

Visual Research Methods: A Novel Approach To Understanding The Experiences of Compulsive Hoarders: A Preliminary Study

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Abstract

Objective: Compulsive hoarding is a syndrome characterised by excessive collecting and saving behaviour that results in cluttered living space and significant distress or impairment. This study set out to gain a greater understanding of the personal experiences of compulsive hoarders in addition to attaining their evaluations of attending a therapy group.

Method: Using a participatory photography methodology, a purposive sample of 12 members of a hoarding therapy group were recruited. Participants were asked to take photographs which best captured their hoarding problems. The photographs were then used to encourage narrative dialogue in a subsequent semi structured interview.

Results: Seven key themes emerged from the data including: Feelings of isolation and vulnerability, lifestyle disruption, losing and misplacing, clutter and metaphor, rationalisation of the acquisition of hoarded items, failed previous support and the benefits of a therapy support group.

Conclusion: The study concluded that the experience of hoarding is both psychologically and physically distressing with numerous impacts upon everyday living and relationships. The study also concluded that visual research methods may be particularly helpful when generating qualitative evidence within this specialist field.

Keywords: Compulsive Hoarding, Visual Methods, Qualitative, Experiences

Özet

Görsel Araştırma Yöntemleri: Kompulsif Biriktiricilerin Yaşantılarını Anlamada Yeni Bir Yaklaşım: Bir Önçalışma

Amaç: Kompulsif biriktirme, dağınık bir yaşam alanı ve anlamlı bir stres ya da bozulma ile sonuçlanan aşırı derecede toplama ve biriktirme davranışı ile seyreden bir sendromdur. Bu çalışma, kompulsif biriktiricilerin bir terapi grubunda yer almaları ile ilgili değerlendirmelerine ulaşmanın yanı sıra kişisel deneyimlerini daha iyi anlamak için tasarlandı.

Yöntem: Katılımcı fotoğraf yöntemi kullanılarak 12 kişilik bir biriktirme terapi grubu oluşturuldu. Katılımcılardan biriktirme sorunlarını en iyi tanımlayan fotoğrafı seçmeleri istendi. Bundan sonra fotoğraflar birbirini izleyen ve yarı yapılandırılmış olan görüşmelerde betimleyici bir diyalog oluşturulması için kullanıldı.

Bulgular: Verilerin incelenmesi sonucunda izolasyon ve hassasiyet hissi, yaşam tarzında bozulma, kaybetme ve yanlış yere koyma, dağınıklık ve metafor, istiflenen eşyaların toplanmasının rasyonalizasyonu, geçmişte yetersiz destek ve terapi destek grubunun yararlarını da içeren yedi anahtar tema saptandı.

Sonuç: Sonuç olarak bu çalışma istifleme davranışının hem psikolojik hem de fiziksel olarak zorlayıcı olduğu ve günlük yaşam ve ilişkiler üzerinde birçok etkisi olduğunu göstermiştir. Bunun yanı sıra görsel araştırma yöntemlerinin bu çalışma alanında kalitatif kanıt üretmede kısmi bir yardımcı olabileceği sonucuna varılmıştır.

Anahtar kelimeler: Kompulsif biriktirme, görsel yöntemler, kalitatif, yaşantılar

INTRODUCTION

Compulsive hoarding is a syndrome characterised by excessive collecting and saving behaviours that results in a cluttered living space, significant distress or impairment (Frost RO, Hartle T 1996). The hoarding syndrome exists along a continuum from normal collecting to a psychological condition that often compromising safety and quality of life of the individual, family and others. The items collected are often perceived to be useless or of limited value and precludes the individual's living space to be function for what it was intended for such as cooking, sleeping, cleaning. Interference with these functions makes hoarding a serious problem placing individuals at risk of falls, fire, poor sanitation and health risks (Frost et. al. 2000; Kim et. al. 2001).

The current status on the most appropriate classification of compulsive hoarding has had an important consequence in our understanding of hoarding and in many ways has been an obstacle to hoarding research (Grisham JR Norberg MM, 2010). Currently compulsive hoarding is classified within the OCD and OCPD disorder which has led to the underestimation of the significance of the burden of disease associated with compulsive hoarding, inconsistencies with the respect to appropriate clinical comparison group in hoarding research and difficulties comparing findings across hoarding studies. Compared to obsessive compulsive disorder (OCD) and many of its subtypes, compulsive hoarding has received relatively little empirical study (Tolin DF et. al. 2007) The majority of research conducted to date has been quantitative, emphasising treatment outcomes such as the serotonergic medication trials for OCD (Black DW et. al. 1998; Winsberg ME et al 1999), cognitive behavioural treatments for OCD (Mataix-Col D et. al. 2002; Abramowitz JS et. al. 2003), cognitive behavioural treatment therapy for compulsive hoarding (Tolin DF et. al. 2007; Steketee G et. al. 2010) and multimodal treatment (Saxena S et. al. 2002). More recently a study of cognitive behavioural therapy for geriatric compulsive hoarders (Ayers CR et. al. 2011) was conducted.

Other studies have included understanding the contributing factors of the development of this disorder (Landau D et. al. 2011) and exploring whether compulsive hoarding is a subtype of OCD (Steketee G et. al. 2005; Abramowitz JS et. al. 2008; Pertusa A et. al. 2008).

More recently studies have explored the effectiveness of support group therapy for hoarders,

using more novel approaches such as self help books (Frost RO et. al. 2011) which are perhaps an encouraging sign that a paradigm shift is occurring in our methodological choices for researching this subject. However, there remains a deficit in qualitative studies in understanding the experience of sufferers of compulsive hoarders.

The authors of the present study could find few referenced qualitative studies on compulsive hoarding and only one which utilised the media of photography or video. In a study of eight compulsive hoarders, Cherrier H Ponnor T (2010) used a video ethnography in the form of a documentary with their participants. Their study demonstrated the positive role video footage may have in advising and educating sufferers or those who wish to find out more about the disorder. Other qualitatively based studies, have explored the experiences of hoarders and how they find meaning in their compulsions. (Wilbran M et. al. 2008; Kellett S et. al. 2010). Both of these studies used semi structured interviews as the data collection method, which was transcribed and analysed using interpretative phenomenological analysis. Kellett S et. al's (2010) study identified four super-ordinate discrete, but interacting, themes were found: (1) childhood factors; (2) the participants' relationship to their hoarded items; (3) cognitive and behavioural avoidance of discard; and (4) the impact of hoarding on self, others and the home environment. The themes as a whole described people entrapped in massively cluttered physical environments of their own making. Efforts at discarding appeared consistently sabotaged by cognitive/behavioural avoidance, thereby creating maintaining factors of associated personal distress and environmental decline.

These authors could find so specific reference to exploring the experiences of compulsive hoarders using participatory photographic methods.

Visual Research Methods

Visual Research Methods are broadly described as those, which utilise the media of photography or video as a principal component of their data collection.

Since their inception in the late 1970's (Stasz C, 1979), the intention of such methods has been a specific attempt to balance power between participant and researcher. Moreover, the active involvement of participants in the research process has the potential to create new opportunities in knowledge generation and methodological development.

The use of visual images in generating narrative can be particularly powerful in engaging participants

in the research process, which perhaps explains its widening acceptance in a variety of health and social science arenas (Warren S 2005; Knoblauch H et. al. 2008.). Numerous studies link visual methods with “Participatory Action Research” most often carried out in rural and urban communities (Wang CC, Burris M 1994, Hergenrather KC, Rhodes SD 2008, Prins E 2010,) which is claimed to augment an empowering role for research participants and with it, the opportunity to bring about change in local policy and procedure. One of the best examples of such techniques is “Photovoice” (Wang CC 1999).

Photovoice allows participants to take photographs that address salient points in their life experiences and present them with a detailed narrative to either a group situation or an individual one to one interview. The principles behind this contemporary approach incorporate empowerment and reflection and again, the realignment the power balance between researcher and participant.

The power of the visual image can facilitate a smooth and clear communication of life experiences, expertise and knowledge. Photovoice, in a variety of applications has proved a popular and flexible methodology in a variety of studies of living with difficulty, especially so in the fields of living with HIV, disability and negative experiences of immigration (Streng J, Rhodes SD 2004; Rhodes SD 2006; Jurkowski J, Ward P, 2007). Interestingly a variant of these “participatory photography” techniques is the Photo-elicitation method, which involves the inclusion of a photograph during the course of an interview. This insertion of this media is governed by the researcher and may include archive images or images taken by the researcher themselves (Harper D 2002).

Given the complex nature of hoarding and the impact on life experience it may have for the individual, the researchers in the present study felt that the visual research approach would be a both a necessary and legitimate choice.

METHOD

This study set out to understand the experiences of sufferers of hoarding utilising a Participatory Photographic Methodology embedded within an interpretivist paradigm. The approach emerged as a hybridisation of established techniques such as Photovoice (Wang CC 1999) and the Photo-elicitation method (Harper D 2002) discussed earlier.

Ethical approval was sought and obtained, and a purposive sample of twelve attendees of a compulsive hoarders treatment group, who had a diagnosis of compulsive hoarding was recruited to the study. In qualitative research sample size is considered unimportant as the focus remains on meaning and not on generalisable hypotheses (Crouch M, McKenzie H 2006). On consenting to take part, participants were asked to take up to three photographs of their choice which best captured their hoarding problems. The photographs then formed the basis of a semi-structured interview lasting approximately 30 minutes.

Participants were given the freedom to choose paper photographs, or digital images captured on camera or mobile telephone media. To facilitate the flow of narrative throughout the interview process, the researchers used the acronym “HOARD” as an outline structure in the discussion of the participant’s photographs. Acronyms have been used in this way before, with considerable success; especially in community based participatory research (Hergenrather KC Rhodes SD 2008).

Interviews were digitally recorded and transcribed verbatim.

The “HOARD” acronym is identified in figure 1

Data were analysed using the framework analysis technique inspired by Ritchie J Spencer L (1994) which was the obvious choice when the researchers wished to give a detailed review of associated complexity balanced with holistic understanding. This analytical process consisted of a number of specific stages including:

Familiarisation: Which involved the researchers reading transcripts and listening to digital recordings repeatedly in order that they became fully immersed or we wish to describe as “being marinated” in the data.

Charting: Involving the previously indexed data into thematic chunks or headings which facilitates the easier identification of evidenced verbatim from participants.

Mapping and interpretation: Involved a visual representation of the themed data and the exploration of associations, the making of theoretic propositions from the data and exploring the potential for analytical generalisations (Yin RK, 1994).

Transcriptions and themed data were exchanged between the two researchers in an attempt to assess of theme reliability and as a means of validity enhancement.

Figure 1

The HOARD Acronym

- H** Tell me what HAPPENED in this picture?
- O** What would you like to OVERCOME and what are your goals?
- A** Can you imagine life without ALL of this stuff?
- R** How is your life and RELATIONSHIPS affected by this problem?
- D** What would you like to DO about it?

RESULTS

Seven key themes emerged from the data which captured the experiences of the participants. For the purpose of brevity, short extracts of qualitative evidence will be presented. One theme specifically explored the benefits that participants had derived from the therapy group they had been attending is discussed last.

Feeling isolated and vulnerable

Participants identified how their hoarding problems left them feeling vulnerable and isolated, especially with regard to allowing visitors into their homes.

"My biggest dread I don't drive is that somebody is going to bring me back in the car from somewhere and they are going to say to me "could I pop in to use the toilet".

"Well I can't have anyone around I have not had anyone around for years "

"Well I don't have anybody in the house apart from my two daughters who don't like coming"

" I used to have friends over for dinner; I used to have people stay none of that can happen anymore "

"I'm scared, I'm scared that if anyone comes to the house they will see all this stuff it is why I can never have anybody here"

Losing and misplacing

Participants reported their frustration at trying to find important documents amidst the chaos of their hoarding environment. This presented particular difficulties for them in the domains of having to pay for duplicate copies of documentation considered important.

"I am losing stuff all the time, I lost my passport"

"That's life as a hoarder.... it becomes very expensive you have to buy everything again pay triple

for things don't get done and even when I found the tax return form two weeks ago I said to myself I will put it somewhere safe, to use next week andthen I couldn't find it"

"Yes, just so I can find things, sometimes I spend an hour looking for a piece of paper....I spend a lot of time looking for things"

"Everything so jumbled and chaotic it means I can't find things when I need them"

Lifestyle disruption

Participants reported often dramatic changes to their lifestyle as a result of their hoarding.

"I'd get down on my hands and knees and I'd put cushions on the floor because it hurt my knees and I would crawl under the furniture that was wedged between the walls in the hall, these were chairs I had found in the street and there was things on top of them and things either side holding things up and it was literally a little space underneath that you had to crawl through and once you passed there you could stand up again, and then from there was only one option you had to go upstairs all the way to the top to the computer, and I'm talking about a five bed roomed house"

"This was the worst part of my life actually I'd have a rolled up mat and I'd unroll it in the top landing through the doorway because that's all the floor space there was. To open the door even a tiny wedge squeeze past ...maybe even put hand round to actually get in"

"Because there was nowhere to sit because everything was piled with stuff, walking from one end of the room was impossible"

"Everything has to be washed up and put away immediately, because the mice being there makes it more imperative have everything out of their reach, I can't even put it on a plate rack because they will get up there"

"I've stayed up all night to prepare for the gas man"

Metaphor and clutter

Participants used metaphorical language in the description of their hoarding experiences.

"It's just a barricade. And I have discussed it with other hoarders, because it is like a barricade really to stop other people coming into my life"

"It almost seems to be like a living mausoleum so it's very static"

"If I look along the length of my room, it would be a sea of stuff with tiny passages that's what it would look like. It is like a sea with tiny bits in it, like total chaos"

Rationalising the acquisition of hoarded items

Participants made numerous attempts to rationalize and almost justify why their environments had become congested with clutter and hoarded items.

"I buy because for a bargain price I just you know try to rationalize it and I think of that charity shop won't get very good money"

"I've worked from home for years and years, so this has contributed to my problem, because obviously through the door comes loads and loads of paper"

"But second hand you can buy 20 blouses for 40 pounds, ... so I do that"

"I always bought lots of things for my parents"

Failed previous support

Most participants reported that they had received previous help or support for their hoarding problems, but that these had been inappropriate, ineffective or not helpful.

"I was starting to give things away but I wasn't fast enough, and also a hoarding expert who came to help me, made me worse than ever"

"But what happened was the worker that came to my house felt like she wasn't making progress with me and without telling me or talking to me about it, because I'd missed an appointment and she's been off sick I was sick whatever I've forgotten she decided that I was avoiding her so she asked to be changed and let someone else have a try"

"Well I have tried over the phone support and I haven't found that it has shifted. I also had life coaching from three different people and that hasn't shifted it either."

"I have also have had one lot of CBT but we never got on the hoarding"

"They put this guy to be my care worker or whatever they were called, and this guy just filled me with dread. He was just like a psychiatric nurse, because I'd seen psychiatric nurses when my friend was in a psychiatric hospital and I felt that when he spoke at a meeting, if he came to my house he would just get the blitz team in and I couldn't even cope with the thought of that. He never called on the phone to see how I was, he never came to the house he was a total waste of time for me so I asked him not to come any more"

Beneficial group support

Participants commented positively on the benefits of the therapy group they had been attending, they made specific reference to practical, emotional, motivational and per support issues.

"And getting advice from the group leaders and from the other people in the group as to you know their struggles and how their achieving things and that firstly gives me ideas for things I can try and secondly gives me the helps with my sort of motivation to do it"

"Well the group leader gives you encouragement and sets what you have to do for the next month and offers encouragement he comes up with some basic suggestions"

"Yeah its I admit things more and I get more response, the more shameful things I admit the better it is because some of the people are very good. It's been wonderful, and I've had more support recently and that feels good after the group"

"I go away thinking gosh I must do something"

"I think hearing about other people's struggles and how they overcome it

secondly, gives me the helps with my sort of motivation to do it"

"For me it motivates me when you hear people making progress"

"Well it's been very helpful emotionally because the people in the group are very supportive"

DISCUSSION

This study concludes that sufferers of hoarding experience a variety of distressing limitations to their lifestyle and that these have the potential to have a profoundly negative impact upon their mental health. Moreover, these problems seem to be compounded by physically mediated issues such as poor sleep, the loss of comfortable surroundings in which to relax and concerns about the hygiene of living spaces.

This study also concludes that a therapy group for sufferers of hoarding appears effective in giving practical advice, offering peer support, providing motivation and emotional support.

Finally, this study has shown that Participatory Visual Research Methods appear well suited to undertaking research in this complex specialist area.

Similarities were found in the findings of the present study with work already discussed Kellett S et al. (2010).

However there were a number of unexpected findings from the present study which these authors believe could have arisen from the methodological choices taken.

Until now, much research into the complex phenomenon of hoarding has been quantitatively based (Tolin DF et al. 2007; Steketee G et al. 2010; Saxena S et al. 2002; Ayers CR et al. 2011) with perhaps, an emphasis on the development of outcome instruments such as the Saving Inventory Revised (Frost RO et al. 2004), Saving Cognitions Inventory (Steketee G et al. 2003) and the Clutter Image Rating (Frost RO et al. 2007).

While these instruments are exceptionally useful in guiding clinicians when making decisions about best evidence based treatment of sufferers, they fail to address the equally complex humanitarian and ecological aspects of hoarding.

We make a number of theoretical propositions from our data based upon the current lack of qualitative research available within this speciality.

Our study has identified that participants are cognizant of their hoarding problem and make little attempt to deny or trivialize it. The use of participatory photography serves as a means of further supporting this point, as one would expect participants to be reluctant to engage with such a method. Furthermore, participants report psychological benefit from the reinforcement of seeing photographs of their hoarding environment change over time, as they gradually begin to dispose of the unwanted clutter. This illustrates well the power of the visual image in supporting flow of narrative and engaging the participant in dialogue.

Furthermore, the participatory nature of the present study appeared to realign the power balance between the researched and the researcher, this we argue has contributed positively to the validity of our study.

Until now, little was known about the experiences of sufferers of hoarding from an emic perspective and we have confidence that qualitative methodologies will have an important part to play in our future understanding of this problem.

Limitations, recommendations and implications for practice

Despite being small scale and qualitative, this study has uncovered some interesting and thought provoking dimensions of the problem of hoarding, therefore making it a useful contribution to knowledge. We would recommend the extended use of qualitative and contemporary approaches to future research of

sufferers of hoarding as these essentially maintain the "person" as the focus.

Therapists and clinicians may wish to consider the benefits of hoarding therapy and support groups with activity based elements to engage participants with a visual and narrative dialogue about the way in which hoarding affects them and their lifestyle. This seems especially important given the fact that many of our participants reported previous negative experience of supportive interventions from their local agencies.

CONCLUSION

Compulsive hoarding is without doubt a distressing and exhausting disorder which can have a profound negative impact on many aspects of physical and mental health. This study has not only illuminated some of the experiences of sufferers, but also the benefit they reported from attending a group therapy.

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