Behavioural and Cognitive Psychotherapy, 2023, page 1 of 13
doi:10.1017/S1352465823000425

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'A more human approach . . . I haven't found that really': experiences of hoarding difficulties and seeking help

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(Received 2 May 2023; revised 3 August 2023; accepted 11 August 2023)

Abstract

Background and aims: People with hoarding behaviours often struggle to engage in treatment. This study aimed to explore the experiences of a sample of people who identify as engaging in hoarding behaviours and who are seeking support. Exploring motivation to seek help, the barriers those who hoard face in accessing support and what facilitates accepting help, can aid understanding of how best to intervene.

Method: Eight individuals who self-identified as seeking help in relation to hoarding behaviours were recruited via social media and support groups. Interviews were conducted by telephone or video call, before being transcribed and analysed using interpretative phenomenological analysis.

Results: Participants described complex help-seeking narratives and reported continued ambivalence about addressing their hoarding behaviours. The four group experiential themes identified were Wrestling with identity; Who can I trust?; Services don't fit; and Being overlooked: 'they're too busy looking at the thing, not the person'. Difficulties trusting others and services were identified; services were experienced as rejecting and many participants sought help for problems other than their hoarding. Problems accessing appropriate help for hoarding were predominant in the narratives, although participants who had accessed peer support described this as valuable.

Conclusions: There are both internal (e.g. fear of judgement; feeling overwhelmed) and external (e.g. service gaps) barriers that make finding useful help for hoarding behaviours very difficult. Services may facilitate those seeking help by taking a compassionate and person-centred approach to hoarding problems.

Keywords: Help-seeking; Help-seeking intention; Hoarding; Mental health; Service-users

Introduction

Difficulties with hoarding can have a significant impact on individuals and those around them. Hoarding involves an accumulation of possessions that affects functioning and can cause significant distress or impairment, with diagnostic criteria focused on the extreme difficulties around discarding hoarded objects (American Psychiatric Association, 2013; World Health Organization, 2019). Emotional attachment to, and important personal meaning of, the hoarded objects is widely documented (Kellett *et al.*, 2010; Kings *et al.*, 2020; Roster, 2015). Tolin *et al.* (2008) explored the social and economic effects of hoarding behaviours, noting occupational impairments, co–morbid health issues, threats of eviction and, in some cases, children or vulnerable adults' removal from the home. Familial impact is highlighted in Büscher *et al.*'s (2014)

scoping review, which described the 'shattered families' of people who hoard. Hoarding behaviours have been subject to media attention (Discovery Studios, 2010; Screaming Flea Productions, 2009) as well as explored in clinical and research literature.

The prevalence of hoarding disorder is around 2.5% of the population in the mostly European countries for which good data exists (Postlethwaite *et al.*, 2019) but levels in the community may be higher (Samuels *et al.*, 2008). Despite this prevalence there are no specific treatment guidelines from the National Institute for Health and Care Excellence (NICE), with hoarding only mentioned as a possible complexity of obsessive-compulsive disorder (National Institute for Health and Care Excellence, 2005). Cognitive behavioural therapy (CBT) is the most recognised approach to the presentation. Treatment aims to enhance motivation to discard objects, develop skills in organising and problem solving, reduce acquisition, enable discarding and promote relapse prevention (Steketee and Frost, 2014). A meta-analysis of CBT interventions reported pre- to post-treatment effect sizes of 0.82 and 0.70 for hoarding severity and clutter, respectively (Tolin *et al.*, 2015) and a more recent meta-analysis (Rodgers *et al.*, 2021) found larger effect sizes with some evidence of maintenance of improvement. Despite these medium-to-large effect sizes, many people leave treatment with remaining difficulties: there are low levels of clinically significant change across all outcomes, particularly in relation to clutter (Tolin *et al.*, 2015). People with hoarding behaviours may be more likely to drop out of treatment than others with obsessive-compulsive difficulties (Mataix-Cols *et al.*, 2002).

People with hoarding behaviours are also unlikely to present for treatment voluntarily and have been described as having poor treatment compliance (Robertson *et al.*, 2020; Worden *et al.*, 2014). Bratiotis *et al.* (2016) explored requests for hoarding treatment information, finding that most were from carers or clinicians: only 30% of requests came from individuals who identified as hoarders, and of those, only 34% contacted to seek help or treatment. Considering service-users' perspectives, Rodriguez *et al.* (2016) explored the acceptability of hoarding treatments via online survey. Individual CBT, professional organising and self-help books were the options that (narrowly) met the acceptability threshold. Acceptability was linked to personalised support, accountability promoted and the respondents' beliefs that the treatment would be effective.

Few studies have explored the experience of seeking treatment or support from the perspective of people who hoard. Ryninks *et al.* (2019) interviewed older adults receiving practical and emotional support for hoarding behaviours and highlighted the importance of the relationship between client and volunteer, the client feeling in control, and the process feeling 'client-led'. Challenges to receiving help were identified, with subthemes including shame, embarrassment, and clients' difficulties in discarding items. In summary, people who experience these complex and debilitating difficulties seem to struggle to engage with services, therefore the British Psychological Society's Division of Clinical Psychology (2015) recommend further research, particularly in relation to improving engagement with services. The current study explored how individuals became motivated to change their behaviour or to seek help as well as their experiences of the help offered.

Method

Design

Eight semi-structured interviews were conducted to capture the experiences of adults seeking help for hoarding. The topic guide covered participants' relationship with their hoarding behaviours; their motivations to seek help; their perceptions of support; and the barriers to and facilitators of seeking support. Interview data were analysed using interpretative phenomenological analysis (IPA). The sample size was based on guidance by Smith *et al.* (2009).

https://doi.org/10.1017/S1352465823000425 Published online by Cambridge University Press

Recruitment and procedure

All recruitment materials were reviewed by a service-user panel and an individual with hoarding behaviour. Consultation focused on the language used concerning hoarding behaviours in these materials and in the interview. The study was advertised on a hoarding charity website (Hoarding UK, 2022) and Twitter. Study information was disseminated by facilitators of support groups across the UK.

Adults over the age of 18 who self-identified as seeking support for hoarding behaviours were eligible. As hoarding difficulties commonly occur alongside other conditions, there were no exclusion criteria relating to co-morbidity.

Potential participants were emailed a participant information sheet and had opportunity to ask questions before consent was taken. All those who requested information about the study went on to participate and have provided informed consent for the use of their anonymised data in publication. Due to COVID-19 restrictions all contact with participants was remote, with one online video and seven telephone interviews (determined by participant's preference). The majority (6) of the interviews lasted around 50–60 minutes, with two taking longer (approximately 100 minutes). Recordings (one video, seven audio) were transcribed for analysis.

Data analysis

IPA is a phenomenological approach that was appropriate for the research aim: making sense of the participants' help-seeking experiences and the meanings attached to them. Analysis began on an individual level and followed the step-by-step approach described in Smith and Nizza (2022). Two interview transcripts were coded by two of the team to verify agreement in relation to keywords and statements within the data. Tables of personal experiential themes were created, detailing the experiential statements contributing to each theme, with corresponding quotes. These were used for the group analysis stage: a search for similar and contrasting themes in the individual data. Throughout analysis, the research team considered, debated and agreed themes, ensuring findings remained true to the data.

Quality

Findings based on a small sample and subject to the interpretation of the researchers may lead to questions around validity and quality. This study considered Yardley's four principles of trustworthiness (Yardley, 2000). *Sensitivity to context* is demonstrated through exploration of the existing literature, consideration of ethical issues, choice of approach and sensitivity during interviews, analysis and write-up. *Commitment and rigour* were achieved through immersion in relevant literature, careful sample selection, effective and considerate interviewing, and commitment to the analytic approach (i.e. participation in IPA training and supervision). *Transparency and coherence* are evidenced through the clear presentation of data and descriptions of the research and analysis process. Finally, *impact and importance* is demonstrated in terms of adding to a limited literature, as well as the practical and clinical impact of a greater understanding of hoarding disorder.

Reflexivity

IPA takes into account the knowledge, experience and epistemological stance of the researcher and highlights the importance of reflexivity. As stated by Smith *et al.* (2009), ongoing awareness and exploration of personal ideas throughout the planning and execution of the research are key. Before interviewing participants, MMcG engaged in a reflective interview to explore the assumptions and expectations that had resulted from her clinical work with people with hoarding

https://doi.org/10.1017/S1352465823000425 Published online by Cambridge University Press

Table 1. Participants' demographics and support received

Pseudonym	Demographics	Self-described help received
JB	M, 50s, lives alone in private rented home	Coaching group; private counselling; OCD/hoarding support group
GD	F, 60s, lives alone in private rented home	Private counselling; MH services; liaised with, but did not participate in, TV programme; OCD/hoarding support group
TC	M, 30s, lives alone in rented social housing	GP (medication); MH services – CBT; Housing support worker; OCD/hoarding support group
AN	F, 70s, lives with partner in owned home	GP; IAPT services – CBT and EMDR; charity advocacy; private counselling; research participation; liaised with, but did not participate, in TV programme; OCD/hoarding support group
RO	M, 30s, lives alone in private rented home	GP (medication); MH services – CBT; OCD/hoarding support group
DS	F, 40s, lives alone in rented social housing	GP; primary care counselling; CBT (for depression); MH telephone support; self-help books; OCD/hoarding support group
PB	F, 40s, separated and in custody dispute, lives in owned home	Social services – intervention enforced; decluttering support organisation; counselling (both private and NHS)
VI	F, 60s, lives alone in owned home	GP; MH services – psychological therapy; TV programme; charity website

behaviours. Reflective notes were taken throughout the study and discussed regularly within the research team and in IPA workshops. These highlighted assumptions about participants' relationships with professionals being challenging, particularly around de-cluttering, and that pressures in the mental health system in the UK would result in people feeling that effective treatment was not available.

Results

Participants

Eight adults who self-identified as having hoarding difficulties and having sought help took part in the interviews (see Table 1). Participants varied in descriptions of their hoarding behaviours (see 'Wrestling with Identity' theme). Participants also varied in their ability to differentiate or describe clearly the help they had received. An unexpected complication in the narratives was that, despite self-identifying as seeking help for hoarding, only one (AN) had specifically requested intervention for hoarding from NHS services. The narratives of others were more complex. Some had actively avoided mental health services or confiding in health professionals (see *Fearing mental health labels* and *Trusting others with the reality of hoarding: being judged* subthemes). Others had interventions enforced due to their family's (RO) or statutory services' concerns (PB).

Findings

The group experiential themes and subthemes are described below and are illustrated in Fig. 1. Table 2 shows each participant's contribution.

Wrestling with identity

This theme encapsulates the struggles as participants described conflicting attempts to define and address their hoarding behaviours.

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Table 2. Group experiential themes and subthemes with each participant's contribution

Group experiential theme	Subthemes	JB	GD	TC	AN	RO	DS	PB	VI
Wrestling with identity	'Fortress' or 'prison': the relationship to 'stuff'		√	√			√	√	√
	Is there a problem? 'The H Word'	√	√	√		√	√	√	√
	Fearing mental health labels	√							√
Who can I trust?	Trusting others with the reality of hoarding: being judged	√	√	√	√	√	√	√	√
	Trusting support groups: 'a whole new world'	√	√	√	√	√	√		
Services don't fit	Falling between services: not ill enough or too ill for help		√	√	√	√		√	√
	Searching for the right support: 'It wasn't geared towards me'	√	√	√	√	√	√	√	√
Being overlooked: 'they're too busy looking at the thing, not the person'	Clearing under pressure: 'It is almost like being bullied'	√		√		√	√	√	√
	Overwhelmed by the task: 'How do you do it? Where do you start?'	√	√		√		√	√	√
	'Emptying the bath while the tap is running': finding the right starting point		√		√		√	√	

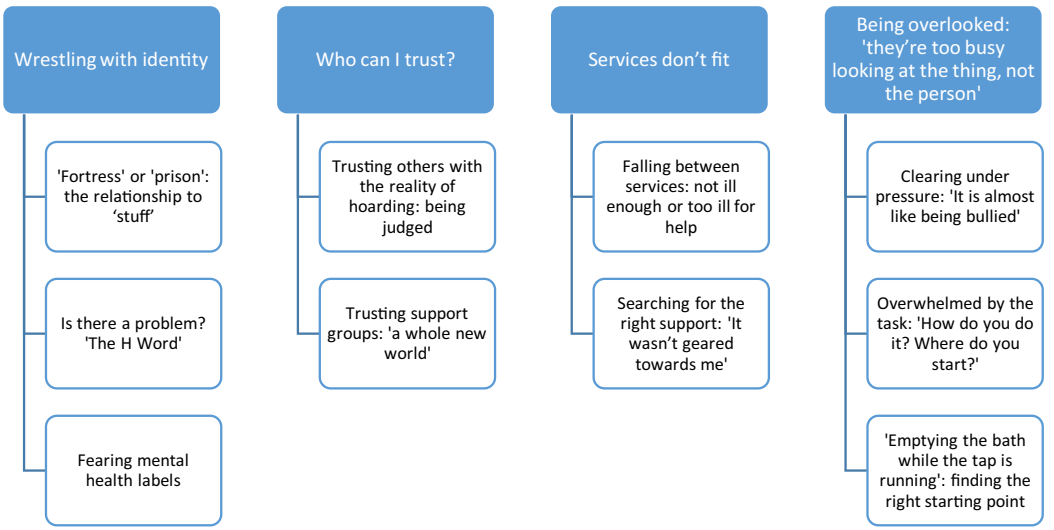

Figure 1. Group experiential themes and subthemes.

'Fortress' or 'prison': the relationship to 'stuff'

Participants reported contradictory experiences in relation to their possessions, which provided safety but also caused problems. GD expressed this: '*my little . . . fortresses, for any situation. And now it's become like a little . . . prison's the wrong word; it just, it feels like a sort of security net*'.

TC also described conflict, identifying that hoarding protected him from significant change, in this case moving from his parent's home to his own accommodation: '*maybe subconsciously I didn't want to throw it away, because if I threw it away that meant I had to move out*'.

PB very explicitly detailed the restriction and negative impact her possessions had: '*I felt trapped. I felt trapped by the house. I felt trapped by the situation. I felt trapped by the stuff*'. Yet, even when fantasising about a solution, the relationship with possessions continued to be a

https://doi.org/10.1017/S1352465823000425 Published online by Cambridge University Press

significant pull '*it got to the stage where I could've happily just locked the door of my house and walked away. Apart from the fact there was stuff in there I still wanted*'.

Is there a problem? 'The H word'

Contradictory positions were also expressed in how participants defined themselves and their behaviour. This was unexpected, as all participants had self-identified as having hoarding difficulties, but there were clear differences in how participants used terminology around hoarding. Some could apply the label to others, but only three referred to themselves as a 'hoarder'. Several predominantly used hoarding as a verb: a behaviour they happened to exhibit. Some repeatedly referred to 'the hoarding' or their 'issues with hoarding', suggesting a sense of distance between themselves and the problem, whilst others struggled to say the word at all, which led to the title of this subtheme. RO switched positions throughout the interview, at times describing it as only a problem for others: '*For them it was a problem … I always thought "what is the problem?"… for me it was completely normal. There was nothing wrong with hoarding*'. Later he acknowledged, '*I think with hoarding it became a problem in terms of … it came to an extent where I thought to myself I couldn't go on any longer, that I'd lost my … mind*'. A similar contradiction was noted in JB's description of the impact of his hoarding: '*I'm not freaked out. But what does freak me out actually is the thought that, I'm renting this place, and if I was asked to move…*'.

DS reported hinting about the extent of her difficulties to clinicians: '*I did mention a bit to my doctor that I was depressed, and my house was a bit cluttered*'. Despite accessing mental health support, she was unable to disclose her struggle with hoarding: '*because I'm so scared, I've not specifically asked for one-on-one proper counselling … specifically to address the "h" word*'.

Some participants seemed to make sense of their hoarding by comparing themselves with other people. GD described being reassured by others she perceived to be 'worse' than her at the support group. She noted, '*Some, one of them had a lockup to store things in. And I thought "I'm not at that stage yet"*'. Similarly, TC was reassured by his friend's actions: '*I've got a friend who's a bit of a hoarder. So, she'll go to places like* [shop] *… she'll hoard things in her house, and she'll have like stack fulls of toilet roll or water or kitchen roll … in a way she kind of feels it's a bit normal as well*'. However, comparisons with others could also provide motivation for change. GD described being inspired by the recovery of others: '*She'd really turned her life around and she was the one that introduced me to this* [support group]'.

Fearing mental health labels

Related to ambivalence regarding problem identification, some participants described wanting to avoid being 'labelled' as having a mental health issue. This then influenced their options for support seeking. JB described extreme stigma regarding mental health problems within his culture and his fears of experiencing racial prejudice in services, '*there's also this, this stigma of, of black men … you know dangerous, mad, crazy, violent black men. So, I'm always kind of aware of that and this label of mental health … So that's what stops me; I don't want "seeking mental health services" on my record*'. VI also wished to avoid being labelled, describing her options for help as either a professional decluttering organisation or mental health services: '*it's a business model or … go down the mental health route, it's now recognised as a mental illness … I think the hardest thing is being labelled. I don't wanna be labelled* [pause] *I think there's a great stigma attached to that*'.

Who can I trust?

All the participants described difficulties in disclosing their hoarding behaviours to others, due to past negative experiences.

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Trusting others with the reality of hoarding: being judged

All eight participants feared making themselves vulnerable to others by opening up about their difficulties. Many had experienced criticism and rejection related to their hoarding behaviours. JB described a powerful emotional response to the prospect of being judged: '*the thought of somebody coming into this flat and just seeing the horrible-what a horrible place. And it's also the fear that I'll get reported for being a fire hazard … um, so that, that's pretty well, scary and embarrassing … there's kind of fear, and a shame*'. This fear was also described by DS, '*if somebody came in at its peak, I would've, I literally think I would've tried to fight them or had a heart attack or something really horrific. Um, I would be absolutely mortified if somebody saw it at its worst. Um, I would just feel* ***terrible*** [her emphasis]'. She considered what might make it more tolerable should she access help and summarised a hope that services are '*not gonna judge you and tell you you're just terrible*'.

Some participants described a mistrust in services, due to feeling judged, but also lacking faith in what organisations could offer. PB was subject to social care input in relation to her hoarding difficulties and found it difficult to engage with and trust services: '*I never really felt they got much beyond the "you've got a problem", sort of thing, to find out actually what it was and how they could help*'. Her experience was frustrating: '*they didn't refer me to anybody or anything like that until stuff had already been escalated, and yet they then criticise me for not having moved on enough*'. RO reported that services '*don't listen to me*' and others described a lack of faith, including VI: '*I've got no confidence in my GP, at all*'.

Trusting support groups: 'a whole new world'

Amid the struggle to trust others, there was one situation where many of the participants felt able to open up regarding their difficulties: six of the eight participants had accessed support groups in relation to their hoarding. GD discussed the value of opening up to others with similar experiences: '*It opened a whole new world up to me cause when you don't share because you're too ashamed, you feel like you're the only person suffering from it*'. Yet for some, struggles to identify with other group members made things harder at first. RO had noticed being the only attendee of the support group from his ethnic background: '*I don't see anyone else in my community, or is this a problem, or are there other people like myself who are experiencing difficulties?*'. He described initially finding it difficult to talk, but that with the support of the facilitator he was able to overcome this: '*I thought to myself I would pull out y'know during the fourth, the third or the fourth session, because er I can't do two-way conversations with these people … but y'know the coach, he guided us through … putting everyone at ease*'.

Services don't fit

All of the participants described finding it difficult to access help, in some cases because they did not fit service thresholds, or because they thought the support on offer was not the right fit for them.

Falling between services: not ill enough or too ill for help

Some described practical and resource barriers preventing access, for example VI: '*I don't have a computer. I don't have the internet, everything was online*'. Many participants spoke of being told that the complexities of hoarding meant they were not able to access certain services, and frustratingly, that pressure on services had raised the threshold for referrals to others. AN described feeling '*cast aside*', reflecting that '*sometimes it seems you have to be a lot worse to get the help. Whereas that seems to be the wrong way round! … if they helped people more beforehand, they wouldn't get to as bad a stage as that*'. TC reflected on previous interventions and his perception that similar support would no longer be available: '*I've not had a support worker for a*

https://doi.org/10.1017/S1352465823000425 Published online by Cambridge University Press

couple of years now. And I know the funding's changed. Things have changed and they've cut back on a lot of funding and the time that support workers can have'.

Searching for the right support: 'It wasn't geared towards me'

Participants spoke of mental health services being focused on pharmacological interventions or imposing unrealistic time pressures: '*you only get six months anyway. And so that was another trigger*' (TC). They described struggling to find a model of psychotherapy which suited them '[CBT] *wasn't really helpful, wasn't sort of geared towards me*' (AN), and some were uncomfortable about professional decluttering, for example VI reflected, '*I'd rather it was somebody who cared about me … when it's a business; there's a detachment there*'. Despite their fear of judgement, participants had searched for help outside NHS pathways, including some taking part in research and featuring on reality television shows. The most positive reflection on the support available came from PB, who had eventually accessed a social enterprise organisation with a specific focus on hoarding: '*So, it's a combination of, of tools that she knows works by experience, um, personal rapport and the fact that she's encouraging and can see positivity*'. It seemed that participants hoped for both a familiarity with hoarding and a positive, caring approach to their difficulties. This contrasted with the majority of their experiences of help offered for hoarding.

Being overlooked: 'they're too busy looking at the thing, not the person'

All participants reported that services focus on clearing their 'stuff' without considering their personal circumstances, leaving them feeling overlooked. In addition to the above quote, PB stated, '*I never felt like a person with social services. I felt like someone who hoards*'.

Clearing under pressure: 'It is almost like being bullied'

Six of the eight participants described a fear or avoidance of support that felt pressuring with regards to discarding. VI called for a more compassionate approach to support for hoarding difficulties: '*my experience of it is almost like being bullied into it … that approach doesn't work well with me. What works better is a kindness approach. A gentler approach. A more human approach … I haven't found that really*'. TC described that he needs tasks adapted to suit his pace: '*my mental illness can get in the way … that's why I tend to work slowly cause I might have weeks where I'm pretty bad, and I have to sort of sit back a bit and just wait for it to pass over*'.

Overwhelmed by the task: 'How do you do it? Where do you start?'

The pressure from services to discard belongings led to further struggles with motivation. Participants being overwhelmed by the prospect of clearance was common. GD stated, '*I never seem to get round to clearing up and deciding which clothes have got to go, but anyway where do they go? How do you do it? Where do you start?*'. VI spoke of dreading the prospect of clearance: '*there's the horrible sinking feeling when I come back … it's such a horrible job to do, you know it's horrible*'.

Several participants also expressed experiencing circumstances that felt like events were conspiring against their discarding: '*And it was actually quite minimalist in the bathroom … and then the bloody plumber came and ripped up all my* [chuckles] *work … sometimes I get a little bit superstitious like … there's forces against me … So, I kind of gave up*' (JB).

'Emptying the bath while the tap is running': finding the right starting point

Participants described interventions as focusing on their stuff, rather than tackling the underlying causes of hoarding behaviours. Several expressed that support should initially focus upon what

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causes the hoarding behaviours, particularly in relation to acquisition. AN shared her partner's analogy for this: '*It's like emptying the bath with the tap still running, if stuff's still coming in*'. DS supported this view: '*I mean there's two parts, the … main thing is you've got to stop acquiring and deal with that as well … the clearing itself is um, secondary*'. In support of the idea that help should start with the underlying issues, PB stated, '*my head was actually in a better place, I'd just finished sort of two terms of counselling. And so, when I started having to deal with the stuff … um, I found that, yes, I could actually deal with stuff*'.

Discussion

Issues of insight and motivation are known to be challenging in hoarding treatment (Frost *et al.*, 2010); however, given the methods of recruitment into this study, participants' ambivalence about whether their hoarding was problematic was a surprising finding. Even within the interviews there were fluctuations in insight and motivation, as there can be over the course of therapy (Hartl and Frost, 1999). All but one participant described issues around identity and acceptance, questioning: were they a 'hoarder'? Was their hoarding as bad as others'? Was their hoarding a mental health disorder? Identifying hoarding behaviour as problematic connected to an ambivalence about their belongings: was their stuff protective or restrictive? This ambivalence has been described previously, with hoarded possessions described both as precious and junk (Kellett *et al.*, 2010). Frost *et al.* (2010) suggest that only some individuals who hoard identify their behaviour as an issue and seek help, but it is of interest that of the eight current participants, recruited to a study explicitly exploring help-seeking for hoarding, only one had sought help specifically for their hoarding behaviours. Huggett *et al.* (2018) noted that mental health diagnoses are labels associated with stigma, and that there are varying degrees of stigma attached to different diagnoses. It may be that participants perceived a hierarchy and considered that the stigma attached to being a 'hoarder' would be intolerable. Most of the current participants described accessing psychological therapies or counselling for other mental health issues including trauma, grief and depression. Whilst some of these interventions were helpful, the hoarding behaviours remained a problem.

Ambivalence about changing their hoarding behaviours was exacerbated by issues with trusting others. Most participants described trauma or difficult early experiences, which have a link with hoarding (Chia *et al.*, 2021). All expressed fear of opening up to others about their hoarding behaviours and some spoke of previous rejections. For six participants, meeting with peers in support groups had allowed them to develop positive and trusting relationships, but only in that context. Several participants described a mistrust of statutory services and, for most, the shame and fear of judgement prevented help-seeking for hoarding.

Participants described a poor fit between their perceived needs and available interventions, which led to ongoing searches for help and several looking outside of NHS services. Several described barriers in accessing NHS services, with some having been told that their difficulties were too complex for some services but did not meet the threshold for others. This is a common difficulty for those seeking mental health support for complex needs (Naylor *et al.*, 2020).

Participants described that hoarding interventions offered often focused on clearing items, rather than on understanding their difficulties. Frost *et al.* (2010) describe hoarders thinking that those trying to help are 'not on their side', related to the lifetime of criticism and pressure they have experienced. Current participants felt overwhelmed by the prospect of clearance and some gave considerable thought to when the 'right' time was to seek help, which was problematic given waiting times for NHS treatment. Several feared that intervention would be pressuring so opted to avoid it altogether; others noted that interventions focused on clearance seemed pointless if they were still collecting.

The findings indicate that insight, motivation and beliefs about what intervention would best help are likely to fluctuate in people who hoard. The variation in preferences for treatment has

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been noted elsewhere (Robertson *et al.*, 2020; Rodriguez *et al.*, 2016). A recent exploration of beliefs around hoarding behaviours led to the authors concluding that the current models of understanding hoarding are not sufficiently complex (Tinlin *et al.*, 2022). This seems pertinent given that if an individual can overcome the internal and external barriers identified, there is little offer of choice or flexibility in relation to interventions provisioned. Current participants' experience of the support offered by statutory services was poor, despite long-standing calls for further development of services (Büscher *et al.*, 2014).

Clinical implications

The findings suggest that those who hoard may seek help for other mental health difficulties, related to both a fear of judgement and beliefs that services will not offer effective treatment for hoarding. Due to the important role of support groups for participants in the current study, co-production of services and peer support may offer valuable tools in facilitating the disclosure of the problem, increasing motivation and supporting treatment progress. Perhaps once in services, a strong therapeutic alliance may help overcome that fear and facilitate disclosure. When hoarding is identified as an issue, insight and readiness to change should be considered before intervening. Tolin *et al.* (2010) suggest that people who hoard often remain in the 'precontemplative' stage of Prochaska and DiClemente's (1982) Transtheoretical Stages of Change Model. Given that participants described feeling that interventions did not start in the 'right place' (naming the need to tackle acquisition before beginning to clear), supporting them to identify goals that they wish to focus on first seems likely to be helpful. Miller and Rollnick (2012) suggest strategies such as 'agenda mapping' (similar to agenda-setting in CBT) to manage this.

David *et al.* (2022) proposed incorporating concepts from approaches such as emotional regulation, mentalisation and attachment within CBT and these ideas seem likely to help given the current participants' experiences of interventions. Participants all spoke of the value of non-judgemental relationships, therefore professionals should strive to create a compassionate bond, which focuses on understanding the problem. Chou *et al.* (2020) propose a compassionate-focused therapy (CFT) intervention where the evolutionary model is presented to help understand hoarding; emotions and behaviours are attributed to motivational systems, and techniques focus on mindfulness, soothing skills and compassionate responses. Several current participants identified social deprivation or trauma as key influences upon their hoarding, suggesting that a model of understanding their difficulties as a response to threat and a means to survive would likely be acceptable to them.

Strengths and limitations

Despite the context of the COVID-19 pandemic, the eight semi-structured interviews provided a wealth of qualitative data. Remote interviewing may have supported recruitment as it is not invasive of an individual's space. Whilst the self-identified nature of the sampling leaves questions about the diagnostic status of the current participants, it is in line with the IPA approach and all accounts confirmed hoarding as having a significant impact on functioning.

This study recruited an adequate number of participants, and their gender, age and ethnicity were varied without purposive sampling. Whilst some participants responded to advertising online, a key source of recruitment was through support groups. Participants actively accessing this support are understandably more liable to identify it as beneficial. Had recruitment been through mental health services, alternative findings are likely.

Several participants described being from minoritised backgrounds and three of the eight spoke of the influence of their ethnic and cultural background upon both their hoarding and their help-seeking. Unfortunately, data regarding race and ethnicity were not collected routinely: we note our

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own bias as white British researchers in overlooking the importance of collecting this information (see Pillay, 2017).

Further research

Given the participants' narratives, further research should explore cultural influences, both on the development of hoarding behaviours and on responses to services and treatments within the UK. The importance of this understanding has been highlighted in Sweden and the US (Fernández de la Cruz *et al*., 2016; Martin *et al*., 2018). The specific impact of racism should also be considered in relation to seeking and receiving help (see McKenzie, 2006).

Participants often described feeling that they had received poor support from services. Given the diversity of interventions described and varying levels of reported acceptability, further exploration around the role of the therapeutic relationship in delivering treatments would be advantageous. In some areas, social enterprises appear to be offering therapeutic, person-centred approaches and providing positive testimonials (Clouds End, 2021). More empirical analysis and evaluation of these interventions and their impact would be valuable.

Research specifically exploring the value of support groups for those who hoard would be beneficial. It could be that this support is valued because people do not feel pressured to change, or because they are seen as individuals rather than being defined by their hoarding. This leads to questions as to whether these support groups can facilitate change, which would be valuable to establish empirically.

Conclusions

The findings depict complexity around recognition of hoarding behaviours as problematic and the accessing of help for individuals who hoard. Fluctuating insight and motivation, as well as a fear of judgement appear to be significant internal barriers to help-seeking. When the problem is recognised, other barriers are experienced such as not trusting services, being excluded or the support available not being suitable. Treatments offered were experienced as unacceptably focused on clutter, leaving the individuals feeling overlooked. Descriptions of traumatic backgrounds, feeling let down and stuck dominated the findings. Given the current lack of clinical guidelines and appropriate service provision in the UK, perhaps these participants are in a hopeless position. However, if clinicians and services can offer a compassionate approach, with flexible person-centred interventions, individuals who hoard may feel more able to access services and to engage with the interventions offered. Co-production and peer support may offer opportunities to improve treatment.

Data availability statement. Research data are not shared due to lack of consent from participants.

Acknowledgements. None.

Author contributions. **Megan McGrath:** Conceptualization (lead), Formal analysis (lead), Investigation (lead), Methodology (equal), Project administration (lead), Writing – review & editing (equal); **Amy Russell:** Formal analysis (supporting), Investigation (supporting), Methodology (supporting), Supervision (supporting), Validation (equal), Writing – review & editing (equal); **Ciara Masterson:** Conceptualization (supporting), Formal analysis (supporting), Investigation (supporting), Methodology (supporting), Supervision (equal), Validation (supporting), Writing – original draft (lead).

Financial support. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Competing interests. The authors declare none.

Ethical standards. The authors have abided by the Ethical Principles of Psychologists and Code of Conduct as set out by the BABCP and BPS. Ethical review and approval was provided by University of Leeds' School of Medicine Research Ethics Comittee.

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Cite this article: McGrath M, Russell AM, and Masterson C. 'A more human approach … I haven't found that really': experiences of hoarding difficulties and seeking help. *Behavioural and Cognitive Psychotherapy*. https://doi.org/10.1017/S1352465823000425