The Impact of Counselling in Compulsive Hoarding Interventions Within the Context of the Social Model of Disability: Finding a Way Forward

By Megan Karnes

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INTRODUCTION

The purpose of this study was to explore the impact Health and Safety problems created by Compulsive Hoarding had on the client's ability to receive psychological support. The project was prompted as a result of the researchers work with a UK National Mental Health Charity which involved weekly contact from people impacted by the personal, interpersonal, ethical and legal impasses created in regard to rights around this issue.

The aim of the research was to better understand the practical handling of Compulsive Hoarding, especially in regard to Mental Health, in order to accurately inform the design and development of an improved systemic model.

The researcher engaged with all elements of this problem in her role, as such there was no significant bias. Importantly though assumptions made by the researcher prior to undertaking the study were found to be mistakenly conceived this has meant that the structure of the research evolved from its original conceptualisation.

Following the Action Research model defined by Zuber-Skerritt (1996) a multi-source feedback model was used in order to avoid simplicity and draw relevant conclusions. Quantitative methodology was chosen for its usefulness in determining 'descriptive statistics' with the potential to provide information which was easy to summarise, compare and analyse. (Denscombe 1998 p.178)

This small scale research project was designed to formulate an initial point of comparison as such it was intentionally limited. The scope of the research was limited to one London Borough and one London support group.

Triangulation involved Qualitative interviews with a housing professional, a hoarding specialist and a Compulsive Hoarder.

ABSTRACT

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Disorder and chaos are words commonly associated with Compulsive Hoarding. An unexpected situation is that those two words run rife throughout all areas of engagement with the disorder. Nothing is uncluttered. The complete mess created results in a systemic structure that does not support people who Compulsively Hoard, their families, community members and/or service providers.

This study was designed to explore the Mental Health aspect of Compulsive Hoarding. The hypothesis was that a large percentage of the population Hoard, the behaviour created health and safety risk that placed the right of the client to be treated as if they have a recognised mental health disorder, and/or disability, in direct conflict with the systems that are in place to potentially support them.

The study used a multi-source feedback Action Research model. Both Quantitative and Qualitative methods were incorporated in a three tiered exploration that involved housing support professionals and people who Compulsively Hoard.

Incomprehension inspired the research. In four and a half years work running a UK National Mental Health charity the researcher encountered every classification of participant within this problem. Compulsive Hoarders, of course, but also their spouses, children and neighbours; Housing Support workers, desperate to find a way out of the vacuum created by the sucking away of their time, resources and patience; Emergency Services, Environmental Services and the media all made contact too.

The strengths of the methodology included incorporation of information from broad range of perspectives that included professionals and Service Users.

The limitations included the misconceptions on which the original proposition was built which resulted in a reconfiguration of methodology that delayed the process.

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Another limitation was a low response rate across groups which lessened the capacity to use the data to make broader assumptions.

The second phase of the research, which will investigate the Mental Health intervention structure, will begin in July 2009 and involve using the same methodology.

The results reveal that whilst the situation is complex, none of the participants see it as unmanageable in the long term. The recommended way forward seems to involve developing a consistent, informed, client led intervention structure. As such education and training for all parties would be beneficial.

Approximately seventy species of animals hoard food in order to ensure survival. Studies show that humans and animals share same the subcortial region in the brain that drives this instinct (Brown 2004).   Although the ancient Greeks recognised compulsive collecting (Jefferys 2008) the word hoarding was not used to describe human behaviour until the 1960's by Bolman and Katz (Galizia 2006). Frost et al define a compulsive hoarder as a person who collects but fails to discard possessions that appear to have little or no value (Frost and Gross 1993), whose living space becomes unfit for purpose and who experiences 'distress or impairment' in functioning as a result of the clutter. (Frost and Steketee 1999)   Research has found that potentially only five percent of hoarders come to the attention of professionals (Gilbert Guide 2008). When the problem is reported to authorities and the hoarder is deemed to have broken health codes, sanitation laws or anti-social behaviour regulations, they can face punitive legal action, including eviction (Frost et. al. 2000). "I don't agree with criminalising hoarders...This doesn't work in the long term because it doesn't help the person break out of their pattern…It would be more useful if, when councils inspect hoarders' premises for health and safety concerns they involved another agency to assess the person's mental health to see if the hoarding is part of a psychological problem." (Bexton 2005)

The purpose of this literature review is to examine existing information about compulsive hoarding in order to explore ways in which counselling might become an integrated element of a multi-tiered intervention structure in the UK. Research shows that compulsive hoarding behaviours are similar in the UK and Australia. In 2007 Australia began the process of developing guidelines for hoarding. Some US States have cross service Hoarding Task Forces (Slatter 2007),

yet in the UK there is no structured policy in place and less than fifty CBT [Cognitive Behavioural Therapy] therapists have the expertise to treat severe hoarding problems (Branscum 2007). "The extent and severity of hoarding makes it clear that this can be a problematic condition from the standpoint of public health threat, costs to the public and even loss of life. Effective social and/or individual intervention for problematic hoarding is clearly needed." (Frost et. al. 2000 p.234)

In the context of hoarding even clinical evidence does not allow for a simple discussion. While now considered more than a personal eccentricity (Abromowitz et. al 2008), it still is not presently a clinically recognised disorder in its own right. Instead it is listed in the DSM IV TR as one of the diagnostic criteria for Obsessive-Compulsive Personality Disorder (OCPD) (Neziroglu et. al 2004). This criterion was based on Freud's theory of anal fixation, although that rationale is no longer considered valid (Menzies and de Silva 2003). The OCPD criterion is often disputed (Frost and Steketee 1998) (Claiborn 2006b). More commonly hoarding is discussed as a manifestation of Obsessive Compulsive Disorder (OCD) (Veale and Willson 2005), but recent research reveals that hoarding is often, but not always, OCD (Pertusa et. al 2008). Comorbidity has been found with schizophrenia, eating disorders, brain injury, dementia, social phobia, depression (Steketee and Frost 2003), psychosis, Pica, Prader-Willi syndrome (Neziroglu et. al 2004) and Alzheimer's, etc. In fact 92% of compulsive hoarders have at least one other mental health disorder (Sorrentino 2007). 'Diogenes Syndrome' also involves hoarding but includes self-neglect and squalor (Steketee and Frost 2003). Chromosomal links (Samuels, et. al 2007), frontal lobe damage (Brown 2004) and brain dysfunction (Saxena 2007) have been cited as potential biological causes. While these facts pointedly expose the lack of clarity amongst researchers about what causes and how to classify hoarding, Professor Paul Salkovskis succinctly states "Knowing which area of the brain

is affected does not help you in treatment one little bit." (http://news.bbc.co.uk/1/hi/health/ 4101931.stm)

If clinical data isn't particularly useful in terms of clarifying the 'what is' of compulsive hoarding, information on treatment doesn't necessarily point a coherent 'what to do' either. Even if treatment were readily available the efficacy of CBT intervention leaves much to be desired. The recently published 'Therapist Guide' details 43 clients entering a trial, notes a 14% dropout rate before commencement and a 26% reduction in hoarding symptoms at week 12. After 26 sessions, with only 17 patients remaining, the result was a 45% reduction in hoarding behaviours. (Frost and Steketee 2007) Findings have consistently shown that people who hoard respond poorly to Exposure and Response Prevention (ERP), CBT and Selective Serotonin Reuptake Inhibitors (SSRI) medications (Starcevic and Brakoulias 2008).

Perhaps the passage of time has diminished the fact that in the 1930's Carl Rogers became the first to focus on evidence based psychological treatment in his exploration of Person-Centred Therapy (Rogers 1931). In 1939 using The Component Factor Method, Rogers stated that an internal dynamic of 'self-insight' was "worthy of evaluation" (Rogers, 1939) Rogers ultimately finds that "The most powerful determinant [of successful counselling] would appear to lie in the attitudes of the person himself" (Rogers 1980: 207-210). Lack of insight has consistently been proven in regard to compulsive hoarding (Steketee et. al. 2000). In one study only fifteen percent of elderly compulsive hoarders were able to identify the practice as problematic. (Frost et .al. 2000) "'When you are looking at obsessional patients, hoarders seem to stand apart, and they don't respond well - if at all - to standard anti-obsessional treatments...' Dr Fineberg (a specialist

in OCD) said many hoarders tended to believe they were acting rationally, and did not need help."
(http://newsvote. bbc.co.uk/mpapps/pagetools/print/news.bbc.co.uk/ 1/hi/health/3769677.stm)

In non-hoarding research, Baines, a person with OCD and a Clinical Psychologist, found that according to reliable indicators three clients in her CBT study showed no measurable reduction in depression. She used (Beck's Depression Inventory), anxiety (Burn's Anxiety Inventory) and meta-cognition (Meta-Cognition Questionnaire) after four months of therapy. Instead the most significant change seemed to result from 'a collaborative counselling relationship' with clients describing an intense need to feel heard and understood. While not discounting the impact of some CBT interventions Baines stated that "Two earlier views have been reinforced; that the process of therapy is at least as important in relieving distress as the interventions employed and that not all interventions are equally acceptable to clients and should be tailored to the individual." (Baines and Wills 2002 p. 275) Prouty has researched interventions when psychological contact is impaired (Prouty 2002). In an effort to evaluate current research in Humanistic Therapies, McLeod cites Humanistic Psychotherapies: Handbook of Research and Practice to demonstrate parity between humanistic and CBT outcomes (McLeod 2002). There is at present no known research exploring Humanist therapeutic interventions in regard to hoarding.

In the US Neziroglu et. al have adapted their intervention strategy from substance abuse models. They state explicitly that there is not a one size fits all structure and that the interventions can vary from client to client. (http://www.adaa.org/GettingHelp/newsletter/2007/ Hoarding_Intervention .asp) The Los Angeles Department of Mental Health recognises compulsive hoarding as both a mental health and public health problem, but focuses their

information leaflet on psychological management stating clearly that "Negative results can occur when interventions are not carefully planned with a group of professionals with hoarding knowledge." (http://dmh.lacounty. gov/cms1_046522.pdf) 'Hoarding and Intervention-Helping Hoarders Get Treatment' suggests that a multimodal therapeutic structure might include CBT and ERP as well as psycho-educational development of organizational skills, decision-making and improving the ability to prioritize responsibilities, claiming also that therapy may take more than one session per week and involve home visits. (http://www.ocdchicago.org/images/uploads/ pdf/EP09.pdf) Mass Housing, a US social housing resource, breaks roles into two categories 'Enforcer' and 'Support' but does not see counselling as the only option for the Support role. The Enforcer sets clear firm limits in a non-judgemental way and may be someone in the public sector or housing. The Support role provides hands on non-judgemental support, but does not enforce. This role could be held by a case worker, a psychotherapist, an occupational therapist, a resident services coordinator or lawyer (Sorrentino 2007). While not all exclusively counselling focused, these US models look at ways of individualised strategic interventions.

"Body found in litter tunnel maze" (http://news.bbc.co.uk/1/hi/england/beds/bucks/herts /7816373.stm). "Rubbish hoarder ordered to pay £38,000 clean-up bill" (http://www.telegraph. co.uk /news/uknews/4327023/Rubbish-hoarder-ordered-to-pay-38000-clean-up-bill.html). 'Hoarding: a community health problem', a US study undertaken in 2000, details increased likelihood of falling, increased exposure to illness as a result of spoiled food, debilitating respiratory problems for the person who hoards. When there is family the clutter can endanger both self and others (Frost et. al. 2000). In the case of animal hoarding non-human life is also threatened (HARC 2002). Most counsellor/client agreements contain a 'harm to self or others' clause which allows the counsellor to break confidentiality at times when the client poses a risk

(http://www.bacp.co.uk /members/info_sheets/P11.html). The question can them become how would this legitimate legal concern pose problems for a counsellor working with a client who hoards? How is risk assessed?

Fairfax, Virginia has had a successful intervention programme which began in 1998. In spite of this their website informs people about the risks, without discussing mental health:

"Increased Risk of Fire

The accumulation of combustible materials, such as newspapers, clothing and rubbish, can pose a severe fire hazard…Homes with severe hoarding suffer more extensive damage during a fire emergency because of the amount of combustible material inside and a delay in fire fighting due to obstructed windows and doorways.

Increased Risk of Structural Damage

The volume of hoarded items, often stacked from floor to ceiling, is extremely heavy and imposes structural loads up to 500 percent above the minimum design load. Structural damage threatens the occupants, public safety personnel and adjacent buildings or townhouses…

Increased Risk of Disease, Injury and Infestation

The storage of hoarded items makes cleaning nearly impossible, which can lead to unsanitary living conditions and increases the risk of disease…."
(http://www.fairfaxcounty.gov/dpwes/trash/hoarding/public_safety.htm#)

A UK study 'Mental health service users and their involvement in risk assessment and management' suggests that service users themselves are distressed about the risk they pose and recommends a greater role for people experiencing psychological distress to be included in assessing their own risk (Langan and Lindow 2004)?   Is this possible when the client does not acknowledge the problem as is the case with so many who compulsively hoard? Would this lack of capacity mean that a hoarder could be proffered rights afforded under The Mental Capacity Act 2005? (http://www.opsi.gov.uk/ACTS/acts2005/ ukpga_20050009_en_1) Could a person who hoards be considered disabled?

Certainly disability, and thinking about it has transformed in the last forty years when in 1972 physically disabled and institutionalised Paul Hunt wrote a letter to The Guardian newspaper encouraging other people with disability to work with him in order to take more control over their lives (Hunt 2001). The Union of the Physically Impaired Against Segregation (UPIAS) was formed in 1976 as a result (Hinshaw 2007). Less than ten years later Oliver coined the term Social Model of Disability (Barnes and Mercer 2004) and the United Nations declared 1981 'The International Year of Disabled People' (http://www.gmcdp.com/ UPIAS.html). Many began to accept the idea that the problems created were not solely a result of the disability itself, instead that the main causes of social exclusion and marginalisation were physical and psychological barriers put in place by society. (Implementing the Social Model of Disability Theory and Research-Barnes-Mercer-2004-Disability Press) "The Social Model of Disability gives us the words to describe our inequality. It separates out (disabling barriers) from impairment (not being able to walk or see or having difficulty learning)…[and] it enables us to focus on exactly what it is which denies us our human and civil rights and what action needs to be taken" (Morris 2000: 1-3).

"According to the Medical Model the problem of disability is…due to [a person's] individual impairments and therefore requires medical interventions to provide the person with the skills to adapt to society" (http://www. brainhe.com/TheSocialModelofDisabilityText.html). Clinical diagnostic criteria are also used in psychology in order to quantify the presenting problem. (Llewellyn & Hogan 1999) Dewsbury, et. al, question the validity of reducing scientific truth to a relative experience. "The Social Model, in whatever form, has the great merit of producing an interactionist account of disability, wherein disability is seen as a construction and thus necessarily a responsibility is shared by all parties...There is nothing much wrong with this, except insofar as it implies…that there is no 'reality' in the first place." (http://www.dirc.org.uk/ publications/articles/papers/88.pdf, p. 157)

The Medical v Social Model disagreement causes contention even within the 'Disability Pride' movement. "…I think it excludes those of us for whom living with an 'illness' is as much of a challenge as living with society's attitudes towards it. The Social Model and Medical Model should be able to co-exist. They're not truths, they're MODELS…they provide useful ways of understanding it from different perspectives." (http://www.bbc.co.uk /blogs/ouch/2007 /07/what_makes_one _disabled.html)

Pinder (1997) defends a similar stance by saying "My argument throughout has been that if we want to fully understand the ambiguities of lived experience, we need to come to grips with the many interlocking webs of significance in which impairment and disability are embedded. On their own neither tells the whole story."

Shakespeare and Watson (2002) suggest that one way to appease 'Social Model traditionalists' could be to differentiate impairment and focus the Medical Model thinking primarily on chronic illness. In *Defending the Social Model* dissenting views within the Social Model are discussed and encouraged while at the same time reminding the movement that the enemy is not internal disagreement, instead winning "the battle for a Social Model understanding of society and our lives' (Shakespeare and Watson 1997).

Mental Health is not experienced in a vacuum. The counselling suite, clinical trial, research centre and/or political rally are stops along the way in the lives of people affected by psychological disorders. In Modernising the Social Model in Mental Health Maria Duggan (2002) states that "To be afflicted with mental health difficulties, means among other things to suffer at a subjective and social level. In turn, this means that those caring for and living with users often suffer with and on behalf of them. But in policy terms the story is rarely narrated from this perspective, and is consigned to the domain of 'clinical experience' or research into users' lives. We know from user research that people want mental health interventions above all in the form of consistent relationships with professionals, and that counselling and talking therapies are also highly valued. Talking in the context of structured relationships is in itself one kind of 'Social Model' of mental health work, and we neglect this basic insight at our peril." Understanding peril as experienced by a neighbour as well as the compulsive hoarder seems to be the challenge in coordinating an appropriate response.

While most people collect something at various points in their lives clinical evidence shows we still know very little about the behaviour (Brown 2004).   In 'An Introduction to Hoarding' a man discusses the impact of his wife's hoarding on his life. "I buried my wife yesterday…After fifty

years of marriage, her dying words to me were not 'I love you.' They were 'Don't touch my stuff…What could I have done that might have made things different?'" (Gilbert Guide 2008 p.5, p.9)

This research seeks to specifically address the legal and psychiatric conflict presented when dealing with compulsive hoarding. Steketee et al (2000) have looked at the impact of hoarding on the community. Clinicians struggle to find an effective treatment for the yet unclassified disorder. While the headlines scream, the scientist's debate and the civil servants create band-aid responses to plaster a problem, people who hoard continue to isolate themselves, create fissures in communities and pose a serious risk both to themselves and to others.

The limitations of this research are that initially it will need to focus on gathering quantitative data within social service roles and only in one London Borough. In looking at integrating a focus on the mental health aspect of compulsive hoarding, the researcher hopes to clarify gaps in understanding outside psychological services.

In this research study a quantitative questionnaire will be distributed to housing support and other relevant public sector services within the London Borough of Islington. The questionnaire will be based on Steketee et. al. (2000) but will also include information about referral into mental health services. Two specialist therapists have agreed to be interviewed. Using semi structured questions the researcher will look to further explore the reality of hoarding support in the UK within the context of the Social Model of Disability. The findings will be triangulated by sending a questionnaire based on the results of the Islington survey to another London Borough.

METHODOLOGY

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This study was designed to explore the Mental Health aspect of Compulsive Hoarding in the context of the Social Model of Disability. This study was designed to explore the Mental Health aspect of Compulsive Hoarding. The hypothesis was that while a large percentage of the population Hoard, the behaviour created health and safety risk that placed the right of the client to be treated as if they have a recognised mental health disorder, and/or disability, in direct conflict with the systems that are in place to potentially support them.

The researcher, who had no expertise in the area of UK housing, held a preliminary interview with Vanessa Hemmings, a Floating Support Worker with Islington Single Homeless Project (SHP). (Appendix A)   Based on the information obtained, along with informal consultation with recognised specialists in the US and the UK, a short Quantitative questionnaire was designed. (Appendix B) An adapted version was created to be more relevant to Services Users. (Appendix C) The resultant Qualitative and Quantitative data was used to formulate post research Qualitative interview questions that were used with Hoarding specialist, Satwant Singh, M.Sc. (Appendix D) and a Compulsive Hoarder (CH11), who chose to remain anonymous. (Appendix E) All interviews were recorded and transcribed.

An internet based questionnaire was designed and sent via email to sixty-three housing organisation contacts. A link was also placed on www.Hoardinguk.org, a website built by the researcher to be used in conjunction with the project. Twenty-one contacts were no longer reachable as a result of defunct Islington Government website information. An electronic document version was later distributed via email to the remaining forty-two housing organisations. The researcher also personally delivered/collected paper copies of the survey throughout the Borough. Out of the forty-two successful contacts twenty-one respondents participated in the survey across all formats, six of whom did not qualify to participate because they were outside the London Borough of Islington.

The second phase involved circulation of the adapted questionnaires to people who identify themselves as Compulsive Hoarders and attend a London Support Group. Seventeen were distributed, five were returned.

Qualitative triangulation interviews explored participants understanding of the Social Model of disability; how a Compulsive Hoarder's personality affected their interactions with services; how each person defined their role in the situation; how types of tenancy impacted a person's rights; what support was available if a person was evicted; what is the impact of lack of Compulsive Hoarding clinical diagnosis meant; how the participants aspirations were impacted by the complexity; what triggers people into services; whether or not Compulsive Hoarding was comparable to other long-term health disorders; whether or not Compulsive Hoarding was 'unfixable'; how each participant of the process evaluated the other. This data was only intended to round out the meaning of the Quantitative statistics and was only used in that context for the purpose of the study. The researcher recognised post triangulation phase that the Qualitative questions were exhaustive enough to warrant their own study.

Although included in the original survey design, no clear entry point into Environmental Services or Emergency Services was found. As such these important areas will not be considered in this research other than in the context of their place in respondent's answers. The researcher intends to expand the scope to include them at a later time.

The strengths of the methodology included incorporation of information from broad range of perspectives that included professionals and service users.

The limitations included the misconceptions on which the original proposition was built which resulted in a reconfiguration of methodology that delayed the process. There was a low response rate across groups which lessened the capacity to use the data to make broader assumptions.

This research was carried out within the BACP guidelines for counselling research. All personal information from respondents, other than the professionals who agreed to participate, was withheld in the interest of maintaining confidentiality.

FINDINGS AND ANALYSIS
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The research proposal was centred on the hypothesis that Compulsive Hoarding was a clinically recognised form of Obsessive Compulsive Disorder and as such warranted consistent referral to psychological treatment which was proven effective. (Appendix F) Instead it was posited that consistent legal and social interventions, such as eviction and Anti-Social Behaviour Orders, were used. It was stated that this was a significant factor that maintained inefficacy and prevented the delivery of appropriate systemic support. Further, the proposal raised ethical questions about Compulsive Hoarding in the context of the Social Model of Disability. Prior to undertaking any interactive research, two out of three of these assertions were found to be untrue.

The Literature Review summarily discounted two important points which were originally postulated. Compulsive Hoarding was found to have no independent clinical status within the Diagnostic and Statistical Manual of Mental Disorders (DSM IV). Its only recognised place was as a symptom of Obsessive Compulsive Personality Disorder. (Neziroglu et. al 2004) Thus the initial premise that Compulsive Hoarding was a clinically recognised Mental Illness was incorrect.

The impact of the lack of diagnosis was explored with the triangulation interview participants. All three had experienced a blockade to appropriate support as a result. CH11 went further and stated that as a result of her other diagnosis, she felt stigmatised and judged, which meant that Compulsive Hoarding specific treatment was not made available. The inability to obtain clinical recognition was proven to be an important problem within the systemic management structures. So the hypothesis that there was a lack of appropriate Mental Health referrals was partially correct, albeit based on the wrong assertion.

The conceptualisation of the efficacy of clinical treatment for Compulsive Hoarding, based on the researcher's understanding of the success rates of Cognitive Behavioural Therapy with Exposure and Response Prevention (CBT with ERP) for

people affected by Obsessive Compulsive Disorders, was also inaccurate. The assumption of the efficacy of therapeutic interventions was significantly diminished as a result of extensive examination of available research materials. (Frost and Steketee 2007)

The questionnaire calculated a range of between twenty-six and fifty-nine Compulsive Hoarding clients who required professional support during the designated period.   The suggestion that Compulsive Hoarders represented a 'large percentage of the population' was unverifiable based on that data. An indefinable, but interesting, outcome that occurred was that whilst the survey was only distributed electronically to forty-two people, and hosted on a newly built site for which no other promotion was done, three hundred seventy-eight people viewed, but did not complete, the questionnaire online within the two week span it was active.   Whether this reflects direct word of mouth referral or search engine hits is unverifiable but the high level of interest does potentially reflect the large numbers of people affected as originally surmised.

In order to better understand the extent and levels of professional engagement, two types of service users were defined by the researcher. 'Best Case Scenario' clients represented the clients with the least number of interventions required by professionals. 'Worst Case Scenario' clients were those with the highest frequency of engagement. Best Case Scenario and Worst Case Scenario clients presented in almost identical numbers across the spectrum of need, only when looked at in the context of percentage did any identifiable differentiation occur.

On both the high and low end of the spectrum the figures were identical. Between 1-5 interventions- Best Case Scenario/ Worst Case Scenario: 33%; 6-10 interventions- Best Case Scenario 7%; 11-15 interventions- Best Case Scenario 13%/ Worst Case Scenario 20%; 16+ interventions- Best Case Scenario/ Worst Case Scenario: 33%) Three out of five Compulsive Hoarders (60%) detailed between 1-5 interventions, which tallied with the combined data from the low end/high end professional data. One cited 16+ interventions. One did not know.
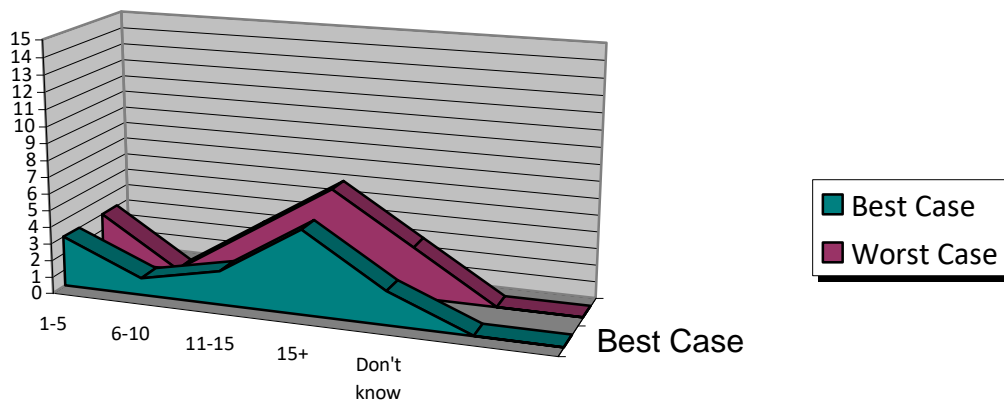
Housing professionals reported that ten out of thirteen 'Best Case Scenario' and seven out of eleven 'Worst Case Scenario' clients had been referred to Mental Health services. This data was validated by Compulsive Hoarder respondents. Four out of five of Compulsive Hoarder respondents indicated they had been given a psychological referral.
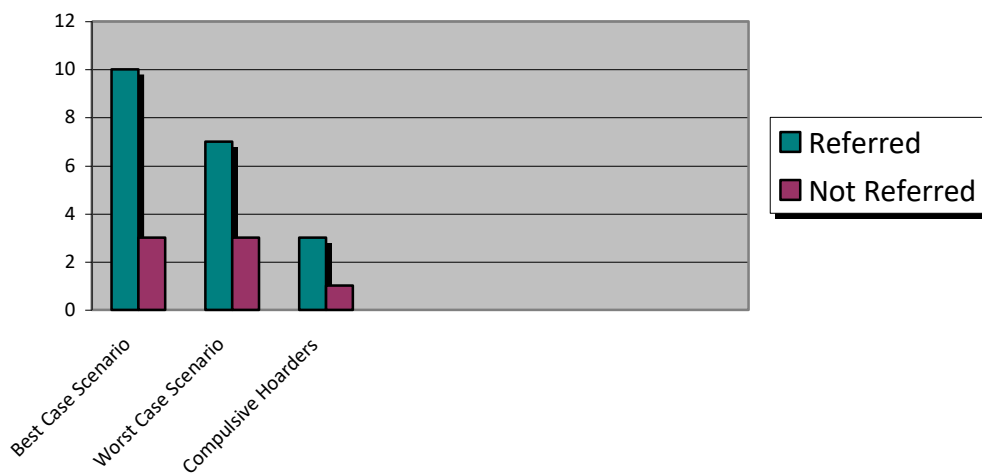
The use of the term 'intervention' was found to be unhelpful in determining the type of Mental Health support offered. Whilst a significant percentage of both professionals and Compulsive Hoarders responded that Mental Health referrals had been made, a small minority mentioned it as a 'most effective' intervention. Two professionals and one compulsive hoarder stated that it was the 'least effective' intervention. In the Qualitative portions of the questionnaire 'therapy' was talked

about by two Compulsive Hoarders.   The deduction made from this was that respondent's interpretation of 'intervention' did not equate with CBT. Instead the 'intervention' seemed to correspond to a Mental Health visit which would not have been the researcher's definition of psychological intervention; instead it represented a social one. This reasoning was substantiated by CH11's view that her involvement with Mental Health was a 'tick box' measure.

In regard to legal/social interventions as assessed by professionals, no BEST CASE SCENARIO PARTICIPANTS experienced ASBO or Child Protection issues were reported. Conversely four Worst Case Scenario clients had been threatened with ASBOs and five with eviction. One out of five Compulsive Hoarder respondents cited experience of potential Eviction and another one of five an ASBO. Combined data showed that three of five Compulsive Hoarders had children. One lost custody to their partner and the other was threatened with Child Protection orders as a result of the Hoarding.   From such a small pool of respondents these results support the existing data on frequency of social/legal interventions (Frost and Steketee 2000).

The ethical quandary as originally presented focused on the acceptability of denying people care because they posed a Health and Safety risk to themselves and others. In spite of the confirmation of the frequency of social/legal interventions the research produced, another dilemma was made apparent. Two out of five Compulsive Hoarders reported that they did experience some sort of legal threat. Conversely very few of the housing support workers indicated that this had occurred. The reasons for this might have been an interpretation of the word 'threat'. One Compulsive Hoarder said yes to both the threat of eviction and loss of their children, but when this was explored it was revealed that their spouse had threatened eviction and a helpline support worker misjudged a situation which resulted in Social Service attendance. No formal legal action was taken in either situation. It was acknowledged by the researcher that a lack of formal action would not have made the fear less for the person who experienced these threats.

The statistical data and qualitative interviews introduced the idea that although the Health & Safety risk was recognised, Compulsive Hoarding was primarily tolerated in deference to the person's Human Rights.

The Qualitative aspect of the questionnaire revealed similarities between professionals and Compulsive Hoarders thoughts on appropriate solutions. Frequently professional respondents who completed this section cited 'time', 'support', 'ongoing', 'relationship' and 'trust'. Alternatively 'force', 'threatening', 'demanding' and 'directive' were listed by professionals in response to least effective form of intervention.

A significant area of difference was found between professionals and sufferers in the area of whether Compulsive Hoarding could be defined as a significant Mental Health problem and/or disability in the Social Model framework. 100% of people who Compulsively Hoard said that the disorder was a significant Mental Health issue and a disability, although several qualified that as not necessarily true in all cases. Only 40% of professionals agreed with those statements. These data reflected the ambiguity and lack of consensus found in published materials about this subject. (Pinder 1997) (Shakespeare and Watson 1997)
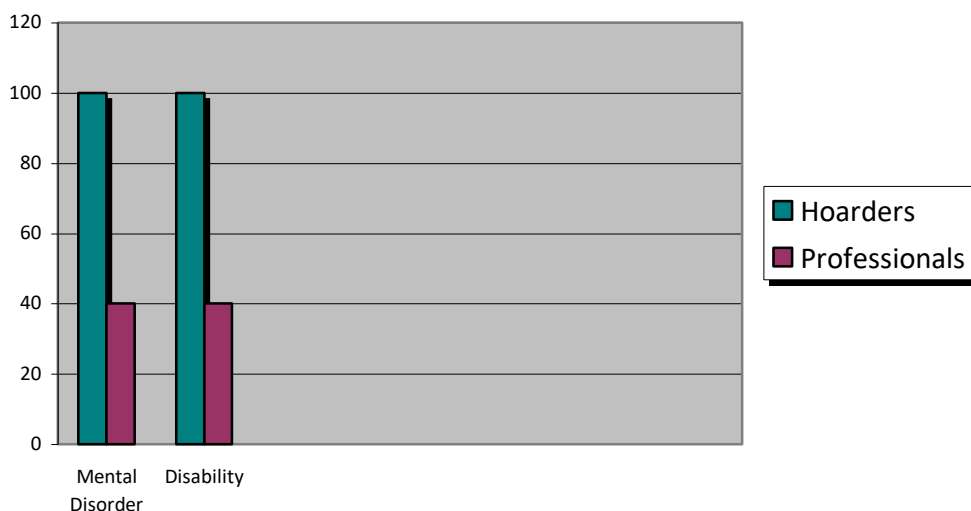
Hemmings and Singh both explored their roles in the context of a desire to work as a part of an integrated team of trained professionals, but CH 18 articulated it most

succinctly. "I believe a combination of good CBT (at the right time for the client/patient) together with 'Home Help' is the most effective treatment for Compulsive Hoarders. It also needs regularity in order to a) gather momentum after a slow start, b) prevent relapses c) provide encouragement for the Hoarder by witnessing their own progress and do this would, in turn, lead to a more positive outlook in being able to envisage a better future & the realm of possibility." (CH18)

This intervention was perceived to be effective, but when support ended the problem recurred. All qualitative respondents agreed that long-term ongoing support was likely to be required. The most resonant argument for this was made by Satwant Singh, MSc. "We need dedicated people trained in the area so that they can actually do outreach work. The main work needs to be done in the environment and that's crucial. Knowing that people are coming into a different setting doesn't get the point. That won't really help them deal with the problem as such."

Both professionals and Compulsive Hoarders discussed a coordinated support structure. Existing research on the benefits of a multi-disciplinary, integrated team of consistent support (Sorrentino 2007) was validated by the research.

None of the Qualitative interviewees were aware of the Social Model theory prior to the researcher provided definition. All agreed that it was a significant Mental Health disorder.

None of the respondents in housing support roles had received training in regard to Compulsive Hoarding.

Qualitative triangulation information interviews proved useful means of providing insight and understanding to the Quantitative data.

CONCLUSIONS AND RECOMMENDATIONS
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Whilst aspects of the initial proposal were invalidated as a result of having been wrongly conceived, some of the basic premises were confirmed through the research process. The Mental Health aspect was problematic in the management of care, although not for the reasons originally postulated. It was suggested in Perusa, et. al. (2008) that a clinical recognition for Compulsive Hoarding should be considered for DSM V. The researcher agrees this to be an important step forward.

The Health and Safety risk activated social/legal interventions, but the surprising finding was the fact that in spite of the risk, in the majority of cases, the person's right to live as they choose was deemed more important. Although seemingly a positive outcome, the researcher raised the issue as a result of a deep concern about the dangers posed. Ultimately ignoring this problem does not seem the way forward, but until such time that appropriate systems are put into place this appears to be the least worst option.

In Modernising the Social Model in Mental Health, Duggan (2002) explored the conflict between Service User's voices, 'clinical experience' and policy. (p. 3) In spite of disagreement about definition, the majority of professionals and Compulsive Hoarders believed that client led, supported interventions were the way forward.

None of the existing research about Compulsive Hoarding specifically explored the impact of training on outcomes, but in an Australian study identifies the first factor of CBT success as "specific skills, on-the-job learning and assessment, and recognized training with formal acknowledgment of skills in a qualifications structure" (Mulcahy and Pauline 1999). The impact of the lack of such support was made glaringly clear by CH28 "I have been searching for correct help/diagnosis for a variety of connected problems of which hoarding is the most obvious to other people (often the only problem that is believed) all of my life-well since 6, I am now 56." (CH 28)

The lack of awareness about the Social Model of Disability would benefit from more promotion. How can people protect their rights, if they are not aware that they have them? (Ramon & Williams 2005)

One of the most valuable outcomes in regard to moving forward was that the value of relationships in obtaining results, mentioned by so many, was reconfirmed. At times the researcher put too much faith in technology and resisted making direct contact. Once that hurdle was overcome, the support and enthusiasm for the project grew incrementally. As such there seemed a real potential that for this piece of Action Research to help create change.

This highlights Zuber-Skerritt's (1996) contention that Action Researchers "…should accept and welcome the point that since our writing emerges from a different set of relationships (collaborative and action-orientated, rather than authoritative and observation orientated)." (p. 25-26)

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