Background: There is limited research into the experiences of receiving and providing help in the context of hoarding disorder. **Aims:** The present study aimed to explore the experiences of older people with hoarding disorder receiving help and volunteers providing support to people with hoarding difficulties. **Methods:** Qualitative methods were adopted to investigate the lived experience of participants. A total of 7 volunteer helpers and 4 people with hoarding disorder were recruited and interviewed using a semi-structured interview, designed to explore experiences of providing and receiving help. Qualitative analysis of the interview data was performed using Interpretive Phenomenological Analysis. **Results:** Four superordinate themes were identified: relationship between client and volunteer; 'live life again'; challenges; and supporting volunteers. The relationship was crucial in providing a trusting foundation from which clients felt able to move forward. Volunteers provided a space for clients to talk and appropriate self-disclosure helped to build a relationship. The informal and 'non-professional' status of volunteers enabled clients to take the lead and feel more in control of the therapeutic process. Volunteer flexibility and lack of time constraints contributed to clients 'making space' for themselves both in their home and their lives. The support from volunteers enabled clients to 'live life again' and created a domino effect, bringing about improvements in other areas of their lives. **Conclusions:** The findings are discussed in relation to the training of health professionals to work with people with hoarding difficulties and the implications of the findings for treatment approaches and service provision.

Hoarding disorder is characterised by "persistent difficulty discarding or parting with possessions" and "causes clinically significant distress or impairment in social, occupational and other important areas of functioning" (American Psychiatric Association, 2013). This difficulty results in the accumulation of possessions and causes living areas to become cluttered and their proposed use significantly compromised. Hoarding has been reported to result in economic, familial and social burden (Frost, Steketee, & Williams, 2000), along with creating feelings of shame and embarrassment that often prevents others accessing the home (Coles, Frost, Heimberg, & Steketee, 2003).

Studies have repeatedly reported evidence that symptoms of hoarding emerge in mid-to-late childhood (Frost & Gross, 1993; Grisham, Frost, Steketee, Kim, & Hood, 2006), with symptom severity increasing with every decade of life (Ayers, Saxena, Golshan, & Wetherell, 2010). Eckfield and Wallhagen (2013) reported significantly higher rates of hoarding in adults over 55 years old and evidence suggests that

older adults may have greater impairment in executive functioning compared to younger adults with hoarding disorder (Dozier et al., 2016). According to service providers, hoarding difficulties pose a serious physical threat to older adults (Kim, Steketee & Frost, 2001) and are significantly associated with concerns relating to health and safety in this population (Ayers & Dozier, 2015). For example, hoarding disorder has been found to increase the risk of falls, fire hazards, food contamination, social isolation and medication mismanagement in older adults (Ayers et al., 2010). Although there is high comorbidity with hoarding and other mental health conditions (Mataix-Cols et al., 2010), Pertusa et al. (2010) reported that there is an unwillingness amongst people with hoarding difficulties to acknowledge their problem as a mental health difficulty and to access help from services, consequently hoarding disorder is widely thought of as a difficult problem to help with (Tolin, Frost, & Steketee, 2012). Agencies who are responsible for supporting adults in later life provide a key route through which to identify and work with hoarding difficulties (Frost et al., 2000); however, evidence suggests that supporting elderly clients who hoard represents a significant challenge to services (Turner et al., 2010).

Psychological intervention studies have repeatedly reported modest successes and high rates of drop out when working with this client group (Stekete & Frost, 2007; Turner, Steketee, & Nauth, 2010). Ayers, Wetherell, Golshan, and Saxena (2011) recruited twelve adults aged over 65 years to examine the impact of a manualised cognitive-behavioural therapy (CBT) protocol for hoarding disorder. Although the findings revealed statistically significant changes to depression scores and hoarding severity, only three adults were identified as treatment responders and at follow-up their progress had not been maintained. Ayers, Bratiotis, Saxena, and Wetherell (2012) used a qualitative approach to explore therapist and patient perspectives of their specialised CBT protocol. The therapeutic relationship, exposure exercises and home visits were reported by patients to be most helpful whereas cognitive-behavioural formulations and techniques were not helpful. Therapists considered session and homework compliance to be critical to treatment outcomes.

The majority of studies investigating working with people with hoarding difficulties have focused on understanding the experiences of professionals and public sector workers. Negative and judgmental attitudes, as well as burnout, frustration and helplessness have been reported (Frost, Tolin, & Maltby, 2010). More recently, Holden, Kellett, Davies, and Scott (2016) explored the experience of professionals (e.g. social care, mental health, environmental health, fire service) working with clients that hoard. They found that professionals experience and approach their work in discrete and dissimilar ways, identifying three distinct clusters of professionals: therapeutic and client-focused, shocked and frustrated, and pragmatic and task focused.

Given the outcome data and reported difficulty of working with people with hoarding difficulties, it is important to understand the factors that act as barriers and facilitators in supporting them. Service constraints, including increasingly pressured finances, are causing services to seek new ways to support their clients. Evidence suggests that support from non-professionals may be helpful in enhancing clients' physical and mental wellbeing (Taft et al., 2011; Uhm et al., 2016). The present study aimed to explore the experiences of clients and volunteer helpers within the context of a UK-based charity providing support to older adults with hoarding difficulties.

Method

Participants and Recruitment

Participants were recruited through a UK-based charity that provides advice and assistance to enable older and disabled people to continue living independently. The charity's 'Making Space' project was developed to offer practical and emotional support provided by volunteers to older adults with hoarding tendencies. All volunteers receive a half day hoarding psychoeducation training as part of their induction. The support provided by volunteers is open-ended and sessions are tailored to meet the client's needs regarding frequency and duration. Although decluttering can be a focus of the support, volunteers primarily provide support according to the goals that clients are motivated to work on. A purposive sample of eleven participants from the Making Space project participated in the study. Four clients, who self-identified as having hoarding tendencies were interviewed in their own homes. Seven volunteers, including those who worked with the four clients in this study, were interviewed at the charity's office base. Ethical approval was granted by the University Ethics Committee (16-148).

All volunteers working for the project were sent an information sheet inviting them to participate in an interview about their experience of working with people with hoarding difficulties. Clients of the project were approached by the volunteer currently working with them or sent a letter inviting them to participate in an interview by post. All participants consented to take part in the interview and completed a demographic questionnaire.

To establish clutter severity, volunteers were also asked to complete the Clutter Image Rating Scale (CIRS; Frost, Steketee, Tolin, & Renaud, 2008), a self-report measure of amount of clutter in the home. The CIRS comprises nine photos of increasing clutter representing a kitchen, a living room and a bedroom. Each room is scored (1-9) and a composite score is calculated. A score of four and above is indicative of problematic clutter. To assess the presence and severity of acquisition, discarding and clutter behaviours, all clients completed the Savings Inventory Revised (SI-R; Frost, Steketee, & Kyrios, 2001), a self-report

measure of hoarding severity. The SI-R is a 23 item questionnaire with a total score of 92, a score of 40 or above is indicative of clinically severe hoarding difficulties.

Design

Qualitative methods were adopted to explore participants' experiences in depth and identify new concepts (Pope & Mays, 1995). Interpretive Phenomenological Analysis (IPA; Smith & Osborn, 2008; Smith, 1996) was considered a suitable approach for this study as it captures an individual's personal experiences and recognises that our experiences influence how we view the world around us (Yardley, 2000). IPA is concerned with an individual's subjective report, rather than formulating an objective account. It is a dynamic process whereby the researcher adopts an active role to take an insider's perspective and use their own conceptions to interpret information (Smith & Osborn, 2008; Smith, 1996).

Data collection

All interviews were audio recorded with participants' consent and lasted between 40 to 60 minutes. The interviews were transcribed verbatim and anonymised (V1-7; C1-4) to ensure confidentiality and privacy of participants. The interviews were semi-structured and aimed to elicit information about volunteers' experiences of providing help and clients' experiences of receiving help. When volunteers had worked with more than one client they were encouraged to consider all clients, rather than focussing on their experiences from one particular relationship. An interview schedule with open-ended questions was developed prior to the interviews using relevant research literature and was used to facilitate the participants' ability to tell their story in their own words, a central premise of IPA. Participants were encouraged to speak freely and openly about their experience and played a central role in the interview.

Analysis

The data from the qualitative interviews was manually analysed using IPA and classified and coded by key concepts, themes and emerging categories (Smith & Osborn, 2008). The background and stance of the research team was cognitive-behavioural, and interpretations of the interview data were taken from this position. Each interview transcript was repeatedly read and listened to. Initial notes and possible codes, summarising the experience described by participants, were noted in the margin. The transcripts were re-read and theme titles that emerged were noted. To maintain the phenomenological nature of IPA, key phrases and words from the interview data were used to describe themes. The same process was followed to analyse each interview and new theme clusters were checked against the original transcripts as they emerged to ensure foundation in participants' narratives and shared understanding. Themes were updated by shared meaning as the analysis progressed and a number of superordinate themes were identified. Themes with low frequency across participants or weak evidential base were discarded.

A number of validation methods and credibility checks were adopted. Regular meetings were held by the research team to ensure transparency of process and collectively move from data collection to final interpretations. The research team individually reviewed a sample of the transcripts which further helped the primary researcher to reflect on the development of themes. In keeping with the principles of IPA, the analysis presented is the researchers' interpretation of the data and other interpretations and perspectives are entirely possible.

Results

Sample Characteristics

All participants identified as White UK. The seven volunteers' ages ranged from 32-84 years and the four clients' ages ranged from 63-88 years. All clients identified that they had a problem accumulating and discarding numerous possessions and had never sought professional help for their difficulties. Volunteers had worked in the project for an average of eleven months (ranging from 4-24 months) and had worked with an average of two clients each (ranging from 1-4). Only one volunteer had previous experience of working with people with hoarding difficulties, describing their experience as "limited". Additional sample characteristics are provided in Table 1.

[Table 1 about here]

Ratings on the CIRS (Frost et al., 2008) confirmed that clients who volunteers had worked with and referred to were compulsive hoarders. A score of four or more on the CIRS was reported by volunteers across the three room areas of kitchen, living room and bedroom (ranging from 4-9). Three of the four clients interviewed scored in the clinically significant range on the SI-R (40 or above; Frost et al., 2001) at the time of interview; however, it is noted that clients reported that their scores would have been higher at the start of their contact with volunteers. The mean number of session reported by clients was 21 (Range: 15-25) with sessions typically lasting 1-2 hours.

Qualitative Analysis

Four superordinate themes were developed: relationship between client and volunteer; 'live life again'; challenges; and supporting volunteers (see Table 2). All eleven participants provided example quotations of themes, ensuring adequate coverage across participants. Each theme will be discussed in turn using direct quotations to illustrate them.

[Table 2 about here]

Relationship between client and volunteer

Volunteers described that "*a lot of the early visits were in effect building up a relationship"* (V1), as well as a consensus that helping the client "*wouldn't happen if the relationship wasn't there"* (V7). Clients and volunteers both highlighted the importance of there being space to talk, where clients had someone to talk to and felt heard:

> *We spent a lot of time just, talking really, not necessarily about her belongings, but just talking in general. And, I think that, that helped her...I just listened…we had a bit of a laugh together*. (V5)

> *Having someone to talk to certainly makes you feel an awful lot better about going through everything and facing one's demons or one's embarrassment.* (C1)

> *We sit and chat…I find (volunteer) coming to chat just as important, just as helpful as the work (volunteer) does, because I can talk…we get on well, it's very easy, I can be myself with (volunteer).* (C2)

Shared interests or experiences, as well as appropriate self-disclosure and an open and personable style from volunteers helped to build a relationship with clients:

> *Having that relationship and similar life experiences, we've been able to engage with each other…I do think that me being myself helps a lot.* (V7)

> *Our interests are very similar. I love doing crafts as well so when she is talking about making things it is something that we can share, and I think all those things are important to her.* (V2)

Volunteers and clients emphasised the importance of their informal and 'non-professional' status in their ability to build a relationship and trust with clients:

> *I think being volunteers…I think they kind of appreciate that we're there because we want to be, not that it's our job…it's that kind of approach we take where it is really kind of informal, it's not official, there's not a huge gap between us and them so that helps with the trust.* (V7)

> *There's a separation between us and the local authority, or health professionals, mental health professionals, because they sometimes see those people as the boss or the people who are putting pressure on, the people in charge. They see us as more of a friendly face.* (V3)

> *I would say I trust (the charity). Big word, you know, trust, you can't apply it to many things*. (C4)

The ability of volunteers to be flexible and take their time was also identified as an important part of the relationship that developed:

> *I think the fact that we use volunteers. We're not on a time schedule…I think that is the joy of volunteers! We have the time or we can make the time whereas somebody in paid employment, there is only so much they can do*. (V7)

> *We are not a professional…whether you are a doctor or a psychiatrist or psychologist you come with a label, so we're not a professional…and I think we just have time and flexibility, which sadly professionals don't because they have so many other things to do.* (V5)

A further aspect of the relationship between client and volunteer was clients feeling able to take the lead and be more in control of the therapeutic process:

> *We sit down, have a chat and I'll then say "now come on (volunteer), we'll do something"…And then (volunteer) comes and does a bit more with me. Always with me, always with…(volunteer) never pushes me*. (C2)

> *I accepted that I was a hoarder…I was up for it…It's always me to say "enough of the chat, let's get on with something"…so it's very much led by me and it's never, it's never led by what (volunteer) thinks we ought to do or what I should give away…it's all written down on forms as to where I want everything to go so I'm in control, which is brilliant.* (C1)

This stance was echoed by volunteers, who identified that "*you are very much guided by the client*" (V6) and "*we are there specifically to help them at their own pace…we haven't got targets to meet*". (V7)

'Live life again'

Participants described how the project "*enables people to live their lives again…to get to a better place in their lives…to have hobbies…and make friendships*" (V3). One client described how the support he received "*means we can stay in our home*" (C2). Others described how the support from volunteers enabled clients to make space:

The most helpful thing has been being able to enjoy her home again…it's changed her life really I think…it was having huge impacts on her mental health and her mental wellbeing and being able to walk around and kind of have that clear space has given her that clear mind…she doesn't feel the need now to buy things and collect things and fill that space again. (V3)

I mean all of these bags and stuff have been sorted through and it's all here so I can get to things…It's a way of sorting out life…it's sorting out your life as well as your belongings…I'm aware that it's going to be a long process, I mean, there is a lot of other stuff that is going to have to go and be sorted through. But there is now light at the end of the tunnel, because the journey has been started. (C1)

In addition to making space, clients described feeling supported and noted improvements to their overall psychological wellbeing and quality of life as a result of input from volunteers:

The difference is amazing…they have made an incredible psychological difference…it has given me back my, some self-respect. It's made me more positive. It's given me a purpose in life, it has potentially given me a way of making money…I can now stand up for myself more, it has given me confidence, self-confidence as well as self-respect…it's been life changing. It has been incredible. (C1)

It means sanity really…in terms of me, the impact on me is massive…you would go under, you would go under somehow (C4)

It helps us to cope with work I couldn't do on my own. If I tried to do this, well, I'd never get through! (C2)

Participants described how support from volunteers created a domino effect, enabling clients to address problems in other areas of their lives:

It has had such a wonderful knock on effect because she's being really resilient and is sorting out a lot of different problems in her life. (V2)

It's been a learning curve for me as well…I'm learning that, things that used to worry me, even a few months ago, I find I can just take it in my stride, keep things in perspective. (C2)

It enabled her to start something that she actually wanted to do but didn't know how to do it. (V3)

> *It's made a massive difference…I have gone through a stage of evolution really, so originally it was the decluttering…I've had to sort of move another area in my mind…instead of just decluttering, during the period you have been helping me, I haven't gone under.* (C4)

Volunteers also described a sense of fulfilment and achievement from their work supporting clients, as well as a motivation to address difficulties in their own lives:

> *I am a people person, so, you know, I do, I do get quite a lot out of it…I do find it satisfying, rewarding…and exciting.* (V5)

> *It makes me happy because I'm retired and I like something to do…we do it because we feel we are doing something useful and, it keeps us busy…I like to be involved and doing things so, that ticks that box rather well.* (V1)

> *I enjoy it…it's exciting and I actually am interested in, sort of, the Psychology side of it…It has motivated me to do more clearing, so yes, I'm probably, yeah I'm gradually reducing the amount of stuff that I have, which is good.* (V6)

Challenges

Participants described feelings of shame and embarrassment about the state that their home was in, as well as experiencing challenges with the physical environment that hindered the development of the therapeutic relationship:

> *I was so, ashamed and embarrassed about the state that it was in. And I used to worry for days ahead about people, who were coming in…I would start panicking seriously up to a week ahead, and hardly sleep the night before.* (C1)

> *When I actually came to work with a client, I probably hadn't appreciated some of the, it's not health, but sort of hygiene aspects to the work…the moth infestations, it was a real challenge at times.* (V6)

All participants reported difficulties in discarding possessions, including difficulties with access and having enough room to work:

> *Getting in the house! To manoeuvre into the front door to go into the room, the access to the room was difficult.* (V4)

I had a bag for recycling, a bag for charity, which actually from a physical point of view is very difficult when there isn't much space. So to find enough room, to put the bags, to collect all the stuff in, and actually to just take the first suitcase out… (V6)

In terms of me clearing stuff out, it's sporadic in a way, it's quite difficult for me to concentrate on certain areas because it is everywhere really. (C4)

Letting go of possessions was also challenging for clients and was exacerbated by the physical limitations of some clients and volunteers:

He couldn't actually manoeuvre things…There were practical difficulties because of his stroke…my hearing isn't absolutely perfect so it was slightly difficult to engage with him. (V1)

Her main barrier was her health and her ability to move, so trying to encourage her to make space during the week when I wasn't there is not something that she could do. So I think her health and mobility was, yeah, a real barrier for her. (V7)

The thing that makes it difficult is actually getting rid of belongings…it's so traumatic…it is just so difficult for them, they just get so panicky and anxious…it was just too overwhelming for her…I think the challenging thing was, that she did find it very painful to let go of stuff. (V5)

However, one client described how her difficulties lay in finding a home for her discarded belongings:

I had a pile of VHS tapes and you can't get rid of them. They charge you, the shops won't touch them. (C3)

Finally, volunteers provided a number of examples of uncertainty about their work with clients and feelings of being kept 'at arm's length':

I never really knew whether I was going to get in or not…never quite sure if I would be let in…I was never really that confident, you know, of carrying on…The other frustrating thing is that she would move stuff around, so I was never quite sure what was happening! (V5)

What I found challenging was whether what they were saying was true. (V1)

I sort of found it a little, sort of, frustrating that she did in once sense keep me at arm's length…she was very suspicious about things. (V5)

> *Her paranoia about certain things...It's taken a long time to get that trust with her. And that was a barrier but that's something I had to just kind of keep plugging away at.* (V2)

Supporting volunteers

Volunteers described a desire for additional training on the psychological aspects of working with people with hoarding difficulties, as well as training on how to manage some of the more practical aspects of the work:

> *Having had practical experience, there are aspects that would be useful to include like manual handling, talking about sort of the hygiene aspects…I think probably we could do with a little more awareness or training in terms of how we deal with it*. (V6)

> *I'd like a little bit of training around the psychology of everything I think… just some guidance around those things, about how to deal with someone in this situation*. (V3)

They also described the possibility of more joint working, including the possibility of developing a peer support group amongst volunteers:

> *I think that's quite important, two volunteers to go together. It would help because um, they may see things you don't…if you've got somebody who can go if you can't go for instance…two people see things differently*. (V4)

> *I think that is absolutely key to the volunteers, to be able to offload it…There's a lot of Psychology involved in all this. It would be wonderful if there was opportunity for that sort of discussion.* (V1)

Discussion

Little attention has been given to the experiences of individuals with hoarding disorder receiving help and those that provide help. Understanding the factors that act as barriers and facilitators in supporting people with hoarding difficulties may be an important part of the solution to supporting people and increase service provision in the future. To this end, four key themes were identified in the current study. The relationship that formed between client and volunteer was crucial in providing a trusting foundation from which clients felt able to move forward. Volunteers provided a space for clients to talk, and reported that appropriate self-disclosure helped to build a relationship. The informal and 'non-professional' status of volunteers enabled clients to take the lead and feel more in control of the therapeutic process. Volunteer flexibility and lack of time constraints were also seen as important and contributed to clients 'making space' in their lives and in their homes. The support from the volunteers enabled clients to 'live life again' and created a domino effect, bringing about improvements in other areas of both of their lives. Shame and

embarrassment represented a significant barrier to clients, as well as practical challenges in doing the work through lack of space or physical limitations.

The current findings mirror previous research highlighting that people with hoarding difficulties report the therapeutic relationship as an important feature of the help they receive (Ayers et al., 2012). Having space to talk, where clients had someone to talk to and felt heard was helpful in clients feeling less isolated. Kim, Steketee, and Frost (2001) reported that people who hoard often experience social isolation and therefore input from projects, such as the one described in the present study, may help to broaden clients' horizons and reduce their sense of isolation. The clients and volunteers reports suggested that developing a relationship where the focus is at least initially on the person and their interests, rather than the acquisition and discard of objects, has the potential to create a space for change and bring about improvements in quality of life.

Although the importance of developing a therapeutic relationship is not new, this study highlights the significance of the 'non-professional status' of volunteers, which is consistent with previous findings that non-professionals may be helpful in enhancing clients' physical and mental wellbeing (Taft et al., 2011; Uhm et al., 2016). This has significant implications for services where their very status as 'professional' may act as a barrier to people with hoarding disorder engaging with them. Statutory services could therefore look to collaborate with third sector/charity organisations to offer peer/volunteer support alongside mainstream services or alternatively to offer peer/volunteer support as part of a multidisciplinary service provision. Evidence from the current research highlights the resource effectiveness and benefits to both clients and volunteers by working in this way. However, the study highlighted the importance of ensuring volunteers feel supported in their work and mentoring or peer support may help to facilitate this. Moreover, the findings indicate the need for all people providing hoarding support to receive comprehensive training relevant to their role and highlights the importance of continued involvement of competent others to support and supervise the work of volunteers.

Control is an important factor in hoarding disorder (Raines, Oglesby, Unruh, Capron, & Schmidt, 2014) and the findings of this study provide further support for this. Clients reported feeling in control enabled them to feel able to start sorting and discarding their possessions. Volunteers in this study were also sensitive to the need of their clients to take the lead and feel in control regarding their possessions. This may help to both understand the reluctance amongst people with hoarding difficulties to seek help from formal services (Pertusa et al., 2010) and the importance of the 'volunteer' status in enabling a helping relationship to develop. Compared to working with mental health, social care, housing and environmental health services, for example, volunteers are less likely to be perceived as being in a position to threaten or remove the control that people with hoarding disorder have over their possessions. This is a difficult

problem for services to solve. Given the complexity and challenges associated with hoarding disorder that many professionals report in their work (Holden et al., 2016), the current research highlights the importance of taking time to build a therapeutic relationship and that appropriate self-disclosure and discussion regarding shared interests can help to support this. Professionals may therefore benefit from making changes to their practice to adopt this approach; however, these changes are contingent on service providers recognising the value in this approach and creating space for professionals to work in this way.

The present study has a number of methodological limitations. There was a dominance of female volunteers in the sample but this reflected the demographic of the volunteer pool. In light of the small sample (eleven participants: 4 clients, 7 volunteers) and recruitment from one organisation, the findings may have limited generalisability. Purposive sampling was adopted as the study aimed to explore the experiences of providing and receiving help within a small UK-based charity; however, it may be argued that those who agreed to participate were more motivated to share their experience and clients experiencing greater shame and embarrassment may have unintentionally been excluded (Kellett, 2007). In spite of adopting a number of validation methods and credibility checks, the analysis presented is the researchers' interpretation of the data and other interpretations and perspectives are entirely possible. A strength of the study is that all participants completed established hoarding measures of either the SI-R (Frost et al., 2001) or CIRS (Frost et al., 2008) to confirm the presence of hoarding difficulties, which has been a limitation of some of the qualitative research conducted within the field. This study is also the first study to directly explore the experiences of people with hoarding difficulties receiving support and volunteers providing help. The present study did not focus on helper-helped dyads but this would be an important extension in future research to further investigate the therapeutic relationship between people with hoarding difficulties and those providing care.

Conclusions and Implications

Hoarding disorder continues to present significant challenges (Tolin et al., 2012), as well as economic, familial and social burden (Frost et al., 2000). The present study offers insights into how this could be improved and in particular highlights the importance of taking time to develop a therapeutic relationship and adopting a flexible and informal approach. By adopting this approach, this study found that volunteers with minimal training and people with hoarding difficulties can develop meaningful and supportive relationships. Volunteer or peer support may represent a useful addition to the multidisciplinary team approach. Future studies would benefit from adopting this approach on a larger scale.

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