record of the views of children other than in brief clips of television shows. Chabaud (2012) highlights the risks to this group in terms of physical and mental health with anxiety and depression common to their adult experience. She has devised a checklist for professionals who believe they may be working with a child living in a hoarded house (which has been taken down from the OCDGNO website as it is in the process of being co-opted into the IOCDF of Frost and

friends). This group (children living with a hoarding family member) are therefore a significant group of interest and deserve to have their voice heard. The other absent voice here is that of the hoarders themselves. The views of hoarders about how their behaviour affects their families would be incredibly valuable in developing an approach to the problem. Thus far, only Kellett (2010) appears to have addressed this problem and even then, only as an emergent theme rather than as the object of study. In families there may be many possible solutions being acted out all over the country and indeed the world but if the components of the family are examined in isolation using impersonal and generalised questionnaires aimed at quantifying inconvenience, how are we to find out?

This realisation has led to the formulation of this question:

What sources of help do family members of compulsive hoarders seek and why?

Strengths and limitations

As Hopia et al (2016) have noted, the reporting of integrative reviews is in most an unsatisfactory business and leaves many such reviews open to the criticism that they are not fulfilling the requirements set out by Whitemore and Knafel (2005). Whilst every attempt has been made to satisfy these requirements in reporting, there remain some problems. Firstly, in reporting the grouping of papers for analysis.

As will be discussed in chapter 8, the delineation of research as “qualitative” is contentious, as there is no definitive uniformity in qualitative research and even the underlying philosophy can be widely divergent from one study to the next (Rolfe, 2006b). Perhaps it is better to look at the papers as constituting “waves”, with the first wave being those papers published before DSM-5 which sought to describe experience, the second wave examining relationships between the phenomena described and the third attempting to produce interventions to ameliorate the effects of those phenomena described in wave 1 and 2. The hermeneutic approach to this review allows for a temporal charting of developments in the knowledge around families and hoarding. How it is developed through successive investigations. And how the findings of previous reports are appropriated by their successors in new ways. I can offer an interpretation of the evolution of understanding family experience hoarding in the clinical literature from the perspective of someone who has reviewed this at three separate intervals over five years.

Using the eclectic methods of searching described above enabled a richer description of families' experience of compulsive hoarding to emerge. However, as a new researcher, there are possibly areas of exploration which were missed. In addition, combining principles of different methodologies makes the reporting difficult and in places unclear. The preliminary use of a limited number of social science databases in the update is an example of an area where further exploration may yield a greater number of papers and potentially balance the results which are naturally steered by the clinical/medical literature from which the papers were principally gathered. Methods for exploring non-academic literature were not entirely systematic and this process could be refined for future use with reference to methods employed in other disciplines such as English literature and history.

With texts as long as these, the production of a workable analysis after the mode of that employed for research papers was not a viable option. A narrative analysis would be most appropriate here. Patterson (2008) suggests that this has the benefits of focusing on perspectives and in hindsight I would have been better served undertaking one. As I mention above, this was a bold step for a new researcher and one I hope to develop in the future, improving skills in literary and narrative scholarship through appropriate channels at my institution and elsewhere.

A lack of familiarity with the methodologies employed in some of these papers will have weakened my ability to offer sufficiently robust critique. Use of a systematic tool will hopefully, despite its inherent limitations, have improved my performance here. A problem with grouping papers by type for analysis was finding a place for Tompkins (2011) case study which did not sit easily with either group, having neither a developed set of themes or statistical findings.

Despite many of the measures employed to try and ensure no new papers were missed, these methods were all fallible and as such it can never be guaranteed that some did not escape my attention. The resulting number of papers for analysis was small. Use of assistance from a librarian may have helped in improving the integrity of the search. Alert systems may not have been sensitive enough to notify me of all new literature as it emerged owing to missed sources of alerts leading to useful accounts not being set up.

Emergent thoughts following literature review

27/04/2014

Today has been something of a race against time I am already late leaving but must get this down now. It is impossible not to become angry at the sight of where the major players in the hoarding world are taking things. To me there is no thought given to anything but publishing as much as possible as fast as possible. What is not being thought of is the effect that this increasing medicalization is going to have on families – their expectation of treatment for their relatives and their expectation of understanding from outside will not be met by measuring and packaging their pain or their perceived needs. I am finding this lit review to be very depressing and I can't wait to get out the other side and go and meet some real people.

Reading the journal entry above, I remember feeling that I still had limited understanding of the complex and fluctuating experiences of families hinted at in the autobiographical literature and that the only way to find this was to begin to engage with them first-hand and face-to-face. It wasn't the process of reviewing literature which I found depressing but the apparently hasty arrival at generic answers to what seemed to be anything but a generic problem.

According to Jones (2006) literature reviews repeat and reinforce the skewed versions of truth produced by the literature itself, favouring larger quantitative studies and losing essential details. By including literature from as broad a range of sources as possible, the mechanism of construction of hoarding disorder, involving clinical, academic and media aspects which intertwine and feed each other becomes apparent. It also offers new ways of understanding experiences of hoarding which the limited amount of formal literature could not. Before the furrow is ploughed any deeper, perhaps it is time to re-examine the field and look at alternative readings of the hoard.

Chapter 3 A dance through iterative qualitative research

Introduction

“Just as dance mirrors and adapts to life, qualitative design is adapted, changed, and redesigned as the study proceeds, because of the social realities of doing research among and with the living.”
Janesick, 1994 (p.218)



Figure 12- The steps of a dance through iterative qualitative design

Chapter one of this thesis explored ideas about compulsive hoarding and its origins, features, and effects, giving an account of how the idea of a specific compulsive hoarding problem developed throughout the early part of this century to become an object of clinical inquiry and ultimately a psychiatric diagnosis. From one point of view, a psychological discovery (a significant number of people struggle with managing their possessions to the point of impairment) was made (Frost and Gross, 1993) which led to the development of further discoveries (the features of the disorder, the populations affected by it, treatments etc) which gave greater clarity to the emergent discovery (Frost and Steketee, 2014). But to other eyes, a system of medicalisation of deviance fed by moral panic led to a wider and wider variety of human behaviour being classified as unhealthy, eventually taking in a person's possessions as signs of illness (Herring, 2014). As reported in chapter one, some of those affected by this issue found common cause in seeking a solution to it and to its effects on them throughout their childhood and beyond.

In chapter two a review of the literature revealed that family experience of having a member or members with a hoarding problem can have disastrous consequences for individuals and families and this is compounded by the lack of knowledge around the subject and the scarcity of appropriate support to date. The search for a "cure" for hoarding featured heavily in the literature, even when the literature claimed to focus on families, and the notion of family accommodation appears to implicate the family in the illness, requiring a "cure" for this accommodation to be found as well. However, might this behaviour also be termed "supportive" or "acceptance"? There was some indication in the literature that the family could live with the hoarding problem and its effects whilst maintaining family functioning and that it was in fact when the family functioning suffered that relationships struggled.

In this chapter I begin by outlining my position at the outset – my philosophical and methodological ideas and their point of origin. This has a bearing on institutional ethics, creating some complications for ensuring institutional approval which I will come to next. Following this, I describe the evolution of the methodology with reference to Janesick's (1994) chapter on "The Dance of Qualitative Research Design" using the three stages. Firstly, in act one, I will describe and comment on recruitment ("warming up"), my journey around the country, the city of Hull and the internet looking for participants. Also, to report the parallel searching experiences of my yet-to-be co-researcher which will demonstrate the way in which a "mutual recruitment" took place. In act two "exercises", I will describe and comment on the turn the research took when we began to work together, the experience of collaboration and its limitations and the ethical issues it threw up. In act three, I will outline

the bespoke approach to data analysis we took and reflect on our experience of making sense together.

Social constructionism and research

Having looked at compulsive hoarding for two years already, I had found that I looked on the diagnosis of hoarding disorder with incredulity, amazed at its inclusion in the DSM-5 (APA, 2013) despite the slender body of evidence offered of its existence as a “mental disorder”. It looked to me from my explorations so far and encounters with people involved (see below for some examples) as though approaches to this problem in this country were more measured, person centred and understated (despite the NHS Choices website conflating hoarding with OCD and suggesting that SSRIs and CBT are pretty reliable treatments (2014)).

I guess here is a “lens” (Anderson, 2004) developed prior to meeting any potential co-researcher. A sceptical one and a dominant one. Meeting some of the people I have come across has reminded me that family members experiencing problems with their loved ones’ possessions are looking for answers. Approaching them with a sceptical tone regards the hoarding itself and its portrayal as a problem diminishes their genuine distress. They have been alerted to the fact that this is being taken seriously and the label of disease indicates to them the existence of a cure. How can I help, then? Helping is after all the initial intention of my interest in the subject. Isn’t it? Surely, I am not just some dreadful voyeur, craning to see round this or that person to get a good look at their mountain of possessions or their seriously messy life? But then, without that curiosity, would there be any research? Would there be any mental health care? Anderson draws the reader’s attention to the dangers of circling around our own preconceived ideas and not seeking contradictory views or anomalies. In meeting my first co-researcher I found some views which challenged my anti-problem theories about hoarding. But we haven’t met her yet...

This work takes as its ontological and epistemological basis social constructionism, which follows from GH Meads symbolic interactionism (Burr, 1995) in asserting people construct their world through their interactions with each other. Berger and Luckmann (1967) have a more sophisticated genealogical history for social construction, citing its roots in the sociology of knowledge with the work of Mannheim, for instance. They suggest that the world is constructed through ideas’ externalisation (people acting, having an idea – writing it down), objectivation (this idea is taken up by others who read the book – it becomes “fact”)

and internalisation (next generation inherit this idea as part of the numerous facts making up their world).

Gergen (2010) describes social construction as a language, a tool. It is not a Truth. It does not seek to replace other viewpoints. But it does give us a means to ask questions of those claims made to objective truth by others (Gergen uses the example of psychiatry). It roughly comprises of the meeting of three perspectives; linguistic and literary theory found in the work of Jacques Derrida (in particular the idea of deconstruction, 1976), Kuhn's (1996) ideas of the generation of scientific knowledge and the critical theory of Michel Foucault (1970; 2002). Social constructions include social construction itself, which many find problematic or even nonsensical (e.g. Hammersley, 2010). What social construction offers, Gergen (1999) suggests, is possibility. We construct therefore we can offer new ways of understanding and being together using this theory or tool. Gergen (2004) cites the examples of conflict resolution, therapy and research as areas where social constructionist ideas have proved particularly fruitful. Other applications are also on offer in education, for instance and more recently the Taos institute has held an inaugural social constructionist approaches to health event (Taos Institute, 2016).

Burr (1995) highlights four characteristics of social constructionism which she states are not exhaustive or mandatory for a text to be described as such. I have attempted below to identify how this text tallies with her criteria

1. A critical stance towards taken-for-granted knowledge. Given the origins of the hoarding disorder diagnosis as described in chapter one, and the influence this diagnosis has had on the research to date, the deconstruction of this concept would allow for a wider and deeper exploration. Grant (2001) has commented on how there may be a fear of taking critical, deconstructionist positions in mental health research owing to the potential for the unleashing of huge amounts of guilt in those involved in delivering mental health care. Recent bitter exchanges between psychiatrists and psychologists over how we understand and work with mental health show the strength of feeling. Some researchers with mental health nursing backgrounds have cited social constructionism as the means by which we practice, making such an approach to our research natural and even essential (Grant, 2001; Rolfe, 2015). But for others, it is nursing as a whole which is an essentially constructionist discipline (e.g. Holloway and Freshwater, 2007). The relational aspect, then is important to this project. A dialogic or a collaborative approach is required rather than a detached, objective one. Rather than seeking to discover knowledge "out there", we are aiming to construct new ways of understanding (Law, 2004). We engaged in conversation

and went together along a journey. Not interviews or observation but shared experience. We explored the possible understandings of hoarding and possibilities for constructing ourselves, too.

2. Historical and cultural specificity. Gergen (1999) claims knowledge is specific to culture and history. As a psychologist, he says, you have to look beyond the person in front of you to their context. Also, your job is not then done as these contexts continually change. This later developed into ideas of persons constructing their own stories, which is where we come in. The social psychology from which Gergen takes his stand is the thing which attracts me as a psychosocial practitioner. I am familiar with the problematisation of people affected by life which the social psychology movement offers a counter to and I have found it to be damaging, limiting and disempowering. People are not machines in need of reprogramming. They are messy and contradictory. Truth does not exist. This is a problematic statement at the best of times but in the post-truth era, exemplified by a distrust of “experts” and “fake news” in favour of appeals to emotion, this could sound like an anti-knowledge position. It isn't. It is a position which asserts that there are stories vying to be heard in every interaction (Gergen, 1999) If this series of events and conversations had taken place just two years earlier, the language would have been different, there would have been no formally enshrined concept of “Hoarding Disorder”.
3. Knowledge is sustained by social processes. The structures and processes operating in and around support for people experiencing problems with hoarding relatives appear not to be conducive to new or bespoke ways of responding. Being able to understand a problem from a personal non-professional and emotional perspective has been attempted but has stopped short, the ultimate “voice” residing with the traditional guardian of knowledge. In the end, the clinical research has generated knowledge which shifts focus from the local situated relationships within families to a generic set of similar features. Perhaps by exploring the experience of help-seeking in collaboration with a family member affected by the problem, it would be possible to produce new suggestions by drawing attention to previously overlooked issues. What cannot be avoided, is the final voice of the author (Etherington, 2007). So even in this attempt to escape certain social processes employed in healthcare and medical research, I am still an academic conducting research in the qualitative, social science image and have not escaped the situation described by Foucault (2002), in which power and knowledge exist in symbiosis and by default those in power determine what constitutes knowledge, which serves to perpetuate their positions of power.

4. Knowledge and social action go together. This is particularly noticeable in act II, when the influence of Tracy on the research process brings us into proximity with providers of services in an attempt to improve understanding and provision. This doesn't seem to ring true with Alvesson and Sköldberg's (2009) reading of social construction but it comes across strongly in *Invitation to Social Construction* (Gergen, 1999). This also takes us to Grant's point that knowing an unjust system exists and we are part of it, we must act (Grant, 2001).

People are not just "sponges" absorbing the consequences of the constructed universe, they are active, decision-making "rhetoricians" weighing up ideologies (Burr, 1995 p.83). If we create our world through discourse, then ontology proceeds from epistemology; is epistemology, even. Parker suggests three categories of object: ontological (material thing, never knowable), epistemological (talked-about thing, never accurate) and moral/political (created through discourse and sitting also within epistemological). This is problematic as we could confuse political with ontological (actually, Parker claims that things are passed off as ontological for nefarious reasons – see schizophrenia example) and I think this has happened. But who is to judge what is "real"?

Gergen (1999) describes the effect upon two students of a seminar around constructionist texts he has organised. They are devastated and horrified. All they take for granted has been called into question. Gergen tells us that there is a necessary "dark night of doubt" which precedes the grasp of constructionist potential. *This has a personal resonance for me. As a 21-year-old divinity student with established ideas about how the world and the world beyond that world worked, I had a crisis of faith. A term I have come across is "spiritual emergency" (Grof, 1989) or you might consider it "existential crisis" (Wolff, 1950) or "identity crisis" (Erikson, 1968) – all previous certainties are challenged and the sense of self, so bound up with these things, is in question too. The search for meaning has been underway ever since, and I think that in arriving (as much by accident as by design) at this point, completing a PhD and involved in the world of what is commonly known as "mental health care" stems from that. I note that Gergen himself came from a Southern Baptist background, which he embraced with relish as a child.*

In the light of the impossibility of objectivity, researchers must "...acknowledge and even...work with their own intrinsic involvement in the research process and the part this plays in the results that are produced" (Gergen, 1999 p.160).

Burr stresses the need for every attempt to be made not to privilege the account of the researcher over the researched in reporting interpretations of the research. Here she stresses the need for reflexivity. The aim of the research is to have usefulness, rather than to report a discovered truth. So, the purpose of the research is to construct rather than discover. This means that it is not neutral, is ethically founded in the need to do (Gergen, 1999). This need suggests an ethical imperative to act. A starting point for research grounded in action, as suggested by Grant (2001) above.

Steier (1991 p.1) notes that constructionist approaches to research call into question the notion of distinct disciplines. *I can see the world expanding and the carefully delineated spheres of knowledge fading away to enable purer forms of inquiry.* He won't even entertain cross-disciplinary or interdisciplinary ideas (after all how can you have an inter-disciplinary space between two non-existent disciplines).

I am unsure if it is the result of my earlier grounding in theology and philosophy, but I find it unnecessary to label research as owned by a particular discipline. More people will benefit if it is more freely available and not labelled as being "for" anyone in particular. Illich (1971; 1976) questions the appropriation and commodification of knowledge which transforms people from autonomous into heteronomous subjects.

Gergen and Gergen (1992) ask whether research is an act of discovery or construction. Where do categories come from? Social consensus. They go on to talk about "further research" as "further entrenchment" in the position established by the original consensus and this too relates back to Latour and Woolgar's laboratory observations. Results which do not fit with the existing body of knowledge are then dismissed as being "outliers" or "anomalies" (Law, 2004).

In defining constructionist approaches to research, Gergen (1999) claims empirical research holds to 5 tenets. Remain dispassionate, control the conditions, convert observations to numerals, search for *the* answer and separate truth from practice. What these tenets aim to do, is to remove the research from reality and deny their contextuality, says Gergen. Gergen makes the case for the use of empiricist methods and data but *in context*. You can find numbers within this document, lending a certain perspective to the earlier chapters. In fact, without these numbers, there would be insufficient case made for pursuing this inquiry in the first place. We can and do invoke these numbers in making our own case(s). What is required is the abandonment of the binary Qualitative/quantitative. Gergen finds many qualitative methods equally problematic. He brings up three "forms of research" he finds "particularly exciting". It can be seen from this text that all of them contribute to the method

employed in this thesis. Narrative allows us to challenge the tyranny of “sacred language” and the cultures developed and perpetuated by this. Collaborative Inquiry provides for the development of mutual goals and the inclusion of multiple voices including the investigators (although I would argue that this term applies to all involved if the project is truly collaborative) and Action Research, which demands neutrality be left behind in the light of the need to address issues of power and inequality.

By reviewing the literature I have found that the experiences of families living with a member who hoards have not been widely researched and the few interventions offered to them are focussed on reducing the hoarding rather than the well-being of these family members. Few have asked these people in detail about their experience, choosing instead to develop their own theories about causal relationships. The issue of family accommodation has been examined in cases of compulsive hoarding as a possible mechanism for exacerbating the problem. This has not been derived from the detailed accounts of those family members affected, although these have been called upon to provide retrospective evidence for this theory. So, I am interested in the experiences of family members of compulsive hoarders and their needs. What do they think will help? Where do they look for help? What stories can they tell?

Chapter 3 Act I: Warming up - Setting out – ways and meanings and the coming together of two travellers

Development of ideas up to ethics submission

The collective story, the story as yet untold which can empower those it gives voice to (Richardson, 1990), is the aim of this project. If the prevalence of people with a hoarding problem which could be classed as clinical is a high number (Steketee and Frost, 2014), why do so few seek help? Perhaps they do not want it. Perhaps they do not see this as a medical issue. The aim is to find what narrative brings these missing persons together as a counter to the received wisdom of the cultural narrative of the psychiatrically dysfunctional hoarder and their miserable family (itself a member of a new narrative group which superseded the narrative of the eccentric).

With such evident scarcity of qualitative data regarding any aspect of the phenomenon of compulsive hoarding and with the subject of family experience being such a personal and necessarily descriptive one, a qualitative investigation presents as the natural path to follow. It is hard to understand what the motivation was in using a survey to describe the experiences of people in diverse and adverse situations (Tolin et al, 2008) but the weight of importance given to this has been enormous (Tompkins and Hartl, 2014). Even in the case of studies which have employed a more sympathetic (or appropriate) methodology, the whole picture has not been obtained due to the participants being only one or two from each family (Wilbram et al, 2008; Sampson, 2013). Furthermore, it could be argued that the method employed in these studies (interpretative phenomenological analysis – IPA) (Smith, 2006) requires an unachievable goal. By this, the aim of employing reflexivity in order to achieve objectivity, is meant.

As a reflexive add-on to the above paragraph, once I began reading Gergen (1999; 2001; 2010) and I grasped the notion of collaborative research I saw less of a need to “redress a balance” in the evidence offered on the subject of families and compulsive hoarding at this time. The issue was more one of providing the right evidence by employing the most appropriate tools (Mills, 1959), these being modified in response to developments in the research (Janesick, 1994). Rapport (2004) reminds us that this is not a popular move in some circles, despite the pursuit of humanistic tools of research being an ongoing quest for others. She goes on to warn about the risks of taking the research method as the starting point over ethical and personal justifications for the use of particular methods (e.g. focus

groups or interviews). Jones (2004) has argued that interviewing has become a process in which the researcher's assumptions form the limited parameters of inquiry. This stands at odds with the stance taken by Newman (1999) in which researchers join in with their participants where they are. Gergen and Gergen (1992) suggest "tentative interpretations" of phenomena (p.88) by the researcher as a starting point. These interpretations can then be shared and the resulting dialogical explorations can inform further the original interpretations.

It was clear that understanding of the complex nature of compulsive hoarding is in its infancy and many aspects are yet to be addressed. Never is this more evident than in its effects on families. The research conducted so far using IPA (Wilbram et al, 2008; Sampson et al, 2013; Rees et al, 2017) had produced interesting insights into the experiences of families but I wanted to know what family groups (including the member or members with the hoarding tendency) would say to each other if they were able to share their experience as a group in a research context, slightly removed from the everyday context. I needed the flexibility to adopt, adapt and develop methods in agreement with the whole team for reasons of convenience (realistic commitment, ease of use), comfort (agreed boundaries, sense of control) and viability of the project. At the Royal College of Nursing (RCN) international research conference, 2014 I thought I found the answer.

I am still fancying myself as a grounded theorist here. ALL IS DATA – I couldn't get it out of my head. I had already taken this idea to my heart before I had heard Lee Yarwood-Ross and others from the Grounded Theory gang at Manchester Met speak in Glasgow (at the RCN international research conference 2014) and now I felt I had to do this. I had to engage in this iterative process. Of course, at the time I had not really spent any time examining what other iterative methodologies existed. In fact, the idea of leafing through a BIG BOOK of methods for qualitative research made me feel quite fidgety. I couldn't understand the idea of a prescribed way of proceeding which could encourage creativity, spontaneity and iterative processes. It made no sense. How could it?

The initial proposal for this thesis when I made my scholarship application in 2013 was the use of grounded theory to explore the sources of help sought by families of compulsive hoarders. In reviewing the literature for a second time, it has come to light that there is a gap in the literature which precedes this question. The opinions and experiences of adult children of hoarders have been consulted with regard to the effects upon them of growing up with a relative who saves things but there is no extant study or other record in the extensive and eclectic literature reviewed for this work which seeks to understand the experience and therefore the needs of children growing up in hoarded houses now.

What happened after this was I reviewed the literature with reference to family experience and applied for ethical approval to research family experience as described in chapter 3 That lasted a while and had some enduring influence on where I eventually ended up. In particular three ideas:

1. All is data – this was evident in the way I approached the review and it had been very fruitful.
2. Use of an iterative process. Again, there are parallels with the thematic analysis method used in the review.
3. Literature reviews only serve to skew thinking in the direction of existing ideas. Well, maybe this one wasn't literally applied but it served as a warning to maintain a healthy scepticism, and hopefully would remind me now and again not to fall into certain traps of language.

But shortly thereafter:

It would therefore appear to be more pertinent to gain insight into the lives of children and young people who are living in this situation now. Whilst the iterative approach of classic grounded theory (Glaser and Strauss, 1999) is still a valid and appealing method for exploring this new territory, a combination of the constraints of the three-year PhD format, the requirements of local ethics committees and the wish to attempt to portray the experience of these young people in a way which is relevant to them as much as it is to the academic and clinical worlds has led to the exploration of other techniques such as narrative methods (Riessman, 1993; 2008) and performative social science (Jones, 2004).

Jones (2014) describes performative social science as the attempt to reach people with relevant and worthwhile information and insights beyond the small audience usually granted to an academic journal paper. It is meant to be accessible both physically and intellectually. This entails the use of creative means to develop a shared language (Denzin, 2004). This may be during the research process if the project is collaborative or may be in dissemination or both. In the case of working with a family to explore real-life events and strategies this set of rules seems highly appropriate and fits with the idea of flexibility and adaptability in design. From a practice point of view, too, what would be the benefit for me, potential collaborators or anyone grappling with the issue of compulsive hoarding if the discoveries we made during the project were tucked away in a journal somewhere where access would be limited to those with the relevant accounts and research/publishing/discipline specific knowledge?

I wanted to produce something from the research which could be useful and accessible to anyone who came across it. That choice of wording is deliberate. I liked the idea.

Furthermore, due to the proximity of the researcher (funny how I used the third person there) to the subject within the context of his own family, methods of autoethnography (Ellis and Bochner, 1996; Ellis, 2009) were also considered. Photo-elicitation (Snyder and Kane, 1990) has also been discussed along with creative writing. Several attempts have been made to capture the elements of each of the methods mentioned in a form usable for conducting a piece of research.

All this led me to reflect upon the attempt to develop a “magpie method”, incorporating creativity, co-production, and narratives. Very early on I posted a question on Research Gate asking if anyone had tried to marry narrative research to grounded theory. The first answer I received was a very dry and somewhat patronising description of grounded theory. Despite quite a bit of interest around this question later, I felt that creativity and grounded theorists perhaps were not easy bedfellows after all.

This belief in the need for flexibility and development of ideas and approaches relates to Janesick’s (1994) notion of the dance of qualitative research design, which informs the three act structure below, with its identifiable “turning points” leading to adaptations or adoptions of method to meet the needs of the study. Janesick describes how new methodologies build on existing ones and develop them in new directions depending on these existing forms for their genesis. Reporting an evolving methodical process requires a degree of reflexivity to enable the reader to follow the process. Mills (1959 p.197) advocates vociferous journal-keeping to be ready for and aware of developments in one’s own ideas. Research comes from one’s own life experience and each individual is living within the context of their research. This notion becomes more pertinent in the next section of this chapter. By keeping track of thoughts, readings, occurrences, encounters and the rest, we are able to call upon these when they are required by circumstances or opportunity. In essence, just what the researchers from University College London below discovered. This is in essence the practice of reflexivity but as a matter of course, not confined to the context of a single project.

Reflexivity is the practice of examining one’s own position to the research, acknowledging the mutual influence of researcher and research on each other and in this case of researchers on each other (Etherington, 2004). It comes in various forms for various ends (Marcus, 1994). In using this term I am specifically referring to a deliberate acknowledgement of position and intention to give an audit trail not in order to foster

objectivity, but in the interest of robustness and whilst fault has been found with Lincoln and Guba's (1985) attempts to map qualitative methodologies to quantitative standards (or equivalents) of robustness (Reason, 1994; Sandelowski, 1993; Rolfe, 2006a; 2006b) it does offer a newbie like me something to measure my work against.

"Often, the inchoate nature of intuition tends to resist record keeping, requiring patience, skill, and sometimes sheer force of will to keep records of intuitive impressions and their context. It is not easy to blend the left-brained skills of documentation with the right-brained skills typical of intuition."

Anderson, 2004 p.325

Following this comment Anderson goes on to describe the unpopular "process grid" which she devised for use by her students, leading to her assertion that individual researchers will need to find methods of capturing their intuitions suitable to their individual needs. I found mine early on. It is the large white space and the felt tip pen. I had already used this to capture my developing themes in the scoping stage of the literature review (appendix 3), but I have since used it in developing ideas of methodology and process and sometimes simple pertinent questions. I have photographed as record various of these scrawls.

Procedural ethics

Adams et al (2015 p.60) suggest that there are three aspects of ethics affecting autoethnographic work. The first of these, procedural ethics, refers to the requirement for proposals to meet standards for human subjects research as assessed by an institutional review board to ensure compliance with relevant regulations and agreed principles of autonomy, beneficence and justice. Situational ethics, considered as decisions made in a specific context which arose from developments in the project, are discussed in act two, where they sit with other issues of development. Relational ethics will be addressed at chapter six. Whilst this aspect is a feature of the research throughout, the move to include myself in the text opens up new issues which fit well here. This research project was reviewed by the research ethics committee of the Faculty of Health and Social Care (now the School of Health and Social Work) of the University of Hull. This included forms for informed consent and assent (for children), a data management plan, information leaflet and poster for recruitment as well as a letter of invitation for potential participants who met an interview benchmark and a directory of local and national sources of help for anyone experiencing difficulties relating to hoarding or other associated problems.

The initial working proposal was to employ collaboration with narrative principles and arts-based methods. Namely, researchers (myself and a family comprised of cohabiting generations) would operate as a research team (including myself) reflecting on data generated by individual team members in whatever format they chose to use which reflected their experience of living with a family with a compulsive hoarding behaviour. These ideas stem from a version of Wengraf's (2001) Biographic Narrative Interpretive Method (BNIM) utilised by Jones (2004) and Hollway and Jefferson (2000) but without most of Wengraf's original method. The idea that researchers needed to be trained in researching their own experience felt somewhat insulting to me and I therefore wanted as much of the nuts and bolts of the research design to be co-produced as possible. To bring in a method from someone else did not match this intention. Essentially, it undermines the principles of codesign (Iversen et al, 2012). Therefore this sentence concluded the design description:

"The co-researchers will form a research team which will agree upon the design of the research and therefor these suggestions are subject to revision."

Risks to potential participants (identified from the literature review) included distress at discussing emotionally difficult subjects, conflict amongst family members over the hoarding, and misreading research for therapy. In addition, there was the risk of discovery of a safeguarding concern. In this case I would notify the family that I would have to make a referral immediately and encourage them to help with this.

The design presented difficulties in the ethical approval process, owing to the level of ambiguity inherent. Even after I finally attended the committee in person to explain the principles behind co-creation of method and the ownership of the research being of all those involved, I still had some questions about informed consent being levelled at me. I found this very difficult as the principle is that those taking part in the research decide on and influence the research design and implement the research.

Ultimately, I had to include a description of what form the study might take so there was something to consent to, with the additional clause that this was just a suggestion and the design was expected to be finalised collaboratively with participants. There is ambiguity around many aspects of the application owing to the fact that this is merely a suggested design and the final project will be shaped by collaborative consultation between all involved.

The plan for recruitment was to begin with canvassing for participants using posters, flyers and presentations. I was careful to keep the wording open as possible to avoid creating a stereotype. This wording was remarked upon by one community service manager as "not getting to the point". Perhaps this hampered recruitment. I also specified participants

should not be involved with statutory services at the time as I hoped to find an example of a family which managed the hoarding in such a way as to be able to provide helpful examples of how to live with hoarding. This potentially limited suitable participant numbers too far, as some contacts came to me with suggestions of families on their caseloads. I also hoped to find a family with two or more generations under the same roof, perhaps with children (their experiences having not been the subject of research as yet). This meant the necessary creation of an assent form for children to sign as they would still be subject to parental consent to take part.

If someone contacted me they would be given an information leaflet to ensure they were in full knowledge of what they were consenting to and the powers they would have to determine how this is shaped. They were also given the “sources of help” document, in case they were in immediate need of help or had come to me seeking help and not wanting to be involved in research or there is some other reason why it was appropriate for them to seek help immediately.

If they found the suggestion (and the researcher) agreeable (they were to contact me) I was to send them a letter of invitation asking them to make arrangements with me to visit them at home to sign consent and assent forms (if necessary) and agree the mode by which we would proceed. After this, participants would be free to leave the project at any time, the team (including them) deciding what to do with any data they had provided so far.

Ethical approval was granted in February 2014 and it was agreed that I would notify the chair of any developments. I did this by letter in January 2015 as reported below.

Recruitment

As the recruitment process continued (and responses continued to bear no fruit) the definition of gatekeepers broadened to include anyone encountered anywhere who might know a family meeting this description. There were responses from conference attendees, service providers and colleagues which initially looked very hopeful. There were some very near misses. But in the end, it was one of my early gatekeepers from a not-for-profit non-statutory service provider who provided the connection I was looking for. Sort of (see figure 13 for illustration).

Recruitment to this study may be difficult. The willingness of adult participants to be involved in research about families and hoarding so far has been linked to their attendance at support

groups. As far as I am aware, there are no support groups for young people in this situation. The other problem with recruiting in this way is that there will be a very specific set of reasons why people attend such a group and it would be fantastic if we could rule out this possible skew by recruiting from somewhere where the factor in common was age rather than grievance. I propose trying out local young peoples' services buildings and popular venues (such as fast food restaurants, games shops etc) but also approaching local and community radio and using the internet.

As part of the networking and awareness raising stage of this project, I have addressed support time and recovery workers from a local NHS trust. This has raised many interesting discussions around how many current clients there are with hoarding problems and what the access to them is like. A problem with following this route of recruitment is that they are already receiving a service from mental health workers and therefore will not necessarily fit the bill for what I want (actually, they could do). I am also trying to avoid lengthy ethics meetings with NHS and social services and many of these people have involvement from both.

This leads me to a (very long and sometimes uncomfortable) telephone conversation I had with a professional declutterer and organiser in September of 2014. She laid out her understanding of hoarding and her own sub-categories of hoarding. There were those who could not be helped, those who could be re-trained, those who were “wanna-be hoarders” and therefore were seeking help (this made me think of innocent witches drowning and guilty ones floating then being drowned. It also reminded me of some of the reaction to people with personality disorder diagnoses I had come across as a nurse and clinicians' reactions to them. (In fact, research suggests the comorbidity rate of hoarding and personality disorders could be significant (Frost et al, 2000; Mataix-Cols et al, 2000; Samuels et al, 2007;2008)).

She seemed very embittered after a very negative experience with psychologists at a conference where she and her team were, she believed, treated as lacking credibility due to their lack of professional qualifications despite their extensive experience working with hoarding problems. She also decried the current research base developed in the USA as inaccurate, flawed and biased. This is a key point for this thesis; who is the expert and what do they know? Before Mataix Cols et al became interested in Frost and Steketee's work, people like this woman were already expert at obtaining clutter free living space for people (as were Matt Paxton (e.g. 2011) and Suzanne Chabaud (2017)), despite some methods which may not have been of equal benefit for everyone they encountered.

A third source of early information and ideas was the hoarding specialist for a housing association with concerns all over the midlands and South-East of England. She stated she would not be comfortable allowing access to clients for the purposes of research but may know of alternative ways of recruiting. Her organisation's research department, in conjunction with the University of Coventry, was conducting research into hoarding in the UK and may prove a useful partner in this process. Sadly, it appears that this project was never completed. The training offered to professionals working with compulsive hoarding problems proved to be very informative and useful in provoking thoughts about how best to work with people with hoarding tendencies and their families without risking my personal safety or offending the people involved. In addition, a conference organised in Ipswich, Suffolk by her organisation to establish a new hoarding task force for the area, has invited me to chair a table as part of a World cafe event and this will enable further networking and may produce further suggestions for how to access populations.

A further opportunity from this came on the form of a presentation spot at a National Housing Federation workshop in Halifax in February 2015. Presenting my challenge to the established wisdom on compulsive hoarding was not really the appropriate move for this event, which focussed on finding solutions to problems, but I did make some new connections

Using a familiar figure with family experience of hoarding here reported as "C" as a sort of preliminary consultant seemed like a good idea initially but there are major problems once you get past the common experience stuff such as impaired living conditions and social awkwardness. She herself had lived with a relative with a severe hoarding problem and had appeared on a television programme in which the home was cleared before embarking on the foundation of a hoarding consultancy, becoming something of a figure in hoarding work. C herself indicated the differences between individual cases in her email but there is also the cultural dimension. Hoarding in Britain may not be viewed in the same way as it is where she lives. Even ignoring the fact different ethnic populations may have different views regarding hoarding, the general national context made up of historical attitudes to health and illness, possessions, morality, cleanliness and who knows what else is sufficient to suggest to me that for identifying potential problems and considerations for a project taking place in Britain, it is necessary to have a discussion with people here. I hope through links in Suffolk I can perhaps gain access to a family for this purpose. Another option would be to contact the OCD help group in Hull so I'll do that next. (15/8/2014)

I attended this group and made a pitch for participants. The group were very welcoming but could not think of anyone with a hoarding relative or habit they were aware of. They taught me a lot about the tensions OCD can create between family members.

Following these long treks around the country I began trudging the area around University with a bunch of flyers for the project. I called in to all the charity shops then drove around the city in the car visiting community centres for the same purpose. The pursuit of this elusive family was a lengthy and frustrating affair, with several near-misses. In the interest of expediency, I have not included all details. Obstacles to people taking part varied but revolved around a central issue of shame. In one case, a family member could not bring herself to talk about the issue. In another, accessing the family home proved to be too much for the prospective hoarding family member.

Archibald and Munce (2015) determined that few researchers employing qualitative methodologies have realistic expectations of their ability to recruit or the time needed to recruit. In addition, they claim that few papers offer details regarding the recruitment process making the development of successful strategies difficult owing to lack of available data. In response to this criticism, as much detail as is available from the recruitment process in this project is offered here. Recruitment did not proceed as first expected in the original proposal but some of the principles offered for successful recruitment by Archibald and Munce can be seen in the narrative here:

An amazing thing happened. It happened and I am not sure if it was the direct result of the hours of social media time, door-to-door shop bothering, general chit-chats or completely unrelated academic work. A good relationship with a student who found her means to shine when she needed to- but I met that student again, as arranged by her, with her mother. Her mother is a wonderful, warm, gregarious ex-teacher and musical theatre veteran with a house so full of items from throughout her life and her interactions with the world that she can no longer accommodate her grandchildren in a bed in a bedroom when they come to sleep over. What a bizarre mixture of relief, excitement and longing to help came over me. And there's the thing. This is a research project. It might not help. I am a nurse, for god's sake. I HAVE to help. This is an amazing moment.

When I had to leave (it was a clinical practice day for me and I had to run). I instinctively wanted to hug my student and tell her how well she had done. I wanted to hug her mum too – to let her know that it's ok to feel all of those things she feels. She asked me to hug her and I was ecstatic. This is going to be a pretty intense experience. I gave her information about the project and told her I would give her a week to think about it. She wanted to start

now. I said she needed to think about it and told her I would expect to see her at home for an interview before commencing and that there would be a time commitment for everyone which would need to be taken into consideration. I also told them I would email out a “sources of help” document and a letter about the study. It was very hard to leave and that has caused me to think about how and if the time is managed for research team meetings during this project. Then I come back to expectations – the students know I am interested in hoarding. They also know that no-one else around here is. If the scale of the problem is as big as previous research suggests, there could be a lot of people out there looking for a solution and they might think that I have it. I don’t. I am not even sure I believe in solutions in the sense most nurses might think of them. If there is an answer it is to be found through this research project, amongst others.

Nearlies

Well, I kind of had an inkling, you know. It was all too smooth – too easy. A woman who just wanted to help and be helped. That first time we met at the library cafe we spotted each other before I had entered the building and we knew we were there for each other. Two rather romantic souls with a problem in common. However, despite the revelations about the past, the present and reservations about the future it all seemed so SURE. This was going to happen. I even had to ask her to calm down and give the matter more thought. She was still keen even after that. And then...

The email.

A long and lovely email full of apology and concerns and fears and warm wishes and a bit of guilt, perhaps. But it was over.

Shit.

I give myself a few hours to think about it. I can’t make her do this and I still might hear from my other lead at uni or from J over in Liverpool. But I haven’t heard from those people and it is September (nearly October) and I have so little time left.

Just at the very point where emergency measures were being discussed- leverage? Complete change of plan? I get another email from a colleague – her friend has given his blessing for me to email him about the project. Hard not to get too excited about it. I send her an over-exuberant reply, wait until I’ve calmed down (three days) and email S. I gave brief details and attach the poster/flyer. He replies later that day (Friday 9th October) to say that his sons are all students and are away so distance contact by email will be required (I may

suggest Skype if they are willing, or a mixture of both). There is a lodger at their house. It is not mentioned whether or not he or she would be involved (although I hope so). He also says that his wife may not be prepared for such a level of involvement and he will discuss this with her and get back to me. Oh. My first instinct is to reply asap (I am on my way out with Sarah when I read this and she is not amused at my reading it), I decide to allow the time required and by way of a reply I will then send the information leaflet and elaborate a bit about the amount of autonomy co-researchers have in their level of involvement. The wait is killing me. I am struggling with concentration and each incoming email is making me jump.

Needless to say, this did not pan out, one member of the family stating that they did not want the family involved in such an enterprise. Meanwhile, on the road...

This Friday I will be at the National Archives for the Family sociology workshop day. I hope I can make some links there. Last Friday I had a chance encounter with a friend of J who has worked with Sophie Holmes, clinical psychologist and Surrey hoarding guru (see Holmes, 2015). There's always a new opening in this hoarding malarkey but I am still thinking about the amazing "Mrs Dove" from Newland Ave, as she is now christened.

Turns out none of these routes bore fruit and it was the initial suggestion above of making links with people involved in the Suffolk project which brought Tracy and I together. In fact, I could have saved myself a journey, because it was the very first contact I made who gave us our introduction.

At some point there was a confluence. Two people who had been in search of the same thing arrived at the same point. That point was a person and that person introduced the two parties. Enter Tracy, someone whose family experience had brought her to a place of help-seeking. She is looking for answers. She arrives at me. I arrive at her. The direction the next part of the story now takes differs significantly from the neatly outlined clever-clogs plan reported above. This was outlined in my letter to the ethics committee of February 2015.

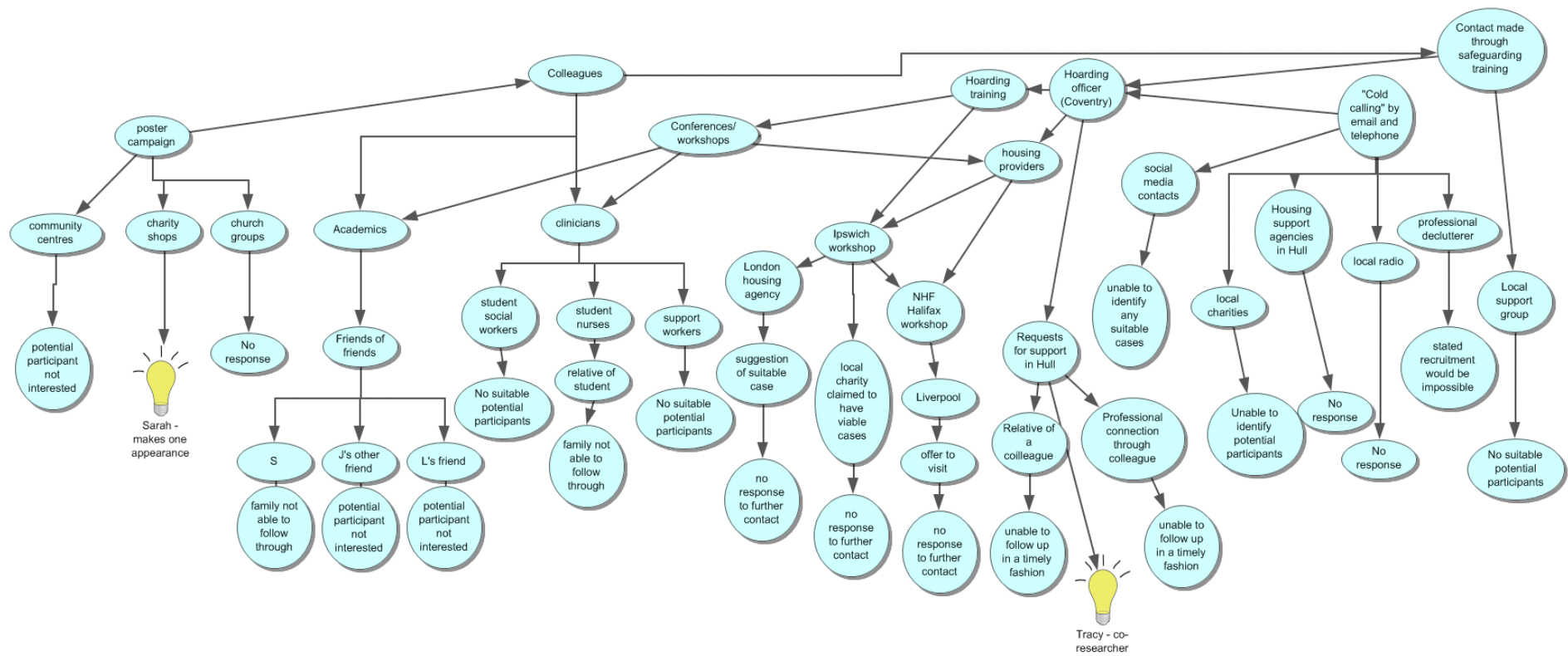


Figure 13 - Tim's recruitment journey

Tracy has been trying to find help with her mum's hoarding since 1998. First the GP, then the community mental health team, countless social workers, charities, church groups, professional declutterers, community activists, researchers and clinicians all over the local area and nationally have been approached, often with a promise of some solution which never came to fruition (see appendix 9). Unbowed and spurred on by her mother having been removed from her house to residential care owing to the condition of the property, Tracy had approached a local charity and managed to arrange a support worker for her mum. Tracy had found Yasmine Harman's story (of looking after her mother) inspiring. The problem was, compulsive hoarding was not a problem this worker was used to and the issues noted above to do with attachment to possessions and the need to proceed slowly and carefully with removing and organising items was not known to her. As a result of this, the relationship between the support worker and Tracy's mum was in jeopardy, with no alternative source of help. Tracy was very knowledgeable about compulsive hoarding and hoarding disorder. She had spoken to all the same academics and clinicians I had (and some I hadn't) in trying to find support. But the knowledge of local services did not match this. And the messages given by hoarding specialists of help being at hand had turned out to be unfounded in our local area. An account of this is offered in the form of Tracy's script for a performance we gave at the 2017 Public Engagement in Performance Conference (see appendix 9).

The thing is, as we spoke about the dimensions and perspectives of the phenomenon of hoarding, we both became very animated about the cultural aspects. We talked about Warhol and his "collection" of neatly labelled shoeboxes full of all kinds of artefacts which filled his apartment and we talked about antiques and there was a mutual appreciation for the other's knowledge and energy, as I perceived it. I resolved to help in whatever way I could with this lady's project. Perhaps involvement could bring about the elusive family of co-researchers. After all, I knew how little there was out there in the way of help, having spoken to almost all the same people as she had and having found similar responses locally to my inquiries.

What Tracy produced was a proposal for funding from the local CCG to start up a project delivering training and education around hoarding to statutory and voluntary agencies in the local area. Along the way, there were visits to the local Fire and Rescue Service, community radio and local charities as well as health professionals and national figures in the world of hoarding. There was a lot going on. I was not aware of this as a part of the research until I attended for supervision to express my dismay that I was being roped into something which did not help with my PhD aspirations but was at least in the right subject area. I described what I had been talking about with Tracy. I described her aspirations and our common experience – how well we got on. My supervisor told me I had already started the data

gathering. Couldn't I see? Here was a product? Perhaps the products would not look like I had imagined they would when I set out to recruit, but here they were, nonetheless.

I am of course, not a person with practical experience of working with people with a compulsive hoarding problem. Tracy is willing to be involved in the research project in the interest of trying to prevent future occurrences of this type of situation for others. We do not immediately agree to do research together. In fact, at first, I do not recognise what it is that we are doing. We meet a couple of times at her house to talk about her situation and what we know about available help, then what we could do to develop a source of help (in the absence of any such resource locally). I am discussing this in supervision when it becomes apparent from my supervisor's comments that there is a research project going on and Tracy and I are conducting it. I have already spent several hours talking to Tracy and getting to know her background and family history as well as current circumstances. What is evident is that the idea of artistic representations of experience described in the original model of the methodology have been replaced by something altogether more dynamic. We are to speak on local radio in the run-up to what will be a bid for a grant from the local clinical commissioning group to begin to raise awareness of the complex problem of compulsive hoarding locally. This sounds rather like the beginnings of action research. Or is it cooperative inquiry? Appreciative Inquiry? Participative Action Research?

Reflection on warming up process

Janesick (1994) compares the design of qualitative research to dance, comprising of three phases: warm up, exercises and cooling down. She notes the elasticity of qualitative methodologies which enables them to adapt to the developing needs of the study. She identifies the need to state one's ideological stance at the outset in order to allow influences on question development. The first lesson learned through this process was one of patience. Not to force things. This means not only avoiding hurrying to conclusions but also taking care not to try to force things to a neat conclusion.

Janesick provides an example from her own research. She has initial ideas for the research design but these are modified as she learns about the impressions and ideas and understandings of the community she is researching. Were these unsuccessful attempts at recruitment effectively pilots (Janesick, 1994, p.212), informing the refining of the recruitment process (by this I mean teaching me to be patient and perhaps more broad-minded)?

It could be inferred that serendipity played the most significant part in this process, but not without considerable efforts on the part of both mutual-recruiters. Patience and that old

chestnut tolerance of uncertainty were major factors in the eventual formation of a team. That team was not what had been envisaged by Tracy or me. She had been in search of an expert and I had been in search of a family fitting a certain description. Casting the net wide and employing a host of different networks was essentially a success but in the context of my original expectations I saw it as a failure and describe it so above. Flexibility and adaptability proved essential ingredients in enabling research into a little-investigated phenomenon from a very personal angle to take place.

In fact, the co-operative model discussed in the next chapter is only workable in the context of having such a capable and adaptable co-researcher. On serendipity, Makri and Blandford (2012) have published research which suggests serendipity is created, or at least encouraged, by the parties involved. Maximising opportunity through exposure to experiences increases the possibility of serendipitous occurrences and the ability to spot the “right moment”. The recording and immersion in research activity as suggested by Mills (1959) no doubt aids this. Given the amount of exposure I had sought and the number of connections we had both made, serendipity had perhaps been given an encouraging nudge.

Archibald and Munce (2015) report that despite the essential nature of the relationship between researcher and potential participants in successful recruitment for qualitative studies, this aspect is often absent from reports of qualitative research. They cite four areas of qualitative research recruitment which require attention: characteristics of the researcher, institutional and community gatekeeping, understanding participants, and determining the participant sample. The characteristics of the researcher can be essential in this. Enthusiasm, knowledge and regular contact are all identified by Archibald and Munce (2015) as essential to successful recruitment. It is notable, then, that despite my forging links with various people around the country and the city, it is the people I had the most regular contact with who were directly involved in the project. The difference between the way Archibald and Munce (2015) describe recruitment and the way I experienced it is that they describe an awareness of the process being instituted by the researcher, employing certain skills in the interest of fulfilling the need to recruit participants. In the case of this project, I would hold that there was a mutual recruitment process in which both parties had need of the other and this facilitated our agreement to work together. The enthusiasm was evident in Tracy as much as it was in me and it was the negotiation of what we would do rather than if one of us would join in with.

Prolonged engagement with the community/ prospective participants will increase recruitment, especially outside of the research setting (Archibald and Munce, 2015) but this can be difficult to sustain after the project and it is crucial that the researcher does not leave

the participants with nothing after the project is concluded. This is also described by Adams et al (2015) in their discussion of relational ethics, which advocates principles of friendship as essential in considering life after the project. This is in a difficult area, as expectations are still high following the conclusion of the research. I have struggled to maintain the involvement in the cause which I feel I owe to Tracy (and which will be the natural next stage of my research into hoarding) at the pace which Tracy would like to see, I fear. The relationship we have developed is more than researcher/researched and more akin to friendship but the amount of time we can spend together is limited and we are not as close as friends. This, as Tracy has commented on before, can feel rather strange. These issues of relational ethics will be considered throughout but with a focus in chapter six.

Chapter 3 Act II: Exercises - Working together – on a mission



Figure 14- Tracy and Tim, 2017

Collaboration

Act II is themed around Janesick's (1994) second stage of qualitative design, "exercises", which she defines as "ongoing design decisions". These are made through piloting and responsive adaptation (p.213). Whilst there was no official "pilot study" in the case of this project, there was a period of time before we commenced official research work in which we got to know each other within the boundaries of working with compulsive hoarding. At this time neither of us considered ourselves as researching together or even getting ready to do so. It felt to me that were somewhere close to Heron's (1971) discussion between self-determining persons (described by Reason (1994) as "authors of their own actions" (p.325)). This period allowed us to pilot our ideas and beliefs with each other through discussion, sharing our contacts, connections, readings and plans as described by Reason (1994) and Heron (1996) in the first stage of co-operative inquiry. It also allowed us to get to know each other closely perhaps allowing us to become more comfortable in saying things which we might otherwise have held back (Loubere, 2017). This has relevance for the sense of agency Tracy felt as much as for her being comfortable in talking about experience. Reed (2008) describes participation as an ongoing process rather like a contract. Discussions of this nature enabled the negotiation of that contract and re-appraisal of its effectiveness and

suitability. Tracy stated at the outset she was happy to help if it helped her and I hoped to be able to help her in some way even though I didn't consider that part of the research project. I hadn't considered that the source of help being looked for could be me.

It was apparent to me from my clinical work as well as a natural progression from my reading of Gergen's ideas for a dialogic approach to research and practice (1999; 2003) that new knowledge and workable ideas are better developed collaboratively with the people affected. It is how care is effectively planned and delivered (Department of Health, 2008; 2015) and as such was a part of my daily working philosophy when I began this PhD exemplified in the early psychosis declaration (IRIS initiative, 2012) and the work of Richard Bentall (2004; 2010). I didn't know how it would work and had some ideas which brought together various different groups of people, originally considering a group of young people as researchers of their own experience with a focus on empowerment and strengths and later exploring the idea of a similar model with a community centre group. As is outlined above and suggested by Janesick (1994), this idea evolved and developed in reaction to developments during recruitment but the imperative to collaborate persisted.

From the beginning, principles of codesign were to be employed in the development of the method. Codesign has its origins in Scandinavia and is popular with public service designers (Chisholm, 2017), involving as it does those who will access or be affected by the service under development. The researchers facilitate the project which is conducted by experts by experience (although in our case, this was a fluid role, with both of us at times facilitating different aspects). Co-design offers better co-operation, immediate validation of ideas, originality, user value of ideas and better understanding of needs argues Chisholm (2017). Iversen et al (2012) emphasise the historical importance of making values a central issue of participatory design, warning against the reification of methods and participation over the essential negotiation of values.

Mutual experts. We both bring expertise (as in co-production) but where descriptions of co-production tend to describe "experts by experience" (a phrase seen by some as belittling that experience (Grant et al, 2010)) and facilitators as separate entities bringing their necessary talents and knowledge to the party, here the lines were blurred. In lieu of a better term, I have still employed "expert by experience" in places despite its potentially loaded connotations. Tracy facilitated meetings herself and for a researcher this requires the ability to tolerate some uncertainty (again), this time in relation to control. Not being in control is part of every human's normal state of being. In fact, I found myself an anti-expert, if you like. This comes from a suggestion of adopting a "not-knowing" attitude (Etherington, 2004; Gergen and Warhus, 2001).

I offered up a suggestion for how the research might proceed as described above, utilising a family group and artistic representations of experience for group analysis and individual reflection. Tracy signed her consent to this and further developments as negotiated and decided by us together. Hollway and Jefferson (2000) claim informed consent compromises the integrity of responses but Merrill and West (2009) insist that informed consent is never optional despite the power imbalance it suggests. The pre-existing relationship between Tracy and I perhaps served to counter the effects of this, as suggested by Archibald and Munce (2015). Or it may be that the format of the research (open conversations in which we reflected on action (Schön, 1983)) did not present with the same set of challenges as a formal series of interviews (even semi-structured interviews) regards the dynamics between us.

Various typologies of participation have been developed over the past five decades (Reed, 2008), indicating that there are better and worse forms of participation delineated by numerous factors such as degree of participation, direction of communication, theoretical basis and purpose of the research. Synthesising these in response to growing sense of disillusionment about the ability of participation to yield the benefits hoped for all involved, Reed (2008) has made eight recommendations for best practice.

1. Stakeholder participation needs to be underpinned by a philosophy that emphasises empowerment, equity, trust and learning
2. Where relevant, stakeholder participation should be considered early and throughout the process
3. Relevant stakeholders need to be analysed and represented systematically
4. Clear objectives for the participatory process need to be agreed among stakeholders at the outset
5. Methods should be selected and tailored to the decision-making context, considering the objectives, type of participants and appropriate level of engagement
6. Highly skilled facilitation is essential
7. Local and scientific knowledges should be integrated
8. Participation needs to be institutionalised

Despite Reason's (1994) claim that by

“Co-creating their reality through participation” (p.324)

“Persons can with help, choose how they live their lives, free from the distress of early conditioning and restrictive social custom” (p.325)

I would say that this is in tune with the suggestion made by Gergen (1999, 2001) and Burr (1995) that there is the possibility for the discourse to change but I have reservations about all of the above terms (co-operation, collaboration, participation) because of their sometimes-tokenistic application. Cornwall (2008) describes how large institutions and official bodies apply the term to forms in which stakeholders are passive recipients of information. Reed (2008) calls for the institutionalisation of participatory practices but as Cornwall observes this has the potential to restrict the autonomy of people to participate in traditional ways (the examples she offers are demonstrations, strikes and petitions). With this in mind, perhaps true participatory research should call to the researcher rather than being initiated by them. This idea is particularly interesting in the light of the unusual circumstances of mutual recruitment experienced by Tracy and I and is resonant with the ideas suggested by Wacquant recalled by Frank (2012) of the call to action. To this end, I began wondering if there shouldn't be a joint approach to ethics processes and if the ethics committee shouldn't have more of a lay presence. I wanted to bring Tracy to supervision with me. Now I think she should have had access to her own supervision without me. There is a strong ethical message to Cornwall's paper whilst Reed has gone for a more rigour-focused route but the end results are closely aligned (not perfectly, I'll grant and perhaps a blend of the two would be the best way forward for those considering research proceeding from a critical position, where ethics and rigour are so closely entwined from the beginning and are in process throughout).

An overarching idea is that of participation as process (Reed, 2008 p. 2421) rather than a matter of simply selecting the right tools and getting on with it, there is awareness of the fluid and ongoing nature of participation.

“...a long-term relationship where the parties develop mutual trust and respect as they learn from each other to negotiate potential solutions”
(p.2422)

This approach requires flexibility (p.2422); Janesick (1994) describes the qualitative research methodology as elastic, like the spine of a dancer, the researcher choreographing the study in response to

“...the social realities of doing research with and among the living” (p.326)

Issues of knowledge, power, trust and shared learning expressed in Reed, (2008) Tracy had conducted extensive research of her own spanning more years than mine and this offered a degree of parity and troubles the notion offered by Reed of local and scientific knowledge being synthesised. Long conversations in our pre-research relationship had culminated in our sharing of acquired knowledge and resources regarding compulsive hoarding.

Continuing shared experience and reflection (still an ongoing process as we review this work for future purposes) furthers the sense of equity through mutual learning, I believe.

However, conversations concerning the nature of the text have revealed continuing issues of power which cannot be reconciled through researcher reflexivity. To my mind, the answer to this lies in truly co-authored accounts which present multiple perspectives as recorded by multiple participants in their own words.

As mentioned elsewhere, it is regrettable that it was not possible to include all family members in the research equally as per the original design. Knowledge of the boundaries of the family system, as identified through careful understanding of the research question, would enable identification of all relevant stakeholders. Whilst this was established before commencement of the project, geographical and relational factors influenced accessibility, the hoped-for research team ultimately becoming a partnership between Tracy and me as other potential members were rendered inaccessible. However, Reed (2008) suggests that at some point one must “draw a line”. In the case of this PhD project, time is an unavoidable factor and so is the commitment to certain ethical principles. Advice given about how to approach the problem varied, but my own position was that it is unethical to begin to record potentially emotionally difficult conversations with people who as yet do not know you and who do not have the same resources available to them as other participants for support (for instance, the “sources of help” leaflet offered contained some national organisations but immediate one-to-one help was only detailed for local residents). A decision of ethics of consequences (Etherington, 2004) trumped a question of representation for me there.

As the goals of the research were negotiated to include the interests of both parties, we were well aware of what we working towards. Whilst Reed (2008) draws our attention to the risk of silencing opinions through the seeking of consensus, Forbat and Hubbard (2016) found that attempts to produce collaborative research can in fact result in divergent accounts.

Reed (2008) makes it clear that methods can only be selected once other factors, such as who is involved and to what degree and for what purpose have been answered. This made things difficult for the ethics application as I did not yet know. Despite the methodological alterations which took place as a result of events throughout the research, the project could have proceeded from a stronger start had we already established a partnership with agreed purpose. I did not meet with Tracy’s mum alone and in hindsight, this is regrettable as she may have spoken more freely in that situation. This would have allowed a more equitable representation in the data. Whilst I am confident in my ability to facilitate group discussion from a clinical perspective, doing this in a research setting was new and I think could have been improved by agreeing in advance with both parties what the topic for discussion was.

The process of reflection which will continue after this project is finished offers a means to examine this issue in conjunction with my co-researcher. Also, changes in contexts, through the stages of the research process, necessitate adaptations of method (p.2425 and Janesick, 1994 as mentioned above).

To return to the point Cornwall (2008) makes above, there is a position taken by Rees (2008) which supposes researcher and participant(s) are receptacles of knowledge. He does not allow for the possibility that the impetus for participation may not be at the instigation of a researcher. This leads to a slightly protectionist stance towards participants and a concern with objectivity which could undermine the relationship and the object of the work if that object is to achieve change. There is a particular idiom in his review which does not square with some of the principles and theories here but what the review and its recommendations offers is a helpful and structured way of examining issues of participation. However:

“power is an inherently political process rather than a technique” (Cornwall, 2008 p.281)

The cyclical model of action and reflection into which we fell fits the description of co-operative inquiry (Heron, 1971; Reason, 1994; Heron, 1996). Heron (1996) asserts the difference between co-operative inquiry and other forms of participatory research is that by and large these are concerned with practitioners examining practice (action research, appreciative inquiry), involve an imbalance of power (Participative action research) or are included within co-operative inquiry (action inquiry). Based on Heron’s descriptions and the broad church which Reason (1994) and Heron (1996) describe co-operative inquiry as, this would appear to be the best terminology for describing this phase of the research.

“So, in co-operative inquiry, all those involved in the research are both co-researchers, whose thinking and decision-making contribute to generating ideas, designing and managing the project, and drawing conclusions from the experience, and *also* co-subjects, participating in the activity being researched” Reason p.326

In the fourth edition of their Handbook of Qualitative research Denzin and Lincoln (2011) offer participatory research as a distinct paradigm. Heron (1996) claims that what he calls “mainline qualitative research” (p. 9) is conducted without the significant consultation of those participating in operational issues. By contrast, co-operative inquiry is “research *with* other people” (p. 19). Heron (1996) notes that this commitment is epistemological but also *political*. This comment brings to mind Foucault’s (1961) discourse on power and psychiatry as well as knowledge and its disenfranchising uses (1969). In addition, there is a link to Illich’s (1976) Medical nemesis (echoed by Brandon, 1990) where he describes the protectionist stance of medicine in regard to “specialist” knowledge being used in the

protection of the profession itself. Participatory forms of research necessarily contain principles of democracy and community (Bergold and Thomas, 2012). It also harks back, for me, to Barker (2009) and before him, Peplau (1952). Being with the other, meeting them where they are and employing a commonly agreed language to produce an agreed outcome. This democratisation of language is brought up by Bergold and Thomas (2012) who advocate the representation of participatory research through media and in language accessible to all and judgements of quality relevant to all those represented by and included in the research. To this end, our reflective discussions served to offer opportunity to air any concerns or negotiate future direction as well as evaluating shared experience. We were able to check with each other our perceptions of experience.

Persons are self-determining (Heron, 1971) and as such should not be treated as less in the name of inquiry as this would invalidate claims that the study is a study of persons. Reason (1994) sets out that this means to truly do research on persons:

“each person’s agency is fundamentally honoured in both the exchange of ideas and the action” (p.326).

“This worldview sees human beings as co-creating their reality through participation; through their experience, their imagination and intuition, their thinking and their action” (p.324)

This last quote is reminiscent of more suggestions by Gergen (e.g., 1999; 2001) which advocates action research, narrative research and collaborative inquiry as methods commensurable with social constructionist epistemology.

Reason (1994) suggests there are 4 phases to co-operative inquiry. These phases can be clearly identified through our research project, if the first of these was arrived at more serendipitously than Reason’s text would suggest (although, as discussed above, serendipity perhaps relies on a good deal of effort).

1. Propositional knowing – We come to some agreement about what we think might need to happen regards compulsive hoarding and its effects on families. We shared our experiences of trying to find a source of help in our local area which eventually led to us finding each other. This experience of exploring the available resources to help with hoarding together allowed for later decisions to be made about how and what to do in terms of the study, informed by knowledge of each other’s’ resources and limitations (and character). We began with an open conversation about Tracy’s situation with her mother and from there began to develop plans for a local intervention or programme of education around hoarding.

2. Practical knowing – We act on this and put into practice our ideas in developing and pitching our CCG funding bid(s)
3. Experiential knowing – immersion in the experience of developing the funding bid, the proximity of the research project was at times more distant, despite the regular reflective meetings. Reason suggests that during this phase co-researchers may be:

“excited or bored, engaged or alienated; they may sometimes forget they are involved in an inquiry project; they may forget or otherwise fail to carry out and record the agreed-upon procedures; or they may stumble on unexpected and unpredictable experiences and develop creative new insights” (p.326)

This fallibility and creativity was evident in our not meeting for some time after the failed public vote and in what we found through our analysis

4. Propositional knowing - We reflect on our initial ideas in the light of our experience and this can be seen in act III below. Reason calls for a “critical return” to the original state of propositional knowing (p.327) and this is where we ended up (see chapters 4 and 5), analysing our original ideas through the lens of our experience.

In talking about researcher and researched co-existing within each of the participants, Heron implies (using the term “critical subjectivity”) a high degree of reflexivity. Heron (1996) identified early on in the development of co-operative inquiry that “only shared experience and shared reflection on it could yield a social science that did justice to the human condition” (p.2) in a “quest for personal and social transformation” (p.2) enacted between self-directing persons. Here he troubles traditional notions of roles in research, reversing or combining those of researcher and researched. The sweep of co-operative inquiry expanded to include political considerations.

Conversations

Interviews historically have consisted of a researcher and a respondent with neatly defined roles undertaking an exercise in which the rules are concrete (Gubrium and Holstein, 2012). The researcher attempts not to influence or contribute to the results of the interview as the respondent has the answers which need to be extracted without contamination. Following the narrative turn in social science towards the end of the last century, interviews were seen from a more constructionist stance (Gubrium and Holstein, 2012; Holstein and Gubrium, 2000). The interviewer cannot possibly hope to get untainted information from respondents

due to a whole host of contributing factors including the interview pair themselves. Regular organised meetings for reflection on the CCG bid and attendant issues as suggested by Reason (1994) were recorded for transcription. Topics for discussion were generally agreed at the start of each meeting. Although some provisional understanding might be reached at the end of a conversation for next time this would usually be quite practically based (a to-do list or a report back on actions taken in between meetings). This is in line with “experiential knowing”, the third phase of the co-operative inquiry model which informed the structure of this phase of the research (Heron, 1996; Reason, 1994).

Early on I was directed towards a paper by Todres and Galvin (2005) on breadth and depth in qualitative inquiry. I had this in mind when pursuing the original model and it persisted throughout even if not in the intended way. As Tracy and I met and talked, a great deal of fine detail about her experience and that of her mother and siblings came out. This degree of depth of experience and richness of data provided opportunities on occasion for introducing new characters into the story. There was Julie, Tracy’s mother, the support worker, Dean, Tracy’s brother and a variety of service providers. As each new character was introduced, I would become extremely excited at the prospect of adding a new voice to the story by gathering a recorded conversation with them and seemingly with each one, this opportunity disappeared as soon as it was introduced. In some cases, there are notes to capture the essence of what was said but in two cases the relationship which linked the person to the research broke down before they could even be approached and in two cases intended future meetings never took place due to other commitments. This has left little which can be used here owing to only small amounts of conversation taking place after consent had been given.

Background details to do with Tracy’s relationship with her mum had already been put into the public domain by Tracy herself during a community radio interview we gave together (reported above). A meeting with Tracy and her mum and another with Tracy and Sarah from Dove House were arranged following initial unrecorded meetings seeking consent and introducing each new voice to me and the project. This meant that some conversations went unrecorded (most regrettably, the initial meeting with Julie and the one with Dean), but consent was granted in those meetings for information to be used from notes taken with agreement if both parties felt it appropriate and the ethical position is more comfortable for me than springing a microphone on someone who has never seen me. Also, the quality of the information gained will hopefully be richer in relational context (reference required), even after just one meeting (typically these were quite long). These issues are also raised by Vogel and Funck (2018a)

I arranged with Tracy, at her instigation, to meet with her mother together. It was not long before Christmas 2015. Her mother had been displaced from her home for months (six, perhaps?) and was living in residential care. She had agreed to meet with me. I was excited at the prospect of her signing up to perhaps two meetings between the three of us, possibly even to include a volunteer from a local charity who had been attempting to help with clearing up her overloaded house (thus far to no avail). The meeting was at times challenging for Tracy and I saw how a comment here and there from her mum really inflicted some acute pain, although mum appeared not to notice this. She spoke of her deceased son, her life as a child in a Japanese concentration camp, her hatred for her things and her need to keep them. The meeting, intended as an introduction, ran for almost two hours. She agreed to meet again and we discussed venues (she expressed a preference for the pub). Following this, she and Tracy were going to go away together for Christmas. Everything was looking very good indeed. The frustration lies in the inability to capture such rich data on tape. Looking back on this with some distance, I would do exactly the same again. It was the right thing to do. In addition, brief introduction would not serve to make Julie comfortable or well-informed about the project. This would likely compromise engagement (Archibald and Munce, 2015) and could potentially prohibit her from consenting to be involved at all.

After Christmas, things looked different. There had been no further input from the voluntary worker, after Tracy's mum had stated she did not want her involved any more. Events led to our not being able to meet again and I had no recording of our initial meeting due to my not being prepared for such rapid developments. I had wrongly (perhaps) assumed it would be necessary to provide an introductory meeting and build a relationship with this person before she began to tell me all about potentially painful events. In particular, I wanted to ensure she understood what the expectations of the study were in relation to her involvement in a research team conducting data analysis. Perhaps unsurprisingly, she was completely uninterested in this, being apparently glad of having someone new to talk to and someone who was interested in her story. Bergold and Thomas (2012) speak to this in their discussion of degrees of participation. In essence, someone with as little influence over the direction of the research could not be called a co-researcher. This was exactly the feeling I had about this at the time. Essentially, it was the two of us...

Well, nothing came of it. There were events and conversations between Tracy and her mum which led to them not speaking for a while. It just didn't happen. Had we had longer, we could have ridden out the contours of the relationship, perhaps.

Similarly, in working with Tracy's brother, Dean:

Dean stated that it is important to get his mum the appropriate help but he would like to see other families get the help they need in the future. Here, here. I was going to record us, but it doesn't feel right to do that when you have just met someone without them having a full knowledge of why. Dean is returning soon and has agreed to be recorded and perhaps involved in other ways.

This unfortunately was not to be. But the interview notes offered various insights into topics arising from Dean's experience of his mum's hoarding. Vogel and Funck (2018) have suggested the use of note-taking during interviews as a viable alternative choice to recording and transcription which my experience of looking at transcripts of my recordings seems to back up (see act III). The semblance to ethnographic methods of observation is, Vogel and Funck (2018) argue, proof of the viability of the method. Participants can be hindered in their responses or intimidated by the presence of the recording equipment and the notion of permanence this suggests. My belief was that the development of rapport would enable richer data to be generated.

Holloway and Freshwater (2007) describe a narrative interview as one in which the researcher tries to suppress their desire to speak so that the stories of the respondent can be captured uninterrupted. This does not describe the animated exchanges between Tracy and me. Etherington better describes it in her explanation of the reflexive interview. Etherington (2004 p.140) notes the traditional psychotherapeutic position on disclosure – don't! This is the same for MH nurses, although as she also notes, narrative therapists sometimes advocate the use of disclosure in helping clients to form new narratives (e.g. White and Epston, 1990). *I too have made my responses to people's stories available to them as part of my therapeutic interactions as a practitioner. Intuitively, rather than as a result of some particular form of training (unless it is a remnant of pastoral care (practical theology as it was referred to by Alan Main at the University of Aberdeen back in 1994/5)). Is this why self in research seems the right fit?*

In reflexive interviewing (Etherington, 2004), the interviewer responds to answers; joins in, even (this reminds me of Newman's (1999) suggestion that we join in with the dance). Not simply adopting techniques to get more out of the participant but experiencing a "reciprocal desire to disclose" (Ellis and Berger, 2003). In our conversations I tried to maintain as much space for Tracy to talk as possible but not necessarily convey some air of neutrality. I am after all an interested party. I came into this through personal interest and that is inescapable. I was involved. There is a warning from Forbat and Hubbard (2016) that disclosure from co-researchers can create tensions and dissonance between parties in meaning-making. Responses can be cut short or can be contrary. The development of skills

is essential to producing better results. I am new. My skills are not yet developed. Jorgenson (1991) states

“how interviewees make sense of and respond to the interviewer’s questions is embedded in the larger process of coming to know who the interviewer is”

Interview situations contribute to what is narrated by “constructive practitioners of experiential information” (Gubrium and Holstein, 2012 p.32) in other words, who is telling what to whom? (Frank, 2010; 2012) I am glad that at the time when we were conducting these meetings, neither of us had a permanent place at the University. Using a meeting room there offered a space which, whilst not neutral, perhaps, did serve as a reminder that this was research. At the same time, this could have served to inhibit Tracy by reminding her that I was not there as a mental health professional. Previously we had met at Tracy’s home and in that environment, I may have felt more inhibited and Tracy may have felt more relaxed. However, given that we had met several times before we commenced recording, we had become more familiar with and relaxed with each other. Grinyer and Thomas (2012 p.221) suggest multiple interviews allow us to go past private and public accounts (I would say you can observe continual repositioning in conversations with Tracy as we navigate between project and reason for project). This echoes Goffman’s (1990) description of public and private. The subject behind the respondent not only retains the details of his or her inner life and social world but, in the very process of offering them up to the interviewer, stories the information, assembling it into a coherent account.”

“He or she is, in a phrase, “always already” a storyteller”

(Gubrium and Holstein, 2012 p.33)

That narratives are not simply reported by respondents but are the product of an exercise of co-creation between the interview pair (Holstein and Gubrium, 2000; Gubrium and Holstein, 2012) is a suggestion taken further by Frank, who observes that the narratives employed are just that. They are chosen (consciously or unconsciously) from a bank of pre-existing narratives by the teller for their own purposes. They are trying to convey something about themselves and their experience. Furthermore, the listener may not hear the story the way the storyteller imagines they will (Frank, 2010). These ideas will be explored further in act III below.

In conversation with Tracy my own sense of role was quite fluid. I initially began talking to her at her request as a potential source of help. To me, at that point, there was the possibility of working together to do something about hoarding awareness and sources of help in our local area but she didn’t fit the description of my intended recruited family group.

The idea of involvement in research having therapeutic effects for some but not being therapy Merrill and West (2009) highlight the difficulty for researchers in avoiding the temptation to do so – like my supervisor said, in fact. Initially, I saw this as problematic, but reading Denzin (1997) and Heron (1996), I became unsure of the need to remain at a remove from the research. I became excited by the prospect of the imperative to act. This is not as an attempt to deliver therapy but as an ethical response to a perceived injustice (Denzin, 1997). Perhaps what I found in Tracy's proposed project was the means to do this whilst still retaining some distance

Hollway and Jefferson (2000 p.4) describe "defended subjects" as psychosocial subjects defending themselves against anxiety after the mode of Melanie Klein (Hollway and Jefferson, 2008). From our conversations, I can recall Tracy's anxiety at the thought of having to go into her mother's home to tackle the mess (something she had done many times before) in the knowledge that the job would not be done for the last time. Hollway and Jefferson (2000) identify that anxieties defended against are both "present and past".

Self-knowledge in psychoanalysis and as researchers allows for greater understanding of not only self but also that which is studied – also allows for noticing "defences against anxiety".

"The idea of a defended subject shows how subjects invest in discourses when these offer positions which provide protections against anxiety and therefore supports to identity."

(P.23)

This quote offers an insight into the workings of both researcher and subject (or co-researchers and co-subjects, as Reason (1994) suggests above). What Hollway and Jefferson (2000) describe is a collaborative enterprise with defined roles. What Tracy and I have hopefully tried to do is more akin to the co-operative inquiry discussed above. What Hollway and Jefferson (2000) give us is a reminder that investigators do not go out and find facts. Although, at the outset, I sought safety in being the "expert", offering up knowledge gleaned from my reviewing of the literature and interactions with people working with compulsive hoarders up to this point. These were a common starting point for our explorations as we had both talked to some of the same people about some of the same issues and had learned the same things.

Hollway and Jefferson (2000) note that one of them had certain biographical details in common with one of the respondents in their study. Furthermore, Tony notes that "I enjoyed interviewing Tommy because I liked him" (p.65), going on to say that this was because of the similarity of their experience. Having certain aesthetic ideas in common and both being animated by the subject of study meant that I liked Tracy from the outset. The fact that we

had both taken long and often frustrating journeys to find each other only added to this. Diary entries often praise her bravery, intellect and energy. In conversation with Tracy it would have been easy to promise the earth, in all sincerity, as a result of my combined professional and personal proclivities.

In working with Tracy, Hollway and Jefferson's (2000) work served to guide me in working in a space somewhere between research and therapy. Not that I consider what we were doing to be therapy or even intentionally therapeutic, but the possibility of unintentional therapeutic consequences was raised early on and this text offered helpful guidance in this regard. For instance, on "the long game" as I call it in one note, Hollway and Jefferson state that it is of no benefit to hasten towards a concrete "answer" when one needs to build rapport (p.28). To say that there was an intentional building of a relationship for the purposes of research between Tracy and I might be a bit disingenuous. The process was organic. We got on. We were set upon a common purpose before we realised that purpose could be the focus of a co-researcher relationship. When we did agree to work together as researchers, we made a rule that we (I) would hit record without mentioning it at the start of our meetings or as soon as was possible (this was not as easy as it sounds, owing to the intensity of the content of some conversations). Sometimes, things would be missed and opportunities would slip by but there was an ethical drive not to put method (or even PhD) before wellbeing. The principles of medical ethics take one so far but there is more to consider as will be discussed further below.

Grinyer and Thomas (2012) state the value of interviewing on multiple occasions or longitudinally. However, they also note the risks such as getting too close to be able to disagree or too distant to maintain rapport. Novices often leave an interview full of joy at the rapport they established but with no data (p.223). It has been suggested the higher the rapport, the worse the interview. There is an optimal level. Was this exceeded by spending time informally with Tracy before commencing or was it enough to get us through the times of no contact and allow frank reflection immediately after the project and onwards. And what of relational ethics in this? Adams et al (2015) suggest the "friendship as method" approach, described by Tillman-Healy (2003) as:

- Prioritising the relationship, including being there for participants and not making inappropriate demands on their time, resources or emotions
- Nurturing the relationship by whatever means appropriate and being willing to change patterns of interaction to accommodate the relationship
- Addressing possible conflicts in the relationship and the research project/process explicitly

- Acknowledging issues of confidentiality, loyalty, and critique in ways that meet both the demands of the friendship and the demands of the research
- Maintaining the relationship after the research is complete and no longer possible

The difficulties of employing such an approach are in maintaining both positions as researcher and friend. Such an attitude could raise complications regards objectivity if that were a concern but, in this case, it is not. It could also raise concerns about the effects on the researcher of the need to “please” the co-researcher with the produced report.

Following our meeting with Julie, Tracy was clearly upset and this had repercussions for what to do as a result. We went to a neutral space for a debrief.

Emotional proximity produces a distortion in our ability to accept “objective truths”, according to Dworetz (2014) and this necessitates a moderated approach to delivering difficult news (such as the news that participating in a research project will not cure a relative with hoarding tendencies). I think of conversation with a hoarding professional 11/9/2014 about how one can communicate “professionally” with a client but when the problem is closer to home, the ability to do so is lost due to emotional proximity. We need to be honest but in a much more empathic way with carers and family members. Hoarding is often intractable and no-one as yet has produced a “cure”, but there may be ways to help everyone live more comfortably, being more mindful of each other’s needs. This point of view may be contentious given the writings of many who claim to have developed treatments for hoarding and scales for measuring it, but we must also remember the diversity of reasons for hoarding and range of needs this represents – describing Hoarding Disorder as the problem to be fixed is a misnomer due to the fact that the only criteria for this diagnosis are those of scale of problem and “distress” which at present does not appear to be well qualified.

Tracy’s role was also fluid, as we would expect if we follow Reason’s description of self-directing persons above. In our meeting with Julie, Tracy’s mum:

During this meeting, Tracy acted as an active interviewer. She asked open questions and developed lines of inquiry. When it came to making suggestions for future meetings, everyone was very involved. For a bit of illustration as to how the roles of interviewer and interviewee were interpreted independently, see table 2 in chapter five, produced from the transcription service’s labelling. Bergold and Thomas (2012) report on how roles develop and evolve for all parties over time (especially in protracted collaborative projects). They observe that this phenomenon has long been known in ethnographic studies.

Reflection on exercises

Newman (1999) troubles existing ideas in healthcare delivery and research by suggesting that medical formulations of problem and solution or health and illness are incorrect. For her, health is not something you possess or do not possess, health *is* (p.229). She uses a metaphor which I find both apt and appealing of a “dance of empathy” (p. 227) performed by patient (*sic*) and nurse/researcher. Attending and joining are the requisite moves.

“You do not dance in order to get somewhere...you dance because it’s meaningful to you.” (Elliott, 1996 quoting Brother David Standl-Rast, cited by Newman p.227).

Dialogue is rhythmical and the practitioner must listen carefully and find the rhythm in order to join in until order emerges from the chaotic. This means just what it says – join the dance. No stopping or steering or changing the record. This is where Newman introduces the concept of “tolerance of uncertainty” (p.228) which resonates for me as someone who has spent so much time trying to “get the rhythm” of people to join them and to be with them in their experience rather than problematizing it or segregating them (I am thinking here of Phil Barker, 2009). Looking to sociology and little stories for additional means to understand hoarding rather than psychology or psychiatry enables a broader view of the construction and enables the focus to shift from the individual affected (or labelled).

Part of joining in meant going with for me. Being a supportive, steady, interested presence; allowing plenty of room for Tracy to speak, to lead and to explore theories of what might be happening without handing out solutions, unless this was requested. How consistent this was I can’t be sure but I hope my practice in my “other job” helped to produce a safe space in which Tracy felt confident in being able to speak.

Our firefighter can no longer join us for the radio interview on Thursday. There is to be a stand-in, we are told. However, it emerges later during our meeting that this stand-in can not take part. A suitable person will be provided, we are assured. Tracy is awaiting an email from the CCG regarding funding application for a training package around hoarding. She says she has rung them and has been told that the volume of applications is high and therefore they will contact later. She will email me with news. At 18:45 I realise that whilst picking up the children, making tea and eating tea I have not had my mobile with me. I worry that I have missed an email of importance – even more so to Tracy – and I am the only person who will be bothered about it apart from her. I feel extremely guilty and hurriedly dash off to get my phone but when I look at the emails there is nothing from Tracy. I suspect there is no money but decide not to pursue the matter, allowing Tracy the time to adjust.

An over-protective attitude to participants and co-researchers, carried over, perhaps, from practice (Etherington, 2004), somehow needs to be balanced with the previously mentioned “friendship as method” (Tillman-Healey, 2003) approach in ensuring there is integrity and support in the process. Whilst I might have seen the funding bid as a separate issue to the research, without it, there was no research and Tracy’s struggle to find help was what brought me to her in the first place

“Knowing together is a dynamic process” – (p.318) changes occur as relationships change and the prism shifts. This process – or dance – needs no end point and this is problematic for some (me) in the light of the lack of tidiness it presents for examiners and supervisors but it does lead very neatly to the unfinalisable nature of persons as expressed by Arthur Frank (2010; 2012). This is an essential concept in the final stage of analysis in act three.

Jones (2006) states that he hopes a process of changing narratives might occur following the sharing of informal carers’ stories, hence the need for this approach to be turned on professional carers. When I look at Hollway and Jefferson on the subject of psychodynamics in research, they seem to be quite squarely focussed on the “subject” and this comment of Jones’ seems to chime with this notion. But in an enterprise where the aim is to work, as Heron (1993) puts it, as interacting self-determining individuals, the subject is everyone. This exposes everyone to the same risks. Transference will affect both. In this instance the after-effects of the experience for me were of feeling alone – and without purpose. I worried that I would perform a traitorous act if I wrote down a “final” version of events.

Etherington’s (2004) narrative inquiry has a position that marries narrative and social constructionist ideas. She acknowledges the impact of narrative on identities – continually reconstructing ourselves in relation to others (Frank, 1995). This can have a therapeutic benefit – and a cost to us the researcher (Etherington, 2004) or, I might like to add here, a benefit to us, the researcher. In this instance, with two people attempting to hold the same position, might the cost and benefit to each be variable?

Our construction continued outside of the formal research space (meaning the allocated time and place for meeting, rather than agreed boundary for engaging in research) and I would argue that some of the most significant work existed in other spaces. Hollway and Jefferson (2000) talk about the whole data around a person as including the transcripts, their memories and the mentions of those persons in the accounts of others during the study. This brings to my mind “All is data” again. Had I been able to recruit more family members or had more time to allow for their re-joining the project, this could have added an even richer picture of Tracy and me. Having spent so much time together we were comfortable in giving opinions about each other and making observations. We also ask each other questions and

share insights. H&J talk of dreaming about their participants and daydreaming about them and the same was true here. There would be times when Tracy and I reported having been thinking about each other and our developing “project”.

Etherington (2007 p.613) the lengths to which Fay Martin goes to verify her notes; typing them sitting alongside her participants as she talks to them and this not being able to get around the problem of the final voice being hers. This reminds me that whatever I do to try and maintain some authentic voice of Tracy I will fall short

Kim Etherington’s (2007) ethical guidelines for reflexive relationships

1. Remain aware of the potential power imbalance between researcher and participants, especially where there are current or previous boundary issues created by dual relationships, and where there are issues of race, gender, age, etc
2. To negotiate research decisions transparently with participants, and to balance our own needs with those of participants and agencies involved
3. To provide ongoing information as it becomes available, even when that requires the use of appropriate and judicious researcher self-disclosure
4. To include in our writing and representations information about research dilemmas that may occur, and the means by which they have been resolved
5. Fisher (2004) (q. p.214-5) “Relational ethics conceives personhood and autonomy as social constructions which can be best be respected through mutual understanding and dialogue”

I hope that there is a sufficient degree of transparency

There is a strength in possessing a reflexivity developed through professional life (as therapist) p.201 which can be expanded in a research role (e.g. in representation). – We should show relationships from beginning to end for others to see how we came to know what we came to know. A problem here is that the partnership between Tracy and I began before we realised we were conducting a piece of research. In addition, there is a problem here if the relationship does not “end” in the traditional, therapeutic model sense typified by Peplau, for instance (1952). A partial resolution is offered by Frank (2012) in the form of “an ending”, which is more of a pause for reflection

Informed consent is only possible in a limited sense when using aspects of the process are as yet unknown (Etherington 2004; 2007) and it is for this reason that a working model of the methodology was offered to the institutional review board, with the understanding that it would change. The ethical consideration of power relations was touched on in discussion with the committee by visiting in person to address issues. Etherington (2007) gives a frank

illustration of how it is possible to underestimate the power possessed by participants and in this, effectively disempower them

“The link between reflexivity and ethical research seems to rest on transparency.”

(p.604)

Situational ethics

“Processes for engaging with others ethically as projects unfold” (Adams et al, 2014 p.60).

Situational ethics refers to ethical decisions made within a specific context, taking in the whole of the situation and avoiding an inflexible absolutism or moral relativism (Fletcher, 1966). The context from which this research project proceeded after I began to work with Tracy was a very different one to that described in the institutional ethics application. Here was a family with a need which was not being met and who were falling between services, each of which was holding someone else accountable for providing assistance. Tracy’s long search for help had brought her to me, not as an end point and source of help as she had imagined but as someone else who had found local attitudes to this problem dismissive and unhelpful. Whilst we could not speak for all cases like Tracy’s, it was evident that the purpose of this research for Tracy was to bring to light something hidden. So we now had a requirement to describe experience and seek help at the same time, in the hopes that the exposure of family experience would expediate better help.

Following Tracy’s recruitment, we then took in other members of her family as they became available, with Tracy acting as a secondary gatekeeper. This privileges her account of events over those of her mum and her brother by virtue of our intense collaboration in contrast to the passing meetings I had with her relatives. The project is a collaboration between two co-researchers rather than a larger group as was hoped. Each of these additional family members was introduced to the project and to me at length to best replicate the proposed recruitment process set out above in the procedural ethics section.

Co-operative inquiry brings with it a different perspective on ethics. The imperative for conducting the research is an ethical one (Reason, 1994; Heron, 1996), arising from a perceived need or injustice with the intention of bringing change or challenging this. These beginnings may set up certain expectations in participants/co-researchers (Etherington, 2007). “Ethics of consequences” is a phrase employed by Kim Etherington (2004) to signify the need to be aware of potential outcomes which may not meet the expectations of those taking part. At least initially, there was some apparent disparity between Tracy and I about

why we were doing what we were doing. She wanted to produce a practical intervention and I wanted to pose a challenge to current thinking. If we had not discussed this frankly and regularly and had not reached an agreement which seems to accommodate both of these ideas without necessarily silencing either, we could be steering a course which led to disappointment or distress on seeing the result. The production of an intervention may come about and hopefully our work will contribute to some improvement in the experience of people involved in cases of hoarding but the end product of my research will be writing.

I also overlooked the sense of responsibility which can be instilled in someone once they have agreed to join you. The shared ownership which I thought so important to fostering a sense of common purpose and belonging could easily tip into stressful ruminations on amount of effort put in or committing sufficient time. This too is true for all parties. Once a piece of research has been completed, published findings can be used by some in a capacity which is undesirable to those involved, as in the case of press reporting which can sensationalise and distort of findings (Wadsworth, 1998). As mentioned above, we had already appeared on local community radio at Tracy's suggestion, to draw attention to the difficulty in accessing support locally. The decision to use her name rather than report anonymously was one Tracy took herself. The repercussions of this appear to have been positive to date

Olesen and Pedersen (2013) remind us that power in action research is an unavoidable issue. There will always be "othering" and this tension between post-constructionist ideas and the concrete notions of self used by all of us will not go away. We must be reflexive in our practice and especially in our analysis as people may not recognise the account given of themselves in the research and this may cause offence or distress. I kept a journal during the project which I shared at times with Tracy. Yang (2015) raises the issue of participant reflexivity. We do not, he claims, afford the same qualities and abilities to participants as we do to researchers. I hope that in the account offered in this thesis, participant reflexivity is evident. By meeting several times over the course of the project, a reflexive environment was fostered between us. Additionally, I made my reflexive observations available to Tracy as a matter of course in conversation as can be seen from chapter four. In meeting during and since the project phases described here, both of us have initiated reflexive discussions and shared insights.

Denzin (2003) indicates the inherently inappropriate nature of the biomedical ethics model employed by academic institutions the world over in application to many qualitative methodologies and in particular participatory methodologies. The format of institutional application forms and processes does not reflect or recognise the differences of approach

which have developed since the institution of international codes of ethics in response to Tuskegee and the like. Denzin (2003) demands action from performance ethnographers. Research which addresses injustice or inequality by its very nature is required to take a side. As Gergen and Warhus (2001) have noted elsewhere, for constructionist therapists, too a neutral position is an unethical position, or at best an unhelpful one. Gergen asks:

“What is it for professionals to inform the world that we know most about each other when we care the least...Is this a good model for our relations with each other?” (p.91)

Providing a platform for the voice otherwise repressed is, Etherington (2007) argues, an aspect of feminist research which carries an ethical imperative. This certainly sounds familiar, if we recall Denzin (1997) and Conquergood’s (1992) respective thoughts on the intrinsically ethical purpose of research. In these cases, it is the space which is created together for the voice, which is encouraged or respected. By dedicating time and space to reflection on the process, and by conducting a joint phase in the process of analysis, an attempt was made to allow evaluation of the research from both co-researchers’ perspectives.

Etherington (2007 p.82) states it is the collaborative nature of the research that allows ethical decisions to be made. Collaborative witnessing is the term Ellis (Douglas and Carless, 2016) uses for her work with Rawicki, in which they explore his experience of the holocaust together. In describing collaborative witnessing, Ellis et al (2011) use the term “co-storytellers”. She also speaks of “being with” the teller. This is exactly how I contextualise the unique position I have in my research with Tracy in which my skills are employed.

“I committed to doing and writing autoethnography with Jerry as if I were a person in his story.” (Ellis q. Douglas and Carless, 2016)

For Gergen, (1999 p.154) curiosity employed within the practice of transformative dialogue typifies the way in which academics must move away from talking and listening in a “top-down” manner to a “bottom-up” (by which he means beginning in “the world of action”. Anderson (2004) advocates action from research rather than simply idle curiosity or the promulgation of further research. In fact, how can we even have research existing in isolation? As nothing more than an exercise in curiosity? Building knowledge/ethics from the bottom up rather from the top down (academy) is a message she gives which echoes in Denzin’s (1997), Heron’s (1996) and Gergen’s (1999) work. This owes its origins to Gramsci’s reading of Marx, perhaps – research and practice and politics necessarily bound

up together in the one person, the organic intellectual (Hammersley, 1999; Goodman and Grant, 2017).

Chapter 3 Act III: Cooling down. What just happened? The aftermath of rejection

“Narrative -based methodology considers the story as telling of actions and events in others’ lives that encourage reflection and self-understanding for the narrator.”

(Rapport, 2004 p.9)

“The turn to narrative enquiry shifts the very presence of the researcher from knowledge-privileged investigator to a reflective position of passive participant/audience member in the storytelling process. The interviewer as writer/storyteller then emerges later in the process through her/his retelling of the story as a weaver of tales, a collage-maker or a narrator of the narrations.”

(Jones, 2004p.36)

Following Janesick’s third stage of qualitative research design, cooling down refers to developments at the end of the study. She highlights the difficulty in identifying an endpoint to a research relationship which can be a close one. Frank (2012) suggests that rather than reaching the end, we must necessarily identify “an ending”, with the understanding that the process will continue with each new reader and their interpretation of the text. Janesick returns to the notion of flexibility and adaptability in employing a gradual withdrawal, identifying the ultimate responsibility of the researcher in producing a narrative even if “rigorous guidelines” are followed (she offers various examples). There are ethical arguments for the continuation of this relationship outside the context of the research project as mentioned below (Adams et al, 2015). Despite attempts to cultivate a democratic system of analysis in this project, there is still plenty of truth in this. Thick analysis and thick interpretation, Janesick (1994 p.216) argues, should balance out thick description (citing Denzin, 1989), embodying a passion for understanding people by spending equal time on analysis to that spent in the field. The process of writing and re-writing, sharing and comparing observations has been long. This has had the benefit of allowing time for reflection and development of ideas (although it has created tensions around timescale).

Following the narrow public rejection of the CCG bid, we gained space. Fuelled partly by a feeling that we had not been understood and partly that we had to compromise significantly to produce what we felt the CCG wanted to hear, the focus moved away from the “problem” to perceptions. This was a subject which had made various appearances throughout our

project and discussions with each other and other people. We met to discuss our experience, the transcripts and our wishes for the future. We examined what we learned.

Narrative analysis (as opposed to the analysis of narratives e.g. Content analysis, discourse or thematic analysis) – “treats stories as actually *constituting* the social reality of the narrator(s)” (Etherington, 2004 p.81). Foster et al (2006) refer back to Dershimer (1991) who points out that social constructivist (sic) approaches are likely to lead to multiple insights rather than a grand truth. The idea that all of this work when completed is fed into the brain of one person who does as they will and makes pronouncements about findings (that’s a plural, isn’t it?) just doesn’t make sense here (Frank, 2012). In the picture below is the result of Tracy’s initial impressions of the transcripts captured on a whiteboard. It is also a record of my hopes and expectations for what Tracy would say about our working together. It is also a record of our experience together. And it is a political statement about power and voice. The research question was about help-seeking. Where do family members go for help. There was a “why” attached to the end of that question. Below is my account of events immediately following our attempts to capture an overall “flavour” of our reactions to seeing the transcripts for the first time and meeting up after a long break. This marks the start of moving toward an understanding of why.

Throughout this project, we followed a cycle of action and reflection after Heron (1996) which created a space for ongoing and developing analysis. A summative exercise is therefore never going to represent the end. The best it can offer is a pause, or “an ending” as Frank (2012) puts it. Perhaps a more concerted effort to analyse and take stock. This is apparent from some of the results of the free association exercise we did reflecting on the project as a whole as well as the transcripts of our conversations. Akin to Schön’s (1983) reflection on action, as opposed to the cyclical process outlined above, reflection in action this is essentially a meta-reflection on reflection-in-action (Rolfe, 1998)

Hollway and Jefferson (2000) spot that interviewees or respondents can self-censor and edit as they go along to produce a narrative pleasing to the researcher, rationalising their own existence, countering any possible interpretations they do not wish to be explored. The example of Tommy’s apparent wish to present a “rosy” picture (in Tony’s eyes – his experience having not been enjoyable) of a childhood marked by adversity (p.56) is used to demonstrate that straight textual representations of respondents’ words may lead to the loss of a lot of vital contextual information. One way that we have tried to address this during analysis (whilst acknowledging that there is no definitive or “true” narrative) is by conducting it together. This is advocated by Bergold and Thomas (2012), who also request that the language and methods employed be accessible to non-academic co-researchers. In fact,

the first examination of transcripts was carried out by Tracy and this was then fed back to me, with phrases and insights written down on a whiteboard as they came up (although this idea admittedly came from me so how able Tracy felt to reject this suggestion if she found it disagreeable is not knowable). It is regrettable that all the writing was done by me as there were points where so much information was being generated at such a pace that it was difficult to keep up. In addition, emphasis may have been given to ideas or phrases which were not deemed important by Tracy. However, the application of the whiteboard was to enable live commentary on the board and its contents in the hopes that this would provide an equal opportunity to shape what was emerging and allow for stories to “call out” for further analysis in the second phase of analysis.

Dialogical narrative analysis (Frank, 2010; 2012) proceeds from the position that stories exist as independent entities, called forth in the service of storytellers, who may piece together fragments from a selection of stories to form a unique new whole. Stories are a finite resource and it is therefore the stories which will form the focus of analysis. Storytellers are unfinalisable. Frank cites this as a fundamental ethical commitment of DNA. There is no – so there you go moment at the end of DNA. Storytellers do not have access to the full catalogue of stories to draw on and for some resources may be very scant. The analyst’s art is to draw on their experience as a witness of many stories “hearing how multiple voices find expression within any single voice” (Frank, 2010 p.3). We must remain suspicious of monologue, acknowledge the independence of stories and the unfinalisable nature of persons and resist the urge to summarise “findings” in favour of offering possibilities for further listening and responding.

Free-association gestalt exercise

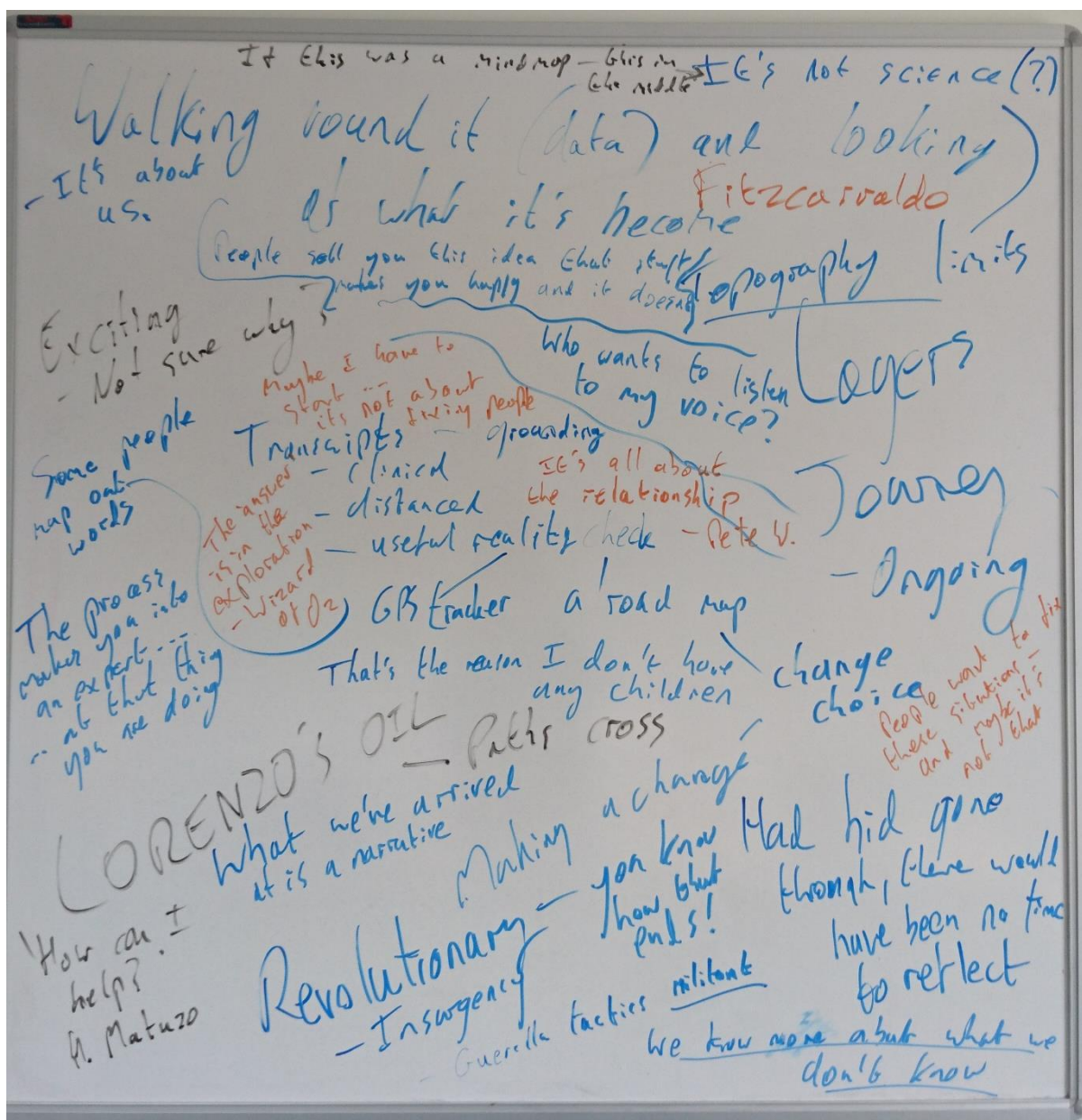


Figure 15- results of free-association gestalt analysis exercise

Tracy and I met at an appointed time (not an easy arrangement) after she had had about a week to look at a large number of transcripts and form some rough first impressions. I deliberately (although the agony nearly killed me) did not look at these. Whilst I waited for Tracy to arrive on the appointed day, I made notes. I wrote down my expectations, hopes and some rough impressions of what kinds of things might be mentioned formed from my memories of our conversations (see appendix 10). Tracy is delayed and this benefits the process. When Tracy arrived, I missed her arrival and found her talking to a colleague with whom she shared a connection. We did some catch-up chat – projects we could and could

not get involved in. I have missed her. Then Tracy asked me what was required. So, I described the above and she began.

Analysis was initially focused upon the whole text, referred to by Hollway and Jefferson (2000) as the “form (gestalt)” of the data which suggests that “the whole is greater than the sum of the parts” (Hollway and Jefferson, 2000 p.68). We described “Walking round it (data) and looking at what it’s become” also “topography”. It is highlighted by Hollway and Jefferson that new researchers can miss much in their attempts to hurriedly break down data into codes, decontextualizing texts.

“It is hard to pin down subtlety and intuition, but we believe that using these capacities unavoidable once the researcher has posited a psychosocial subject.” (p.68)

Or two psychosocial self-directing persons. The whiteboard emerged all kinds of ideas through this free-association exercise (figure 15 above). I recorded them in a mix of colours initially with no awareness of any particular rhyme or reason as to why. Some things I did write in strategic places on the board (narrative was written underneath “Lorenzo’s Oil”, for instance) as I felt the urge to do so.

She described the textual experience, I think we could call it. Seeing this dialogue on a page. I looked at her page and was surprised by the tidiness of it. My attempts at transcribing our conversations had not looked as neat as this. Where was the overlap of sound and ideas? Where was the energy? What was I looking at? We talked about how this would sound if read aloud as a script. We produced this, but we didn’t produce THIS! However, Tracy seemed to like it. It gave solidity to our endeavours, our process. This had been our aim when we began. To produce materials which could be analysed in some way. Well, here we were. That was what we had. And having that meant that we had completed something.

Suggestions have been made that with the development of technology it is no longer necessary to employ transcripts when the original data can be made available, embedded in reports and allowing for increased transparency and rigour (Markle et al, 2011) but Tracy’s reaction served as a reminder that emphases differ from one co-researcher to another, creating tensions within the researcher which must be addressed (Ellis, 2007). There is also a re-assuring solidity to having transcripts available and the added practicalities of thesis submission. Narrative research requires us to tolerate uncertainty if we are to produce research informed by “variety, discovery and surprise” (Hollway and Freshwater, 2004). And tolerance of uncertainty is our recurring refrain. Perhaps the solidity of paper copies

offers a sense of security in the face of the uncertainty posed by not yet having analysed the data.

“The analysis of selected stories takes place in attempts to write” (Frank, 2012, p12)

It does not present ends, its strength proceeding from “the opening it creates to further representations” (*ibid*). In preparation for the exercise described above, I wrote down my expectations and hopes as to what Tracy would have found and thought by looking at the transcripts. After I had asked her for her views and interpretations, she asked me what I had made of the whole experience and as a response, I was able to share my hopes with her. Beyond this, we both made records of our explorations during the recruitment phase of this project, which we brought together in a presentation at the 2017 Public Engagement and Performance Conference. This process allowed us to analyse further our experience of help seeking from different points of view and by presenting it to audiences (we have presented again since then), for those hearing the story to engage in analysis. The process is one which will be ongoing for as long as the presentation is performed.¹

Tracy went through issues which stood out for her and these were all on a meta-level. I offered opinion and reaction to these insights and wrote down as best I could the stand-out phrases and words, some directed by Tracy, some agreed and some of my own choosing. Tracy asked me questions about some of the issues she raised and I asked questions of her about some of them. When we had exhausted these, Tracy asked me what I had written before she came. We discussed these ideas, hopes and thoughts. Some of them we had already talked about. A big one was “I am not the same person I was at the start of this”. Tracy seemed surprised and asked me how I was different. I struggled to express it at first. Untangling it seemed impossible. Moments like this always fill me with admiration for Tracy who does not seem to struggle with expression in this way. Tracy offered responses to my lists which produced further material for our board. Eventually she had to go. The experience

¹ Dissemination through the use of performance, conducted in a non-academic language is intended to aid accessibility for all audiences and create an emotional reaction when the audience through the use of visual spectacle. As more audience members are asked to stand up to represent a potential source of help or knowledge approached by myself or Tracy prior to finding each other, the audience comes to realise just how long and difficult the search was for Tracy. Engaging audiences through performance enables greater understanding through use of shared language and emotional resonance (Jones, 2010)

was intense and quite tiring but I only noticed this after we had finished. Photographic records were made of the board. On the way out, Tracy mentions something about how we have worked and this prompts me to quote a friend of mine, whose clinical maxim is “it’s all about the relationship.” This must be added to the board, we decide. It is. As near the middle as I can manage. I retake the photograph.

Hollway and Jefferson (2000) conducted a second interview, offering opportunity to check own suspicions but allowing time for both parties to reflect in between. They attempt triangulation having both researchers listening to the tape and analyse data together but time does not allow more thorough process in context of PhD. The problem of “telling it like it is” research is the assumed transparency of self and problem. Riessman (2008) states that we can never give voice as we do not have the experience of the other to draw on. In addition, we must take an interpretive approach to ourselves as well as those we research – we are not neutral.

This harks back to an earlier comment Tracy makes, that the research is “all about us”. At some point, it ceased to be a project around finding a solution to a problem and became an exploration of meaning and existence. This sounds rather grand but you have the evidence before you. I describe my explorations of autoethnography and Tracy finds agreement with the description of that particular methodology. In fact, as we have gone through the various observations we have made, I have attempted to provide Tracy with methodological footnotes regarding narratives, social constructionism, performative social science, collaborative research and autoethnography. This was not an attempt to create an equality of research knowledge, rather than to justify or clarify some actions or decisions. If, as Bergold and Thomas (2012) suggest, Tracy had received training in research methodology, we could have ended up with a much more rigid end product and couched in language which would be less accessible.

In telling each other our stories of exploration and help-seeking we each referred to existing stories. Frank (2010) believes all stories have an existence of their own and are only appropriated by storytellers, never created. There are three overt examples in our wall of analysis. These are The Wizard of Oz, Lorenzo’s Oil and Fitzcarraldo. The first two are called upon by Tracy. The third was offered by me in response to her suggestions. These titles are shorthand for stories of type. Lorenzo’s Oil was brought up by Tracy to illustrate the chance encountering which led to a solution to a problem. In the film, this is a much more obvious and definite solution than in our work, but the insinuation made me feel very satisfied. Like this enterprise had genuine beneficial effects, even if that was not the aim. I offered Fitzcarraldo as a reply because it exemplified doing things the hard way and I felt at

that point that this was a difficult way of doing research and a complicated way of seeking help (looking for an answer to hoarding in Hull rather than looking for a solution to Tracy's mother's problems alone). I think I considered both Tracy and I to be the kind of people who will haul a ship over a mountain if we deemed it necessary. Of course it could be that this is sheer bloody-mindedness.

The Wizard of Oz is quoted by Tracy. "The answer is in the exploration". The search for solutions/understanding in the wider community (and the country) has led to a greater feeling of understanding.

Dialogical narrative analysis

Conducting the exercise described above, we reflected on what had been learned during the fieldwork and it is this which directs the attention towards the stories which will be included in the analysis (Frank, 2012 p.12). Dialogical narrative analysis, Frank (2010) tells us, is not a prescribed methodology. He offers suggestions for questions which might be useful to put to the stories we identify from the data, but these are not set in stone and should be adopted and adapted as required by the narrative researcher (as used in appendix 11). Finding this appealing, I have some reservations. Notably, the newness of the enterprise. Having never undertaken this before, I set out some preliminary questions, taken from Frank (2012) in appendix 11 for me to map stories against. I also had to bear in mind that Frank suggests that some questions will not apply to some stories and this is as important in analysis as those which do.

Carl Leggo gives us a story – he goes to talk to a group of oncologists about narratives. He devises a rubric for analysing them. He doesn't like it but many of those present do and he still gives it to grateful students BUT he posits, misinterpretation is dangerous and harmful. For this reason, the certainty which could be engendered by use of a tool should be avoided – we should be "tentative" in telling stories with an awareness of the fleeting nature of interpretation. Here again I can hear Ken Gergen saying that constructions are temporally and culturally bound/contingent. Leggo (2008) and Frank (2012) both suggest that narrative analysis is never completed, as readers of the text will continue to contribute to the process through dialogue with the text. I hope my use of a prop will be forgiven.

Another area of difficulty for me is the skill of "phronesis", which Frank (2010; 2012) describes as the ability to hear which stories call out to me. In this regard I have simply done my best and revisited my annotations several times to weed out narratives which do not constitute story (that is, they do not employ imagination, rather they are technical

accounts). Frank (2010) reminds us that we are already all narrative analysts, meaning that we undertake this exercise all the time in everyday life and not all stories call out to everyone. As mentioned elsewhere here, storytellers and listeners rely on a set of resources for telling and hearing stories. My own stock will not be as broad as someone like Frank himself, who has spent twenty years telling and hearing stories. Many of the stories in our conversations were boldly borrowed. That is, they are repetitions of everyday events, media stories and encounters retold, what Carl Leggo (2008) refers to as...

" stories sanctioned with an appropriate value by their public transmission" (p.3)

Leggo (2008) argues it is sometimes not the content but the telling that makes a story engaging or boring and it is these characteristics which make a story call out to be heard. Frank (2012) says much the same but reminds us that even if the retelling of a story is reliant on the telling to make a specific impact, the story "always exceeds the particular language in which it is told" (p.11).

At some point someone has to produce the "story of sorts" – the version of events that will comprise the finished whatever-it-is (Leggo, 2010). How do we prevent it becoming one person's version of events? Can we? We tried and are still trying. In hindsight, I regret not having recorded (possibly as a video) our analysis session, which would provide increased transparency and given us something to refer back to when reviewing this text. But then, the Tim and Tracy looking back now at the analysis at such distance may not have the same resources with which to make sense of what they saw. And in every instance of revisiting and retelling, new stories would be told and heard (Frank, 2012).

I ask Tracy if she will consider writing something to add to the story. Something of her own story, perhaps within the same timeframe I offer (2012-2016). She tells me that 1998 would be the most appropriate beginning and I tell her that she can do what she can and if it is only bullet points that would be very helpful. Perhaps in the future we could do more. She has been told by friends that she should write down her story, she says, but when she considers the popularity of narratives of abuse for entertainment, she finds it distasteful. She is going to try reading someone else's account of growing up in a hoarded home, perhaps. I give her some suggestions (then forget to give her my copy of Jessie Sholl's "Dirty Secret" when she leaves).

According to Bakhtin, stories consist of an abstract, orientation, complicating action, resolution, evaluation and coda. Frank suggests that stories can be incomplete, in that they may not have all of these elements adding that any definition of what constitutes a story should be "...fuzzy at the boundaries." (p.11), whilst Leggo (2008) drives the point home with a list of genres which spans the alphabet.

Frank's simple typology of stories (1997; 2012) was designed for use by clinicians and service users. In offering just three types, each of which can simultaneously be present in any story, it offers a means of considering the motivations and effects of storytelling and stories in a busy environment. It also offers a manageable approach for a beginner in dialogical narrative research. And essentially from Frank's point of view, it focuses attention on the stories and leaves the people unfinished. Restitution narratives are essentially stories of illness and cure; chaos narratives are incoherent and disordered and quest narratives are those in which illness sets off a search for meaning. By enabling everyone to play the "truth games" they are caught up in with a degree of skill, through examination of their own resources and constructed narrative, Frank hopes to promote what Foucault (1997) referred to as "care of the self". Frank identifies the risk in developing a typology which could be misappropriated as a means of sorting "good" from "bad" but asserts "The dialogical test of a typology is whether it enhances people's capacity to hold their own in circumstances of vulnerability."

(p.17)

Foucault's relations of power, Latour's actor network theory and Bourdieu's cultural habitus all had an effect on the work of Frank (2010; 2014) in his consideration of narratives and their uses. Frank (2010, p.93) asks how storytellers can use the resources available to them to tell their memories as stories and how they can tell new stories about themselves.

"Stories are the ongoing work of acting or performing memory"

(p.92)

In most of the stories occurring in the transcripts, these are recent memories. Their shaping through narrative resources available to Tracy is evident throughout. In those transcripts where a story is being told by two people, there is a clear evidence of how one person "holding their own" as Frank puts it, disadvantages another. Frank (2012) gives the definition of this phrase as

"Holding one's own is a response to vulnerability; sometimes this response is spontaneous, other times it can be strategic and reflective." (p.14)

At times the person disadvantaged is not present to speak for themselves (notably this is true of Dean, Tracy's brother. However, they may have their story voiced by another (as perceived by them) as a counter. Julie offers a different story for reasons why Dean is not currently involved in her and Tracy's lives, for instance (but this is at a cost to Tracy, who is cast as a villain in this particular tale).

"...DNA imagines life as primarily a condition of vulnerability." (Frank, 2012 p.12)

“Stories revise people’s sense of self, and they situate people in groups”

Frank, 2012 p.2

In particular, in this intimate piece of research, the sense of self keeps resurfacing. There are narratives which can be appropriated for identity purposes – the Children of Hoarders narrative, for instance. But such narratives and all narratives have limitations, edges. We are Venn diagrams, crossing over many narratives. Untidy and incomplete. At times incoherent. Some narratives outlive their usefulness for identity formation purposes and are laid aside, potentially to be taken up later when they again become relevant or attractive (when they call out).

Arthur Frank (2012) offers three issues of analysis in regard to endings:

1. An analysis that has been truly a dialogue should end with appreciation for the storytellers and their art
2. Analysis can end with the relationships that stories instigate
3. An ending can recognize how people’s lives are affected by how they use or misuse their imagination

These three issues raised by Frank inform what comes next. Tracy and I continue to work together both in educating students and other groups about our research and experiences. We tell our story. The tentative approach to making finalised statements about findings follows from the unfinalisable nature of a continuing story and the contingent nature of our particular story. Frank’s third rule is one which we can attest to. It is the nearest to an ending that we can come (although we must bear in mind that this doesn’t constitute “the end” rather, it is “an ending”).

Leggo suggests that we invite people to make their own interpretations of our narratives – “I seek to resist and even subvert unity and closure...” Leggo (2008) suggests that narrative should be looked at in the sense of the verb rather than the noun. It goes on. It is active. That best captures what happened for Tracy and me, I think.

Reflection on cooling down

“The turn to narrative enquiry shifts the very presence of the researcher from knowledge-privileged investigator to a reflective position of passive participant/audience member in the storytelling process. The interviewer as writer/storyteller then emerges later in the process through her/his retelling of the story as a weaver of tales, a collage-maker or a narrator of the narrations.”

(Jones, 2004p.36)

There have been many comments made above about how stories about hoarding are dominated by particular tones. Using DNA allows stories otherwise unheard to be brought forward. In particular, DNA is interested in identity and self-determination which both feature strongly in this work.

To achieve a completely democratic process we would need, I think, to have the same degree of power. I hope that we achieved a significant move in that direction for future development. As I have said elsewhere, a person with less experience and confidence than Tracy may not have been as able to contribute as well using these methods so it is essential that the co-design process is as accessible as possible and this principle carries through the execution of the project with regular reviewing and stock-taking. Our conversations serve as a means for achieving this to some degree, although they were hampered by our availability at times.

One limitation here is my lack of experience. Frank (2012) makes some serious demands of researchers to call upon their stock of stories and use their “cultivated capacity to hear” (p.11). I think that as an experienced mental health practitioner, I have heard many stories and have learned some specialised skills for listening (and Frank (1010) appears to agree), but this was a new venture and as such I am a novice. In the literature review stage of this thesis, I read several memoirs of people who had grown up in a family home affected by hoarding. I also extensively read and watched accounts from other spheres of life such as clinical case studies and documentary programmes, all of which presented narratives although as Frank has observed, some of these are not stories. The distinction lies in the application of imagination. So, a child imagining they lived with another family formed by their imagination is different to a technical narrative of someone’s compulsive hoarding written by a psychologist, which is dependent on expertise.

Analysis of the data by software package could have raised questions of accessibility and undermined the constructionist ethos of the project by deferring to an “unbiased” methodology the benefit of being impartial but this is not an aim of this research. We “took a

side” (Denzin, 2003). In fact, coding of any sort has the potential to stifle involvement and silence voices but as a novice, I needed a means to give it form. The analysis in this research is still the development of method and is still the research. In fact, in all research studies, the analysis generates data as whatever rigorous prescription for coding is the final decision resides with the researcher (Janesick, 1994; 2004), so with this in mind, the collaborative nature of data generation had to be maintained. “The analysis does not seek to find similarities across stories, and is not interested in conceptual themes, but instead values the messiness, depth and texture of lived experience.” (Etherington, 2004 p.81)

Chapter 4 - Stories

This chapter reports the results of the exercises described in act III of the previous chapter, an analysis in two parts which aims to bring together reflection on the experience of pursuing the setting up of a hoarding training and education resource in Hull with the experience of being a carer for someone with a hoarding problem. By using the whiteboard exercise first, I hoped to produce a focus for analysis which was located in the experience of both Tracy and me. The resulting ideas from the whiteboard were about the project as a whole and our future hopes, what we were aiming to achieve through this exercise in analysis and through conducting research in this way. All of this linked back to the idea of help-seeking and motivation. As well as pointing to stories and their importance for both of us.

Cobley (2014) holds forth that the form of the story gives it its significance. Perhaps in our expectations of what a story should look like we do not notice the stories we encounter and tell as a matter of course (Frank, 2010). Leggo (2010) claims narrative offers “possibilities of meaning” (p. 5) of which there are many (also, McAdams and McLean, 2013). This sounds like Ken Gergen. Rather than setting our meaning in stone, stories open up “possibilities for wide-ranging connections, questions and insights” (p. 6). Let’s allow the reader to make their own sense of our tales, too.

Stories do not all call out to everyone (Frank, 2010). “I am not interested in hearing what a friend ate for breakfast unless the story is told in a way that is full of interest.” says Leggo (2010 p. 5). Narrative analysis needs to look at those stories which individuals and /or groups do not relate to or overlook and why as much as it does those which they become caught up in. By summing up the fieldwork experience together, I hope to show how the principle of “phronesis” cited by Frank (2012) in the selection of stories for analysis takes account of how

“Judgement depends crucially on what has been learned during fieldwork” (p.12)

And by attempting to decipher what has been learned jointly, to try to counteract the inevitable bias of one person (me) having to produce what Carl Leggo (2010) refers to as “the story of sorts”. Kim Etherington (2004), too, acknowledges that in the end the researcher will have the final word. I tried to begin identifying stories by picking out a focus for each of the conversations and I have done this below. Of course, these are just my interpretations and should be considered in conjunction with the whole set of expectations and hopes which I have regards working with Tracy. Not to mention the results of the whiteboard exercise. I just thought I had better start somewhere in engaging with this process.

Table 2 - focus of conversations identified from reading of transcripts

Transcript number	Focus (broadly but not exclusively)
WS_10001	Planning
WS_10003	Normalising
WS_10004	Identities/relationships
WS_10008	Roles
WS_10009	Family
WS_10010	Things and meaning

Having gained some insight into what mattered to us it allowed for an exploration of those stories we told and heard in our conversations on the project. This is where DNA came in. Frank (2012) holds DNA to proceed from a position of acknowledging the vulnerability of storytellers and examining the defensive function of the stories they tell. This lines up with Hollway and Jefferson's (1999) notion of "defended subjects" to an extent, although for Frank (2010; 2012), the subject is never finalisable, only the story. The similarity comes from the understanding that there is a defensive function to storytelling. Dialogical narrative analysis concerns vulnerability (Frank, 2012). For instance, Blix et al (2013) aim to tell stories from the margins of the popular, looking to increase the stock of stories available to members of a marginal community.

Frank (2012) recommends that only intact stories, not quotes or excerpts, should be analysed and I have tried to remain true to that principle, although I have at times used quotes from stories as working titles during the analysis process (e.g. "I've got to do something about this"; "So she can live in that and she'll walk out looking immaculate"; "You know you are going to lose something, so you want to acquire something"). It would not be practical to reproduce all of them in this text so I offer exemplars instead. In doing so I am in no way suggesting that this is a definitive version of or reading of the data. It is offered as a response to my question as a point for eliciting further responses from readers (Frank, 2012; Leggo, 2010).

Stories emerge from dialogue (Frank 2012). We tell stories based on the stories we already know, as a means of expressing something more than the content of the story and listeners hear stories through the filter of all the stories they ever heard and this raises the question of what resources (stories) are available to those telling and hearing stories? How do these

limit the ability to tell new stories? This last question is echoed in the work of Grant et al (2015) in their description of “narrative entrapment” with regard to the position of mental health service users after Ricoeur (1990), who states that we are already trapped in stories and as a result tell stories. In this instance, the term could be perhaps expanded to take in the carer.

The stories which emerged from DNA can be typified as falling into four groups, each of which is a set of variants on one story, influenced by numerous factors which can be seen in the proforma I drafted for use in analysing them from a chapter by Frank (2012) (appendix 11). Questions suggested by Frank (not necessarily all applicable to all stories) are grouped together as resource questions (what resources can storytellers and listeners draw on?); circulation questions (who tells what to whom?); affiliation questions (how do stories put people within or without groups?); identity questions (what identities can storytellers imagine using these stories?) and what’s at stake (how do storytellers “hold their own”?) Sometimes one particular type stands out or occurs in isolation but more often than not, several are present at the same time.

In brief, “the campaigners” is a story about an attempt to develop an intervention or training package for people working within statutory or voluntary services to raise awareness of the specific needs of people with compulsive hoarding tendencies. It involves technical accounts, notable characters from clinical and academic hoarding backgrounds and professionals from many different services. This is a quest narrative, the protagonist (Tracy) being animated to embark on a journey of discovery by an affliction (the consequences of her Mum’s hoarding)

Often found alongside “the campaigners” is the story of “the carers”. In this familiar tale, the principle characters are family members (and a nurse) although service providers do make regular appearances.

“The curators” is a story about holding on and about identity (as are all of these stories). It features things and value, which sometimes centres around tastes and cultural references but sometimes is more about family and nostalgic value. Also, the oppressive pace and wasteful nature of modern life is contrasted with ideas of reuse, recycling and creativity. There is a wanting to be different expressed in this story.

“The experts” is a story about the search for knowledge, initially a particular form of medical knowledge about hoarding residing within a particular person which can be harnessed by “the campaigners” and “the carers”. The influence of “the curators” upsets this story by adding in a broader understanding of expertise.

I went through the transcripts examining what I at first identified to be stories and entering them into a table (appendix 12). I then looked again at the stories to see how they were similar and test them against my developing eye for story. At this point, during completion of proformas some of the identified stories were found not to be sufficient to exist even as partial narratives and these were scored out. The remaining stories were examined for the best examples to show each type (acknowledging that they will still contain elements of all types) as reported below.

Tracy is not the only voice present, either. Tracy's mum features in two of the transcripts and her presence and actions saturate the writing. We spent a good two hours in conversation getting to know each other after signing consent to the project, before meeting again for a recorded conversation which revolved largely around family. The unrecorded conversation gave me a lot of detail about her experience and background. Much adversity and some traumatic experiences. It would be easy to lament the missed opportunity to capture this data but the relationship was essential to the process and continues to be present even if we are not in regular contact.

There is also the voice of S, a charity shop manager, artist, and avid fan of discarded things. She is only present in the final conversation, despite my earlier meetings and conversations with her. That conversation offers a discussion around what makes people keep things. How these reasons can differ from one object and person to another. This conversation marks a turning point. It is something I felt compelled to do but which is not sitting within the frame of the original research project. I am following a lead, I know not where. This is something I like to do. It has been suggested this is the avoidance of ending.

And then of course, there is my voice. A mental health worker turned academic, interested in old things, comics and "hoarding". The only other regular character apart from Tracy. The transcribing was carried out by an independent agency. They were not informed of the identity of the "interviewer" and "respondent" as the reflective conversations between Tracy and I and our erstwhile contributors were not meant to be construed as interviews in the sense of an expert researcher eliciting data from a respondent. Rather, the constructionist reading of our interactions described in chapter 3 act II posited that in conversing we were constructing knowledge. And the suggestion of Reason and Heron that there were two self-determining persons present contested the traditional role descriptors. What the transcription service did was label them as they perceived what they heard. The resulting labels are displayed (Table 3, p.182) and discussed below with regard to how perceived roles shifted between Tracy and me throughout the research as well as in the transcribed conversations. In the same way that I did not want to impose a particular structure on these

conversations, I do not want to direct people as to how they read them, only offer my observations from the analytical processes described. Therefore in script 1 I am S2:Tim; in script 2 I am “Interviewer; in script 3 “Respondent”; in script 8 I do not appear; in script 9 I am “Interviewer” and in script 10 I am “Speaker 2” again.

Story 1: The crusaders

It seems appropriate to put “the crusaders” at the beginning as this was the story which first brought Tracy and me together. Our first recorded conversation was around planning to make the CCG funding bid. The characters are numerous and all providers of some sort of service or assistance. The narrators are casting themselves as a repository of professional knowledge about hoarding (Tim), for example and a campaigning help-seeking family member (Tracy). We have met a few times before now so we know each other and have a specific agenda.

R: Yeah. But sorry, to go back to what Heather was saying, but she was talking about some of the support groups that she’s had dealings with in the past, and they have been in fire stations and she was talking about a woman that had come up to her, and she was just attending these meetings because she just wanted to go and listen to what was being said, she didn’t particularly want to contribute, and apparently she was going to actually kill herself and she went to one of these meetings, after about 3 weeks she decided that she wasn’t going to kill herself, and that she was going to approach someone in the group to see if there was a way of dealing with it. People who feel that they don’t have a problem with it might still be interested, there’s still a support group to go to isn’t there? If you want to live with your stuff that’s absolutely great but maybe you might want to go to a support group where a fire officer will give you some best practice advice about how to minimise the fire risks, or how to make sure that you don’t get trapped, or that nothing is going to fall or cause you any problem. And also, to make people aware of how difficult it is for people like to come in, because I think I did see on that Richard Wallis thing, they did send a whole team of firefighters in and I think there was probably a gap of about that, where they had to-

In Tracy’s voice we can hear a campaigner and a concerned family member but also an expert who has researched hoarding and sources of help extensively. Someone who wants help with their parent’s situation but who also wants to achieve something bigger. Sometimes these are in tension.

“...I feel like I’ve got a bit of a conflict going on in terms of committing time and resources and energy and everything else into doing this for other people who are unknown as yet, and that I’ve also got the added pressure of trying to keep the ball rolling for mum...”

This seems at first glance to be a straightforward case of limited resources but there is a reason for engaging in this bigger campaign beyond helping her mum. Frank (2010; 2012) refers to attempts to maintain the sense of self in the face of threats as “holding one’s own”:

“T: Doing this, I much prefer to do this. And in some ways, it’s almost like a distraction from what I need to be doing for mum. If you see what I mean.

Tim: Yes, I guess you’re doing something about the same problem but it’s not as immediate is it,”

Tracy suggests that perhaps her approach to organising local education and training and national events is a way of avoiding going back into the house. She describes feeling as though she is being violated when she touches things to clean/tidy. We do not discuss further details of her own childhood although she does mention that there was the threat of removal by social services at one point.

“I would have been so grateful for someone to have done this even if it had just been to getting to the point of, Tracy, don’t even bother looking for anywhere else because it doesn’t exist”

“...for my own self-actualisation I much prefer this, this gives me a lot of enjoyment.”

R: I met this guy there, cos we were sitting around a table very similar to this in a room, but there were a lot more people there. Basically it was one of these things where the guy, he was quite good actually, a guy called C_, and he’s the Engagement Manager from the CCG and basically what he was doing was he was giving you all the hacks, how to hack your project to get funding, in terms of delivering the presentation. So you had to go through the exercises in here and what he was saying was, “Turn to the person next to you and write up your spiel, deliver it to them and get them to do the same back.” So that was it really, so he was just saying that 150 had applied, and 123 went to public vote. So I guess the difference, maybe the ones that didn’t achieve the, that didn’t (inaudible; over-talking 00:20:06) that it was safe, that it didn’t-

I: **It’s gonna be a long day!**

R: Well it turns out they’ve got half a million on offer at £5,000 a pop, a lot of people have got more than one project in, so they’re not just bidding for one lot of 5. So basically what he was saying is every project that gets the thumbs up, and it only has to achieve a 51% percentage rating to get the thumbs up, will go through. He said there are more projects than money but as long as it gets the thumbs up they’ll all go

through. Apparently a lot of people that were there kind of know this, and if they've got quite a large organisation what they ask their organisation to do is to go along on the days of the public vote to basically vote in favour of their projects, which is perfectly okay to do apparently. They've got presentations on 23rd January, 6th February, 20th February and the 27th, that's the one that's been allocated to us, and the reason we've been allocated the 27th is that's the day for presentations that are city wide delivery applicable, whereas some of these are specifically in East-West or North, whereas the last one relates to all the projects that are across the city or aren't geographically defined in one particular area.

So basically that's the day of the presentation on the Saturday and they need everything in by 19th February. So if you've got a presentation they want it on a memory stick or emailed or whatever medium it is, and they need it by then at the absolute latest. So you kind of just went through and basically said-

These conversations are usually ostensibly about some project or action earlier ones are about putting together the original bid for funding from the CCG whilst later ones explore ideas or motivations for these proposed actions. In the first instance, the projects were separate, with the research being the reflection on the process of the CCG bid. As time went on these grew closer together, however. In the previous chapter, the reasons why this is an ethical requirement are set out by Norman Denzin (1997) and others. Looking at this now with a little distance it is clear to me that it would be unethical not to act where possible. Social justice is an essential ingredient of mental health working, for me but also for many others. My clinical background has a strong element of this and my affiliations to some groups and movements align with this still. Maintaining a distance was managed through reflexive diaries and separating the research (reflection on the funding bid) from the funding bid itself.

So, for my own self-actualisation, I perhaps prefer this, too. Taking action.

Story 2: The curators

We make a story about how things are not valued by modern society in a way they previously were. Waste and taste leave things to the elements. My Grandma's hifi. Tracy's mum's coats.

Two (or in the last case three) protagonists discuss the qualities of things kept and things admired. The characters involved are family members sometimes but the real stars are inanimate objects. The story crops up repeatedly and I think it is at my own instigation (certainly this is true in the last instance, where I brought together Tracy and Sarah for the purposes of talking about material things).

Each person offers examples of things they find valuable or interesting. Tracy has a background in museums and a keen sense of aesthetic values and found this really interesting. What things are storytellers or enable us to tell stories?

In this first story, "making wishes" Tracy tells me her answer to a question we have been told we will be asked in turn on local community radio. Tracy wants this awful problem to go away, or at the very least for someone to help. I want people to re-appraise their relationship to possessions. Through telling her a story, I invite Tracy to imagine with me a different time and place where there is less stress and pressure to achieve and conform.

S1: So my response, I've got two is that I wish I wasn't personally involved in this, I wish this wasn't an issue for me or my mum to be dealing with, I wish this didn't exist within my life or mum's life. However, that being the case that it is my next best wish would be that there would be something in place to help deal with this. And that is my wish that something does come along that helps people to deal with it.

S2: That's nice, yeah.

S1: I spoke to G about referencing the fact that he is helping and it kind of made it look like he didn't really want ...

S2: It could be a bit awkward, couldn't it I suppose, advertising himself on a (inaudible 1:15:13.2) ...

S1: I know, and I'm really conscious of that. So I'm just going to talk about it in very general terms.

S2: (Inaudible 1:15:20.6) list of people ... (inaudible 1:15:22.0) not for people to meet, I'd wish for us to be a (inaudible 1:15:25.6) sort of stuff oriented I think.

S1: Is that what you're going to ... yeah, yeah. I agree with that as well.

S2: It didn't matter so much, stuff.

S1: We can talk about it with the distance of time but having worked in museums, you know, when you kind of look at, say, for example, the Victorian era and I always think the Victorian era was ... life was extremely hard but it was a lot ... more simple and it was a lot slower and I think there are things that we've lost.

S2: Definitely. When I was still a ... before I did my nurse training and everything, (inaudible 1:16:06.6) I had this wonderful notion, (inaudible 1:16:09.8) had this wonderful notion that she would be like a sort of ... almost like a traditional breadwinner and I'll be some sort of farmer's wife, you know, spend the days baking and tending the chickens.

S1: Wonderful utopian ...

S2: You know, growing vegetables and just pottering, maybe doing a bit of crochet, don't know how to crochet, I've no idea. Just pottering, you know. Tending things.

S1: Yeah.

S2: Potting things by hand ...

S1: I always think we're cavemen in the space age but we haven't evolved into this ridiculous ... (inaudible 1:16:55.3) wheel that we're all in.

S2: We get sort of sold on the idea that we have, don't we, because our phones can receive emails we think that we're better receive them all the time. When in fact we might be best in context and just open when you're at the right place.

S1: Carriage bringing ... have a written letter that takes about a week or two to ... Seriously though I totally agree, I don't think this gives us anything really that we need.

S2: So instant, you know, now, now, now, now.

S1: But it's like everything else though, isn't it, it's kind of like being ... the demands and the pressure it just doesn't ... not sure what's to be gained from it.

S2: I don't think it increases productivity.

S1: No, I don't think it does at all.

Valuing things for their aesthetic, monetary or sentimental value, usefulness, durability or quality arose several times. Inevitably more so in conversation relating to City of Culture prospects. In "the legend of the coat", Sarah had been talking about the emotion attached to moments when people brought their relatives' possessions to her charity shop, which supports a local hospice. Tracy responded with this story:

S1: So you know that reminds me, sorry to make it sound a bit ... bit sad and a bit morbid, but when my grandma died, my mum said, she said she can't go on like that, she needs a coat on, even on, when, you know, for her funeral. And all of my grandma's stuff, we couldn't find her real coat because we thought, well where she's going she's probably going to be cold, she's going to need a coat. And so me and my mum went round town to try and find an overcoat but because my grandma was incredibly petite, there wasn't anything and we went around every single like charity shop, second hand shop trying to find something. And we found something that was just perfect and the woman in the shop said, oh it's a lovely coat that, you know, who is it for? We said right, it's for an old lady and we wouldn't tell her what it was for, we just daren't, it was just like, I don't know it was just ...

S3: Just say you were having a party for her.

S1: Well we said oh it's for my grandma.

S3: Yeah, she's going to (inaudible 35:25).

S1: She's about that size, that will be perfect.

S2: It's a very high compliment to pay that coat isn't it, I would say?

S1: Absolutely.

S2: So (inaudible 35:33) dress and everything is –

S1: Absolutely.

S3: (Inaudible 35:37).

S2: Yeah?

S3: Yeah.

S1: The last coat she'll wear a while. But I just didn't feel like, I don't know because it just too . I would have told her but I just wasn't sure how she'd take it.

S3: Yeah.

S1: Or how affected she would be, but she probably would be fine, yeah.

S3: Given her an interesting story.

S1: Well this is it, if I'd have known that.

S3: That's it.

S1: She could have said, tell you what we got a couple in here today (inaudible 36:02), but yeah.

S2: The value of the coat is greater because of the story, I feel like the story then becomes the (inaudible 36:24) becomes the coat, takes it place on the –

S1: It's a legend of the coat.

These stories have a universal quality to them. They concern experiences which are not common to everyone but they address themes which are. I have struggled to come up with the correct name for this group of stories. But I hope "the curators" captures the celebration, curiosity and study of material possessions and their attendant stories and connected people which came out in these narratives.

Story 3: The carers

The concerned family member and the nurse. Characters are family members and a catalogue of professionals. In this first example story, "Well, if she doesn't want me, let's call it a day", I hear Tracy describe her own and her mum's feelings of not being listened to. There is also a description of what is experienced as a potential act of sabotage.

...her car on my drive. So, I go out on Sunday and my mum said for us to go out in her car, sorry I'm talking about all this rubbish and I don't need to. I moved everything out of my car into her car, I moved my car so I could move her car out of the way and

I looked down and there was a nail in her rear tyre; it's a nail and I don't know if you've ever used these at home, but it's got like a plastic 'U' shaped thing going through one side of it, like you can tac a wire to the skirting board, I don't know what you call them, but it was very strategically placed on the wheel just like that, just where the tread runs onto the shoulder – I mean, (inaudible 00:00:47) to be paranoid about things, it really did look like somebody had just got it and stuck it, cos I'm thinking, "How could you run over something like that?"

Anyway, it's taken us from Sunday to today to try and get it sorted and because I've had a really busy week I said that I could only help her today, so I ran around trying to get an equivalent tyre sorted, and it meant us going to a place on Hessle Road to get the tyre swapped over, so I picked my mum up this morning, thinking I needed to be back here for 2 o'clock. So I picked my mum up and we came back to my house and I said to her, "Do you want to have a look at this nail before we set off?" because she was going to drive her car, I was going to follow her. And when she got in the car she couldn't reverse it because I'd left the handbrake on a bit too hard and she couldn't release it, and she'd been trying to reverse the car and the handbrake had seized onto the brake. So she got out of the car waving her arms at me and I had already set off to drive behind her. And she's going, "You put the handbrake on too hard!" So I got out of my car and I went round to her car to try and release the handbrake and she went, "I've already done it." I said, "Well what are you having a go at me for? I've had to move my car now; I'm going to have to reverse it back up so that you can get back out – what a nightmare. Do you want to go and get this tyre sorted?" And she said, "Oh, don't bother coming." I thought, "Okay, fine then, I won't bother coming." So I packed my car up and I went back in the house.

So she got back in the car, she was sat there for about 2 or 3 minutes and then she drove off. And I just thought, if she says that to me what do I do? Okay, I won't come then. So, just as I came back because I'd nipped to the Post Office to post my friend a birthday card, just as I came back she was parked up outside my house, so she was leaving her car on my grass. I went, "No, you can't park your car there anymore. The reason that I put the handbrake on is because you asked me to park your car up here and it just doesn't work." So basically she's blaming me for everything that's ever gone wrong. I said, "I've had enough of everything; your car is not my responsibility, your life is not my responsibility." And she was like, "You've got me into this

position.” I said, “Okay then you sort it all out then. What do you want me to do?” So we just had this massive row.

Someone said we both want the same things; she wants validation and so do I, she wants it from me and I want it from her – does that sound about right to you? But then I have to think to myself she’s a grownup human being and she asks to be taken seriously. If she says something what do I do? I’ve got to take her at her word, I can’t... I’m sorry.

The relationship between Tracy and her mum is clearly a frequent point of return during our conversations. This connects to the question of narrative resources, with Tracy questioning who has the parent and who has the child role. The conversations witnessed and Tracy’s accounts suggest the relationship is intense, difficult, antagonistic, and loving. Two characters are trapped in an absurd situation, seeking the same thing from each other and defending themselves from anxiety and vulnerability at each other’s’ expense. In this next story, Tracy is talking about searching for solutions, this time with more emphasis (in my understanding) on the carer role than the crusader. The story is more personal. I notice in this story my clumsiness in skating around an issue which Tracy appears not to want to talk about. Signs of a novice. Tracy was very good at telling me when we needed to leave things but below I appear to be holding my own by retreating to talking about my literature review when Tracy is there before me.

S1: And that is exactly what I’ve been asking for for the last five years from social services and I just wish someone had have turned round to me and went, Tracy, we don’t have it, if you want to find one help yourself but we don’t have one. But they just tried to make out they did and they didn’t.

S2: There are other ... trying to think of ... not necessarily aren’t that many books for frontline workers like that but for family members there’s a book called Digging Out.

S1: Yeah, I remember you mentioned that and I haven’t ... I’ve just put it into my Amazon book list but I haven’t got around to ... there’s part of me that doesn’t ... I want to read but sometimes I’m worried that their story might be too difficult for me to consume.

S2: Yeah, that’s why when I was talking about the ... all those real life accounts that I felt (inaudible 1:03:17.7) to incorporate into the viva report I started sort of telling you

about one of them but then I thought like I don't know if you'd really want to read those. And I didn't think you maybe would, you know, don't know, not for me to say, I guess.

S1: I think I found my mum's clutter distressing enough, traumatic enough, and I think what I'd need to do is approach other people's clutter very much more in a kind of more of a clinical way and more of an academic way related to this. And I think, again, 'cause I'm looking at this in two different ways, sometimes it's hard to make sure that I ... don't know, (inaudible 1:04:10.2) myself in the sense of not allowing myself to be honest ... pathetic but ... traumatised by, you know, you were talking about the Collyer brothers and things like that, I mean I just ... it's just so horrific, isn't it, you know, some of the stuff. And I think I would be able to look at that within a training context while I felt removed from it, like I'm telling you so I'm just a conduit to tell you this. But to actually look at it I think I'm a bit ooh, a bit squeamish about it at the minute.

S2: I think that's why it's easier to look at the Collyer brothers because they are notably eccentric.

S1: Yeah, they are an extreme ...

S2: Removed by 70 years of history and, yes, they are really, really vivid pictures of the inside of the mansion and even Langley's body but they're in black and white which changes everything, the people in the pictures are clearly from the past because they're dressed differently and it just softens the blow a bit, doesn't it, whereas you read Barbara Allen's autobiography or Kimberley Rae Miller's and it's really a punch in the face.

S1: Yeah, exactly.

S2: Yeah, it's quite difficult.

S1: Yes, I'm trying to avoid that at the moment.

Tracy's relationship with her brother is returned to on occasion, too. She expresses frustration at the unequal distribution of emotional burden (as she saw it at that time) and the

lack of available time he seems to have for visiting (D and his family do not live locally and he has his own business). Julie defends him on this when Tracy becomes angry about it.

So have you been down to see the rest of the family, have you been to see your brother?

R: No. We, we went to see, no, no we haven't seen them, no. You were going to ring him weren't you?

R2: Yeah, I keep thinking I will do, you know.

R: Well that was nearly six months ago wasn't it. We went to see them in November didn't we and it's like May now, so.

R2: I haven't seen my great grandson for ...

R: Nearly six months.

R2: You've got pictures of them haven't you in your ...

R: Yeah. I don't, I don't know what to do about that Tim. I really don't know.

R2: Why, do you know about it or something, I mean, do you know about me brother, not me brother, me son, it's your brother isn't it?

R: Tim knows that D hasn't been in touch.

R2: He's upset about something, you know, because he wanted me to stay down there with them.

R: And me mum said she was going to ring him.

I: Yeah.

R: A couple of months ago. Because I tried ringing him and he just wouldn't answer the phone to me. Maybe a bit of time's gone past now, I don't know how he would be feeling about it but, part of me feels that I suppose at first I was really angry that he wasn't interested and now I just think, he's just not interested, you know, and it's like, well he never has been has he, he's never really been hands on.

R2: Well he's got a lot on, he is running a business and, you know.

R: Oh that sounds like a massive excuse.

R2: Well, he does, you know.

R: I've got a lot on.

R2: A one-man business, it takes ...

R: He chose to do it.

R2: Well, you know, that's why he is busy so, he can't ...

R: Yeah, well, he always comes out with reasons like that and it's always to do with the fact that he's busy and he's got ...

R2: He did ring me, but, you know.

R: Well he rang you but you were here didn't he?

R2: Yes, but I couldn't really go into any details because you was there.

R: Well, the problem is that mum hasn't been home and she hadn't realised that he'd not sent her a Christmas card, your birthday came and went in February and he never sent you a birthday card, he never sent her a Mother's Day card, so he's obviously got a problem but I don't know what the problem is. And at the end of the day, if he's got a problem with me that's fine, well it's not fine, but, okay that's, you know, I am big enough and ugly enough to cope with the fact that he's got a problem with me but I don't understand the problem he's got with my mum.

R2: I think you was laying it down too much and he didn't want to face all of that.

R: And if that's the case, then he needs to take that up with me or ignore me but why is he ignoring you? That's what I don't understand, but then ...

R2: Well, because you, you took me away from his place. It wasn't my doing and he thinks it's my doing or running away from him, you know, or something. He thinks I have got a grudge against him and I didn't because I didn't know ...

R: I'm not sure, you know, but mum keeps making up excuses for him and at the end of the day, he's a 45-year-old man, he's not a child, do you know what I mean? He's a grown up adult and he's behaving like a child.

R2: He is my child!

R: I said nowt to that can I, you've trumped me on that one.

R2: You can't get away from that. So ...

R: So we are kind at a bit of a stalemate basically there. I mean it's something that, I mean we spoke about that at the beginning didn't we when we said it would be good for you to ...

I: Oh we did, but I just thought, when we met up in November and you had the photographs and everything, it just seemed like there was something quite positive about that and it looked like it was going somewhere, you know.

R: Well, yeah, I mean I am in touch with my niece all the time, you know, and she is, and she kept saying, you know, my door's always open. Come and see us whenever you want. I don't know, it's just that we haven't, I don't know for whatever reason, I think, at Christmas things started to sort of accelerate for me and I suppose ...

R2: You were short tempered with him wasn't you, so, he says I am not going to take all that. He has had to finish with both of us because of it, I could see that, you know, because he can't deal with it with you and it's about me and so he's had to, but he did ring me once and I am afraid I didn't sort of get down to it too much, you know, but I don't know ...

R: Alright, so are you going to ring him.

R2: I am thinking; I really don't know.

R: Right.

R2: I don't know how to go about it because.

R: Is that what's stopping you from ringing him?

R2: I don't know what to say to him, you know, because what's gone wrong, it wasn't my doing it was you, that said, taking all your stuff away, you know, it wasn't me that said I am taking me stuff away, but it's been.

R: Oh you've got Teflon shoulders you.

R2: I know, but he hasn't been hitting it off with his son either so, you know, there's a bit of a ...

R: I don't think it's us, I think it's him. I think he is having a real hard time with everyone, that's what I think.

Story 4: The experts

In the initial stages of this project, Tracy viewed me as the expert and I dispensed information from my literature review and other reading, which is what I had been doing in a variety of settings (see chapter three act one). This allows me to defend myself against anxiety about being “caught out” as a fraud. The epithet of “expert” made me extremely nervous as I did not work with people with hoarding tendencies and this felt strange to me. Tracy, after seeking expert help for so long (again, see chapter three act one), makes appeals to this experthood as a defence against her anxieties about her mum’s hoarding and the apparent lack of availability of the promised “answer”.

This is one permutation of “expert”, borrowing from technical accounts and medical discourse. It is told by a professional to a carer in a quite teacherly fashion. There is little room for expression or discussion. The experience of one party is silenced by the technical account of the other. There is also no voice afforded to the person discussed and described as ill.

“Schizophrenia?” is essentially a technical narrative that springs out of hoarding disorder told by a researcher to a person looking for answers. It is as though I am reading from a script initially, with Tracy a passive recipient. But when the diagnosis is questioned, both of us become more animated in exploring other ideas. However, when the suggestion of schizophrenia arises the expert is back on the defensive, dismissing this suggestion with an appeal to clinical expertise before returning to more “facts” about hoarding.

I: So basically it’s in 3 parts, you’ve got acquisition and then you’ve got the inability to discard things, retention, and that’s for all those different reasons we’ve talked about, whether it’s sentimental or whether it’s about ideas of usefulness and not wanting to waste things, and then these things build up – this is just the standard, in fact, while we’ve got this on, seems a shame to waste it, doesn’t it? Okay so this is when it was new, one of the possible symptoms, oh no that’s not there, no. Let me find a better one ... never mind, so you’ve got in, acquisition and you’ve got no outs, the stuff, possessions build up to a degree which renders the house unusable or renders rooms in a house unfit or unusable for the purpose they were intended for, so you can’t cook your food because of the stuff, or the cooker is full of like magazines.

So those 3 things and then what the DSM did, cos that definition of hoarding, that was 1996, Tamara (inaudible 01:06:25) set that up, that's part of the CBT formulation of hoarding that they did in 1996. It stayed the same and it more or less how, still using the same definitions, the only difference is that as a sort of caveat afterwards it says: 'The hoarding causes severe impairment or distress' and what it doesn't say is to who, which I think is a real copout, so then who is making the decision? You've left it really ambiguous.

R: What was that again, Tim, the hoarding causes?

I: The hoarding causes impairment or distress; I think it's severe impairment or distress actually.

R: Right, but not to whom?

I: And also the hoarding can't be attributable to another mental health disorder. So, there have been loads of studies of hoarding and all kinds of things in schizophrenia, autism, eating disorders, dementia, dementia in particular cos there's something else called Diogenes Syndrome-

R: Yeah, that's what my mum's been diagnosed with.

I: You said. It's like how do you diagnose it? All these different permeations it's not a hoarding disorder because the hoarding is attributable to something else, I think it's part of that other presentation. The thing is-

R: This is where I get confused also because I'm no doctor, but I genuinely look at my mum, and again, I don't have a breadth of professional knowledge or anything like that; I still remain convinced that my mum might have some form of schizophrenia, mild schizophrenia, I'm absolutely positive of it, and I actually think that's why she says things to me like she did earlier on, because I think that's the schizophrenia, I'm positive of it. Anyway, sorry! But everyone I've talked to says, "No, she doesn't have a form of schizophrenia."

I: To be honest, having met her and working in psychosis services I would struggle to ... I've only met her once I know.

R: That's what everyone says, but I'm ...I don't know. Anyway, sorry, but it wouldn't surprise me if there's definitely a crossover somewhere.

I: This is where I have a problem with this diagnostic idea about hoarding disorder, they're saying that basically so it should exist on its own in its own right, it's a singular problem – are you absolutely fine in all other senses but you've got all this stuff in your house, you can't stop buying things, you can't throw things away and you can't leave your house because of it.

R: And you're absolutely fine.

I: But, when you then look at the literature sort of concerning people with this diagnosis, the comorbidity rates are through the roof, which means basically everybody with this has been found to also have depression/anxiety/personality disorder-

R: Whether that's brought on because of that or whether that happens because of the depression and the anxiety?

I: Yeah, so does this really exist? I found it mind boggling, I really do.

R: It is, it doesn't make any sense whatsoever.

I: I don't understand how it's got to be a diagnosis on its own as a singular thing rather than as a symptom of, because it used to be a symptom of OCD, it was listed as, well that you reckon is only about 15%. 15% of people with a hoarding problem are diagnosed with OCD and 15% of people diagnosed with OCD also have a hoarding problem, so it works both ways. But if 70% of people that have anxiety and depression problems have this, it's just being moved somewhere else; if people listed elsewhere have a symptom of something, or rather than you know, put a discreet disorder, it's a phenomenal amount, it makes me head scratch.

R: That's because people need to put things in nice neat little boxes, don't they?

I: Absolutely, I mean if you do that then if somebody says, "I've got a terrible problem with this, what do we do for that?" we can look it up can't we?

R: Which takes you back to that question of like, if you do ask a hoarder, "How can I help?" it might be that again, it's like the hoarding might not be the problem, it might be loneliness, it might be trauma. Did you watch that thing?

At the end of this exploration, Tracy mentions a television programme about loneliness which we have both watched. After this point things are much more equal, with both of us talking animatedly. This conversational style took time to develop naturally when discussing difficult ideas and topics.

Similarly, at times, Tracy takes the role of expert. This is reads like an “expert by experience” narrative. In these earlier narratives (both the one above and this one). Both of us seem to find these prescribed research roles more comfortable.

I: I know there’s training, is there, for the moment from S’s part of the world, but we’ll worry about that when and if we get a foot in.

R: Yeah, we can always deal with that later. I mean I really like the toolkit, that is good, maybe that’s... yeah, so there’s some value to that but the majority of it is... In fact you know that probably better than S I would reckon! A lot of it the harder awareness stuff. You’re not really doing it. You’re researching it.

I: Oh strike me down!

R: You’re researching it. Well you’re researching it at the same time as you’re living it so really...

I: I spoke to the last time, that’s what she said because I said to her, “Look, I’m going to hand it over to you now because I can’t do this anymore,” and she went, “Well I don’t know what I can do to help.” She said, “You seem to be the expert.”

R: Yeah, well that’s right. The GP isn’t going to be an expert on this. That’s an illness because, you know, it’s...

I: She was like, “I can’t give her tablets, sorry!”

R: Well that’s it in the sort of diagnostic, they’re working to ICD, it’s not! It’s not in there! So they’re in a funny position really.

I: I know, all they can do is treat you for anxiety.

R: And that’s going to be with medication which may or may not help.

I: Well she’s always resisted giving me medication because she said... well as we’ve discussed before, medication doesn’t work for anxiety. The behavioural therapies type... the talking therapies are the best approach. So I don’t know. But yeah, I

suppose it's kind of keeping this into like a nutshell really to get it across. It's really hard, isn't it? Well this is the whole problem, isn't it, people the people that are in the know don't know.

Particularly post-presentation, we have a sense of our own knowledge of the subject (although this starts much earlier when we are planning our intervention for CCG bid). It develops as we progress through the process:

"Who wants to listen to my voice?" I do, obviously. Looking at the transcripts I see a point where I am telling Tracy that her voice is important – more important than those of academic experts or clinicians or professional organiser-types. She has lived the thing we seek to explain, explore, and expel. SHE is the expert. Now she is also the teacher (actually, she was involved in adult education before). We have taught nurses and social workers together and have presented work to academics. However, looking back as we have in preparation for this last presentation and putting together a list of those involved en route to collaboration, I see a lot of people who weren't interested as well as quite a few who did want to hear Tracy's story. Some really wanted to help, whilst others perhaps had other motives. What nobody wanted to hear, I suppose, was Tracy's own story. Most were much more interested in her mum and her stuff.

This traditional reading of what an expert is was very different by the time we had reached the analysis stage. All the way through our work together, we had stories which merged these other stories. In "The greatest act of defiance", we have an example of the experts and the curators merging in a description of and summation of an emergent view on materiality and consumerism. Given Tracy's background in museums and adult education and her (and my) interest in culture, brought together with an energising prospect like creating art or publicising a message using other expertise we possessed was maybe a catalyst for new ways of combining ingredients to produce more positive and hopeful narratives.

S1: Because it reminds me of something that someone posted on Facebook and what people commented on, on it because I think, I don't know if I reposted it or I liked it or something. And it was and you often get these images don't you like a little, do you know what I mean? And it will be like, I don't know, someone has created an image of something and there will be something written in the background that –

S3: Oh yeah.

S1: - (inaudible 54:37). It was a girl sitting, it looked like it was on a train, there was (inaudible 54:41) something like, I'm really paraphrasing here but the greatest act of

defiance you can make in life is to love yourself despite society not wanting you to, because it's kind of like a bit of a rebellious thing. Because, you know, if they want to sell you stuff they want to make you feel bad about yourself, do you know what I mean? It's a marketing ploy, so the best thing you can do is kind of actually say, well actually I don't need all that stuff because I'm probably okay as I am and it's kind of like the sense when you buy stuff, do you know like ... don't know what I'm trying to say ... if you reject ... I can't think of this kind of approach to constantly buying stuff and you settle for what someone else has had or you make something, you make up something else. It's almost like a rebellious act.

"The process makes you into an expert...at that thing you are doing" "we know more about what we don't know" I think I have said more about this elsewhere but it is worth stating here that we were and are in the business of developing expertise. Expertise in ourselves – knowing our strengths and weaknesses and how these can be used to further our research. And expertise in our area of study. Nobody else for miles around knows as much about compulsive hoarding. The second of these statements is particularly important. Being able to say that without any sign of distress. Tracy has come to somewhere she can tolerate uncertainty, perhaps (and so have I). Tolerance of uncertainty is not something found in research studies of a particular bent but that is precisely what we are about here. NEW knowledge. See below...

Frank states that dialogical narrative analysis does not seek to produce "findings", rather it offers new resources for storytelling and opens up discussion. I hope that what is reported in this chapter has raised questions and perhaps resonated with those who read it. There are calls to existing ideas and narratives within the four story types offered here. "The carers" has links to a large body of carer narratives from those informal carers with parents who have multiple services and no services involved due to complexity. "The curators" calls on anthropological writings around the value of things and possessions as archives, as well as ideas of value found in new materialist writings which challenge consumerism and seek to value things and people. "The campaigners" fits within a set of narratives alluded to elsewhere here by Frank (2015). I have expanded on this at more length below. "The experts" relates to a broader set of narratives around identity and narrative identity. Whilst this narrative does not seek to finalise, "improve", "cure" or "resolve" its protagonists, it does pose questions about the nature of expertise and the purpose of expertise in questions of identity.

Chapter 5 – What we learned

Hoarding creates problems for those living alongside it. The problems it creates are legion and complex. In this case, we found that there was no willing party ready to offer the holistic support required by Tracy, Dean and Julie as suggested in the literature. Actually, that isn't quite true. There was a willing party in the form of G but sadly there was a need for skill development and then a lack of resources due to the tenuous nature of funding for third-sector organisations. Official approaches to this problem exist in some parts of the country but they are not uniform and we do not have reports of their success levels.

“People want to fix these situations – and maybe it's not about that.”

This was not the position at the start of the project but it was a point to which we seemed to have come on the day we conducted the free association exercise. Perhaps to encourage the tolerance of uncertainty or to provide an environment of calm curiosity, a safe space for re-appraising situations by those most closely affected was a useful exercise in a therapeutic sense as well as in a knowledge-generating sense. Perhaps they were the same thing. We had set off following the best available evidence from a formal literature review in trying to address the problem of compulsive hoarding. Now we found that we had other ways of looking at this experience and that perhaps some of the consequences of proximity to a person with compulsive hoarding were less negative and may even be positive.

Frank (2016) sets out three discourses of illness. These all have a bearing on the stories reported in chapter four. I believe they are as applicable to people affected by illness as a consequence of the illness of another (a loved one, for instance) as they are to those who are ill. The medical narrative (of illness cured by medical science), the illness-experience narrative (of the quest person embarks on as a result of illness) and the pink-ribbon narrative (of campaigning for recognition and just treatment of the ill) overlap. This offers a way to explore our journey from campaigning to exploring and potentially back again. All of these are powerful discourses in their own ways and together prove even more powerful. For instance, combining the medical narrative of hoarding disorder with the pink ribbon narrative conveyed by the lobbying children of hoarders' campaigning and sponsored conferences, and the memoirists' and bloggers' vicarious illness-experience narrative.

In our case, we can see how social constructions of “problem hoarding” have created a demand for a response which is not answerable by any one service acting alone. A coming together and a sharing of ideas and experience will enable this complex problem to be seen in new ways, opening up the possibility for collaborative solutions which involve the person with a hoarding problem, those caregivers and family members affected, and those tasked

by society with the medical management of what Szasz (1961) referred to as “problems-in-living”. What has happened is what Illich (1976) refers to as the expropriation of health.

Illich (1976) suggests that the expropriation of health has the effect of

“...reducing the leeway that people are wont to concede to an individual when he suffers”

(p.41)

And that Western medicine

” ...turns mutual care or self-medication into misdemeanours or felonies”

(p.42)

The intention behind diagnosis is the eradication of suffering – the killing of pain.

Unnecessary pain, for Illich (1976), is a concept derived from the hegemony of Western medicine. It strips meaning from experience, disempowers people and removes them from their own personal experience and commodifies health, claiming an ultimate definition of this concept for itself. In this context, pain ceases to be functional, meaningful, or transformative as it might once have been in an earlier time or might be in other cultures. Autonomous control over our own health, as we personally understand it has been replaced by heteronomous control of “health” as defined by a medical institution.

Cosmopolitan medicine

“...undermines the continuation of old cultural programs and prevents the emergence of new ones that would provide a pattern for self-care and suffering...based on the denial of each man’s need to deal with pain, sickness, and death”

(p.131)

We now see it as immoral, even, not to avoid avoidable pain so those who refuse help where it is offered must be mad or bad. In this instance, we could say that the family members of people with a compulsive hoarding problem are by implication acting immorally if they do not address their accommodating behaviour. Unless they seek diagnosis of a mental health condition of their own as “evidence” of their distress which permits them to enter the “illness society” (Sontag, 1987). This links directly to what Boland (2012) offers in her insights on reality television portrayals of hoarding and its message of responsabilised consumption, which makes family members morally responsible for management of illness in set of limited, socially imposed terms.

Social iatrogenesis, the damaging medicalisation of society by vested interests, is evident

” ... when suffering, mourning and healing outside the patient role are labelled a form of deviance.” (p.41)

In this instance, the rise in cases of aggrieved people looking for a medical solution to their relative’s hoarding problem (rather than a relief from their own suffering or the help to manage the problem) is inevitable following the increased profile of the issue. This moves the experience from the domain of the family under the control of the medical institution. This is process in motion, however. The process of transforming the status of hoarding into a medical problem is incomplete. I have followed its progress and seen the wish for this status to be conferred from desperate families and from clinical medical professionals and in published research. The dominant voice in discourses of hoarding is no longer the council or the family (the local), it is the clinicians, and a select bunch at that (the global). As this group consolidates its hold on the public consciousness around compulsive hoarding, with the promise of a cure and the development of an industry of organisation, what consequences will this have for the specific and localised cases in which the reasons for accumulation of possessions, reactions to the accumulation and multiple other comorbidities are involved? I suggest it will silence other narratives.

The genesis of the Children of Hoarders group coincides with the emergence of the hoarding television shows which feature some of the people who will go on to be the most prolific academics on the subject. What Illich refers to as cosmopolitan medical civilization has grown to include other allied professions. Illich’s writing predates the rise of evidence-based medicine by 20 years but is directly applicable and perhaps his argument is even more forceful given the biases of publication and funding and the absolute dominance of clinical trials conducted by a priesthood within a priesthood, generating absolutes which are enshrined in guidelines and dominate the direction of public spending. It is interesting to note that Illich is cited as providing the impetus for the development of evidence-based medicine (e.g. Wright, 2003) whilst my reading of *Medical Nemesis* is that he described the state of affairs hegemonic medical culture now presents in negative terms.

The labels applied by psychiatry are not as easily removed as those applied by general medicine, Illich claims (p.90) how can you be a “former schizophrenic”, for example? We may have the recovery model but it is very much the same as the idea of the “recovering alcoholic”. It won’t go away. We could take instead Barker and Buchannan-Barker’s (2005) language of “reclamation”, which steers us away from normative readings of recovery and back towards the personal story. What will we refer to “ex-hoarders” as? And what of their families? What shorthand will we apply? A list of psychiatric symptoms? Their identity is lost

with the loss of their story and with our ability to effectively join them in their experience and offer a collaborative means of support.

Foucault (1967) paints a picture of the rise of psychiatry as the result of questions of productivity. When power is held by those with the money, attitudes towards those who are different change and those who do not efficiently produce are removed in the great confinement. They are of little worth and so any means is acceptable in the attempt to make them productive or reduce their consumption. If you take a look at recent initiatives between the Department for Work and Pensions (DWP, 2009) and some mental health services (in particular reactions to this from disability rights groups, e.g. Disability People Against Cuts, 2018) there appear to be some similarities. If psychiatry is an exercise in power and coercion, isn't mental health nursing an adjunct to that? Does it have to be? Not according to the people who saw me through my degree. What were those seeking to understand or help or be with those who were different in similar ways doing before Kraepelin? Mental health care has not been a profession in the strictest sense of the word for very long (Nolan, 1993). Long before the classification of mental disorders and attempts to prescribe treatments based on symptomology, the approach was more holistic. It was also brutal. And before the confinement, it was not necessarily seen as care. But there was a period in which there was respect for the holy fool, given insights into life temporal and spiritual which the rest of us were not privy to (Foucault, 1967). Looking at other cultures, there are the well-known but little discussed figures from WHO (e.g. Harrison et al, 2001; Hopper et al, 2007) which clearly indicate a worse outcome for people for receiving psychiatric care in cultures following a Kraepelinian model of medicalised psychiatry. There are possible critiques of these figures (e.g. Cohen et al, 2008) but the critiques do not make sense unless they are understood from the single position of Western C20 psychiatry. In employing the constructionist approach, we attempt to employ not only the language of this particular culture but also that of others with different expressions and emphases for talking about differences of human experience.

Whilst medical institutions have a low tolerance for uncertainty and risk, the certainty they offer can be damning and stigmatising (Illich, 1975). More than that, interventions in the name of security and safety can drastically lower life expectancy and quality of life. So here we are, back at iatrogenesis even with evidence-based medicine. The language and apparatus of mental health care (mental illness containment) dominates the discourse around the life of the mind but there is a strong tradition of survivor narratives. These stories of experience challenge the dominant discourse and attempt to liberate people from narrative entrapment (Grant, 2016). Newman's (1999) call for us to engage in a dance of empathic engagement in research and practice (praxis) perhaps finds its answer here. An

alternative view to mental health research and practice than that offered by our dominant governing bodies.

“Professionalisation is the process of closure in which occupations succeed in self-regulating both access to and the implementation of knowledge in accordance with specific rules and codes of conduct” (Correia, 2017 p.5).

For mental health nursing, this is highly undesirable, given that the causes of distress are so variable and the stigma surrounding distress so great, it is necessary to offer such knowledge to as many people as will have it. I am not talking of the knowledge which is not knowledge (the “skills” of gluteal injections and completing section papers, neither of which have much to do with knowledge or care). I mean the knowledge that constitutes the actual care for people in distress. The things which can help people to support each other in accepting and overcoming problems in living. (*Look! I have come back to my evangelical roots. Little surprise but it still makes me smile*). And it makes me think of the early monastic orders who befriended those in distress (Nolan, 1993 p.24-5). They went to them. A seemingly effective antidote to the effects of professionalism lies in collaboration, I think. Knowledge which is co-produced and jointly owned and credited as such offers a democratisation of research without the loss of mechanisms of review (although it could be argued that open review despite its obvious vulnerability for abuse would be preferable to the shady world of peer review e.g. Noorden, 2013; Ferguson et al, 2014 both in Nature). Suggested ways forward come in the form of mad studies, of which Mick McKeown (McKeown and White, 2015; McKeown and Spandler, 2018) has written much lately, as has Akiko Hart (2018), bringing together a diversity of voices and a greater repository of stories.

“Social constructionist theories of human action are not built up or derived from observation, but rather grow from a community of engaged interlocutors”

(Gergen and Warhus, 2001p. 98)

Thus, a group of therapists of a particular school will find evidence which confirms their idiom. If we look at all schools as potentially transformative we open up far more possibilities of approach. In much the same way, I see research (as Gergen mentions elsewhere) in the same terms – different set of lenses through which to look at a person, experience, phenomenon, etc. Therefore, effective therapy will include “the use of many speech genres, including those of the culture at large” (p. 99). This was certainly true for us. Our conversations ranged between musicians, film-makers, cultural events, medicine, psychology, social care, family experience, identity with a broad cast of other characters.... polyvocal participants.

Gergen cites therapeutic theories as new alternatives and innovations to understanding. When I read this chapter, despite the fact that it is not specifically about research, it was the piece of writing which I believe offered the greatest insight into the enterprise Tracy and I were engaged in. I am not saying that we were consciously engaged in an act of therapy (I am not a trained or registered therapist) but it was acknowledged at the start of this project that there may be an inadvertent therapeutic component to it. So much of this chapter rings true for me.

“My role as a therapist is to participate with a client in a first-person linguistic account of his or her relevant life events and experiences”

(Anderson, 1997 p.114 cited by Gergen and Warhus p.101).

Gergen says that being aware of the construction of reality allows for that reality to be suspended when it becomes painful. “...deconstruction of meaning may be an essential precursor to reconstruction (p.101).” In our case, there have been times when a difficult period appears to have been made more bearable by discussing the wider issue. Perhaps that is true throughout. Or at least until very recently. Tracy said last week that at times she was focussed on the big issue of compulsive hoarding awareness and service provision as it was more bearable than the immediate situation with which she was faced.

A collaborative therapeutic style challenges the established “top-down structuring of this quasi-medical field called mental health...” (Hoffman, 1993 in Gergen and Warhus p102) and offers something closer to the narrative based family therapy work of White and Epton (1990) Harlene Anderson collaborative language systems states that the therapist does not have some expert knowledge which gives them a better understanding of another person. Rather, it is essential that dialogue between persons in which the therapist enters with an attitude of “not-knowing”, generates understanding through a need to always be “informed by the other”. I started out her knowing something about hoarding and something about my attitude to psychiatry, both of which I had to maintain a scepticism towards. In terms of research, this demands that existing ideas, models, knowledge, opinions be suspended. This is only ever partially achievable, one might argue. I had certainly already formed some opinion about certain elements of Tracy’s experience and the reactions it provoked. There are times during the transcripts when I can be heard trying to offer a concrete answer from my “expert” position. In particular, earlier on in the project, Tracy had come to me expecting just this and it was not immediately clear what our relationship was. This relationship and the related processes evolved over time. As I said earlier, I am not a therapist. I certainly wanted to engage with my curiosity more than my “professional knowledge”, although this has come

in handy at times, I think. My existing position on psychiatry, therapy and its consideration of the person as a source of knowledge to be extracted.

” therapeutic work is necessarily a form of social/political activism” (Gergen and Warhus p.103) and this could be a positive or a negative activism (so much a part of effective mental health nursing in my experience) couldn’t help but contribute to the direction we ended up taking. Gergen also mentions here that there are developing lines of thought and inquiry into the oppressive nature of therapy along the lines proposed by Foucault in the discussion of typologies above.

Frank (1995) distinguishes postmodern, premodern and modern illness. Premodern has no notion of the medical language of modernity – even to the point of parts of the body. Postmodern asserts the individual narrative of experience against the colonialist medical language. Illness is distinguished as a social phenomenon against the medical phenomenon of disease (Parsons). If we give equal weight to each narrative (Lyotard’s little narratives) we are actively addressing the power imbalance inherent in the grand theories. So postmodern illness narratives challenge existing power structures and enable constructionist approaches. Thus Grant (2001) suggests mental health workers need to be narrative practitioners.

Gergen and Warhus (2001) tells us that for many therapists a change in the discourse is seen as “tantamount to cure”. If we look at the discourses of hoarding available to us, this is certainly true. For us, perhaps, not so much. Typologies can be dangerous, if employed by administrations to delineate good and bad, a manifestation of clinical power (Foucault, 1997). This is not Frank’s objective. He seeks to create an accessible tool for clinicians and patients to examine their own resources and how their constructed narrative has affected their life

“The dialogical test of a typology is whether it enhances people’s capacity to hold their own in circumstances of vulnerability.” (Frank, 2012 p.17)

One strength of a typology is that it allows the stories rather than the tellers, to be finalized. The wounded storyteller is not the wounded healer. There is no attempt to resolve. There just is. The stories of the ill are a source of strength to others (Frank, 1995). “Traditional therapy is based on a medical model of disease and cure” (Gergen and Warhus, 2001 p109). By exploring a client’s problems, they are magnified, pain is amplified and options are few. In a constructionist therapeutic process, “problem” is simply one way of expressing or describing events. Foster believes that “Sharing the common bond of personal experience” (2005, p.9) can have the unintentional effect of reducing the “emotional attachment to the

issue" (*ibid.*) as appears to have occurred through our process of researching together, despite my not being an "insider" from the same community of experience as Tracy but more an "implicated outsider" (Denzin, 1989).

Foster also notes that personal experience might impede our ability to listen to or to understand the stories of others (as Frank would have it, what resources shape how we hear stories). Also, the problem-solving focus of mental health nursing might serve to hasten us to be "redemptive" (p.10) and this would certainly chime with my analysis stage examination on redemption narratives. I found that my clinical experience also threatened to produce a finalised version of Tracy in my mind, particularly early in the project:

Tracy described the beneficial effects of my being a nurse during our planning session yesterday. She didn't say that I was acting as a nurse or that she necessarily saw me as such but during the most difficult time of our work together, I was working as a nurse whilst completing this PhD and that gave me a certain working sensibility. I am not saying it's gone now. Becoming an academic doesn't remove your nursing abilities or capacity to care or the imperative to be with people who need something. But when I was moving between client work and research daily, these traits, abilities, skills, emotions etc would all be more switched on, perhaps.

Tracy has made another suggestion and it's one which I have made elsewhere. Having trained for the ministry (up until the point when blood alcohol level, worry and low mood stopped me), there is something in me which responds to human need. This need of my own leads me to people in need. Jones (2007) explores this in his thesis, where he reports on people who define themselves or derive their own value from their caring for others.

From one conversation to another, the nature of our roles as co-researchers, experts by (different forms of) experience or study, witnesses, activists, friends, interviewer, and respondent (this one allocated by the transcribing service, the roles switching from one recording to the next) shifted.

Table three shows the roles given to the voices on the recording by the transcription service. It is impossible to rule out a certain amount of coincidence (who was doing the transcribing on what day and what their preferred terminology is and how they allocate labels) but there is an equal split between Tracy and I for interviewer role. There are two recordings where conversation appears to have made the identification of an "interviewer" difficult and for me, this indicates a success in achieving some level of equality. We have taken the lead at different times and this has come up in our conversations since, with each of us recalling a time when we felt we were not particularly involved or lacked control. What we did was tolerated these feelings and continued.

Table 3 - Perceived roles in interview pair/group as recorded by transcriber

Roles	WS_10001	WS_10003	WS_10004	WS_10008	WS_10009	WS_10010
Tracy	S1: Tracy	Respondent	Interviewer	Interviewer	R1	Speaker 1
Tim	S2: Tim	Interviewer	Respondent		Interviewer	Speaker 2
Julie				Respondent	R2	
Sarah						Speaker 3

For Gergen (1999 p.162-3), reflexivity is bound up with therapy, as is curiosity. These elements are the chief ingredients in our approach to research, I would argue. We employ those multiple voices mentioned above and called for by Gergen (1999), over the pursuit of neutrality, although his suggestion that pursuit of social change should not be the goal is perhaps less well heeded we eventually did seem to come around to his way of thinking. There is a tension in Gergen's writing, I think. At times he wishes to produce a fruitful dialogue between positions to find a common agreement. At other times he calls out injustice and chimes with Denzin, for instance, in outlining the need for action. So sometimes he seems to call for us to take a side and sometimes not. I don't see this as problematic, simply as a contradiction one has to live with if taking a constructionist tack. Gary Rolfe perhaps offers a solution in his suggestion of the post-modern ironist researcher

In discussing the bid for CCG funding, we talked of reflection and space and even catharsis. If we look at the format and aims of brief solution-focussed therapy they look pretty similar (Gergen and Warhus, 2003 p.110). We were not digging down into Tracy's experience of dealing with her mother and her possessions and her mental state and her interactions with service providers. We were concerned with the future and were effectively addressing Tracy's problems as they arose. Surely this is a far more ethical approach than simply grilling someone about their miserable experience for weeks and hours. Yes, we talked about the situation, we met Tracy's mum and got her brother's side of the story, too. But the valuable quality of this piece of research was its ability to give space to Tracy to address the things she wanted to when she wanted to from a position of mutual curiosity. I too was an object of curiosity – why was I doing this and what would I do when I finished this project and got a doctorate. I continue to consider this through dialogue with Tracy (as well as others in other contexts).

“When we locate the source of meaning within dialogic process, we are essentially viewing the meaning-making process social activity. Meaning, then, is...created in action and regenerated (or not) within subsequent processes of coordination” (Gergen and Warhus, p. 111)

Objectification of symptomology in psychiatry has brought us to a place where we are slicing human experience up ever more finely (Illich, 1975; Francis, 2014). In response, we are developing a mode of mental health nursing which values technical aspects and quantifiable results over less defined and messier interplays between persons in the construction of alternatives ways of being and being with (Grant, 2015; Johnstone and Boyle, 2018). Frank (2015) claims:

“the illness memoirists of the 1980s and 1990s had the explicit project of creating a discourse of illness that resisted objectification of the patient as the carrier of a disease”

(p. 15)

My position. I have much agreement with Szasz (1963). Mental illness is not on the rise. It is psychiatry which is on the rise. Discursive practices are framing human experience in increasingly medicalised language. Witness the new call for more psychiatrists – from people in the street? From psychiatrists. Numbers of mental health nurses are reducing, we are told. We are also told that this is bad. But this is not a logical argument. Only if we can say that mental health nurses are a beneficial resource can we say that. What is increasing is medical diagnosis of mental illnesses. And the number of available diagnoses. Hoarding disorder, along with shyness, bereavement and others is symptomatic of this. All of these features of individual life experience are now cast as crippling curses to be removed so that the “real” unfettered individual can emerge to be the best person they can be (most efficient, least embarrassing, most happy on a scale of 1-10).

By politicizing “wellbeing” in this fashion, it has been depersonalised to an offensive level. A person identifying as a member of the social group “children of hoarders” is not doing so to seek the removal of this status. It is the acknowledgement of experience which they are looking for – validation through sharing stories. There are a wide variety of areas in which they might want to receive help through membership of this affected (Frank, 1995) group. The shorthand “hoarder” allows this group to come into being. By coming into being, members of the group find validation in each other as well as helpful practical advice for maintaining wellbeing but these groups create potential stigmas (Goffman, 1990).

It is hard to see what the role of a mental health nurse in the technical mode would be in this case. The supposedly unwell person is not concerned and therefore wishes no interference in their affairs by strangers. The person suffering distress is not entitled to assistance unless they declare some particular medical complaint or they are afforded formal carer status by their relative “confessing” their madness. Those who were involved reportedly lacked knowledge of the complexities of the problem and more importantly of the complexities of the individual. Due to the confusion and disappointment experienced by Tracy as outlined above, she ended up contacting the only person in the local area known to be interested in the subject – me. We tried to develop a solution where there had been none. We failed and this was seen by both of us as a good thing, the timing not right, perhaps. What followed was a long process of analysis (as suggested by Denzin – 1989), of selves as well as data as the narratives we constructed our reality and ourselves in this exercise. This led to a form of resolution unexpected. A repositioning of self to experience. An ability to stand outside the hoard by looking into it so closely. I am reminded of the process of the body scan in mindfulness meditation. One explores one’s pain closely, feeling its edges and character without becoming caught up in it (Kabat-Zin, 1990). On a much bigger stage this is what had happened, perhaps. The role of qualitative researcher marries so well with this – exploration, description and analysis of experience (Janesick, 1994). It was essential for the researcher to have a sense of the edges of their own experience, too (Bourdieu, 1987) to produce an account which honestly and openly as possible provided an auditable trail.

I now wondered if there is a resistance in a narrative such as Tracy’s to being defined by the needs of another who is labelled ill. A conscripted carer. Is there a risk that by engaging in a crusading narrative to do with hoarding without the involvement or acknowledgement of the person labelled (despite their consent being given) that that person is subjected to a form of narrative entrapment? Especially when the issue is then broadcast, published and discussed on social media.

“Pink ribbon institutions are opposed by groups whose radical politics – emphasising environmental causes of cancer and inequalities in treatment opportunities and criticising institutional medicine and pink ribbon foundations for their neglect of these issues.... But members of these radical groups may also participate in Run for the Cure events, when not protesting them...Only at an academic or professional conference could any of the boundaries seem neat.” (Frank, 2015 p. 16)

This setting re-enforces the need for a constructionist, polyvocal reading and engagement of and with hoarding. Whilst we employed our set of stories in our conversations about Tracy and her mum’s experience and our attempts to find a “solution” we moved between these

freely at the instigation of either party. In our interactions with others we necessarily took up the appropriate narrative tools to engage them in a mode they understood.

Narrative allows the representation of time as it is experienced (that is, not necessarily a linear series of events). Time can be expanded to encompass a whole stretch or can reflect the interplay between the future, the past and the present as occurs in cases of trauma.

This I found particularly notable – trauma in earlier life and current hoarding actions speak to each other through existing narratives from science (the hoarder) in a loop which can at first appear to be a linear cause-and-effect relationship but on closer inspection, occurs retrospectively in the light of attempts to rationalise behaviour which the person finds unsettling or even in the light of others' attempts to make sense of the hoard (family members, professionals or researchers such as me).

So, in responding to complicated and diverse people and situations change of pace, a breadth of allies and stories and a tolerance of uncertainty may offer hope. This of research and practice. They sound similar and, in this shape, might be able to achieve something in both areas. This seemed to have produced some peace for Tracy but I was left with some questions about what would happen if I followed this line of thought. I didn't feel finished. There was something left to do and I had been perhaps unconsciously exploring this since before I met Tracy. In journals and diaries and odd word files, I had been trying to express or explore this in some way.

Interlude 1 - 15.8.14

This bit is here to point to what is coming later on in the second part of this thesis. It marks the first time I wrote in this style about the research process. Previously I had made a few notes post-supervision but this was becoming more digressive and I wasn't sure why. This was written on the same day that I spoke to people from hoarding services for the first time. The first person I spoke to was the person through whom Tracy and I eventually came to be introduced.

It's summer and the campus is very quiet. In particular, Deane is a dull place to be. I find it too quiet to concentrate and end up blurbing on like this instead of doing some good, honest writing. Or looking at job applications (too scary). I am instead doing something I utterly loathe – "networking". A mixture of cold-calling and self-referencing which, after an hour, leads to feelings of nausea. Why can't I write? Oh, I am writing- but this writing is done with a PEN and is about being bored on an empty campus,

A dragonfly just flew over my head! A lovely big, beautiful flying machine. It would be nice to fly. This morning I was discussing this with myself whilst pretending to be discussing it with my daughter. I have often wished to try flying. Not in a machine and certainly not in a huge airliner. I would like to try hang-gliding. It looks so peaceful. I hope I can get to doing some of that.

Boom! Incoming email and the glider has crashed. Now I have "something to do" today. Now I don't want to "network" – especially as this is by telephone! The horror! I just do not have whatever it is that is required to be a successful telephone communicator. Sarah used to have to talk to James when he rang to organise a night out. Now I have to pretend to know what I'm doing...

INTERLUDE 2 - The process of remove

Standing in front of a small seminar room half full of faculty colleagues in January 2017 I was allegedly espousing on the findings of this research. I did not offer answers particularly. I am not sure that I had any or that I could suggest them. After posing various questions and scratching my head a few times, I offered them a poem written in response to my experiences researching with Tracy. It examines how the research had affected me and how I viewed the struggle of managing possessions demanded of people with compulsive hoarding problems but also with everyone. Issues of talking about personal matters and potential shame in participants. And the fear I felt of airing my research ideas in public.

2000/2001 came our first flat

And our first bed.

There's the mattress

In the boot.

A free-to-view Tracey Emin.

The label on the new one says

"We recommend you change your mattress

Every 8-10 years."

It's been 15 or 16 – so long

The details have faded.

Hard times – the mattress bought for us

As was the bed

And everything in the flat.

Now – in our new-found largesse

We splash out – a new voyage.

On exhumation – a plague pit.

No.

A sarcophagus of allsorts.

Kept things – empty boxes, iPads,

Shoes and used tissues

All equals under the same roof

But in the light they are

Separated, segregated, categorised

According to their worth.

Arguments, babies,

Lazy mornings and late nights

Scrawled on this grubby scroll in piss and blood.

Once outside the house,

The stories become too personal

For public consumption.

What if the neighbours see

The evidence of our humanity?

Our failings.

Our weaknesses.

I hurry to cram the thing into the car,

Hoping I am not seen.

My efforts are comic but driven by panic.

Curled and crumpled in the back of the car.

A tatty atlas in the time of Satnav.

It only takes my lone efforts

To topple the thing down the stairs,

Fold it into the car

Toss it in the tip.

(It takes both of us

To introduce and settle the new one).

When we view askance

The possessions of some eccentric

We lose the context

The power of the totem.

Imagine in each envelope

An ocean of experience –

(All that made you you!)

I see that in this mattress.

The whole glorious history.

The enormity of it! The sheer fucking weight.

Then imagine the effort of moving the mattress,

Again and again – decluttering (for fuck's sake)

Afterwards, I start to notice

Tiny dissatisfactions in the room.

A flaked bit of paint

A grubby window

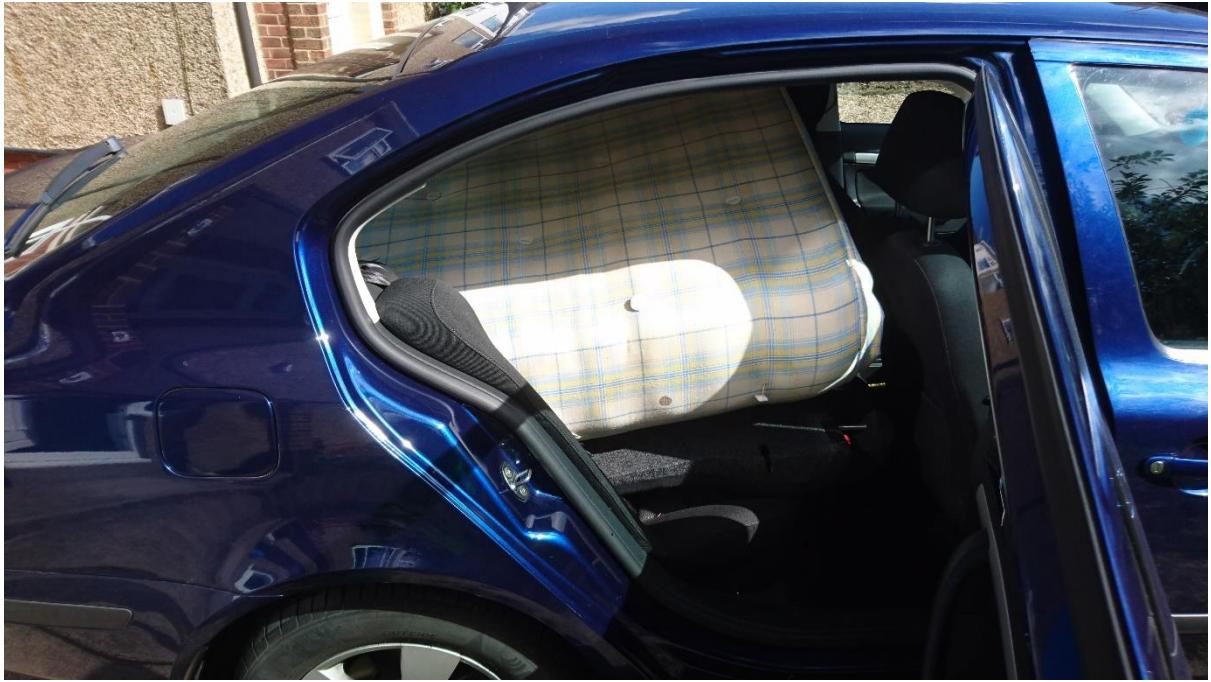
It does not feel good at all.

The sense of this never being “done” presses.

I don't have time for this.

Better to leave it?

I'll do it later.



Chapter 6 – Autoethnography and why it appears here

“Narrative -based methodology considers the story as telling of actions and events in others’ lives that encourage reflection and self-understanding for the narrator.” (Rapport, 2004 p.9)

This text never set out to examine my own inner workings but to an extent that is what happened. I was always present and from the beginning of the “action” phase, looking for participants to take part in a collaborative research project for my PhD, I was aware of and wrote down my own position and feelings in an attempt to promote reflexivity. Kim

Etherington (2003) gives an account of her development of an increasingly reflexive body of research which moves towards autoethnography. This took place over a few years whereas I managed to meander in this direction from one end of a doctorate to the other. Etherington records how difficult it was to gain acceptance in some quarters and the awkwardness with which some colleagues approached her. In the picture here, I am taking a stroll through my interim viva installation and not caring at all about the next phase. At this point I am thinking about how best to get a family to talk with me about their life. Mine is not really a consideration.



Figure 16 - At the interim viva

But something happened (or didn’t) at the point in the research project where “an ending” (Frank, 2012) presented itself. We had made our bid for CCG funding and it had been rejected. Tracy had formed a seemingly new and more tolerant stance regards her mother’s hoarding and her relationship with her was improving. Something had changed and we had enough data to perform an analysis. But I was convinced that we weren’t done.

Who wants to listen to my voice?

Tracy had said during our analysis exercise, now I threatened to overshadow or drown it out.

I worry that I am not giving Tracy equal billing and am acutely aware that her voice is essential to this. Is this OK?

There was certainly something about me that I was only partially aware of at the start. In the sharing and exploring of stories, I was brought back to my original activating interest in setting out on this journey. There was personal proximity to the family tensions of hoarding

but there was also the starting point which preceded that and the one which preceded that. I was still looking for me. The unfinalisable nature of persons should be applied to both co-researchers, shouldn't it? I realised that an old problem was surfacing again. I was scared of being typecast. I had found the mental health nurse epithet too constricting and it appeared that this was in danger of narrowing. The prospect of being an "expert" frightened me because it suggested a closure. The nomadic impulse was being seriously challenged. We had reached a waypoint but the journey was not over and I didn't want it to be.

According to Launer (2002), working with narratives can cause health professionals to:

- Question some of the apparently solid certainties of science and of medicine
- Become more aware of their social and political roles and to examine the power relations in their encounters with patients and teams
- Enrich their work by drawing their attention to the variety of cultures and beliefs with which they come into contact
- Let go of a constant sense of responsibility for other people's problems and to acquire a greater sense of the possibilities open to their participants

(Launer, 2002 *in* Rapport, 2004 p.10)

This exposes Tracy's experience of entrapment in help-seeking and of my feeling of entrapment of the mental health nurse and the potential to find new understandings through interaction with the other.

I grew up on stories. Bible stories, family legend, bedtime stories...

Stories are at the heart of this project. Mine. Tracy's. The story of the hoard and the hoarder; of the crusading clinician as told by Frost and company. The story of diminishing returns of diminishing public services as told by Tracy, Dean and Julie. The story of that mysterious creature, the PhD candidate as told by me. Frank (2012) talks about the story as pre-existing. We do not make up our own stories, we call them forth for our own ends and it is in the ear of the listener that they acquire new meaning. These stories are not new, the meaning we find in them is. If you sit down with a copy of the Oxford Handbook of Compulsive Hoarding and acquiring and leaf through the early chapters, you soon get a sense of the various narratives of hoarding that have existed throughout the years. In that tome, it appears to be suggested that our understanding has evolved over time to become the model of helpful and caring understanding we have now, but closer inspection reveals that in fact, the idea of disease is not far removed from the idea of greed, sin, etc. For me, the only development one can detect from close inspection is the point at which Christian

morality gains influence in the middle ages, shifting understanding from the hoard as power, wealth and success to the hoard as gluttony and greed; a sign of some defect.

“I tell you it is easier for a camel to pass through the eye of the needle than it is for a rich man to enter the kingdom of heaven.”

Matthew 19:24

What resources am I employing when reading Penzel's (2014) account of hoarding through history? Those stories I list above. Bible stories. Clinical stories. My own story of the loss of certainty and the resulting anger precipitated by the discovery that the world was not as simply ordered as I had believed. Tracy's story of searching for answers.

Part of today was dedicated to tidying up the back garden and this caused me to notice just how full the garage is getting. There were three enormous cardboard boxes stacked up on and around the bicycles with a car roof box on top of that! In the garden, the piles of logs on the prospective site of my longed-for vegetable plot are as big as ever and the shed, when I opened the door, spilled out a torrent of empty sacks. In the loft, movement is almost impossible despite the good hour I spent trying to make order out of the chaos up there last week. If I or Sarah were to become seriously ill now, how would we prevent the stuff from accumulating in the house? We have clutter. I like clutter. But some things can easily turn this into something much more than just an inconvenience.

On that particular day, I could envision how if I was feeling a little low, this spectacle of clutter could take on a particular dominant perspective. Witness the power of the “what if...?” This for me is similar to the “what if..?” found in my former faith. What if I die tomorrow and I am not right with God? What if I am not living up to expectations? Not good enough. This powerful sense of personal responsibility for one's own redemption which can never be achieved by the self alone yet demands personal striving for something which one will always fall short of looked to me to be a meeting point for non-conformist morality and happiness in a consumerist society.

Introduction

Autoethnography is the marriage of biography and ethnography (Ellis et al, 2010). It seeks to examine a culture through the experience of the author, who is a part of or is co-opted into, that culture (O'Byrne, 2008). This chapter is perhaps what is referred to by O'Byrne (2008) as a reflexive autoethnography. Classifications of autoethnography are numerous and increasing with the growing popularity of the method. Whilst Ellis, Bochner and Adams (2010) offer a number of variations based on the level of researcher voice in the text, Le

Roux (2016) describes the two ends of a scale based on the emotional content of the work. I see our text moving up and down this at different points, periods of activity being followed by periods of reflection as described by Reason (1994) above. At the same time, we have varying degrees of researcher voice.

An autoethnography can serve many functions but is arguably marked by the move to express a marginal voice and/or challenge taken-for-granted assumptions (Bochner, 2014; Grant, Short and Turner, 2013). Much mental health research proceeds from the assumption that there are phenomena known as mental disorders to be studied (Cohen, 2016). The lack of empirical evidence for these is rarely raised (Grant, 2015; Cohen, 2016, even if there is a professional and public ambivalence towards them (Dixon and Richter, 2017). Dixon and Richter (2017) identify a particular school of mental health nurse thought which identifies relationships as the business of mental health nursing, over evidence-based practice. In the case of hoarding disorder, the flaws in the evidence-based practice argument are clear, for me. A committee has agreed to include a diagnosis with the barest shred of evidence for its existence as a discrete disorder into a highly controversial book which lists many common human behaviours as disorders of the mind (ref) and as a result of this, treatments are proffered based again on slender evidence. The causes and underlying and comorbid issues are many and varied. These are not taken into account, or are co-opted into the medical explanation through a deficit model of health. It makes little sense. When I conducted the original literature review in 2012, such considerations had not occurred to me. But by this point, they were glaring both in their enormity and in their absence from any of the hoarding disorder literature.

Grant (2014) suggests that non-reflexive forms of research are not suitable for MH nursing (2013; 2015) and I think in looking at this issue I can see why. If I had proceeded from the point of wishing to find out what sources of help were sought by families affected by hoarding disorder and had taken the route suggested through the evidence (only including papers which looked at diagnosable hoarding disorder; interviewing people at a chosen location for a set amount of time one at a time; aggregating and coding the data to identify emergent themes relating to hoarding disorder) if I had done all that, I would have done more to cement the concept of a disorder afflicting individuals without ever understanding how this came to be known as such.

Grant acknowledges the hybrid identity he brings to his work as a mental health nurse, academic and survivor/service user (2015), Foster (2005) also notes her dual position as adult child of a parent with psychosis and as mental health nurse (and as qualitative researcher). She celebrates her own uniqueness and finds her place within psychiatric

nursing (sic), where she can be in a place where she can express, investigate and enjoy “difference” (p.3). Moving from the therapeutic use of self in providing care to the investigative use of self in research feels right for me. I am learning what kind of researcher I might be, what kind of academic I might be.

How did autoethnography come about? People seeking to produce “meaningful, accessible and evocative research grounded in personal experience, research that would sensitize readers to issues of identity politics, to issues shrouded in silence, and to forms of representation that deepen our capacity to empathize with people who are different from us”

(Ellis, Adams and Bochner 2010)

There is some resonance here with Tracy’s story of help-seeking. An issue “shrouded in silence” perhaps when she began her search. Hopefully by offering up the stories involved in her story, there is resonance with others who may be moved to empathise. I hope that there is also resonance with my own story of a person in search of purpose, learning and making discoveries himself as Tracy makes discoveries about herself.

What's my autoethnography



There's a story. A familiar one. A man at a certain time of life looking for personal recognition and losing self-belief. Or is it the mature student's work-life battle, fuelled by self-hatred at the self-indulgent nature of studying for a PhD when family duties should come first, shouldn't they? So, am I in pursuit of myself here? Is that what this is all about?

The use of autoethnography in this chapter is to voice the experience of a search for identity on transitioning from the role of care co-ordinator in an early intervention in psychosis team to mental health nurse

academic (note the absence of the term nurse in the first job – this was important to me and others who had joined the team having qualified and registered as nurses. Barker and Buchannan-Barker (2011) offer some insight into the historical reasons for this). Identity and transition has been a subject for autoethnographic inquiry in mental health before now (e.g. Short, 2010; 2013; Turner, 2012) and given the uniqueness of the experience, presents as the most effective mode of conveying it. Foster et al (2005) report on potentially the first mental health nursing autoethnographic study, which began as Foster's doctoral thesis. The importance of this for this thesis is the precedent it establishes for doctoral work in mental health to take non-traditional forms, a move furthered by Grant (2013), Turner (2012) and Short (2010; 2013).

The work was done. We made our funding bid and we lost. We experienced, reflected and learned. There was enough material for a whole book. And in the meantime, I had bagged myself the academic post I had sought since qualifying. But there was one constant. Tracy had become a part of my life whilst I was working as a clinician. I had no caseload anymore, but Tracy still had problems, right? I am writing this account after the fact. After we have discussed these issues more than once. So, my line of thought is a retrospective imagining.

“When researchers do autoethnography, they retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity”

(Ellis, Adams and Bochner, 2010)

But.

Speaking recently of this lingering need to be needed, after Tracy had read much of this thesis, she pointed out passages where I appeared to be insinuating ingratitude on her part. To my mind I was expressing (selfishly, in the heat of the moment) disappointment at not being needed:

I put up my hand, she doesn't take it

By exploring the “holding on” I experienced here, I aim to provide an echo of the theme of saving for reasons instrumental, emotional and valuable offered in relation to the hoarding of objects. I have a transitional object in this period of uncertainty, this crisis? Is that what this is? Would this have been easier if there had been more people involved in the study? Yes. Undoubtedly.

This points up a problem of relational ethics and demonstrates Bochner's (2014) point that ethics can only be acted out, there is no set of criteria one can cover in advance which will serve instead of the working out process occasioned by the research act. In our case, we were able to talk this through, note our differences and better understand each other. The comment was made early in our working together and reflects my focus at the time on the possessions as the source of distress and my belief that practical involvement in clearing up would be helpful. From this distance I can see how a repositioning in relation to the reported problem occurred in me as much as it did in Tracy.

The effects of living some lives are extremely damaging and present us with problems in living which would be insurmountable for many, leading to great distress. By taking a broader view of these problems (as did my colleagues and many others working in mental health), that distress can be alleviated and some of these problems diminished. They don't go away, though. When the focus is solely on the reaction of the individual to the events, they are given a flaw, a weakness which they then accept as a marker (Goffman, 1990). Sometimes this becomes the person, dwarfing their other features in the eyes of those asked to help. This magnifies and exaggerates.

I think Tracy served as a means of carrying on the notion of a clinical life for me. And I wonder if this idea is true for others. Some research has shown that nurse academics primarily identify as nurses and worry about their clinical cache (Smith and Boyd, 2012). In a

culture of evidence-based practice and constantly evolving policy based on this evidence, it is important to be current, to move with the current. In a relational model of mental health care, perhaps some things are not improved by constant hurtling. But as a new member of staff with little to draw on to demonstrate my ability, I was wary of making such a statement. And I am now. So by holding on to the clinical identity (and by extension the student identity) I defend myself against having been “out of line”. I also defend myself against failure. Having felt for so much of my life that I enjoy being different, in this context it is scary. I am not as brave as Tracy. I am struggling to tolerate the uncertainty.

Immediately, this takes me back to my clinical experience working in a team without diagnostic boundaries and finding myself at odds with a demand for the imposition of stricter categories for the experienced of the people I worked with. This issue with hoarding is my issue and it's bigger. It's an issue with the kind of practitioner I see myself as, struggling against (and growing angry with) a different model which has the weight of powerful bodies behind it and is much louder. The anger apparent in my writing has been a topic of conversation and concern in several supervision sessions and perhaps it was the feeling of alienation I experienced when I realised my position which drove this. Finding that Dixon and Richter (2017) could identify a distinct group of people with similar ideas to me gave me hope. But it was easier to have opinions of this kind in practice because I was preaching to the converted where I worked. I chose that place because I knew the team and they knew me and we all had the same views.

Another explanation might be...

There were tensions evident from the beginning of this PhD. Why was I doing it? I had just got my first job in practice and I had secured a scholarship at the same time. Why not just settle in and do a good job? Well, something unresolved. Uncomfortable. Nineteen years after starting my doomed degree in Divinity at Aberdeen, I had completed a degree and got myself a first at that. But this wasn't enough. I had never had a job for more than a couple of years and I could already see the limits of this one.

As this thesis progressed I became more aware of my own voice in it and my own needs being pushed (by me) to the front. I don't say this with any expectation of sympathy or understanding. It just is. There was certainly something I needed that I was not getting from wherever I was supposed to get it. Here's a clue...

Here it is. The chance to write. The chance perhaps to take a step towards writing for a living or at least for a significant proportion of my occupation. I have longed for this since I was 10 or 11 years old. I do not know if this an appropriate topic for discussion here but it has to be worth noting that one of the motivating factors in undertaking this thesis is that it legitimates

the writing. There is a purpose. It is not frivolous, or self-indulgent (well, perhaps this bit is). There have been numerous times in my adult life when I have begun to write and have abandoned the project for other things. Part of the reasons for doing so is a feeling that what I am doing is self-indulgent and perhaps a bit silly. Kip Jones (2010) has stated very clearly that artistic endeavours by academics are for the purposes of impact and communication should not be self-indulgent twaddle. I am a naturally self-critical person and this dictum has infected my mind. I have been reluctant to show work to supervisors due to a fear that I am not “doing it right” or am not being scholarly enough. This despite Kip’s own comment to me on Facebook to be brave and have the courage of my convictions

So here I am writing a great tome about research and families and objects and whatnot and I am permitted to do so. By me. Is it because I am being paid a scholarship or is it because at the end lies a certain degree of kudos (there are not many doctors in my Faculty) or is it that dread beast, the passage of time, as mentioned elsewhere here. To enter my fifth decade with this under my belt and feeling more secure in my career etc. That may never be achieved as there is something in me that seeks certainty and security but cannot quite feel it. That’s been the case since God and I parted company. Who am I? Will I feel like I have found myself when I can call myself “Dr Buescher”? I doubt it.

So by completing the thesis I will complete myself, my journey? Nice idea. This is because of the need to be needed, I think. The fault in Maslow’s hierarchy of needs – it assumes a healthy self-interest unencumbered by history. It isn’t enough, though. Because that will only be one more job crossed off the list. Behind that job are all the others lining up. And, as Deleuze and Guatari (1978) observed, making a case against a particular point of view is something which needs reiterating. The pruning must continue just as the pruning of this idea must continue to maintain an equilibrium (Zeeman et al, 2014). Perhaps the unfinished theological and philosophical aspirations were seeking fulfilment in this endeavour, but this was not necessarily the place. And how would that help anyone struggling with their relatives’ possessions?

I feel overwhelmed and powerless. I can’t fix Tracy’s mum and I can’t offer her the chance to be involved in my PhD. We do have many other opportunities to work together, though. I leave her making plans to call senior persons at the Goodwin and plotting to organise an appearance on radio Humberside. Is this good? Is she manic? Is this the beginning of a new career arm or the beginning of protracted and unsettling entanglement with an unwell and distressed woman? Not a clue.

During recruitment, I had a growing feeling that the project could never be complete as it would never accomplish its original aim (namely, to gain a fully rounded picture of the life of

a family with a hoarding member). (Wait a minute – that sounds like objectivity! And that is not where I had started but it is where my head had arrived at that particular point). What was I doing? What was going to make out of this? My data is weird and who will look at this and say it is fit for a PhD much less publication? Usually comfortable knowing that there is no control, I began to gain a worried sense that the project had gotten away from me and rather than taking on a life of its own, was languishing up a tree somewhere having a protracted snooze.

I consider the transcripts – what will they reveal about the enterprise of making meaning between Tracy and me? Who will they say more about? And what if I see or hear a lot more of myself than I thought I would? Will I like it? Will I be able to put that before others for scrutiny? It's a big ask to ask people to bare their all and I am moved by Tracy's bravery in the light of that fact. No wonder it proved so hard getting a whole family to agree to participate and no wonder people were afraid of hearing and sharing the views of their relatives about their lives together. At an ethics meeting I was asked what I would do if the family pulled out or I could not find a family to collaborate with. I told them I would start again. That is not quite what happened. I sought another route which produced some fantastic insights and some valuable knowledge, whilst bearing only the slenderest resemblance to the original proposal.

I am not writing about what I intended here. I am writing about myself because in moving from practice to teaching I thought I would be able to make more of a difference. I had found my place in clinical practice but now I had upset my comfy applecart without considering what I was coming to. I based my expectations on my own learning experiences. I also had an evangelical approach to psychosocial practice. To change the system, one student at a time wouldn't be enough. I wanted to take up the mantle and challenge mental health nursing students to be reflexive, honest and sceptical. Alas, I had not realised that many students desire certainty offered by the procedural, diagnostic and treatment model of psychiatric nursing. This brought me to real problem regards identity. Who and what was I? These issues were being thrashed out in this thesis as well as in classrooms. Conversations I had about my post-doctoral future filled me with worry when they turned to ideas of my developing specialist knowledge in hoarding, posing the very real possibility of undermining my own conclusions. This echoed my fears about becoming responsible for producing more mental health nurses with a lack of critical thinking skills and a belief that by learning psychiatric diagnoses and legislation they were acquiring appropriate skills and knowledge to do a complex job of human relations.

Without this, I am in a pickle. There are times when pragmatism is essentially a toxic inertia. Sometimes you must take the hit. But then comes the relational ethics again. What about those around you? How will colleagues react to having our methods of working questioned by someone who has only been in the job two years? Who has only published one paper? How can I sit here and write that I think we have it wrong? What about our colleagues in the other nursing fields? What about our colleagues in our sphere of practice? What I write and what others read will not be the same thing (Turner, 2013; Etherington, 2004; 2007)

I found myself back at the point of wanting things to be different. This time, though, I could see a bigger picture

Problem for me is the idea that you must begin with no preconceived ideas about what must change. I disagree. Change is in many cases essential. I am pretty sure Denzin would agree (1987) and I am not sure how your interest is animated (to use Frank's phrase) if you are not in some way passionately moved to act. The coldest of clinical trials comes from a position of wanting to improve practice – by necessity a change. Frank is approaching not from a clinical but a social science perspective and adopts Latour's standpoint that the best way to effect change may be to describe the world. Certainly, Latour and Woolgar's (1978) work is powerful and raises big questions about the origin of knowledge and the power of select hinterlands to generate what becomes "known" more widely as fact. Perhaps Frank is just not being clear enough. Perhaps he wishes us not to have a "finished" answer before we begin. Fair enough. But to not have a sense of what isn't right is not human, is it? I can't park all that stuff and pretend I have a completely open mind (or at the very least an unopinionated one). The standpoint, originating in others' stories which are given "prominence in the report", is to some extent illusory. Those stories are still heard by you and you are you and what makes you shapes those stories in your ear (as Frank has said before (2010))

The point of being creative

This entry above shows my growing awareness of the greater ramifications of seeing hoarding as a problematic construct. It was the whole idea of mental disorders. This wasn't new, perhaps. I had long held the view that schizophrenia is a damaging and unhelpful word. These ideas were joining together. Part of the struggle to express something which was difficult to say can be seen in my desire to respond with creativity.²

Employing creative means in conducting this research project was about making the process engaging and accessible for those involved (Jones, 2006) as well as allowing for representation of the process. The methods employed are adapted and/or adopted according to the needs of the project and those involved. In this way, creativity allows for greater inclusivity, especially in the light of the co-design of the research which does not require all parties to be fluent in research terminology but demands the academic member of the team to be able to find solutions and exemplars from the research literature to facilitate the needs and suggestions of co-researchers.

In writing this up I can see the obvious where I couldn't before. I become unaware of the way my own needs and desires pushed forwards. In the final transcript we can see a disconnect with the previous one, because it is a separate piece of work. It is an attempt to keep the relationship going, keep the need alive. It is aiming to steer the work towards what I find attractive. Well, it takes two (or three) to tango but how I wanted to do art! I could have designed a research project which made minimum demands of participants but I sought a collaborator.

² Jones (2012) tells us that performative social science allows for collaboration across many divides due to "its natural requirement for community". "Like an immigrant coming home" is how one participant describes her experience of a performative social science conference (Jones, 2007) and that sums up pretty well my own experience of meeting together with people of a similar bent in 2015 (Douglas, 2015; 2017). Vannini (2012) has demonstrated how accessible methods of communicating with the world at large can reach those affected by the issues explored in his research and that of others.

But Jones has a problem with text – it is "linear", "temporal" and "the meaning must be precise or risk disbelief". He abandons this in favour of the visual (Rufus Stone, The one about Princess Margaret). Does this mean that my efforts to produce an interactive text can not be classed as performative social science? (According to Barone (2018) it fits the bill for arts-based research) I guess it depends on who it is made available to and how. Accessibility is a key issue here.

Creativity in dissemination and outputs such as the interim viva and report as well as this thesis and previous conference presentation at PEPC 2017 enables greater impact through engaging interest and emotion (Jones, 2016) in audiences as well as increasing the robustness of what is a highly qualitative piece of work by providing not only a research process but also a reflexive emotional process which is hopefully more readily auditable (after Lincoln and Guba, 1985; 1989)

The tools for the job. A notion or ethos or catchphrase which recurs in this thesis. There are the methodological tools appropriate to the stages of the research design process and developments therein. Most of these were in circulation in my mind or in my supervisor's office before they were called forth. Here is an example. For the interim viva, I adopted a performance method. I prepared a room for the presentation. I spent weeks filling it with things from all over the Dearne building. Things which were surplus to requirements. Unused box folders. Broken cafetieres. Souvenir cups and drug company promotional mugs. Books unwanted left by retiring staff. Junk from my house. Withered plants. Nappies (clean) and broken household items and furniture. I wanted the effects of the cramped space to be felt by the examiners. PowerPoint wasn't going to cut it and neither was me blathering on. The installation had the effect of creating dialogue. The set questions became almost an obstacle to the exam itself as interjections from the chair to remind the examiners what to ask disrupted the very answers they sought. The accompanying report employed embedded hyperlinks to further reading, documentary film and my own work as well as offering illustrations and extended quotes in text boxes to break up the text and give it a "scrapbook" feel. Something I hope has continued here.

What came after is perhaps at odds with the ethos of "tools for the job", in that I became caught up in the idea of creative presentation. My supervisors spotted this but getting the message across was difficult. The question asked above (why am I doing this?) clearly had a more complex answer than I had first thought. Complexity began to take the place of creativity as I sought to make the text "cleverer" (I don't know what word to use here). The spontaneity and responsiveness were being undermined by my inability to relax into it. I had lost my mindfulness, my inner calm. Questions of identity amplified by a change in role from care co-ordinator to academic, became bound up with what I would produce. I knew what sort of practitioner I was but I was new at this lark. I was surrounded by inspiring and formidably prolific and respected people but I worried that some of my quirks would not fit well with certain ideals and commitments in the Faculty. My sensibilities about mental health and how best to work with people in distress were aligned to a particular school of thought and this alignment had developed not just in the three years I had had in practice but through the previous nine years of working in the sector in a variety of roles and through the

life before that with its own psychological and social struggles. These were of course going to shape the kind of academic I would be and become. It came as a genuine shock to discover that there is perceived to be a “right way” of doing so many things in academia. There are always rules in any job, but their interpretation has been quite proscribed.

The installation taking shape in room 223 of the Dearne building contains elements of all of my work so far in researching compulsive hoarding including academic sources, popular media (press, film and television), accounts of professionals I have spoken to, autobiographical accounts of people who grew up in hoarded houses. Objects around the room relate to ideas and issues from within the research so far but also contain elements of my own life which indicate the autobiographical and reflective nature of this work and the direction the research project aims to take. By placing the examiners within a 3-dimensional representation of a hoarded room (albeit modified) it is hoped that they will be able to feel the claustrophobia, frustration and embarrassment experienced by those who have to share their living space with this problem.

Reflecting on my discoveries in my own house, it is clear that hoarding is something which is not that far removed from my ordinary life. Other things take priority and before I know it the tomato plants my father gave me to put in my greenhouse are dead but still on the garage windowsill. There are items in the loft which I simply cannot explain. Matt Paxton comments on this in his 2011 book “The Secret Lives of Hoarders”, suggesting that there are levels of hoarding and it is easy to progress through these as other concerns (such as young children) disrupt the normal flow of your life. In a novel twist, my mother-in-law “rescued” our house whilst we were away on holiday. Although I was aware of how unkempt it was becoming, the difference is staggering

The effect of having studied the subject for almost two years now has been to produce a hoard of my own all relating to hoarding. The many papers which I have read and printed off adorn the notice board in the exam room. The many film clips have been abandoned as being unworkable in the time given. They’ll keep. I’ll keep them. In my digital hoard of hoarding information, signposts and locations.

In this study I want to understand a phenomenon which exists as interaction. Interaction between the members of a family and the elephant in the room (or all the rooms). Interaction also between the family members with one another and finally, interaction between the family members and sources of help – for want of a better phrase – be they statutory agencies, church groups, online support groups, the pub, or whatever. In all of this there is also me, the researcher. I want to acknowledge my interactions with these people and their

situation, too. I want to make sense of my own understanding of this. Don't know what this means. Making meaning is done dialogically.

So perhaps this is me. All or nothing. I remember standing in front of a visiting preacher and stating that if one did not believe that God created the world in 7 days (rather than 7 periods of time as some asserted) then one did not believe in God – omnipotent. When I think I am going to do Grounded Theory, I have to do it according to 1967 rules as anything else is a dilution. Then, when I consider that this work is to be coproduced it must also be codesigned and nothing can be known about it prior to the design being agreed, making ethics application difficult for me and the committee. Then when this does not occur and the methodology requires more responsiveness, it must be iterative throughout, adopting what needs to be adopted as the situation develops. This is not simply “eclectic methodology” as I have heard others describe ambiguous qualitative studies, it is a dialogic, responsive methodology, evolving through a process of interactions and altered requirements and utilising the best fit tools available. At times these are existing methodological features and approaches. On occasion it may be necessary to adapt an existing device, tool or approach and in some instances, it may be the standpoint of a method which is required rather than the technical details. To illustrate this development and ongoing dialogue, illustration from diary entries and research conversations as well as insights gained from other sources (such as conferences) have been provided.

There is certainly a language and culture of respect and collaboration informing clinical and research life in mental health. In the case of my clinical life and this piece of research I would say it was a strength. In fact, it was everything. Not everyone needs to be needed quite so much, you might argue. But if you are going to make use of people and their stories and experiences, it seems only fair that you should listen with full attention. Earlier on, I had been flapping at the lack of participants for my research project and now here I was allowing myself to be called upon when required. The time and space afforded by being in the position of researcher. How can this be developed?

Cecil Wright Mills (1959) calls for just such an approach to inquiry in sociology. The methodology adapted and evolving, the creativity required and the maintaining of journals. I must confess to this latter being more sporadic in my case than I think he would have liked. Sometimes it was impossible to write anything and sometimes the compulsion was intense. Discipline as advocated by Mills did not feature in the process. The mind wanders. And as above, often ends up in me evangelising – this should be no surprise given my evangelical beginnings. I am an unreformed nonconformist. A serial evangelist. A search (just a rough

one) of the terms “evangelical” and “research” turned up papers about churches and belief but nothing about an evangelical approach to research. Reading Mills (1959) (and Hammersley’s critique of Mills (1999)), I think I have found another evangelical researcher. An apostle. In fact, one might argue that critical research is evangelical research. Given the call to action occasioned by perceived injustice or other revelation (like Saul on the road to Damascus), there is an ethical imperative to speak out.

I never wanted to produce order out of chaos. I wanted to meet with chaos on its own terms (I am only using this word because it seems the most accessible in the current context – in actual fact, the underlying philosophy of this thesis is that the terms order and chaos do not mean anything for many people and both are relative anyway. They are one way of exploring the phenomenon of hoarding or any other aspect experience. They are tools in one of the possible language games we could play here. They are certainly lucrative for some people (witness the rise and rise of Association of Professional Declutterers and Organisers etc) and they are certainly a source of comfort for many in the face of things which they find incomprehensible. Herring (2014) sets this out very neatly, drawing parallels between religion and hygiene in middle America. But they are certainly not always helpful and the proposition of a binary can produce conflict and resentment as can be seen from the literature review.

Now I am one of those charged with producing more of these creatures – mental health nurses. In fact, there seems to be a move amongst the students towards seeing themselves as “psychiatric nurses” with “patients” who are “ill”. This version of events is gaining ascendancy, it seems. I previously wished to demolish this. I perhaps still do, although this is not the way of all constructionism. These narratives are beneficial to some, aren’t they? They add to our understanding, don’t they? Or do they serve as a distraction from the major causes of misery and madness – abuse, war, poverty and prejudice. Why do we not have a diagnosis of “warmongery”, or “overcapitalisation”? Gergen (2001) reports that he has moved away from this opposition to one particular standpoint or another, although there are clues in that text that psychiatry (p.110) hasn’t been quite so gently treated as empirical research.

But what to do?

Relational ethics

In addition to the research ethics principles epitomised by institutional ethics boards, which remain essential for all projects, and those of situational ethics which arise for anyone actively engaged in research with another human, autoethnographic researchers must consider relational aspects. Autoethnographers must pay particular attention to (process) consent, consequences, privacy and relationships. In chapter three, some of these issues were discussed and here I will consider further issues as a result of my sharing my own experience in this account. By involving the co-researcher in every aspect of design and continually reviewing their wishes and seeking their opinion, consent is monitored and reviewed on an ongoing basis (Lapadat, 2017). I think over our project and wonder if such a degree of collaboration was really achieved and if it can be achieved. There are times I remember as being more or less in control, at times more of a follower and more of a leader.

Adams, Holman Jones and Ellis (2014) remind us that autoethnography risks exposure of those around us – family members and friends. Therefore, we might want to protect privacy using various methods. For instance, I am unsure about introducing my family members into this piece due to potential embarrassment. I know that early on, Tracy had the same reservations. She has since been quite open about things in some very public spaces, whilst I have been more reserved due to perceived messages from members of my family. There is a tension between the desire for greater verisimilitude and the risk of damage to relationships, which leads us neatly to relational ethics. Adams et al (2015) advocate the use of collaborative processes throughout which is something we have aimed for (with varying degrees of success, I would admit). They also advocate the adoption of “friendship as method” (Tillman-Healy, 2013), which is very much as it sounds – being attentive to your co-researcher (they use the term “participant”) throughout and after the research process in the interest of maintaining the friendship and the research. This principle brings together all of the above issues.

Tami Spry (2002) offers this advice for autoethnographers when considering relational ethics:

1. Avoid *self-indulgence* by critically reflecting on our motives for and methods of writing: disclosing information about selves, others and contexts: and, to the best of our ability, connect our motives, methods and disclosures to larger cultural issues. I have come to writing about me in response to having written about the experience of another, through a shared process of reflection and action I have encountered questions about myself which impact upon this and further research and my values

and motivations. In sharing the work with Tracy and my supervisors I hope this issue has been open to scrutiny. At the same time, I am mindful of Turner's (2013) comment that the focus of research can change as it progresses. I realise that this can play with people's expectations. Despite the research following a process of action and reflection, this twist is not expected and risks undermining the important message about Tracy's long and difficult help-seeking journey. I hope that in talking about my response to this, I add to, rather than diminish, the message.

2. Avoid *blaming* and *shaming* when representing experience by learning about ourselves, interrogating our connection to others, to larger cultural systems, and examining "our involvement in perpetuating or being subject to oppressive systems" The degree of self-examination in this work is here to offer a reminder to me as well as others that I am part of a privileged group of people who are licenced to examine others. The issues I talk about in relation to finding help for compulsive hoarding and in considering how we do and research raised in me personal and professional questions about my place in mental health nursing. I have found this to be a real challenge. In essence, chapter seven is largely about this
3. Avoid *heroics* by humbly and critically reflecting on fieldwork experiences

I have had to revise some of my lofty ideas and acknowledge when I was not insightful in my dealings with Tracy. This undertaking was done together but I will happily admit that the driving force was Tracy. It was her search for answers that propelled and still propels us. My reflections on how I felt as a result of our experience (or I should say my experience of our experience) only exist as a result of her dedication to a cause and generosity of spirit in allowing me to be implicated in some way. And these reflections which I call "mine" are punctuated and provoked by our ongoing conversations.

4. Avoid framing self/others as victims without offering a critical analysis of injustice and oppression
5. Avoid *self-righteousness* by acknowledging our identities and privileges as researchers

Whilst I have attempted a thorough account of myself and my influences (which will, of course be as notable for its exceptions as it is for its inclusions), I hope this has not overshadowed the original aim of the research. I am aware that I make some suggestions for practice based on this research experience, when time and resources may be more readily available to me and I am part of a coalition of the willing. I hope these will be taken as they are offered. Hopes for a future culture of mental health care rather than indictment of the tireless kindness of so many people working in the field now who don't want it to be how it is.

6. Avoid *disengagement* with self-others by learning about the histories, cultures and politics of the experiences and cultures you represent

As someone who has only a brief amount of experience in nursing and even less in academia, what aspects of experience do I have the right to write about? I write as someone with the gaze of naivety only offered for a brief time in a new post. I write as someone knowingly selective in their choice of practice area and mode of research. One of many.

Observing these may help to produce what Adams et al (2015) describe as “probable, trustworthy, and resonant autoethnographic tales” (p.96)

The original design for this study bears resemblance to that employed in earlier work by Lapadat (2009), in which members of a qualitative methods class shared autobiographical data with one another and conducted group analysis. With the alteration to the size of the group, the methodology moved more towards a “layered account” as described by Ellis et al, (2011). Lapadat (2017) identifies strengths of co-authored autobiographical work which go some way to addressing issues raised by traditional autoethnography. Firstly, the inclusive nature of the work, extending beyond the academy whilst retaining autoethnographic principles; secondly, the improved rigour of the process by having co-researchers involved equally in the design, conducting, analysis and writing of the research. Lapadat (2017) argues that the presence of the co-researcher(s) reduces the likelihood of narcissistic or shallow work. Knowing that Tracy would be reading what I had written served to promote a degree of reflection and re-appraisal of what I had written and included in the thesis. It would have been more robust had we written together or had I deployed the methods suggested by Fay Martin who wrote “in the room” with those she was writing about (Ellis, 2004). Tracy has added some of her own content to this work but in the case of a doctoral thesis there are limits to how far this can go, perhaps. The need to demonstrate that the work is one’s own presents difficulties regards ownership and authorship.

The power relations between parties involved in the research are flattened in Collaborative Autoethnography, argues Lapadat, enabling those involved to have more confidence in calling for actions, telling certain stories and seeking help. This is true for each other as much for each member of the team themselves. This is only sometimes true in the case of this piece of research, partially because of the unequal starting positions of the co-researchers and partly because of the unequal access to resources throughout and after the project. Whilst we got to know each other reasonably well before commencing the research, it would have been beneficial to find on-campus resources or access for Tracy. Again, in the

context of a PhD thesis this is problematic, but for future projects I would hope this could be possible.

Etherington (2007, p.612) notes the risks of using self-disclosure in presentations and research writing as potentially damaging to academic careers. Foster reports being surprised at some reactions to her presentation of autoethnographic work at conferences (a perceived lack of openness and possible stigmatising effect). She hypothesises the possible causes as stigma towards mental health sufferers and families, lack of professional boundaries/reserve, doubts about the credibility of the method of research (p.7)

Foster's (2005) answer to this problem and its potential sources is;

"...to continue sharing about autoethnography as a tool that might enhance qualitative research." (p.8)

Foster further suggests that the self-disclosure utilised in mental health nursing practice can be equally fruitful in research, as well as potentially being equally disadvantageous. It

"...remains a matter for the researcher to evaluate and justify using criteria for rigour and trustworthiness within their chosen methodology"

(p.9)

Here we need to recall Rolfe's (2006) assertion that criteria for rigour in qualitative studies are essentially anathema, which suggests this may be a more difficult decision than Foster leads us to believe. I can attest to this from my own personal experience at an in-house research conference as recounted at interlude two.

The risks to self through the adoption of autoethnographic methods include a potential loss of credibility through the sharing of details about oneself which could be viewed negatively by those around you, including family, friends and (in this case academic) employers. Perhaps when Etherington (2004) talks about "self-respect" in researchers using themselves in research paying attention to the damaging effects of revisiting abuse. In our case, Tracy revisited neglect and this was a difficult and at times painful process. Etherington (2004) states that

"participants can take some responsibility for themselves and their part in the process"

but that doesn't make for very comfortable reading and if you said that to an ethics committee I am not sure of the response it would get. Additionally, you can't leave the field at the end. You are in it all the time by dint of the fact that you are its point of origin. In our case this is true for Tracy more than it is for me, despite my being affected indirectly by this issue. However, I see some of the troubles Tracy has and I think "that could well be the future."

24.11.2015

Tracy didn't have as much to say as I thought today. She had signalled a very full agenda but I was surprised at the brevity with which the "to do" list was dispatched. The most important breakthrough today was, I think made in the area of delineating responsibilities and the reach of the research project into the training project and vice versa. Although I am still not entirely sure she knows how the whole thing will work and I am not entirely sure that this is true co-production, I have managed to provide some clarity on who is doing what and why. Things academic, it would seem, are to be left to me. Good. Tracy is engaged in much more academic work than she realises already, I think. Tracy will establish a Facebook page for the hoarding education/training project and provide contact points to be given out during the radio interview on Thursday (3/12) with Greg.

At one point, Tracy asks me when we "start" the research bit. "When do you say "tell me about your mother?"?"? I tell her that we are doing that now, pointing out that she has already talked about the distress of dealing with her affairs and the lack of advocacy services as well as the lack of interest from statutory services.

The difficulties posed by collaborative autoethnography are the "...establishing shared goals, agreeing how the group will work together, and meeting timelines." (Lapadat, 2017 p.600) Truer words were never said. Especially when there is a doctorate at stake. In addition, Lapadat reminds us that the regular concerns of autoethnography such a relational ethics are still extremely present. How to seek consent from "implicated others", for instance. Informed consent was obtained from Tracy, Julie, Dean and Sarah but only Tracy has the relative safety of the researcher position, with accessibility to transcripts and drafts. So, in this case, there is only a partial success. I must admit to having every intention of sharing the work with Tracy for her input but had not considered sharing it with all those implicated.

Relational ethics should take account of the possible effects on the reader (Turner, 2013 p.214) despite the impossibility of predicting every response. Turner (p.215) also points out that our motivations for writing and the very thing we are writing can change as we write/do our research. Clearly this project travelled far from its point of departure in one sense and had there not been the reflexive content of the work the beginning and the end would seem incoherent. Sara Delamont (2007) has made the case that there is no way autoethnography can be ethically published due to the implicated parties in the story of the author who may have not consented to be involved (such as parents). I think of my parents when I read this.

I imagine them reading my swears and think that isn't so bad (their beliefs do not condone language like that) then I think of some of my descriptions of behaviour and experience which have gone unmentioned for so long. These would be painful to read, but I think with the benefit of the passage of time and from the context of my now having a stable life and loving family they will not hurt as much as they could have. Some of my comments about the effects of faith may hurt but they are integral to this story and must stay. They can, like all of this work, be contested by the reader(s).

At a further remove are the family of a former friend who is briefly mentioned in the text. This particular part felt too raw to be approached in the frank fashion I originally tackled it. I am quite estranged from his family, although I see his mum now and then and know where she lives. I could go and see her, but I chose to approach the subject with a mutual friend instead. This was because of the emotional after-effects I speak of above, but also because I was unsure if my referring to the event was unsavoury in some way, like I wanted to mention this event just to hold the reader's attention. It certainly held mine. My friend advised that identifying details be removed and this seemed to offer enough room to acknowledge the influence of events without seeming improper.

I am aware that this will make uncomfortable reading for many. When Tracy first read my account of our adventures, she reported feeling shocked and surprised at how the text did not resemble what she imagined. I was alarmed at the prospect of having caused her some offense, having got it wrong. It was the rawness of the account she found arresting, she said. She also noted that it did not read as a collaboration in the way she had hoped. This I found particularly alarming. What had I produced?

"...if I am to reveal a person's identity alongside their words, it is still *my* experience of their words, filtered through my own selves"

(Turner, 2013 p.220)

What this means for Tracy and I is exactly what it says. It brings us back to the "story of sorts" Carl Leggo mentions, and the issue of what resources are available to storytellers and their audiences (Frank, 2010; 2012). We have hopefully increased our stock and in doing so have better equipped ourselves to hold our own against the vulnerability and anxiety we experience in our own lives.

Chapter 7 A man scribbled...Is this the end?

A difficult day today – first excitement at the challenging and energetic (if a bit showy offy) deconstruction of evidence-based practice offered by Freshwater and Rolfe (2004). Then a frenzied bit of typing which will bolster further the argument for mixing methods and in particular introducing autoethnography into the thesis. Then I started to consider again the future. At my institution and in mental health nursing in general. I know there is a group of nursing academics who operate from postmodern standpoints. I know that group is small. I know there are mental health nurse academics. Most of them do not appear to subscribe to this view, but within the mental health field more widely, there is a group of postmodernists at work. I know where some of them are. I've met one.

Alec Grant (2001) pinpoints the problem faced by mental health nursing in having fallen into a dichotomy – are you a touchy-feely nurse or a hard-evidence nurse? The problem, as Grant identifies, is that these are two sides of the same coin. Neither challenges the gross failings of the “mental health system”. Over the past decade a sustained battery of campaigns by a wide array of interested parties has served to put mental health in the news daily for very different reasons than it would have been in the past. Whilst it is to be applauded that headlines about public safety are being overshadowed by stories about undersupply of help to people in need, this arguably again presents two sides of the same coin. Public fear about safety has aligned with concerns about the epidemic of mental disorder and public fear about a lack of psychiatrists (Royal College of Psychiatrists, 2017), inpatient beds (Ewbank et al, 2017), and mental health nurses (Care Quality Commission, 2017), shouting out the old narrative of the need for more (of the same) mental health care provision. The call for social and political responsibility to be taken for the welfare of individuals and families is being made by some. The call for a change to our view of mental health care is being made by some, too (Drop the disorder, 2017; Johnstone and Boyle, 2018). The Critical Mental Health Nurses Network, the Critical Psychiatry Network and Psychologists for Social Change all seem to be composed of similarly-minded people.

But these voices are all but drowned out by the big media profile of royal colleges (Royal College of Psychiatrists, 2017) and richly funded research consortia (e.g. MQ, 2017) which serve to co-opt these alternative discourses through suggestions that inherent individual deficits are the reason why social issues can lead to distress. Even in the potentially more democratic world of social media, messages about the need for more, urgent research into the “causes” (biological) and features and treatments skew public information about how help is to be achieved/ made available. Since the launch of the Power Threat Meaning

framework (Johnstone and Boyle, 2018) (or rather, since 2011), much communication between psychiatry and clinical psychology has been quite hostile and this had become more pronounced in recent months, taking in survivors and academics on both sides.

Outlined above is a suggestion that we don't need to "tackle hoarding disorder" as a mental health issue, because it sends us in the wrong direction. Environmental, relational and social problems ("problems in living") cause great distress but these problems differ from one person to the next and what helps (e.g. "hoarding") one person may cause distress to another. Examining all sides from a distance, allowing stories to be told and heard provides a breadth of resources for telling a new story, enabling exploration of possible new identities to address and accept vulnerabilities (Frank, 2010; 2012; Fisher and Freshwater, 2014; Grant, 2015; Johnstone and Boyle, 2018).

This takes us past hoarding disorder to the bigger issue of my extreme discomfort with positivism and post-positivism as approaches to mental health research and practice in general. Psychiatry and evidence-based medicine, neither of which have much to offer mental health in isolation (Grant, 2014; 2015; Barker and Buchanan-Barker, 2011; Johnstone and Boyle, 2018) but neither of which seem interested in flattening the hierarchical structures within which they originate and operate. And that, inevitably, leads me to identity again.

The logical conclusion of all this has got to be "get out!" (Turner, 2012). But so many mental health practitioners and researchers are disillusioned with or suspicious of medical discourses in mental health (Zeeman, et al, 2015; Dixon and Richter, 2017), there must be a means to challenging this without abandoning the mission to improve lives.

This is not what I wanted to achieve by entering practice or academia and it seems this is true for many others. But perhaps there is a resolution available. Cohen (2016) and McKeown (2018) call for academics, survivors, leftist activists to come together to campaign for the dismantlement of psychiatry. For research that proceeds from a critical standpoint (Mills, 1959; Frank, 2010) acknowledges that there is no evidence for psychiatric diagnoses and the prescribed treatments that go with them (Johnstone, 2014). Whilst he is talking principally about sociologists of mental health, it would seem to me to be a logical direction for critical mental health workers and academics to take, given the importance of social and cultural factors in matters of mental health described here.

Looking out of my office window at the monolithic medical research building with its neuropsychiatrists, I am not under any illusions at what the result of such research or publications may be but there is an imperative in my early experiences working in mental health and in working with Tracy that demands action. An attentive pruning (Zeeman et al,

2014) of medical discourses must be maintained to produce a balance. And this is why Foster's (2005) resolution to continue bringing autoethnography to the attention of mental health academics strikes a chord with me. Increased awareness of why we tell the stories we tell and the effects they have on those people can hopefully help to foster the narrative practitioner described by Grant (2015), adding to the mass of little stories.

Throughout the course of the project, I have become more interested in the way that people understand hoarding and less interested in the concrete diagnosis of hoarding disorder or the proposed interventions outlined in the research literature. I found curiosity to be a better means for conducting an inquiry than knowledge of the current status of the clinical research on hoarding. As discussed above, following this already narrow path serves only to focus attention on one particular narrative. A long history of lionising positivist and post-positivist research in the search for identifiable objects of study in mental health only serves to distract. If the purpose of this research is to improve lives, then it will need to embrace the messiness of lives and the complicated components involved in constructing them.

We are at a critical moment in the history of research Denzin and Lincoln argue (2014). Revelations, which to some are unsurprising, are undermining public confidence in the scientific method, or rather those who deploy it in the name of advancing medical and psychological care (e.g. Bourgeois et al, 2010). Perhaps it is time to be less rigid but more rigorous and offer a greater degree of involvement and engagement to stakeholders in research (Reason, 1994; Heron, 1996) (which is pretty much everyone when your research is concerned with mental health). Perhaps even to go beyond this and simply provide space for stories to be voiced, relating these stories to theories within the context of ongoing dialogue with fellow conversants. To flatten the hierarchy, slow down and generate, analyse and consider all the evidence carefully through more than one lens. This shared, crafted approach offers a sense of producing something of purpose, worth and ownership to those involved in its creation. Materialism in dialogue with social construction

Cohen (2016) describes psychiatry as an agent of capitalist social control. Not in the sense that it has been hijacked, rather that it is an integral component of an evolved system of social control which protects the interests of the dominant class and maintains an imbalance of wealth (p.73). Psychiatry reflects of the pervading culture (e.g. neoliberalism) which preserves its position as an essential part of a late capitalist system. Using examples of slavery, youth, women and political dissent Cohen shows how psychiatry has been complicit in the reinforcement of particular order and cultural values based on historic materialism . Material possessions as an essential element of diagnostic criteria appear to take this to a

place hitherto unknown. Now value of worldly goods as judged by a clinician can serve as an indicator of illness worthy of potentially medical intervention.³

Psychiatric hegemony (Gramsci's notion of the internalisation of control through self-monitoring) (Pozzolini, 1970) in the light of the developing DSM-III and subsequent editions with their accessibility for lay people in language used and rapidly increasing catalogues of disorders. This has served to introduce the language of psychiatric discourse into everyday speech. Capitalism is served by the monetisation of mental illness but more importantly for Cohen, by the maintenance of the means of production and the focus of societal problems being the responsabilised individual. And so the issues first brought to public attention by Affluenza as problems of consumerist excess have been co-opted and re-framed as issues of lack of control ("impulse disorders" or "obsessive-compulsive spectrum disorders") due to deficits in the individual. By taking this stance, the problems of over-consumption and identity defined by possessions as well as the long-lasting effects of trauma for a large section of society are masked and ignored.

Grant (2015) offers us two contrasting paradigms of mental health care. On one hand, the technological paradigm is characterised by the encroachment into everyday life of psychiatric jargon offered by the DSM (as mentioned by Cohen, 2016). The paradigm also identifies interventions developed for the treatment of diagnosed illnesses, existing independently of the lifeworld of the individual, which is given little consideration. This technological paradigm has social and cultural dominance with practitioners, despite a persistent lack of medical evidence for psychiatric diagnosis. This reliance on diagnosis

³ Relationships to material possessions are so estranged that we are unable to discern what worth is. When we have invested no labour in anything we own, we only have abstract means of assessing this (e.g. financial value) and the assessment of worth is then someone else's business, estranging us even further from our objects, which are not the fruits of our labour.

"It is not the consciousness of men which determines their being, but, on the contrary, their social being determines their consciousness" (Marx, 1961q. Crotty, 1998 p.120) – and this is principally an economic being so those with the economic power (hegemony) shape the perceptions of the rest. In the case of psychiatry, this goes right to Cohen's (2016) assertion that psychiatry is an integral part of this system of protecting the status quo (what Marx refers to as a superstructure), whatever that might be, and DSM and its widespread internalisation by millions is an example. Furthermore, the responsabilisation of consumption and disposal of possessions is a further example of such an ideology, misrepresenting the state of existence and masking "the way things really are" (Crotty, 1998 p.121). Looking at oneself through an ideological psychiatric-medical lens alienates one from oneself, suggests Ferguson (2018). As mentioned above, Illich (1975) has drawn attention to the estrangement of people from their experience through the expropriation of health.

The proletariat must overthrow the inhuman system in a revolution which cannot be conducted on its behalf by others. For survivor movements and co-operations this means mad studies must not be – as Beresford and Russo (2016) have identified – be co-opted and overseen by "experts" clinical or academic. Mad studies is essentially "for us about us". It is this model of research which I am advocating and will return to this subject in the conclusion.

produces a focus on measurable outcomes (what has been termed “clinical recovery” (Barber, 2012; Parker et al, 2017)) which are of no meaning to the individual, and a lack of regard for the experience of the individual which, if expressed, is interpreted in terms of the diagnosis (“confirmation bias”, Mendel, 2011).

If we were to take the experience of family members of compulsive hoarders in these terms, we would assess them for signs of disorder and supply them with the appropriate treatment, not taking into account their stories. We may accept a referral for their relative with a compulsive hoarding issue and assess and treat them in the same way. This potentially necessitates and perpetuates a separation and fragmentation of the family system as reported in chapter two.

By contrast to this model, Grant offers the “human paradigm”, which sees recovery as “embodied moral practice, grounded in material and cultural circumstances and personal histories and relationships”

(2015, e51)

centring around the unique stories of the individual and the mental health worker which inform each other to produce sympathetic harmony. This demands close attention to language and the primacy of ethics over technology and a particular cultivated aptitude for narrative competence, defined as

“the capacity for human beings to deeply absorb, interpret, and appropriately respond to the stories of others”.

(p. e52)

I would argue that this sensibility is required in mental health research, too. However, Grant suggests that nurses practicing in such a fashion are the exception rather than the rule and as he and others have observed, clinical life is often far more likely to follow a biomedical model, leaving those of us with the task of educating student nurses in a “rather unsatisfactory middle-ground”, with students gravitating towards such biomedical ideas. In fact, with many students already well-established in mental health services as healthcare assistants this dominant theory is present from the outset of their training and often seemingly unassailable. In research, too. There is a tendency for mental health researchers to adopt accepted terminology and concepts which limit the capacity for exploration and expression. Adopting the principles of sensing the rhythm and joining in the dance as Newman (1999) suggests, offers a way of approaching with patient curiosity but adopting a sense of urgency and taking a side. You are on the side of that person.

Porter and O'Halloran (2009) reject postmodernist suggestions that evidence-based nursing (understood as a positivist or post-positivist pursuit) falsely asserts that forms of knowledge

can be more or less valid than others. In addition, they deny the Foucauldian relation between knowledge and power. They do, however, acknowledge that for the purposes of nursing care, an appreciation for qualitative research, ethical, personal and aesthetic knowing are not held in sufficient regard within the evidence-based practice movement. Complex care and values-based decisions are not addressed by simple questions of effectiveness. They come to the conclusion that evidence based practice is a “necessary but not sufficient component” of nursing care. This invites an excoriating attack from Holmes et al (2009) whose original article inspired Porter and O’Halloran to write, who note that the case for the necessity of evidence-based medicine has not been made by these authors but the case for its insufficiency has. I mention this because in the case of what is commonly referred to and therefore is referred to in this text as “mental health”, there is a particular problem with taking an empirical approach (or even a cod-empirical one, as described by O’Byrne, 2007). As Szasz (1972), Grant (2015) and Cohen (2016) mentioned above, there is a lack of evidence for any mental disorder despite an ongoing search which has lasted decades but there is clearly distress. Distress cannot be a generally applied term understood equally and uniformly across a number of people. It’s shape, size, scope, needs will differ. To attempt to create a uniform intervention for distress caused by the loss of a child in a car crash (for instance) is sheer folly. It only works when we assume there is a disease (post-traumatic stress disorder, for instance). But the disease only exists as a construct of convenience for the psychiatrist. It has no benefit for the person affected (they are not a patient because they are not ill, just experiencing things we might expect to experience in the light of such devastating events). In fact, taking a group of people in distress and labelling them insane thus indoctrinating them into a stigmatised status, then assigning them to a treatment group for the purposes of developing the evidence base ignores the unique nature of distress and as a result, the individual’s needs. It poses a risk of iatrogenesis. Perhaps that is why this research (I mean me) has struggled so much with language. The things I am required to say on information leaflets and recruitment posters could be viewed as luring people into this stigmatised status through the suggestion that this is normal behaviour (although I am fairly certain that anything which unites a proportion of the population as large as 3% based on last UK study results (Nordsletten, 2013b), could be seen as normal). The stigma was created or at least aggravated by the hoarding researchers and television personalities (whom, we will remember, are so close as to occasionally be the same people) through their development of a moral panic (Herring, 2014).

Grant et al (2015) call for qualitative researchers to advance the cause of troubling existing narratives by adding to the stock of stories available for the purposes of re-storying lives,

offering a more meaningful interpretation of recovery than the broad-strokes clinical model and merging the stories of those involved in the research in

“a refusal to separate professional from consumer narratives” (p.285).

In this thesis, there is some compromise in this regard. The collaborative witnessing (Ellis et al, 2010) which informs much of this work is hopefully allowed to develop into mutual appreciation and enrichment. Work in progress, in the long term, for me.

Few people back in 1998, myself included, would have conceived the idea that I would have conducted a PhD. I am amazed and slightly embarrassed about the opportunities I have had and this includes the opportunity to work in such a way as to make a new friend. We talk in practice of learning from the people we work with and this attitude it seems to me, should inform our research. But some forms of research afford this better than others, I think. I am someone who needs to know the people I am involved with and they should be comfortable enough with me that there is no sense of rush. In the case of research, no sense of urgency (for them). I see this sense of being at ease as an ethical necessity. I don't mean making sure the kettle's on and there are tissues available. I mean what Rogers (1961) referred to as core conditions; Warmth, empathy and unconditional positive regard. It was displays of these from friends and family members and the woman who I married which allowed me the time and space to make sense of things with multiple false starts. A hurried agenda of clinical recovery or data extraction or intervention is unlikely to be quite so beneficial or to have such rich results, perhaps.

Rolfe and Gardner, (2005) note that reflection is an essential part of nursing and of nursing research (Rolfe argued to no avail in 1998). RCTs alone offer nothing to a person and context-specific profession like nursing. We need to reconsider what is required for the “science of the unique”. We have things the wrong way around, they argue. Evidence is found after something has occurred, not before. That would be motivation, or legitimation, perhaps? And so are all other forms of evidence. But the practice bit just starts from this “best guess based on what I know” position, after that:

“Evidence-based practice is therefore a reflective/reflexive cycle in which we are gradually modifying our responses in the light of immediate feedback.” (Rolfe, 2006a p.7)

Praxis (Rolfe and Gardner, 2005), or reflection in action (Schön, 1983) is:

“...a series of on-the-spot reflective clinical judgements made in the midst of an evolving practice situation. Seen in this way, evidence-based practice is not for the novice and neither is it for the faint-hearted. It requires not only quick thinking and advanced clinical skills, but

also the skills of reflection in- and on-practice and the ability to evaluate a clinical situation clearly and rationally whilst it is ongoing.” (p.308)

This, then, holds some clues for me as to how to proceed in the education and development of student nurses as researcher-practitioners and for me as a mental health academic researcher-teacher. There is much to learn. There is a big gap to overcome (Rolfe, 1998).

But why is there such a gap? Because the technical rational model of scientific research employed in the actual sciences is allied to the practice of those sciences (what happens in a lab is likely to happen outside that lab too) but nursing research does not conduct laboratory experiments. It uses “the statistical model of research” which is all very well for creating theory but not so good for application to “individual and unique clinical situations” (Rolfe, 1998 p.674) (although now I am thinking theoretical physics must have a bit of that, too?). It attempts to remove uncertainty, whilst here I am advocating (along with Rolfe, I believe) the tolerance of uncertainty as identified by Newman (1999).

Rolfe offers us an example. A nurse wishes to try out a new method of counselling for depression so she groups her patients into two equal groups and randomly assigns one group to the usual counselling and one to the new version. She finds that the new version is more effective. Results for the group indicate improved scores on the scale of her choosing. Individual results can be very varied for intervention and control groups. Now along comes a busy nurse with a number of depressed patients in need of help. She employs the new method because it showed the best results based on the average for the allocated group. The individual unique clients are not considered in either part of this process. We need to know the individuals affected and we need to know how similar people have reacted to a particular treatment to gauge how they will react to that treatment. So, whilst science is concerned with the majority of cases, practice is concerned with individual cases. Rolfe sees this as a possible point of origin for the theory-practice gap, which further noise (dissemination and education from researchers) will serve to aggravate by ruling out the judgement of practitioners. I am implicated here. I teach research methods to undergraduates. I have responsibilities to them in regards to teaching them what they need to know to complete their dissertations and register as nurses. I also have a responsibility to them to ensure they are not lured into a false sense of certainty offered by taking clinical guidelines and psychiatric discourse at face value.

Then there are the ethical problems. Statistical research borrowed from agriculture, an area in which large numbers are the only thing. Individual plants do not matter, it is the size of yield which is important. This is not an ethical way to conduct mental health care. Treatments must be right for individuals. Rolfe suggests there is a case for saying

“...each individual patient is treatment group of one”

Practitioners need, in the light of uncertainty from remote theoretical research findings, to do their own research in practice with their own patients. There are precedents in many disciplines for single case research. Whilst validity will be questioned owing to the dominant paradigm in health research, the provision of sufficient detail about the person, the intervention and the setting will enable decisions about transferability to be made by other practitioners. We can add similar cases to broaden our understanding of the applicability of the findings (adding to the stock of stories). Where data and theory are developed in parallel as in action research, rules about internal validity and reliability are not applicable (Rolfe cites Hammersley and Atkinson, 1983) and following the suggestions above about determining suitable means for researching human experience in mental health nursing, forms such as this are arguably more appropriate and ethically aligned.

I worked as a care co-ordinator, along with a whole team of people with the same title from a variety of backgrounds. We all had the same job. Essentially, keep client contact with psychiatry to a minimum and promote self-reliance and social inclusion using a range of skills, which were not all “prescribed” as part of a “pathway”. The focus was on the individual and the results were good. It was “all about the relationship” regardless of what technical interventions may be involved where appropriate. These were not what made me good at my job. They could be taught. The real skill lay in the building of sustainable relationships of trust which offered a safe space for clients to explore their experience with a higher degree of tolerance of uncertainty in both themselves and their family members (and other professionals involved). This description of my clinical life fits with what my expectations of the role of a mental health nurse should be and I was lucky in finding a place where I could practice in such a fashion with like-minded people.

That said, there is no reason for mental health nurses to learn about diagnosis. There is a necessary requirement for nurses in general to deliver interventions based on the best available evidence. This is problematic given that evidence for the mental illnesses they are supposed to be offering care for is still not in existence. Psychiatric discourse has infected and abused sound scientific practice in an endless exercise in self-legitimation and this has placed mental health nursing in an untenable position. If I sound angry at this point, I think I have a right to be. Research into how best to relieve the pain of problems in living is not a notable feature of clinical guidance for mental health work. Perhaps the clinic is not the place for such issues to be addressed. What this means for me and others who study and train to become capable in providing help to those who experience distress as a result of such problems I hope I am offering a hint at. I know that I am hereby stating my objection to

the governance of mental health practitioners by the Nursing and Midwifery Council (NMC), who seek to increasingly genericise nursing, as well as the abuse of research money by psy professions whose focus is blinkered by professional concerns. I can categorically say that I have found in hoarding and the response offered by the APA and NIHCE the distilled essence of my uneasiness about my profession.

Why not go with the advice of Butterworth's (2017) report and McKeown and White's (2015) call and establish a professional body for mental health nursing that acknowledges the sense of identity associated with the profession, much like the Australian model described by Barker and Buchannan-Barker (2011). Beyond this, why not even consider the possibility of leaving behind the moniker "nurse", which I consider to inadequately convey the uniqueness of mental health work.

In 1980, during the development of DSM-III, the reliability of every category of mental disorder in the two previous versions was found to be unsatisfactory. In attempting to produce a legitimate new edition, a huge statistical fraud was perpetuated. Scientific evidence for the physical existence of mental disorders is still nowhere to be found. Allen Francis, chair of the DSM-IV committee has openly commented on the lack of evidence involved in the diagnostic process of selecting for that edition (Allen, 2014).

What we are left with is a list of forms of social deviancy (Becker, 1997) which may move with current fashions (Herring, 2014). Cohen (2016) offers the example of the removal of homosexuality from DSM-III which was achieved not by some weight of scientific evidence but lobbying and protest both within the subdivisions of the APA and from interest groups outside. Cohen (p. 11) calls on all social scientists concerned with mental health to avoid psychiatric discourses which lack scientific basis, but I see this as something for all mental health researchers to think about. How can we continue to proceed from a position as if it were fact, when in fact it is not? Critical theory has been forgotten in sociological explorations of mental health, says Cohen. Well, it doesn't get much of a look-in in mental health nursing research either. We have to look to mad studies to offer us suggestions for how to proceed here, as mentioned in the conclusion.

So now what? I don't wish to continue to turn out practitioners who do not question what they are asked to do or why. But I do want to help to promote greater depth of critical thinking in those same people. But I can only do that by being a part of a system of training which is characterised by the problems listed above. What's the answer? Fight! Cohen notes that the many mental health professionals he has come across are by and large pragmatists, concerned with practicalities and sceptical of the usefulness of theory. So, fight

one is for the minds of student nurses. To promote and challenge and provoke critical thinking based on an understanding of theory. Fight two is for the identity of mental health practitioners to assert itself by giving up the earnestness associated with nursing:

“A recovery-oriented, autonomy-enhancing approach requires us to relinquish whatever power we have, and to find ways of giving more authority to the consumer.”

(Bentall, 2009 p.287)

As Bentall (2009) has argued, tribalism in mental health services must end and the power mental health practitioners hold must be relinquished in favour of a genuinely collaboratively approach to services if we are to avoid the pitfalls of previous (and current) paternalistic attitudes. In the patient’s opinion therapeutic alliance may be the most valuable and potent ingredient in mental health care (Bentall, 2009 p. 249). I see this and I am struck by the use of the word patient and how it restricts the meaning of this finding by situating the people implicated as “ill” and “well”. What if we were to say that relations between people will be more beneficial for those involved if they are entered into from a position of belief in a beneficial outcome. All interactions.

“Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness [here I would suggest it is more appropriate to insert “problems in living” – in fact, I would perhaps say that the sentence is complete at the word “grows”]”

(Anthony, 1993 q. Bentall, p.266. Additional comment mine)

“Good relationships, it seems, are a universal therapeutic good, and may yet turn out to be the single most important ingredient of effective psychiatric care”

(Bentall, p.260)

Impersonal interventions based on reducing or increasing numerical indicators of clinically defined “recovery” are not for the benefit of individual people. They sanction coercion which has damaging effects on people and relationships, perpetuating or triggering isolation, mental distress and mistrust. In addition, Bentall notes, coercion proceeds from the notion that professionals know what is best for patients despite the historic evidence of harmful treatment and the current lack of evidence for the existence of the disorders for which these coercive “treatments” are being delivered. Lukes (2004) refers to autonomy in terms of freedom from coercion. Bentall (2009) reminds us that this autonomy is a principle of medical ethics.

It may be noted that there is a distinct bent to the lines of argument proposed here. They are indicative of where I find myself now. To take the view that I will not approve of certain

movements in society or in mental health nursing but I will not register my disapproval is simply a vote for the status quo, in spite of its unacceptable nature. And when I say unacceptable, I mean scandalous. The need for movement in mental health has never been more readily trumpeted or taken up, even if the proposed movement may be different according to the background of the proponent.

Through this research project, I have had the space and facility and licence to explore aspects of my personal and professional beliefs which I couldn't before. This introspective approach was instigated by a relational one. My relationship to Tracy as a co-researcher allowed me the space to pay attention to her reactions to me and my reactions to her. In a clinical supervision environment, the focus is pre-determined by the shape and requirements of the service (risk, recovery, safeguarding etc). Here, the reflection on action was able to go beyond this by not being tied to a medicalised model of care. In fact, by not being focused on the delivery of care. Curiosity about experience in a very basic sense allowed enough remove to be able to exercise a deconstructive approach in examining what I was doing in practice and academia. To look at these areas of my existence and myself in them through a lens which went beyond the bounded critique of received wisdom in mental health (Freshwater and Rolfe, 2004)

The ideas I held about mental health nursing had not had time to be explored in depth whilst I was bounded by certain clinical targets and concepts. Free of these, I came to a frightening (initially at least) revelation. Namely, I am not in agreement with the notion of mental health nursing which I am involved in teaching. I had known that I was not interested in delivering psychiatric nursing to "patients" in the traditional system which still operates across the majority of services, but I believed that by entering a sphere of care based on a psychosocial model I could be part of a movement to change this. I didn't experience this. As a result, I thought that by entering nurse education I could challenge the encroaching risk-averse, interventionist clinical culture. The moves towards genericisation of the nursing curriculum and the demands of service providers and students for a more positivist, psychiatry-based model of knowledge is alarming to me. In my work with Tracy, I explored an alternative model. It happened as a result of my latent biases and the explorations Tracy made.

Without the depth of reflexivity employed in this piece of work I do not think it would have been possible for me to acknowledge just how strong and ever-present these tensions in my own ethical and personal motivations were. Taking a personal narrative approach to others must necessitate the same level of scrutiny of the self and whilst the imperative not to "finalise" the other (Frank, 2012) is one which holds promise for mental health research and

practice to develop in exciting ways, offering an alternative to the narrative entrapment described by Grant (2001), it is equally important not to present some glib, “reflexive statement” about the researcher or practitioner which suggests that they will not be involved/affected/implicated. For this reason, the professional title of mental health nurse and its use are unhelpful. They suggest an entity of a particular sort, despite the fact that no consensus appears to exist on what the term refers to (Barker and Buchannan-Barker, 2011; Dixon and Richter, 2017). More worryingly, the term is often construed as meaning the same as “psychiatric nurse” (Barker and Buchannan-Barker, 2011), which carries implications of coercion and social control (Cohen, 2016). Rolfe (2006) has shown us that it is unsatisfactory to announce oneself as a qualitative researcher, either. This phrase offering no degree of clarity as to our mode of operation or purpose.

The answer to these questions of purpose and identity lies in the notion of the craftsman. Mills (1959) offers a means to understand the work of research in such terms which would enable us to fulfil the requirements of Sandelowski (1993) and Rolfe (2006). Mills’ disdain for big grant seeking research (p.103) and management positions makes plain perhaps that one should not expect fame and fortune from the pursuit of honing one’s craft over progressing one’s career. From the perspective of mental health care, Barker (2005; 2009) has long advocated a craftsmanship approach, bringing together elements to construct narratives after the mould of Mills (1959), Barker (2005;2009) and Frank (1995; 2010; 2012) (Grant and Goodman (2017) offer Gramsci’s organic intellectual as a model). I think I like craftsmen because of two related features

1. The commissioning – an artisan is commissioned by another. They are always honing their skills and making a study of their environment and encounters in notes and sketches and models but this not simply for the sheer enjoyment of it, although a love of the craft is an important element of the artisan and drives this endless development and refinement (these words suggest a linearity I find only partially correct, it is not simply that the artisan gets better at their thing, they discover new ways and ideas for expanding the repertoire and sustaining continued involvement). But this work is ready to be called forth by the commissioner (an unfortunate word in healthcare, perhaps, or an apt one). A need is brought to the artisan for something they can provide that others cannot. The skills and experience are brought together with knowledge of the commissioning person to create something bespoke. Different artisans will develop their own way of working, preferred medium, approach to commissioners and individual repertoire of skills. Slowly, attentively and with care and pride, the commission is carried out.

Another commissioned service I am reminded of here is the private detective (possibly because it so appealing aesthetically to me) or a taxi driver. Perhaps the problem with all of these analogies is the apparent passivity of the commissioner. That doesn't do justice to the effort, bravery and brains brought to the project by both parties.

2. The guild meaning

(a) A medieval association of craftsmen or merchants, often having considerable power. So great responsibility, too. The responsibility to stand up to depersonalizing interests which threaten to harm the people we are commissioned to serve. These interests may be those of other professions or those of larger institutions. But the power lies in the guild, together. People who use services and people who provide them, as a collective (McKeown and White, 2015; McKeon, 2018)

(b) An association of people for mutual aid or the pursuit of a common goal.

Here is an often-unspoken aim of our professional identity and affiliation. I am not thinking of the taken-for granted selfless angels helping the unfortunate common goal but the goal of increasing our influence. When I think of "our" influence I refer to the collective group of people involved in mental health services. Mutual aid, the development of knowledge and resources to help each other to improve and attract greater commissions, troubling existing power structures.

(c) A group of species that have similar requirements and play a similar role within a community. This sounds like a description of our band of artisans, too.

In the privileged position of PhD candidate, for the first time, a person came to me with a problem and I was obliged/licensed to say "I have no answer for that and the answers there are cannot be guaranteed to be of help" This felt liberating and ultimately appears to have had a similar effect for Tracy, whilst offering neither of us a sense of ease:

The crisis of representation in social science which the development of autoethnography and other forms of research might be likened to the crisis of explanation evident in mental health practice following (perhaps even before) the publication of DSM-5. Alternative forms of practice which respect persons such as Open Dialogue and the Soteria network called out to me as a practitioner. Alternative narrative frameworks for understanding distress are being made available (Johnstone and Boyle, 2018). The message of respectful negotiation and patience rang true and in them I found the expression of the way I wanted to practice. What would the research equivalent of these be? Patient, quiet and reflexive forms of inquiry

which challenge assumptions. And what kind of practitioner is needed to carry out this work? Must it be a registered nurse?

Goodman and Grant (2017) call for nurse educators who employ the sociological imagination in their role as organic intellectuals (Gramsci, 1975), unconcerned with the bureaucratic obsessions of academic life. I find this message calls to me as a mental health nurse academic dismayed at the absence of identity and attachment to restrictive and coercive practices in prospective registrants on our course. A lack of familiarity with non-medical understandings of mental health among the staff group and an overly-generic curriculum which prioritises interventions over interactions and holds up a model of evidence-based practice which offers little to mental health services or service users due to their being given little if any consideration.

Grant and Radcliffe (2015) describe the ways in which they resist this pervading culture of “education as usual” (which Grant has rightly, in my view, observed as being more akin to training). Grant contests, argues and resists with intellectual depth from a social sciences position whilst Radcliffe operates from an artistic viewpoint, using fiction to raise essential questions and contentious issues. Both acknowledge their marginalised position within their institution and the discipline more broadly, despite the academic respect their work attracts.

They call for curricula which promotes “professional artistry” grounded in critical reflexivity against the current technical rational (Schön, 1983) agenda which packages up model problems and technical solutions that:

“...fail to adequately address the skilled nursing knowledge and related practices needed by students to help them engage in the messy and complex identities, relationships and life and treatment environments of contemporary mental health service users.”

(p.817)

In addition to this increased need for engaged reflexivity there is a need for resulting action (Goodman and Grant, 2017). Knowledge of the social and economic conditions for the development of mental distress requires intervention. As mentioned above, biological causation for mental distress has yet to be determined and Wheaton (2001) has offered us a better use for the psychometric tools currently employed in the labelling of individuals found to be mentally unsatisfactory through their proposed use as measures of quality of life. Taking these as a cue for interventions turned outward, to face those larger factors rather than inward, toward individuals has to be the purpose of mental health nurses (if we must retain the title, and we must at least for now although I do prefer “practitioners”).

Grant also talks about his hybrid identity as a resource for teaching and writing. Historically, mental health nursing has drawn on a rich diversity of recruits from a breadth of backgrounds which inevitably inform the kind of practitioner they will produce. A critically reflexive focus for teaching allows for development of learning by example, how to bring your lived experience out into your work and how to manage or express aspects of that experience which can impact on practice and research safely.

This is all very well here on paper, paraphrasing others, but what will happen when this work is reviewed and when bits of it are (hopefully) published? I am after all only one member of a team of six (and a part time one at that). Will I be a “novelty”? Possibly. I already occupy that position to some extent. The brevity of my clinical career is cited as evidence of my lack of something (experience? Of what? Knowledge? Of what?). My position is taken for arrogance by some owing to this lack. I don't really think it requires decades in practice to see the violations and injustices being taken as necessary acts of care for what they are, although I do think it wouldn't take very long to become accustomed to this view and then not to even see anything at all. To just hold forth the view so often aired that simply by having a job, you are infused with the qualities of patience, kindness and warmth (Grant and Radcliffe, 2015). I don't want to get to that position. I don't want to be cosy with practice as long as practice is so injurious and arrogant. But I don't want to leave it at that, either. I have been made to reconsider my original motivations for wanting to come into teaching (and it was teaching, I had not even considered research at that point even if that is now as exciting a prospect as teaching). I wanted to take the ideas and practice I found so attractive and well-regarded by service users and their families (despite the dismissive and even abusive attitudes and comments of practitioners in other areas of the mental health trust I worked for) and inspire students to try them out and take them up. The tension here is of course that in order to do this I have to be a part of the machinery, as mentioned above. But now I have some examples of strategies for navigating this path and the knowledge there are others (few, perhaps but they are there) of the same view. Conversations with colleagues have proved heartening on occasion, too.

I propose a slow approach to mental health nursing and mental health nurse education and research. In direct opposition to the health research model which clamours for practical application even before publication and the Research Excellence Framework push for more publications in more self-fulfilling journals. Recovery is business best allowed to be conducted at the pace and in the space of the individuals concerned. No reference there. Just an observation. Allocating an arbitrary length of time for the “achievement” of recovery in mental health or problems in living is sheer folly for all of the idiosyncratic reasons elsewhere in this thesis. Demanding that a piece of research be completed in a particular

timeframe only makes any sense in the eyes of the paymasters. Insisting that a set number of hours spent in practice will turn a student into a proficient preceptor is equally nonsensical outside of monetary considerations. All of these things take time and space to complete in varying degrees for each case.

One possible way of thinking about research and practice which might benefit here is “slow”.

The slow movement began with food, as did my involvement with mental health services. Adams, V. et al (2014) draw parallels with the slow food movement in their call for a slow approach to global health research, citing the need to celebrate the local, reappraise what is already there, resist anticipation, favour knowledge over information and allow an iterative process to take place. In a statement which reads not too dissimilar to some accounts of autoethnography, they suggest that instead of following “top-down” models which have tried to establish universally applicable models and interventions, the local, situated beginnings of slow research take account of the understanding of health

“...are found in the often-incalculable mosaic of evidence.”

(Adams, V. et al, 2014 p.181)

Wheaton (2001) offers such an explanation for mental health as a unique experience significantly influenced by the interpersonal reality (Goffman, 1959; 1974). Wheaton (2001) surmises this as being:

“...the reality formed by the aggregation of all our interpersonal experiences in day-to-day life, including not only role enactments but also the casual contacts of day-to-day life, and the observation of others we are privy to by virtue of our social location defined by status, place, and history.”

(p.231)

Running a quick and dirty search for “slow research”, I found plenty of science and health literature but when I searched “slow mental health research” all I got was a catalogue of woes about the pace of change in mental health. I am as upset as the next person about the state of mental health care, but this will only change if we take a careful look at the kinds of research we are engaging in and the narrow set of influences allowed to impact on this. Time mental health research (and care) looked carefully at its aims and the means it employs to achieve them. Do we understand people better by surveying survivors of suicide or conducting trials of forced feeding?

Wheaton (2001) offers a suggested trio of increasing regulation, mistrust and labelling in everyday life as potential contributors to reported increases in mental health issues (p.231). By occupying a position outside of health disciplines with a breadth of theoretical resources

and without a focus on practicality, he argues, the sociologist of mental health is best placed to do theoretical work which challenges the implicit assumptions of much mental health research and can inform our understanding of and approach to working with, mental health. Janesick (1994) makes mention of the need to displace the dominant psychological influence in education research with its psychometric orientation with a flexibility more suited to the human work she engages in (p.46). To this end she suggests an *interdisciplinary triangulation*, broadening understanding of our subject of investigation by invoking other disciplines. From the comments of Wheaton above, I think this is a welcome suggestion for a discipline as liminal as mental health, sitting as it does between so many other spheres of influence and always at risk of appropriation by one or more of these. This then returns me to Mills (1959). The intellectual craftsmanship described in his essay of the same title sits with the craft of caring described by Barker (2008) and the storyteller's craft described by Frank (2010), offering a means to a way of understanding mental health as a sphere of life understood as evidence based but not generalisable. A different form of evidence originating in a different epistemology. Ontologies are only helpful here as locally understood.

With respect...slowing down to listen carefully to the stories of others and pay attention to our own influences may improve the quality of research in more meaningful ways than considerations of rigour based on lists of criteria can offer. It may also open up minds to more inclusive ways of working. Whilst I can only begin to strive for such an approach at this early stage in my career and whilst I am aware that there will be many obstacles I am not yet familiar with, I have identified a motivating and defining focus for future work in researching problems in living and elsewhere.

Given the origin of the suffering of so many of the people encountered by mental health services and researchers, an acceptance that silence in matters such as poverty, inequality and coercion is ethically unacceptable and silence on these matters amounts to complicity on their perpetuation has to bear weight. The professionalisation of research ethics risks estrangement from the real-world setting and issues encountered by participants. Ethics as a starting point for research initially and regularly discussed in conjunction with those involved in the research is not quick but it will add rigour and value to the work. It may be helpful to constitute ethics committees for specific projects based on the mode of research and the issues involved. Particularly valuable may be the introduction of lay members of the ethics committee who are directly affected by the research or topic of research. In addition, people recruited to studies could be invited to talk through their concerns with the committee, not through a set of contact details on the information leaflet but explicitly by invitation from the committee, through diverse and accessible modes of communication.

Look, too, at the messages we send the public. We tell them that there are curable diseases of the mind, which just need the right treatment and all shall be well. Never mind the context in which this is delivered. A sociological understanding is essential to mental health nursing as much as, if not more than, a psychological one. Theology, philosophy, sociology, mental health nursing, and other points less observed here triangulate in me. The broken bits, old newspapers and plastic tat and polished brass plaques.

“...reassembly is as much about change as continuity” says Frank (2010, p.92) and this brings my mind back to Phil and Poppy Barker (2005) and their notion of reclamation – take the bits and make something new and that is definitely craftsmanship, as advocated by Barker (2009), Mills (1959) Frank (2010), Rolfe (1998) and the majority of the authors you have encountered here. And so, I am a crafted craftsman (I still prefer artisan – non-gendered). I find my identity; unfinalisable. I work with what I have; the resources to hand and in my stock to produce something for which I am commissioned by an activating interest or need. I step off the train and I am home, apprenticeship completed, perhaps, but always becoming.

Chapter 8 Rigour and postmodern scripts, limitations

I am sat in the office and above my desk is a checklist for trustworthiness in qualitative research developed by Lincoln and Guba (1985), a copy of which I give to students to help with critiquing papers. In addition to this, I can be heard intoning these standards from a recorded presentation as part of a postgraduate course. Thinking about this thesis, I have credibility covered, I think, but it could be better. A reader could find the means to transfer the findings to familiar people and scenarios, certainly. Many have reported resonance with their own experience. There is, I think, a discernible audit trail in there. And there is undoubtedly an active and ongoing reflexive process. Great. Pass. So why do I feel that it could be so much more? Well, I think I have an answer for that (months later). Having found my place, my bedfellows, if you like, I see how Lincoln and Guba doesn't match up with the postmodern perspective which underpins the research. In effect, they are still looking for certainty when I am offering uncertainty.

Hammersley (2000) claims it is not possible to do research from a "critical perspective" (which he defines as one of understanding society as fundamentally unequal and the task of research as questioning dominant ideologies and exposing injustice) (p.134). The researcher must be "analytical". Hammersley insists that asserting the incompatibility of qualitative methodologies with a single benchmark for assessing rigour implies a more lenient approach to critique with regard to qualitative studies. For me, Rolfe (2006) has offered us the answer here, as has Sandelowski and Barroso (1993). Hammersley claims that criticism of "methodological purists" (2001, p.131) (himself and his student) is that they set standards for validity too high. It is impossible to "relax the standards" for validity as this will diminish the line between the findings of research and lay interpretations of the same phenomena (p.132). He seems to think that parity here will result in the reduction in value of academic research to such a point that funding it would be unjustified.

This is a deliberate misreading, as far as I can see. Funding is perhaps not the reason for doing autoethnographic or other forms of critically grounded research. And does the need to attract funding influence the objectivity of research of all types? In addition, look at the direction research has taken; more collaboration on deeper levels and more accessibility and participation. Parity for different forms of research does not equate to parity for "better" and "worse" research due to their being assessed differently if they have different aims.

In ethnographic research, Hammersley (2000) notes, the researcher is at risk of becoming overly involved in the point of view of particular participants, inheriting their biases as a result (p.153). Maintaining detachment in the researcher is increasingly unfashionable and

unachievable, Hammersley argues (2011, p.5). He warns the danger of reflexivity in pursuit of a “fully transparent” account of the researcher risks undermining the purpose of the research altogether, resulting in a “personal perspective on the part of the researcher, or a contingent co-construction with the people studied” (p.38). In a conversation with Sara Delamont in 2017, she advised me to pay specific attention to scaffolding of insights and theories in this work as a response to such criticisms, which she herself has made (Delamont, 2007). Maintaining a credible position through this project has been difficult, bringing feelings of disloyalty to Tracy and inauthenticity as a researcher by turns but the implications for me of the discoveries made should not be ignored or hidden, I believe. By offering this account, I hope the reader will find issues which resonate. Particularly mental health practitioners, researchers and people who have had contact with them.

Despite asserting that the term has become an instrument of social control through its strict positivist interpretation, Heron (1996) stresses the need for the term validity to be retained in collaborative research in spite of post-structuralist calls for its abandonment (Rolfe, 2006). In fact, Heron describes this idea as “suicidal and nihilistic” (p. 158). Whilst he finds fault with Lincoln and Guba’s (1985) modelling of trustworthiness in qualitative research against positivist criteria, he sees no merit in their collaborative revision (Lincoln and Guba, 1990) of the model either. For Heron, the problem is the appropriation of the terminology by one specific form of research for political interests. To this end, he proposes:

“The challenge after positivism is to redefine truth and validity in ways that honour the generative, creative role of the human mind in all forms of knowing.” (p.13).

Rolfe (2006) offers the suggestion that there is no merit in trying to apply a universal set of criteria for assessing rigour in qualitative research because there is no such thing as “qualitative research”, the breadth of methodologies and epistemologies covered by such terminology rendering the exercise impossible and meaningless. Rather, as suggested by Sandelowski (1993), each research report should be judged by its own validity according to its readers. Derrida (1976) suggests each text is an assemblage of previous texts which can be deconstructed, producing a further text. As Laurel Richardson (2000) points out, research papers like any other text, are forms of literature, attempting to create reactions. Rather, she offers these criteria for reviewing social science papers for publication which also offer some means of determining validity, reliability and truth for Kim Etherington (2004, p.148):

1. Does the work make a substantive contribution to my understanding of social life? Does the writer demonstrate a deeply grounded social science perspective and demonstrate how it is used to inform the text?

This work has done something no work in this area has done before. It has gone with a family member of a person with a compulsive hoarding problem and has reported the experience of seeking help from their point of view and the narrative influences upon the actions taken. It has attempted to keep attention focussed on these narratives and away from the individual case in the hopes of providing a new way of understanding help-seeking. In addition, this work has offered an autoethnographic response to this in its effects on a clinician-turned-researcher seeking to be helpful and finding the resources narrowed by dominant discourses. Learning and growth has been a mutual experience.

In discussing these issues through a lens of social construction, indicated by Gergen (1999; 2001; 2010) as involving deconstruction, issues of power and the generation of knowledge, this work questions how certain dominant discourses make available limited resources for understanding and storying needs whilst silencing others.

2. Does the work have aesthetic merit? Does the writer use analysis to open up the text and invite interpretive responses? Is it artistically shaped, satisfying, complex and interesting?

The construction of this report has been contentious at times but has always sought to provide an engaging and rewarding piece of work to read despite my limited writing experience. This makes a demand beyond the already present demands of a doctoral thesis in health. Criticisms of autoethnography are (amongst others), it's not art, it's not science, not rigorous, theoretical or analytic enough; the writing is too emotional; there is not enough fieldwork; it produces biased data and is self-indulgent. This is a fine line to tread for a novice.

Ultimately, this piece of work is an assemblage of words. Words have a problematic historical position in ethnography, dominating the world of experience by imposing a scientific detachment (Denzin, 1997 p.16, citing Conquergood, 1998). But as we have said in chapter four elsewhere, "this is not science". Can the way the words are assembled, the "voice", the format, even, change the way they are read? Doesn't it rather depend on the reader and the context within which they are read? Barone (2008) suggests creative uses of non-fiction writing as does Richardson (2000) as a means of conveying the uncertainty of constituted voice.

The two-step analysis process hopefully offers resources for interpretive responses in an ongoing dialogue about where help comes from and what form help should take in cases of compulsive hoarding and in other problems in living. It is also hoped that by questioning the prescribed routes to understanding problems in living and developing responses, a dialogue

can be instigated about the role of people who work with and research these aspects of life which are commonly referred to as “mental health”.

3. Is the work reflexive enough to make the author sufficiently visible for me to make judgements about the point of view? Does the author provide me with evidence of knowledge of postmodern epistemologies that convinces me of their understanding of what is involved in telling people’s lives? Am I informed how the author came to write the work and how the information was gathered? Have the complexities of ethical issues been understood and addressed? Does the author show themselves to be accountable to the standards for knowing and telling participants’ stories?

Validity in co-operative inquiry comes from the employment of “critical subjectivity” a “self-reflexive attention to the ground on which one is standing” (Reason, 1994 p.327). Our regular contact allowed us to reflect together and share insights from periods of reflection in solitude. Excerpts from my own reflexive diary are threaded throughout this chapter with the aim of providing a transparent and auditable account of the process. Unfortunately, this does not represent the totality of reflexive material and the maintaining of the diary was at times sporadic. My co-researcher was not obliged to keep a reflexive diary, which in hindsight would have been a welcome addition in promoting validity in the specific context of this project. However, this would be a demanding request.

The risks of co-operative inquiry are unaware projection – allowing our anxieties about matters we care deeply about to influence our perceptions and judgements and consensus collusion – a form of groupthink in which the researchers collectively and subconsciously ignore or gloss over factors which do not confirm their ideas. Reason (1994) suggests that the process of cycling between action and reflection has developed as a counter to this. To some extent (although not as methodically as is suggested from a reading of Reason’s account) this process was employed.

Steier (1991) also claims that there is no escaping the self – the “I” in research. Reflexivity, then, is essential in recognising the construction of the self and this process is necessarily ongoing as the self is continually being constructed “We are talking about a circular process, in which reflexivity is the guiding relationship allowing for the circularity” (p.2) There is a necessary transparency to be employed in acknowledging the object of the constructions employed at any one time in the interest of honesty and (in the situated sense used by Rolfe, 2006) rigour.

4. What is the impact of this work on me? Does it affect me emotionally, intellectually, generate new questions, move me to write or respond in any other way?

Ellis et al (2010) offer a description of varying types of autoethnography, from the least to most involved. This project moves between them at different stages in response to the requirements of the project and protagonists. Perhaps the typology is unhelpful here as there are not step changes at which one would say “now I will move from collaborative witnessing to a more layered account approach”. The movements are more subtle and intuitive. A reader with a particular strong sense of the delineation between types of autoethnographic account might see the text in terms of a series of different approaches, whilst another might see one piece of writing adapting and bending in response to the purpose of the text in that particular place, this being an aspect of the intuitive design of the whole thesis. And this isn’t the only scale upon which the project slides. Leroux (2016) identifies two extremes of autoethnography, at either end of sliding scale. At one extreme is evocative work, marked by vulnerability and aesthetic focus whilst at the other is an analytic approach grounded in realism with an objective focus. This last has been decried by Ellis and Bochner (2006) but is seen by Delamont (2007) and Atkinson (2006) as being the only way of achieving some form of credibility for the approach.

5. Does the work provide me with a sense of “lived experience”? Does it seem to be a truthful, credible account of cultural, social, individual or communal sense of what is “real”?

In this last criterion, I see a problem. The context from which one looks for seemingly truthful accounts will be unique to the reader (Frank, 2010; 2012) and this means that individual experiences will differ. The idea that there is a fixed sense of what is real is incorrect as is the idea of one person being able to grasp another’s sense of what is real. It reads as anti-constructionist. Grant (2014) has highlighted this as a recurrent problem of much qualitative research. So how to proceed here? O’Byrne (2007) states that in mixing methods it is important to consider the paradigm. A reflexive autoethnography (described as one in which the researcher reflects on personal experiences, reactions, emotions, and thoughts as they relate to his or her own or a foreign culture (p.1383)) can be employed alongside postmodern ethnography owing to a common foundation in critical theory (identifiable by a focus on critique, transformation, emancipation and political involvement of a minority). Whilst this paper predates the fourth edition of Lincoln and Denzin’s handbook (2014) with its inclusion of the “fifth paradigm” of participatory research, it serves as a useful benchmark and a reminder that the methods employed in this thesis must unite under one umbrella. And hopefully this has been demonstrated. Narrative, collaboration, reflexivity and ultimately autoethnography together combining in a critique of the understanding, practice and research of mental health through a shared point of origin in social construction.

“...the postmodern ethnographer intends to allow the voice(s) of a marginalised population to be heard rather than to speak their words for them while recognising that this is not entirely possible”

And that

“...patterns do not exist outside the research setting...each difference is different from every other difference.” (O’Byrne, 2007 p.1386)

In the light of this, generalisability is anathema and validity only makes sense in the light of the individual research project or paper. Triangulation employed in the interest of more accurately locating “truth” has little value in this system. O’Byrne argues that in the light of the realisation that there is no objective truth to be discovered or approximated, the idea of mixed methods becomes anathema, too. I would argue that in fact, it is the careful demarcation between methods which becomes anathema. The endless subdivision of subdivisions into more and more niche methodologies. All that remains to do is to report faithfully and accurately the course of the research (Rolfe, 2006). In fact, working within this model, there should be adaptation and improvisation based on the unique nature of each inquiry both through its subject matter, setting and those implicated. This is now beginning to make my point again (which is also Mills’ point and Rolfe’s point and Grant’s point). We need to be intellectual craftspersons (I will herein refer to “artisans” as it sounds less clumsy and is gender neutral).

O’Byrne (p.1388) suggests that a group of interest might “adopt a researcher”, thereby producing two kinds of study data – ethnographic study pre-adoption and autoethnography post-adoption (as the researcher is now a member of the culture under study). As mentioned in chapter six, Frank (2012) has stated that all research begins as ethnography. In the case of this thesis, this adoption of multiple methods to consider the same issue from different angles has been displaced by a reflexive autoethnography on the broader implications of discoveries made as a result of an initial collaborative project evolving intuitively as it progressed. The advantage reported by O’Byrne of allowing the researcher to observe externally and internally the same culture still holds true. The similarity to Reason’s (1994) self-directing persons is evident in the quote following:

“...researchers are the tools of research and thus construct their findings, which, in turn, allows them to act in two different roles simultaneously.”

The difference here being that O’Byrne is only considering “the researcher” in this regard, whereas Reason (1994) and this thesis acknowledge the ability of both (or all) implicated parties to occupy this dual role. Thus, reflexivity is available on a scale impossible within

what Heron (1996) and Janesick (1994) refer to as traditional qualitative research. Reliability, for Ellis, Adams and Bochner (2010), is judged by asking the question “could this really have happened to this person?” (para. 34). Validity is measured by examining verisimilitude and usefulness (*ibid.*). Generalisability equates to “does story speak to readers about their experience or that of those they know?” (para. 35). These questions, I would suggest, are much the same as those posed by Richardson above.

Le Roux (2016) offers her own synthesis of previous guidance on rigour in autoethnography which she claims reflects concerns of both analytic and evocative autoethnographers whilst avoiding the trap of trying to align postmodern methodology with “theory-driven, analytic research” criteria. She identifies:

- Subjectivity
- Self-reflexivity
- Resonance
- Credibility
- Contribution

Le Roux (2016) states that checklists are no substitute for “informed judgement”, but where that judgement is not as well informed (such as in the case of someone doing this for the first time), they are useful. As can be seen from the list here, her recommendations are again much the same as Richardson’s above.

It should also be considered what the purpose of this text is. In reporting our experiences of seeking help for compulsive hoarding and then in response talking about my own identity as a mental health nursing lecturer, I am not seeking to produce a piece of practice guidance. I am speaking to research and practice in mental health by raising questions which have become apparent through this process. These include but are not exclusively how we address the concerns of families and carers, how we engage with evidence based practice as it is exemplified currently within a biomedical model of nursing and how we respond to societal issues affecting mental health. Whilst I offer some ideas for discussion around how we might address these as mental health workers, they are not meant to be “answers”. Sandelowski and Barroso (2002) suggest that research in nursing should be easily and quickly digested by readers in practice and academia, to best be able to apply the findings of that research. This work resists this notion and calls for a slower reading and digestion. Something which would be better applied to all research papers regardless of the neatness and clarity of their scientific reporting.

“A critical reflection, based on a sceptical practice, is thus less a technique and more an ability. It is the ability to live in uncertainty and doubt, whilst simultaneously not being paralysed by that doubt.”

(Freshwater and Rolfe, 2004 p.195)

Conclusion

This thesis has sought to report the experience of a researcher reporting the experience of a co-researcher and the repercussions for each of them in searching for answers to questions around compulsive hoarding, identity and purpose. Narrative, collaborative and autoethnographic methods have been employed in an intuitive and iterative bespoke approach to best meet the emergent needs of the research.

A review of the cultural and academic literature (in the broadest sense) on hoarding, revealed competing narratives with an emergent dominant story of mental disorder which appears to have been embraced by many despite a lack of evidence. It seems families possess a sense of urgency driven by concerns over safety and a lack of time which produces conflict through desperate attempts to normalise and contain the behaviour and possessions of relatives who do not have the same view and experience extreme attachments to these possessions.

An attempt to explore the family experience of hoarding in real time using arts-based methods with a family group proved to be impossible to recruit to in the time given, possibly due to the demands made of potential co-researchers or due to the overly strict sampling criteria. However, family experience and help-seeking came together in the meeting and co-conscription of one family member struggling with her mother's possessions and affairs. Our attempts to raise awareness of the need for improved local knowledge through campaigning did not raise the funds hoped for but we have made an impact with people locally. Further applications for bigger grants have followed and others will come in the future but the process of seeking help in this way provided another result for us in the form of a repositioning and re-evaluating of our understanding of compulsive hoarding and how important it should be in the lives of relatives of people with hoarding tendencies.

A reflective examination of our experience followed by a dialogical narrative analysis of the stories we employed in our mid-campaign conversations suggested four narrative types which interacted with each other in the telling those stories. By exploring this repertoire, it was possible to expand it. This enabled new stories and new identities to be conceived

without the hoarding necessarily being such a dominant distinguishing factor. It was even possible to conceive of certain desirable qualities and values being exemplified in some instances.

The results of this process raised questions as to the usefulness of the emergent dominant psychiatric discourse around hoarding. There may be better ways of understanding this problem which opened up the means to work more creatively and responsively based on our research experience. This realisation triggered another realisation. As a mental health nurse and academic, the purpose and nature of my profession was troubled by this. I initially did not want the project to end, then wanted to steer it toward creative projects, possibly out of a fear of being typecast. I explore some ideas about how to carry on from here as a person very much enamoured of his profession whilst finding some of its connotations and affiliations objectionable.

We have meandered and traversed our way through a number of permutations to arrive at this point. Many questions have been raised and we have learned a few things, too. We have added to the catalogue of stories about compulsive hoarding. And one more story about mental health nursing professional and academic identity. Hopefully these will serve as a resource for others, having a resonance for some and raising questions for some. Accounts such as this are not intended to be generalised but are unashamed in their uniqueness and proud to be “anecdata”, as some would have it. Rather than identify the root cause of problems in living as some deficit in the individual, common to a group in society, the society itself is seen as the point of origin for these problems. Potential resolutions are constructed through the interaction of involved parties exchanging stories which allow an expansion of resources for creating new and more rewarding stories, from which spring the tools for addressing the vulnerability and anxiety which mark human existence under neo-liberalism.

There are various messages on offer here for researchers, service providers and people with hoarding in their lives. For one, flexibility is essential in researching human experience in the real world in collaboration with those whose experience of the world we seek to understand. This requires a tolerance of uncertainty in the researcher and the researched (and the institution) which is not common to health research but (with the development of adapted trials) is perhaps becoming more acceptable. In this research, recruitment was a mutual process, occasioned by much searching and networking but in the end requiring a willingness to be “conscripted” without fears over objectivity. Considerations of methodological purity or rigour could have produced an incomplete account of the experience.

Co-production is a current obsession of health researchers but its application is perhaps not what it could be (Beresford, 2014). In the sphere of mental health, a model for more democratic approaches to research is offered by mad studies. Beresford and Russo (2015) and Hart (2018) suggest better ways of conducting these projects. This model troubles the “expert” position of mental health nurse researchers only if those researchers see a need to be perceived as scientific observers of objective empirical others. If the suggested social constructionist approach is applied, then all are involved in the production of new knowledge, which may answer Rolfe’s (1996, 1998, 2012) demands for practical applications from research as a particular requirement in nursing research. This work has suggested a partial and early move in this direction with some unexpected revelations.

By undertaking a shared approach to dissemination, the suggestion and notion of ownership of the research has been shifted in this work. Presenting at an academic conference as a pair of co-researchers, (rather than a researcher and an expert-by experience) contests the idea of the final say of a single author and may offer an answer to the imbalance posed by academic publishing and internal and external peer review processes. By teaching students of mental health nursing and social work using the same means, we are able to offer the opportunity for students to ask questions (and receive answers) about both hoarding and taking part in research which would be much more difficult otherwise. To take this further, the aim is to publish jointly authored work. We also have a Facebook page which was established during the research but underused. We plan to use this to generate debate by sharing our insights to stimulate debate around hoarding. Both Tracy and I have administrator roles on the site. Our intentions to produce artistic work which engages wider public in debates about hoarding and possessions is still on the agenda, too. Last year, I worked with a local textile artist to produce a bid for grant funding for a project situated in Sarah’s charity shop. The year before, Tracy was part of a larger group which assembled a bid for research funds to investigate service provider experiences of working with people with hoarding tendencies.

In using autoethnographic means to explore and report mental health research, I hope I have offered something authentic and honest which sits alongside work by Short (2012; 2013) Grant (2010; 2013), Turner (2012), and a host of others in increasing understanding of experience and ethics in mental health. Presenting work from chapter 6 of this thesis at the British International Autoethnography Conference 2018, it was notable how prevalent the theme of mental health was, not only in the existence of a dedicated panel session but throughout all panel sessions. Conceiving of mental health as an aspect of complex human experience and paying attention to interpersonal relations as well as subjective experience in autoethnographic forms of research creates a potential for new forms of knowledge to

emerge and new forms of expression of this knowledge. This in turn may allow for greater reach and understanding of the experience of others and inform the way people interact with each other when experiencing the world and articulating ideas differently. The means to a common language and understanding may lie in such approaches and the implications of this for developing a democratic world of practice in mental health are significant. This particular research project offers one of the accumulating little stories which attest to this new set of possibilities.

I hope that the reporting of a sense of things being out of control at times resonates with readers. Research reports and dissertations and theses are expected to present a neat and tidy report of an orderly process conducted in controlled conditions to produce confident findings. This work offers uncertainty, fallibility, hesitancy and emotion. The tools we have are not finely calibrated scientific instruments and the operators of these tools are still human. And this is good. Thankyou for reading this thesis and I hope you have found things which resonate, things which annoy and things which were interesting to you here.

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Appendices

Appendix 1 – poster presentation of literature review from RCN conference 2014


**UNIVERSITY OF Hull**

Background: It has been suggested that 2-5% of the global population experience hoarding problems. The effect of this on families has been under-researched but evidence suggests that it is highly detrimental (Büscher et al. 2013). Statutory service provision for these individuals is currently scarce and family support almost entirely consists of non-statutory support groups.

How Compulsive Hoarding Affects Family Relationships

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Methods: A rigorous and original three stage literature review culminating in a robust literature search of relevant databases which yielded a total of four texts.



Results: Thirty codes which were merged into four themes.

1. Quality of life: impaired domestic and social life
2. Shattered families: conflict and eventual diaspora
3. Rallying round: attempts to “solve” the “problem”
4. Lack of support: absence of outside help

Conclusion: There is a need to undertake a study which develops deeper understanding of the experiences of the families of compulsive hoarders which can be used to influence the development of appropriate services.

References: Büscher, T.P. Dyson, J. and Cowdell, F. (2013) *The impact of hoarding disorder on families: an integrative review* *Journal of Psychiatric and Mental Health Nursing* [online] available: <http://onlinelibrary.wiley.com/doi/10.1111/jpm.12098/abstract>

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The effects of hoarding disorder on families: an integrative review

Accessible summary

It is estimated that between two and five percent of the population experience symptoms of compulsive hoarding. Recent investigation into hoarding has shown that it is a problem in its own right and is therefore being added to a diagnostic manual of mental disorders.

- This integrative literature review examines the impact that hoarding has on family members;
- The comprehensive literature review spans a period from database inception to November 2012. A search of the databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE) and psycINFO together with hand searches was completed;
- Thematic analysis revealed three overriding themes: quality of life, shattered families and rallying around. These themes illuminate the negative impact that hoarding behaviour has on families and the inadequacy of available services;
- The relative lack of robust evidence about the impact of hoarding behaviour on families suggests that further research is needed in this emergent field.

Abstract

Compulsive hoarding affects approximately 2-5% of the adult population. Increasing recognition has led to its inclusion as a distinct condition in forthcoming revisions to the Diagnostic and Statistical Manual (DSM V). Hoarding behaviour can have a detrimental effect on the health and wellbeing of family members. A rigorous review of available evidence using a novel three stage literature search was undertaken: i) an extensive

scoping review; ii) a traditional search of databases including CINAHL, MEDLINE and psycINFO using combinations of keywords and iii) review of cited references and hand searching of selected journals. Evidence was selected using pre-defined inclusion criteria. Papers included two surveys, one qualitative study and one case study. An integrative review methodology was used to synthesise the evidence presented. Analysis revealed three overriding themes: quality of life; shattered families and rallying around. These illuminated the experiences of family members. These articles revealed families under strain and often at breaking point but with the resolve to pull together if the right support is available. This review concludes that further research is needed to investigate the effects of hoarding on family members and how these may best be met.

Keywords

Compulsive hoarding, families, hoarding disorder, mental health services.

Introduction

Compulsive hoarding is a mental disorder which is estimated to affect 2-5% of the adult population. It is increasingly recognised that hoarding disorder is a distinct condition rather than merely a symptom of other mental health conditions. This has led to the suggestion the hoarding should be included in forthcoming revisions to the Diagnostic and Statistical Manual of the American Psychiatric Association (American Psychiatric Association 2012).

Adding the diagnosis of hoarding disorder to the DSM may be beneficial for people with the disorder in ensuring that they receive treatment but conversely it may add a level of stigma (Illich, 1975) and potentially unwanted efforts from health professionals to ensure ‘social inclusion’ for both patients and families may exacerbate this (Wright and Stickley, 2013).

Anecdotal evidence suggests that hoarding behaviour can have a detrimental effect on the physical and psychological health of family members. However, it is currently a poorly documented and under-researched subject. By conducting a literature review this paper examines what is known about the impact that hoarding disorder has on family members and the implications this has for clinical practice and further research.

Background

Compulsive hoarding is defined as an inability to discard items coupled with a compulsion to acquire large numbers of possessions, an inability to use living spaces for their intended purposes due to clutter and distress or inability to function caused by hoarding (Frost & Hartl 1996). **Whilst there are no conclusive figures, the limited number of studies available**

suggest that in Germany 4.6% (Mueller *et al.* 2009) and in the USA 3.7% (Samuels *et al.* 2008) of the adult population suffer from compulsive hoarding either as a single issue or as a co-morbid problem.

Hoarding disorder can have a significant detrimental impact on physical and psycho-social health and wellbeing of both sufferers and their families. This can include dangerous and unhealthy living conditions, debt, physical illness and other mental illness (Frost *et al.* 2000; Frost *et al.* 2010). Family members tend to engage in negative interventions such as attempting to coerce hoarders into discarding possessions and carrying out covert clean-up operations when the hoarding family member is away from the house (Tompkins & Hartl 2009). These approaches invariably produce resentment and animosity between family members (Frost 2010). Very few marriages survive the effects of hoarding disorder, with the majority of self-reporting hoarders in any study identifying themselves as single or divorced (Tolin *et al.* 2008a). Children and older adults have been removed from hoarded homes due to concerns for their health and safety (Tolin *et al.* 2008a). Some studies have suggested that there is a link between growing up in a hoarded house and developing similar relationships to objects (Tolin *et al.* 2010b). The strength of emotional attachment hoarders feel towards their possessions can even overshadow that which they feel towards their families which has led to separations, divorces and estrangement from children, siblings, parents and other loved ones (Frost & Gross 1993; Frost *et al.* 1995; Grisham *et al.* 2009).

Despite the negative impact of hoarding the provision of dedicated mental health services is negligible. Frost *et al.* (2000) found in a preliminary American survey of complaints about hoarding to local Boards of Health that less than a third of the cases had involvement from mental health services and that it was neighbours, police and fire departments who reported cases to boards of health and local health departments. Whilst in the USA, several states

have developed multidisciplinary hoarding task forces (Bratiotis *et al.* 2011) in Britain there is currently no public body to manage hoarding behaviour although there is a suggestion that attempts are being made to develop one (Hoarding UK 2012). The standard of information and support available through the National Health Service (NHS) is at best rudimentary as can be seen from a search of its own publicly available electronic resources (NHS Choices 2012). A review of publically available internet sources that provide help to families with hoarding members indicates that charities such as Help for Hoarders and private psychotherapists and cleaning companies are left to fill gaps in service provision. This may leave families with the challenging responsibility of caring for hoarding members. In order to uncover the current state knowledge and identify implications for clinical practice and future research an integrative review of the available literature on the impact of hoarding disorder on family members was carried out with the following aim.

Aim

The aim of this review is to examine the available evidence on the impact on families of having a member with hoarding disorder, identify implications for clinical practice and identify gaps in current knowledge highlighting future research priorities.

Method

As there are so few documented studies of hoarding, it was essential to identify all relevant sources as thoroughly as possible.

Scoping

The purpose of the scoping review was twofold: i) to explore the extent of the literature and identify the parameters for the literature review (Armstrong *et al.* 2011) and ii) to ensure that

all the terms used were captured because there is a lack of consistency in the terms used for “hoarding” due to the disparate fields interested in this behaviour.

Scoping Strategy

Initially a “rough and ready” database search using the terms “hoarding”, “compulsive” and “disorder” was undertaken, employing no limiters in order to allow as many varied results as possible to assess the viability of this field for review.

Additionally, key author searches, searches of media materials (written, video and audio) and searches of grey literature took place. A search of the databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE) and psycINFO using the terms “hoarding”, “compulsive” and “disorder” was completed and one hundred and twenty-six results returned. A subsequent search of the same databases for articles with the term “hoarding” in the title returned only 130 hits. This revealed that there was sufficient research in existence to be able to take the searches further, with a narrower focus. In addition, a small number of books were identified on the subject of compulsive hoarding and these signposted other sources of grey literature (Whittaker & Williamson 2011) such as websites, films and more books and research papers.

All the emerging themes were mapped on a spidergram, **reproduced for this article using Inspiration 9 software** (figure 1) which took as its starting point “compulsive hoarding” to allow links between themes to be made. These themes were “hoarding disorder”, “symptomology”, “causes”, “what?”, “responses”, “interventions” and “risk”. A notably recurring sub-theme was the area of hoarding behaviour and families. It was this that led to the formation of the research question: What are the effects of having a family member with hoarding disorder?

Figure 1: Spider diagram of scoping review

Figure 1 here

Inclusion criteria

Due to the paucity of literature about hoarding and the aim of including all relevant work the inclusion criteria were wide. The article had to:

- Be peer reviewed;
- Report, investigate or contain information that is related to the experiences of families living with a member with hoarding disorder.

Search Strategy

A systematic search was conducted using CINAHL, Medline and PSYCinfo. Search terms were derived from the results of the scoping review and included “hoarding disorder”, “hoarding”, “compulsive”, “disorder”, “extreme”, “famil*”, “children”, “partner*”, “spouse*”, “carer*”, “parent*” in various combinations. Figure 2 identifies the numbers of papers found and discarded at each stage of the review. An initial 63 papers were identified and reduced to 20 through discarding articles not relating to families, duplicates, book reviews, general interest articles, articles about hoarding as a symptom of another disorder and letters.

These 20 papers were reviewed in full and 16 were excluded as they did not relate directly to family members in relation to the effects on them of their relative’s hoarding behaviour. Four articles resulted. Citation searches revealed no further relevant articles

Figure 2: Systematic search methods and results

Figure 2 here

Thematic analysis

Thematic analysis was used to analyse these papers with varied methodologies (Whittaker and Williamson, 2011). The six step framework of Braun and Clarke (2006) guided this process: becoming familiar with the data; creating initial codes; searching for themes; reviewing themes; defining and naming themes and producing the report. Codes (a fragment of data which identifies a significant feature of that data) (Braun and Clarke 2006) were identified and grouped together into related themes (Aveyard 2010).

Results

Thematic analysis of the four included papers revealed twenty-three codes; these were amalgamated in three themes and 10 sub-themes that were relevant to the research question (figure 3).

Figure 3: Effects of hoarding on Families: themes and subthemes

Figure 3 here

Details of the included papers are summarised (table 1). A synopsis of each of these is then presented followed by a report of the thematic analysis.

Table 1: Summary of included papers

Table 1 here

Synopses and appraisals of identified papers

Quality review was undertaken using selected elements of the Critical Appraisal Skills Program (CASP 2010) including appropriateness of recruitment method, data analysis, research design and ethical considerations. A brief summary of each paper is provided below.

Wilbram *et al.* (2008) used a phenomenological approach to explore the experiences of people with family members and friends with hoarding behaviour. Semi-structured interviews were conducted with ten people who had relatives with a diagnosis of obsessive compulsive disorder (OCD) hoarding behaviour. Carers were found to be struggling to live with the strains on their living conditions and their relationships caused by the hoarding. Participants reported “loss of normal family life”; “the need for understanding”; “coping with the situation”; “impact on relationships” and “marginalisation”. This study used a self-selected sample which raises the question of how representative of family members of hoarders they were. In this study, the hoarding family member was not present and was not approached to contribute to the study.

A cross-sectional internet survey approach was used by Tolin *et al.* (2008b), to examine what effect sharing living space with a family member who hoards has on respondents. In particular, it aimed to measure the level of rejection the 665 respondents felt towards their

family member. Severity of hoarding, the level of insight exhibited, the age at which the informant lived with the hoarder, as well as the relationship of the informant to the hoarder influenced the feelings of rejection participants expressed. All of these factors were demonstrated to be statistically significant across all family relationships with levels of rejection uniformly high. Children of hoarding family members reported significantly higher levels of distress than siblings and female respondents reported significantly higher levels of relationship strain with parents. Respondents who had lived as children before age ten in moderate to severely hoarded houses reported greater childhood distress and family strain. This study relied upon distressed family members recalling events from a long time ago so recall bias may have been an issue.

Further analysis of the data from Tolin (2008b) aimed to measure the level of insight hoarders had into their problems (Tolin *et al.* 2010a) by asking respondents to rate the extent of their family members hoarding problems and their level of insight then estimate the ratings those family members would give themselves. The results, based on 558 participants, indicated that family members believe that hoarders lack insight into the extent of their hoarding and its effects. This study included respondents who tested positive for hoarding disorder themselves in the sample; they may have been hoarders looking for help rather than relatives completing the survey. Furthermore, the instruments used in this study were all either newly developed or adapted specifically for this study; there is no evidence of instrument validity or reliability.

Tompkins (2011) reports on two case studies of hoarders, the primary focus being the implementation of an intervention for them. However, this paper also offers a detailed description of the impact experienced by the family members. Tompkins (2011) identifies this as including “duty”, “loyalty”, “loss”, “withdrawal” and “isolation”.

Themes

The themes identified were “quality of life”, “shattered families” and “rallying around” (figure 3)

Quality of life referred to issues relating to the mental, physical and social wellbeing of family members. This included three sub-themes “withdrawal”, “isolation” and “sanctuary”.

Withdrawal refers to the retreat of the family of the hoarder from the outside world. A husband describes “keeping [the world] out” (Wilbram *et al.* 2008). Tolin *et al.* (2008b) reported that there is a high incidence of social withdrawal in children of hoarders, especially those aged between 11 and 20 years due to embarrassment about the condition of the home. This is reflected in the comments made by a mother to Wilbram *et al.* (2008) about her son being bullied. Tompkins (2011) describes a case in which the individual hoarder is existing in solitude with very sparse contact with her family (once a year) and apparently no other social network. Within the home, there is also a withdrawal by members of the family into areas of “sanctuary”, free from clutter. One mother mentions her son having a tiny Christmas tree in his bedroom and her visiting daughter and son-in-law eating their dinner from trays in her son’s bedroom (Wilbram *et al.* 2008). Many family members experienced isolation; feeling cut off from the world behind the clutter. Tolin *et al.* (2008b) reported the family burden of compulsive hoarding where there was a significant correlation between living in a hoarded house and not wanting people to visit. Wilbram *et al.* (2008) illustrated one person who avoided friendships in order to avoid having to invite people over. Some agreement with this idea was found by Tompkins (2011) however, this study also reports that relatives had a ready desire to be reunited with their hoarding family members and to help them.

Shattered families refers to the impact hoarding has on family dynamics. This included four subthemes “conflict”, “control”, “loss” and “entrapment”. Conflict was expressed through arguments about clutter, failing to discard and compulsive acquiring. Tolin *et al.* (2008b) found that rejection of the hoarder was highest for those who grew up living with a hoarding parent. Negative ideas about parents were found by Tolin *et al.* (2008b, 2010a) regardless of severity of hoarding, level of clutter or the level of insight; this indicated a lingering resentment. Wilbram *et al.* (2008) found that there had been occasions of verbal assault and possibly physical assault as a result of arguments about hoarding. One source of difficulty is the issue of control. This was found to be experienced by family members when they tried to take charge of the hoarding situation by implementing strategies to reduce the amount of clutter in the house (Tompkins 2011, Wilbram *et al.* 2008). Arguments about clutter were also found to be common by Tolin *et al.* (2008b) exacerbated by the denial that there was anything wrong (Tolin *et al.* 2010a). There can be a loss of relationships and social life for the family members of hoarders. In some cases such as that of Betty in the Tompkins (2011) paper it is a family relationship which has been lost. In other instances it is the social life of children and partners which has been lost either to fear of stigma (Wilbram *et al.* 2008) or social awkwardness and embarrassment (Tolin *et al.* 2008b). By contrast physical and emotional entrapment was also evident. Wilbram *et al.* (2008) surmised that these phenomena are very real for people who live with their hoarding family member. A son in the first case study of Tompkins (2011) feared that he will have to accommodate his mother at his home.

Rallying around describes various responses that family members make to hoarding behaviour. This theme included “duty and loyalty”, “collusion” and “hope”. Loyalty and duty often tinged with fear or resignation were identified in the families of hoarders in studies by Tompkins (2011) and Wilbram *et al.* (2008). For example the case of the son in Tompkins (2011) study who, despite his obvious affection for her, is afraid that he will be asked to take

his mother into his own home. Similarly, a mother in the second case study wished her daughters to be the sole providers of her care. By contrast, Wilbram *et al.* (2008), report the words of a husband who would rather have his wife with her illness than not have her; he describes her hoarding behaviour as “part of her”. Collusion is a strategy mentioned in these papers. For example, Wilbram *et al.* (2008) describes interviewees “living with it”. Equally, Tompkins (2011) reports that relatives were aware of the problem but acted as if it did not exist. In their second case study, the daughters met their mother only once a year away from her house and were shocked when they learned how bad things were. Whilst within this theme responses tended to be negative, hope was also identified. Tompkins (2011) describes family members as team members and contactors of help. Even a mother and daughter who had not spoken for years wanted to be reunited and held out hope they could be reconciled when the offer of therapeutic intervention was made. The persistence in acting as “key carers” (Wilbram *et al.* 2008) and in seeking help (Tolin *et al.* 2008b; 2010a) indicated that family members maintained hope that things would get better.

Discussion

This paper has examined the literature regarding the effect of compulsive hoarding on families; the three themes presented a mixed picture. Due to the lack of recognition of the problem hoarding causes, pressure is heaped upon family members to provide the support to hoarders whilst dealing with the invasion of their home by possessions and having their quality of life severely impaired by reduced access to facilities for washing, cooking and even sleeping. This produces increased animosity between hoarding family members and their relatives causing families to disintegrate under the strain, leaving some hoarders to face their problems alone. Lack of insight into the seriousness of their situation regarding personal safety, health and the prospect of prosecution means that they are increasingly vulnerable which increases the distress family members feel. Even when they are physically detached from the hoarding situation, they can not relinquish the emotional attachment to

their family member. The lack of professional involvement in these cases means that the hoarder's lack of insight is addressed only by the improvised ministrations of family members who are desperate for a cure and have no understanding of the condition. This may further aggravate the rejection towards hoarding family members and contribute to their feelings of isolation, defeat and loneliness. Despite this gloomy overall picture, certain contrary cases arise which indicate the existence of hope in families and the ability to overcome the problems and arguments created by hoarding behaviour and form strong supportive teams and nurturing families. Sometimes this is under expert supervision but sometimes it is through the strength of familial relationships.

Whilst the addition of hoarding disorder to the DSM-V may increase the profile of this condition, this may have limited benefit. This diagnostic manual is not used widely out with the speciality of Mental Health and Psychiatry. The impact on families of hoarding has been shown to be a problem, of which there is limited public awareness. Health care practitioners and others that may come into contact with this issue may not know what those living with this problem need or what will help. The lack of support experienced by hoarders and their families is cited to be a contributing factor for the development of this problem (Tompkins 2011; Tolin 2008, 2010; Wilbram 2008). This puts stressful demands upon families and allows quality of life to decline leading to family breakdown. Tompkins (2011) found that families needed more help, and in fact people have been seeking the help of this author. This is also the case with Tolin *et al.* (2008, 2010) who have been contacted by thousands of people requesting help.

In the light of the picture developed from this integrative review it is evident that it is not necessarily the needs of hoarders which pose a problem for mental health nurses as much as it is the needs of those family members affected by the hoarding. Whilst

the hoarding family member may already receive a service in response to a co-morbid problem such as depression, anxiety or obsessive compulsive disorder, family members may not be considered by health care professionals other than in respect of carer support. This review highlights the need for family members' care needs to be taken seriously due to the adverse mental health consequences of living with hoarding. Nurses need to understand what compulsive hoarding is and how it affects family members in order to provide adequate and appropriate support.

Whilst adding the diagnosis of hoarding disorder to DSM-V may be beneficial in terms of awareness raising there is a need to be mindful that it may result in both patients and carers being subjected to unwanted attentions of professionals who wish to help them become socially included when they have been content with their lifestyle. The aim should be to enable families to help each other to live together as they wish, respecting the diversity of personalities within those families. It is important that practitioners do not attempt to produce a kind of social conformity in line with the expectations of the health and social care establishment.

These findings were derived from a sample of papers which included a mixture of methods. This provided a broader range of evidence for analysis but the quality of some of this evidence was not ideal. These papers may not all be situated at the top of the traditional hierarchy of evidence (Sackett *et al.* 1997), but the evidence included was the best available. Further limitations include the information being dated. Developments in understanding hoarding are moving quickly at the moment and these studies, though they address best published evidence, may not accurately reflect the current picture. Finally, only one of these studies was conducted in the UK indicating the lack of attention this issue has received in

this country and questioning the external validity of the findings presented here. Using a novel and inclusive search strategy, this review has identified that currently there is insufficient evidence on which to base changes to practice. Furthermore, this work has been valuable in setting out a future research agenda around hoarding disorder; this should include:

- Epidemiological enquiry into the prevalence of hoarding disorder in the UK;
- Investigation of the beliefs, knowledge and skills of service providers;
- Review of current service provision from the perspectives of the families and service providers;
- Exploration of the perceived needs of the families of hoarders.

This research would help build the evidence base upon which to develop guidelines for necessary services for people with hoarding disorder and their families.

Conclusion

This integrative literature review provided an analysis and synthesis of the available four papers relating to the effects of hoarding on families. Thematic analysis identified three overriding themes; quality of life, shattered families and rallying around. Insufficient evidence was identified to suggest changes to clinical practice. This review has identified the need for further research in order to provide the evidence base for supporting family members of people with hoarding disorder. .

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The effects of hoarding disorder on families: an integrative review

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Accessible summary

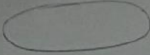
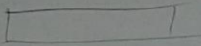
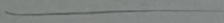



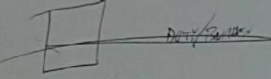




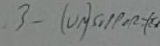


It is estimated that between 2% and 5% of the population experience symptoms of compulsive hoarding. Recent investigation into hoarding has shown that it is a problem in its own right and is therefore being added to a diagnostic manual of mental disorders.

- This integrative literature review examines the impact that hoarding has on family members.
- The comprehensive literature review spans a period from database inception to November 2012. A search of the databases Cumulative Index to Nursing and Allied Health Literature, Medical Literature Analysis and Retrieval System Online, and psycINFO, together with hand searches, was completed.
- Thematic analysis revealed three overriding themes: quality of life, shattered families and rallying around. These themes illuminate the negative impact that hoarding behaviour has on families and the inadequacy of available services.
- The relative lack of robust evidence about the impact of hoarding behaviour on families suggests that further research is needed in this emergent field.

Abstract

Compulsive hoarding affects approximately 2–5% of the adult population. Increasing recognition has led to its inclusion as a distinct condition in forthcoming revisions to the Diagnostic and Statistical Manual V. Hoarding behaviour can have a detrimental effect on the health and well-being of family members. A rigorous review of available evidence using a novel three-stage literature search was undertaken: (1) an extensive scoping review; (2) a traditional search of databases including Cumulative Index to Nursing and Allied Health Literature, Medical Literature Analysis and Retrieval System Online, and psycINFO using combinations of keywords; and (3) review of cited references and hand-searching of selected journals. Evidence was selected using predefined inclusion criteria. Papers included two surveys, one qualitative study and one case study. An integrative review methodology was used to synthesize the evidence presented. Analysis revealed three overriding themes: quality of life, shattered families and rallying around. These illuminated the experiences of family members. These papers revealed families under strain and often at breaking point but with the resolve to pull together if the right support is available. This review concludes that further research is needed to investigate the effects of hoarding on family members and how these may best be met.

Appendix 4 - Codes developed from thematic analysis of research papers during original review (2012)

	STRATEGIES	6 - DEFEAT
	DUTY / LOYALTY	7 - LACK OF INSIGHT
	ENVIRONMENT - PHYSICAL EMOTIONAL	8 - COLLUSION
	USURPATION - FIGHT FROM SOCIAL CODE WARRIOR FROM FIGHT KAMISH FROM WARRIOR	9 - CONFLICT
	DELIVER OR DESTROYER FROM PERSON - NOTION FOR WARRIOR	A - NOPE
	STATUS & PERFORMANCE - MULTIPLE FROM SPANISH FIGHT FIGHT WARRIOR	B. CONTROL
	PROPERTY	SHAME
	LOSS - LOVE & SPACE RELATIONSHIP SOCIAL CODE / WARRIOR FIGHT WARRIOR	DEPENDENCE
	SANCTUARY - FIGHT FROM WARRIOR FIGHT FROM WARRIOR WARRIOR FROM WARRIOR	FORM OF BEING SUCKED IN
	PROPERTY / DESTROYER / WARRIOR	ANGER
	NOT TAKEN RESPONSE	EXPERIENCE
	(UN)SUPPORTED	FEELINGS
	DISORDER	SPLIT CODES
	FROM QUALITY AS CODE	RELATIONSHIPS

RESPONSIBLE SERVICES TO
FAMILIES

Appendix 5 – table of papers excluded at abstract screen during 2017 update

Author and study details	Method	Focus	Sample size	Findings	Reasons for exclusion
Gioia, 2013	Online survey	Examining the relationships among self-reported and parental hoarding behaviours on the functioning of young adults	414	moderate correlations between hoarding and stress, anxiety and depression. Participants differed significantly in self-reported levels of hoarding depending on whether they lived with a hoarding relative or not.	Thesis only partially available as a sample
Sampson, 2013	Survey	The influences of unresolved trauma and family experiences on hoarding behaviour.	387	Positive family dynamics can mediate the effects of hoarding disorder in individuals. Hoarding severity correlates with experience of unresolved trauma and loss	Thesis already reported in review as a published paper
Boland, 2012	Media analysis	Families and responsabilised consumption in makeover TV.	n/a	“domestic consumption ethic” which responsabilises entire families into a model of conformity to social norms of consumption	Thesis only partially available as a sample
Vorstenbosch, 2013	Clinician rated Interview	Family accommodation of hoarding behaviour	52	Most CSOs accommodated with those living with hoarders being the more accommodating.	Published version of this thesis already included in review

				<p>Accommodating behaviour endorsed personal and hoarding family member drives to accommodate, believing that this was helpful.</p> <p>Accommodation eased the relationship between hoarding severity and relationship conflict for CSOs and hoarding family members. It also mediated the relation between hoarding severity and impairment to activities of daily living but only for hoarding family members.</p>	
Eichler, 2011	Literature review and proposal	Group counselling/ed for family members	n/a		Grant proposal only partially available
Yerke, 2009	Case study	Impacts of older adult hoarding	11	Most common impacts were relationships, safety and finances	Thesis only partially available
Chabaud and Garrett, 2012 (USA)	Internet based survey	Impact upon adults of having grown up in a hoarded environment	678 (187)	Adult children of hoarders continue to be adversely affected by their childhood experience	Conference presentation only available as PowerPoint slides without narrative
Nordsletten et al, 2013		Validation of family impact scale for hoarding			Paper reports validation of a scale but does not

					examine experience of families
Wilbram, 2006	Interpretative Phenomenological Analysis	Caregiver perspectives on effects of compulsive hoarding	8		Published version of thesis already included in literature review
Park, 2012		Effects of parental hoarding on adult children			Published version of thesis already included in literature review
Mayes, 2015	Correlational	The impact of accommodating behaviours, expressed emotion, and dimensions of burden associated with hoarding disorder on families	29		Thesis only partially available
Feinberg, 2017	Grounded theory	Accommodation Behaviours and Emotional Impact in Family Members of Individuals Who Hoard	12		Thesis only partially available

Appendix 6 - Synthesis of themes from IPA analyses

Wilbram et al, 2008	Sampson et al, 2012	Sampson et al, 2013	Rees, 2017
Loss of normal family life	Loss of normal family experiences; Loss of childhood home	Experiences of loss <ul style="list-style-type: none"> • Loss of relationships • Loss of family rituals • Loss of future opportunities Loss of a sense of “home”	Psychological and emotional outcomes <ul style="list-style-type: none"> • Negative emotional impacts • Psychological strengths • Self-esteem difficulties • Worry
The need for understanding	Support	Lack of understanding of hoarding behaviour	Perceptions of parental hoarding <ul style="list-style-type: none"> • Lack of parental insight • Struggles to make sense of • Attempts to explain or understand • Perceived normalcy

<p>Coping with the situation</p> <ul style="list-style-type: none"> • Support and role division 			<p>Coping strategies</p> <ul style="list-style-type: none"> • Support networks • Acceptance • Avoidance
<p>Impact on relationships</p> <ul style="list-style-type: none"> • Protective positive qualities 	<p>Interruption to family relationships</p>	<p>Negative feelings towards family member who hoards; Internal barriers to seeking support</p> <ul style="list-style-type: none"> • Social invisibility • Feelings of shame 	<p>Impact on relationships</p> <p>social isolation and limited socialisation within the home, conflicts with parents, reluctance to enter into social/personal relationships</p>
<p>Marginalization</p>	<p>Limited time spent with family</p>	<p>Internal conflicts</p>	

Appendix 7 - Synthesis of quantitative papers from June 2017 update in relation to existing themes from original review

Theme (from synthesis of IPA studies)	Tolin et al (2008)	Tolin et al (2010)	Drury et al (2014)	Park et al (2014)	Vorstenbosch et al (2015)	Chasson et al (2014)	Thompson et al (2016)
Quality of life	<p>Arguments were common between spouses and between children and hoarding parents.</p> <p>Tolin et al (2008) where the social isolation of 11-20-year olds is reported due to withdrawal over embarrassment regarding their living conditions.</p> <p>Significant correlation between the level of clutter in the house and the avoidance of having people come over.</p>		<p>Drury et al (2014) found that relatives of hoarders experienced lower emotional wellbeing than collectors and relatives of collectors</p> <p>Affected across many domains of life – work etc</p> <p>WSAS showed significantly greater impairments to all areas of daily life for HD families</p> <p>HEI and Live with hoarder strong possible predictors of impact</p> <p>Social and emotional functioning impacted</p>	Areas of impairment in offspring related to family functioning		<p>No significant change to quality of life was detected by Chasson et al following their intervention for families, but marginally significant ($p=.05$) improvements in some aspects of coping were noted amongst their small group of participants.</p> <p>The authors note that participants endorsed a high quality before beginning the training anyway.</p> <p>Reduction in self-blame coping style</p>	<p>Carer wellbeing (initially well below general population average) showed significant improvement following intervention and again at follow-up ($p = 0.001$ on WEMWBS), although levels of distress remained the same.</p> <p>No statistically significant difference in any of the COPE measures.</p> <p>Burden scores higher than those for caregivers in other populations with mental disorders</p>
Shattered families	<p>Tolin et al. (2008b) found that patient rejection was highest for those who grew up living with hoarding parents.</p> <p>Negative ideas about parents were found in</p>	<p>no doubt exacerbated by the denial that there was wrong (Tolin et al., 2010c).</p> <p>Tolin et al. (2010c) found that the</p>		Family functioning mediates the relationship between accommodation and conflict.	Increased accommodation = increased rejection and reduced relationship function	<p>Improvements in response to hoarding only occurred from start to mid-point</p> <p>Family issues prevented two of nine</p>	<p>Quality of relationship remained unchanged following this intervention.</p> <p>No improvements to expressed emotion levels.</p>

	<p>both Tolin studies regardless of severity of hoarding or level of clutter or level of insight</p> <p>Arguments about clutter were also found to be common by Tolin et al. (2008)</p> <p>Tolin et al found that the highest levels of rejection towards hoarding relatives were from (adult) children towards their parents, with arguments relating to hoarding behaviours common between children and parents as well as between spouses. The highest levels of rejection were found in those who had shared living accommodation with a hoarding relative at age 10-19</p>	<p>perception of family informants was that there was a general lack of insight across all ages, genders, and family roles of hoarders.</p> <p>It was discovered that the level of insight of the hoarder as perceived by the informants correlated strongly with the level of rejection but whether it is the low insight which brings about the rejection or it is the rejection due to negative childhood experience which leads to the opinion that the hoarder lacks insight is not clear</p>		<p>Insight affects conflict</p> <p>Greater level of hoarding produces greater reduced family functioning which has a negative effect on quality of relationships</p> <p>Severity directly affects conflict</p>	<p>Accommodation moderates conflict</p>	<p>families from completing training</p> <p>Increase in positive reframing and a decreasing in venting, which Chasson et al regard as similar to expressed emotion</p> <p>For now – less self-blame and less venting (EE) and better knowledge about hoarding and MI and improved self distraction and positive reframing –</p> <p>Increased hopefulness</p> <p>None of it better than a bit significant</p>	<p>Improved caregiving experiences ($p = .006$ on ECI)</p>
Rallying around	<p>with the hoarder and had done so for many years and the main source of participants approached to participate in the studies by Tolin et al. (2008b; 2010c) was people who had</p>		<p>Drury et al (2014), Nordsletten et al, (2013) and Vorstenbosch (2013) all deal with the subject of "family accommodation", explaining this as referring to the adjustment of family and individual routine to</p>	<p>Increased accommodation does not significantly affect family functioning</p> <p>Increased accommodation = increased offspring impairment</p>	<p>Vorstenbosch (2013) indicates that a proportion of respondents even help with the hoarding in some way or at the</p>	<p>Attempt to produce reduced accommodation and therefore make their relatives feel less comfortable in a hoarding lifestyle!!</p>	<p>Improvements in knowledge about hoarding</p>

	<p>contacted a source of help, indicating that someone believed things could get better. This help may have come at a considerable financial cost.</p>		<p>accommodate hoarding behaviour</p> <p>Time spent with relative was higher for hoarding families than collecting families</p> <p>Role emotional showed biggest disparity in scores between families of hoarders and families of collectors on SF-36</p> <p>On CBI, emotional burden and developmental burden showed biggest disparity</p> <p>higher rates of accommodation in families of hoarders than families of collectors</p>	<p>Impairment not found to mediate severity and offspring relationship</p> <p>Worse severity of hoarding produces greater accommodation</p>	<p>very least, chose not to comment on it.</p> <p>Severity directly affects accommodation</p> <p>No significant links between accommodation and wellbeing</p> <p>But the greater the level of hoarding, the greater the level of accommodation</p>	<p>through an intervention</p> <p>Surprise surprise it didn't work</p>	
Lack of support	<p>. Tolin et al. (2008b) showed that family members rated the lack of insight as being severe in hoarders whether they met the diagnostic criteria or not. This can be interpreted as showing</p>	<p>The reluctance of people with hoarding family members to invite people over correlates with the severity of the hoarding as does the embarrassment and shame of the family member (Tolin, 2010c).</p>	<p>Respondents believed their hoarding relative to fit the description "lacks insight/delusional", a finding echoed by Drury et al (2014).</p> <p>Drury et al (2014) found that insight was not in fact a predictor of greater family burden in</p>			<p>No statistically significant improvements in hoarding, but increased knowledge appears to have led to increased hopefulness.</p> <p>Authors note a reduction in religious</p>	<p>Satisfaction and helpfulness scores for intervention group high</p>

	<p>many people who are living with someone with mental illness without support. However, it could also show that people who live with hoarding family members find their behaviour unfathomable and frustrating, a sentiment echoed by Wilbram et al. (2008) in their study</p> <p>Tolin (2008b) also highlights the number of hoarders with delusional ideas about their hoarding. Delusions are a mental health issue and there are reports of aggression towards family members in all the studies in relation to these delusions about possessions.</p> <p>. In their 2008 study, Tolin et al found that a significant number of respondents believed their hoarding relative to fit the description "lacks insight/delusional</p> <p>high levels of rejection towards hoarding</p>	<p>Despite discovering that the worse the hoarding the better the reported insight of the hoarder (Tolin et al, 2010).</p> <p>Tolin et al (2010) showed that family informants rated their hoarding relatives as having poor insight regardless of the severity of their hoarding</p>	<p>families of hoarders and put forth the thought that caring for a relative with a hoarding problem with poor insight may cause increased levels of frustration</p> <p>need for family education and support to strengthen the family against the effects of hoarding</p>			<p>and emotional support seeking from participants.</p> <p>Satisfaction scores high for intervention group</p>	
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	<p>relatives and low evaluations of their perceived insight found by Tolin et al (2008; 2010)</p> <p>Caring for a relative with a hoarding problem with poor insight may cause increased levels of frustration as suggested by Tolin et al (2008).</p>						
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Appendix 8 – Table of included memoirs

Publication details	Description	Themes	Limitations
Lidz, F. (2008) <i>Ghostly Men</i>	A biographical account of the Collyer brothers cross referenced with the author's own autobiographical account of his Uncles' hoarding behaviour and the experience of cleaning up after a bereavement	Mental illness Family	Distance from the relative (uncles rather than immediate family) may have reduced the author's level of awareness of the severity of the problem and its effects Recall bias may be evident due to the historic nature of the work
Allen, B. (2012) <i>Nice Children Stolen from Car</i>	A memoir of growing up in a hoarded house with extremely controlling parents and the risks and deprivations that came with it	Threat of removal by child protection Impaired quality of life Shame Social isolation	self-published Proximity to the distress discussed may influence the reporting Recall bias may be evident due to the historic nature of the work
Boudreaux, F. (2011) <i>Where the Sun Don't Shine and the Shadows Don't Play (Growing up with an Obsessive-Compulsive Hoarder)</i>	A memoir of growing up in a hoarded house with a parent who is in and out of mental health facilities and its effects on the family, from the point of view of an adult child	Possible causes for compulsive hoarding Family conflict Relationship breakdown Shame Social isolation	self-published Proximity to the distress discussed may influence the reporting Recall bias may be evident due to the historic nature of the work
Miller, K. (2013) <i>Coming Clean</i>	A memoir of growing up in a hoarded house from the point of view of the adult child	Threat of removal by child protection Family conflict Impaired quality of life Shame	May be self-published (details unclear) Proximity to the distress discussed may influence the reporting Recall bias may be evident due to the historic nature of the work
Sholl, J. (2011) <i>Dirty Secret</i>	Autobiography of the author's ongoing difficult relationship with her mother (who has a compulsive hoarding problem) and it's physical and emotional effects on her both as a child growing up and, in the present,	Family conflict Shame Continuing complex relationship with hoarder in adult life Being affected by hoarding behaviour even when far away	Proximity to the distress discussed may influence the reporting Recall bias may be evident due to the historic nature of the work

Appendix 9 - Tracy's journey script for PEPC 2017

<u>Date (ish)</u>	<u>Event(s)</u>	<u>Character</u>	<u>Ideas</u>	<u>Reflections</u>	<u>Hero's Journey</u>
	Before the Quest		Growing up in dysfunction & challenging circumstances breeds perseverance	War is to blame	
1998 /99	First episode of "hoarding"				
	Chapter 1 Independent Search: <ul style="list-style-type: none"> • Self • Audience 	A long, long list of social workers	Diogenes' Syndrome Start of ongoing feud The Belly of the Whale	Desperation	Part 1 5 Belly of the Whale

		The GP Former GP Practice	Proves to be unhelpful / malevolent (can only offer tablets / potions!) Don't Kill yourself! Anxiety / depression Dementia?	Desperation	Part 1 5 Inducted into the Belly of the Whale
		The CPN Older Peoples Mental Health Team Michelle Reilly	Medication offered Anxiety / depression ? Dementia? Tests Diagnosis	Michelle asks if I've seen "My Mother the Hoarder" on TV	Part 1
		The TV Celebrity daughter of a "Hoarder" (Jasmin Harman)		Enlightenment	4 Crossing the (first) threshold
		Another TV Hoarder			

		The case of Richard Wallace / Andy Honey			
		The OCD Professor Dr David Mataix-Cols The Hoarding Researcher (Helena Drury)		Action	
		The Do-Gooder Councillor		Desperation Disappointment	
		Professional Declutterers (Heather Mattuzzo)	Need an Army	Enlightenment Further Action	Guardians of information / knowledge
		Community Activists f	Royal British Legion Far East Prisoners Of War	Desperation Action	

				<p>Wartime experiences are to blame so they must atone for the burden carried - Retribution</p>	
Oct 15		<p>The Occupational Health Nurse</p>	<p>Suggests I go back to the Carers Centre for a second opinion seeking support</p> <p>Tracy jumps through the hoops to show willing</p>	<p>Illness Recovery</p>	
		<p>The Carer support worker (Carer for Carers)</p>	<p>Suggests I contact G</p>	<p>Desperation</p> <p>Empathy / Fairy Godmother</p> <p>A shoulder to cry on (literally)</p> <p>Mother Figure</p> <p>"Everything will be alright"</p>	<p>Part 2 (Ordeal / Initiation)</p> <p>Mentor / helper / Aid /</p>

		<p>The Charity CEO</p> <p>The radio presenter</p>	<p>Gaccepts the proposal and asks if training is possible Tracy finds Orbit</p> <p>Recycling charity are good fit for ongoing support</p> <p>G suggests hoarding as the subject of his community radio show</p>	<p>Empathy</p> <p>Father Figure</p> <p>Healer</p> <p>Doer / Facilitator / medium for wider contact</p>	<p>1</p> <p>Call to Adventure</p> <p>Mentor / helper</p>
		The Hoarding Trainer	<p>Tracy makes contact</p> <p>Suggests I contact Tim Buescher as he is based locally at Uni Hull</p> <p>passes on my enquiry but Tracy chases</p>		<p>Guardians of information / knowledge</p>

			project relies heavily of Fire service support. Tracy decides to contact them		
Sept 15	<p>Chapter 2</p> <p>Joint Search / Quest:</p> <ul style="list-style-type: none"> • Each other • Sense of purpose • Resources (funding / people etc) • Audience <p>Syncopated research</p> <p>Reflective processes / critical analysis / sense checking</p> <p>Collaborative witnessing</p>	<p>The Researcher /</p> <p>The Lecturer /</p> <p>Hoarding</p> <p>Tim - Co Campaigner</p>	Tracy finally makes contact	<p>Desperation</p> <p>Enlightenment</p> <p>Action</p> <p>Empathy</p> <p>Support</p> <p>Expert</p> <p>Leader</p> <p>Trust & Security</p> <p>Friendship on the Quest</p> <p>Offers a Challenge</p> <p>Validation</p> <p>Direction forwards</p> <p>Brother in Arms</p> <p>Someone to fight the cause with</p>	<p>Guardian of information / knowledge</p> <p>Gateway to another world</p>

		<p>Fire Service Fire Prevention Officers with knowledge of hoarding as an issue</p>	<p>Statutory Services lend their "powers" Storm troopers</p> <p>Later - Backing of the project / funding bid</p>		Allies
December 2015		<p>The Motivational Professional</p> <p>Feel the Fear and Do It anyway)</p>	<p>Suggests access to £5k CCG funds</p> <p>Tracy talks to G who agrees to help with a funding application to CCG</p> <p>Ghas lots of experience and would be co-delivering the project</p> <p>Bid undergoes several edits and is finally submitted</p>		Mentor / helper / allies

		Community Church / Parish Nurse	Establishing a meeting / training venue		
		The Cognitive Behavioural Therapist (CBT) Satwant Singh	Expert	Hopes and expectations not met	Guardians of information / knowledge
		Clinical Psychologist / Cognitive Behavioural Psychotherapist - Dr Steven Kellett	Expert	Hopes and expectations not met	Guardians of information / knowledge
		The Lady in the Van Alan Bennett (as an Expert)	Hoarding becomes part of Popular culture Expert	Opportunity to see hoarding as an issue in a creative context	

		Funding Application to CCG is assessed and passes round 1	Invitation to attend presentation day when Audience to vote for preferred projects Preparation on presentation With G / Tim Buescher	Excitement and hope leads to Disappointment Further reflection = best outcome Becomes a major part of overall research "Lab rats"	Tests & Trials Challenges / Temptation = easy fix Abyss / Vacuum / Apostasis (death) Transformation
		Reconnect Recommence with project			

		The Expert by Experience / Campaigner			
	Chapter 3 a bridge Thesis = currency				
	Chapter 4 Joint & Others Doing - Roll out The big reveal				

Appendix 10 – my expectations prior to whiteboard exercise as written in my notebook whilst waiting for Tracy to arrive:

What is in my head?

- Anniversary of project & no “results”
- I am not the same person I was at the start of this
- I do not think diagnosis helps
- What next?
- Need to get this written

What do I expect (hope) to find?

- There is no tidy “hoarding disorder”
- Collaboration helps
- We need to listen
- Tracy has benefited from this process
- We have much more to do
- I am not selfish and my/this/our research matters

From memory...

- Instability
- Dispute
- Responsibility
- Short-termism
- Overburdened
- Loneliness
- Expert by experience – bin it!!!! – We all one!!! (sic)

Appendix 11 Proforma for DNA for beginners

Resource questions

What resources shape how the story is being told?

What resources shape how listeners comprehend the story?

How are narrative resources distributed between different groups; who has access to which resources, and who is under what form of constraint in the resources they utilize?

What other resources, if available, might lead to different stories and change people's sense of possibility in such settings?

What might be preventing those alternative narrative resources from being mobilised?

Circulation questions

Who tells which stories to whom?

Who would immediately understand the story and who wouldn't?

Are there some people whom you wouldn't tell that story to, and why not?

Affiliation questions

Who will be affiliated into a group of those who share a common understanding of a particular story?

Whom does the story render external or other to that group?

Who is excluded from the "we" who share the story?

Identity questions

How does the story teach people who they are, and how do people tell stories to explore whom they might become?

What is at stake?

How is the storyteller holding his or her own in the act of telling that particular story, in that way?

How do the stories that some people have available convince them of what they have to do and be in order to hold their own?

Based on Frank, 2012 in Holstein and Gubrium

Appendix 12 stories employed in conversations between Tracy and me and how they meet my typology.

story	location	subject	type
A quest	WS 10001 p.1-13	Tracy's search for help	Crusaders/carers/experts
Grandma's things	WS 10001 p.14-15	The value of things	curators
A tidy solution	WS 10001 p.15	Involving the Fire and rescue service in the bid	Crusaders/experts
Hoarders hoard wherever they go	WS 10001 p.16	Tracy's mum hoarding things at Tracy's house and its effects on Tracy	Experts/carers
She says she's got one or two things but she's not a hoarder	WS 10001 p.17-18	Tracy describe the difference in her and her mum's views of the situation	carers
What you can take	WS 10001 p.20	Tracy can handle looking at things from a clinical pint of view, but not a personal one	Crusaders/carers/experts/curators
Super-G___	WS 10001 p.20-21	Tracy has found a source of potential and support in making the funding bid and helping her mum	Crusaders/experts
Making wishes	WS 10001 p.23-24	Tracy and Tim answer a hypothetical question	Curators/carers/ /experts
""Well, if she doesn't want me, let's call it a day"	WS 10003 p.2-3	Tracy and her mum have had an argument after Julie's car got a flat tyre	Carers/curators
I've got to do something about this	WS 10003 p.4-5	Tracy is resolved to try and make space for herself and preserve her identity as more than a carer	Carers/crusaders
Making the pitch	WS 10003 p.6-7		Crusaders/experts Could not identify a story
Life-saving	WS 10003 p.15-16	Tracy recalls a story she has been told by a hoarding specialist about a woman's suicidal feelings being alleviated by a support group	Carers/crusaders/experts
Schizophrenia?	WS 10003 p.19	Tracy has been searching for answers as to what is wrong with her mum	Experts/carers
Loneliness	WS 10003 p.20-22	Tracy and Tim have both watched a documentary about loneliness and found it resonated with them	Carers/curators

Well, yeah people want to belong to a family	WS 10004 p.5-6	Tracy uses the example of a well-known hoarder to suggest that belonging could be what is missing in cases of hoarding	Carers/curators
So she can live in that and she'll walk out looking immaculate	WS 10004 p.6-7	Tracy relates how her mum's appearance and her home are not the same	carers
So I've been trying to look at it in a different way	WS 10004 p.12-14	Tracy has resolved not to get angry with her mum any more but this is proving difficult	Carers/experts
Every time you talk to them they're like "Oh we're fully behind you" and then you hear nothing	WS 10004 p.8	Tracy tells of how she has been promised much but given nothing by service providers	Crusaders/carers/experts
Pitch in	WS 10004 p.8-10		Crusaders Too little narrative
You're researching it	WS 10004 p.10	Tracy describes attempts to find help for herself without success	Experts
I need to start offloading	WS 10004 p.12	Tracy describes feeling burdened and unsupported	carers
Unless I dealt with the anger, I was never going to be able to deal with this in a logical way	WS 10004 p.12-14		Carers/experts Repeat
I hate putting the rubbish out	WS 10008 p.2	Tracy and Julie have been to look at new accommodation but appear conflicted about it	carers
Skeletons in a closet	WS 10008 p.3	A space has been made for Julie's things in a cupboard in her room	carers
He did ring me but, you know	WS 10009 p.4-6	Tracy and Julie talk about the possible reasons for their lack of contact with Dean, Tracy's brother	Carers/curators
But you're still here. You're still alright	WS 10009 p.6-8	Julie has concerns about her health	carers
It seems like a lifetime since we did that presentation	WS 10009 p.8-9	Tim has a suggestion for further attempts to get some funding for research into hoarding	Crusaders/carers/experts

I have been thinking about the lady and the lampshades	WS 10009 p.10-13	Tracy and Tim share stories and descriptions of artistic projects they have seen or would like to do	Curators/crusaders
It's Victorian so it just keeps coming down	WS 10010 p.5-9	Family heirlooms and the difference in perceived worth from one person to the next and how family ties add value to some things	Curators/carers
The legend of the coat	WS 10010 p.18-19	Tracy tells the story of buying a coat to bury her grandma in	Curators/carers
"...at the end of the day, you can always save yourself"			Curators/carers Unable to locate
"You know you are going to lose something, so you want to acquire something"	WS10010 p.20-23	A story about someone who responded to the news of terminal illness by buying excessively from a catalogue leads to suggestions of why	Experts/curators/carers
The greatest act of defiance	WS 10010 p.26-27	Tracy recalls seeing a meme which resonated with her and suggests a nurtured sense of isolation created by corporations exists to force people into buying things to feel happy	Experts/curators