School of Psychological Science

"I felt like I was blessed": A Qualitative Study into the Experiences of People with Hoarding Issues Using the 'Making Space' Support Group and/or Home Visit Service

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Research Project Major – Statement of Research Contribution

1. **How was this project conducted?** (Please underline as appropriate)
    - On your own
    - As part of a group

2. **If as part of a group, how many other group members were there?**

3. **Type of data reported in the dissertation** (Please underline as appropriate)
    - Primary data analysis (analysis of data collected by the researcher themself)
    - Secondary data analysis (analysis of data collected in previous research to address a different research question)

4. **Statement of research contribution:**

Research Project Major – Statement of Research Contribution

Designed Research: I began working on my first research idea over the summer which unfortunately fell through. I used my own contacts within the Making Space charity to set up this project in October and designed it independently. When the design was complete and access granted by Making Space, I informed my supervisor of my new plan and he made sure I hadn't missed anything. **Set-up research**: I wrote the ethics application and interview schedule unaided. My supervisor checked these prior to submission with minor edits. **Generation of Data**: I arranged the interviews with some support from the Making Space team for the initial contact. I conducted and transcribed the interviews alone. **Analysis/interpretation of data**: I analysed the data by myself using thematic analysis. After the themes were written up, I clarified some of the structural aspects of the write up with my supervisor.

Abstract

Hoarding is defined as a persistent difficulty in discarding or parting with possessions, regardless of their actual value. Despite a prevailing interest from the public and the media, there is limited understanding of how to treat the 2-6% of the population with hoarding disorder. Cognitive-behavioural approaches have had some success, particularly when accompanied by home visits. This research uses semi-structured interviews to explore the experiences and perceptions of hoarders accessing the ‘Making Space’ treatment program. This consists of a 1:1 home visit service and/or a facilitated peer-support group based on the cognitive-behavioural model of hoarding disorder. Thematic analysis was used to identify several themes including a feeling of safety and supportiveness, the overall effectiveness of the service in reducing clutter, and a desire for more structure in the support group. The findings indicate that the treatment program is perceived by service users to be a positive and useful service that they credit with great improvements to their quality of life. Further research should focus on the long-term effectiveness of the treatment and its objective utility in terms of items discarded, to assess if it is a suitable alternative to more expensive therapist-led treatments.

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Introduction

Compulsive hoarding has historically been a neglected clinical phenomenon despite the significant impact the disorder can have on the individual and family and the prevalence of the condition in 2%-6% of the population (American Psychiatric Association, 2013 pg 249). Originally considered to be a symptom of obsessive-compulsive disorder (OCD) until its classification as a distinct diagnostic entry to the DSM-V in 2013, it is no longer considered an aspect of other disorders and is now ranked independently amongst the compulsive spectrum disorders (Kalogeraki & Michopoulos, 2017).

Research into the quality of life of people with hoarding disorder found that they had significantly lower levels of satisfaction with their safety, were more often victims of crime, and were overall much less satisfied with their living arrangements than non-hoarding OCD patients. Hoarders were found to have lower objective and subjective quality of life scores in the domains of safety and living situations (Saxena et al, 2011; Ong et al, 2015). Additional research has found that hoarders suffer economic and financial hardship as a result of their condition (Tolin, Frost, Steketee, Gray, & Fitch, 2008) and significantly higher family strain suggesting high levels of frustration and hostility from family members (Tolin, Frost, Steketee & Fitch, 2008). Hoarding also poses a fire and health hazard; 8-12% of hoarders have been evicted or threatened with eviction at some point in their lives due to their condition. (Mataix-Cols et al, 2010). This substantial evidence demonstrating the negative effects of hoarding justifies research into treatment programs that can support hoarders to reduce the clutter in their homes.

Frost and Hartl (1996) developed the cognitive behavioural model of compulsive hoarding which outlines several areas that form the basis of the disorder. They include distorted beliefs about

possessions, excessive emotional attachment to items, and maladaptive emotional responses combined with information processing difficulties.

There is substantial literature supporting the model that suggests dysfunctional beliefs and maladaptive emotional cycles are prevalent in hoarders, making the development of treatments difficult (Chia et al, 2021). They tend to become overly attached to items and show an exaggerated reliance on them for comfort and safety (Yap & Grisham, 2020) with significantly higher emotional over-involvement than non-hoarding OCD patients (Nedelisky & Steele, 2009). Common cognitive distortions include an excessive level of responsibility for ensuring items are not wasted and a fear of forgetting or losing information and/or memories if an item is discarded (Andersen, Raffin-Bouchal, & Marcy-Edwards, 2008; Frost et al., 2018). These maladaptive emotional cycles and cognitive distortions reinforce the hoarding behaviour as hoarders suffer overwhelming negative emotions such as grief and anxiety at the idea of discarding items leading to compulsive avoidance and disengagement from treatment. They also feel positive emotions such as pride when acquiring which encourages further accumulation. In addition to these maladaptive reinforcement cycles, hoarders have been found to have generally lower distress tolerance with greater reactivity and impulsivity in response to negative emotions which means treatment programs must be designed with care to promote an environment where service users are not unduly pushed towards change (Grisham et al., 2018; Phung, Moulding, Taylor, & Nedeljkovic, 2015; Shaw et al 2015).

This model has been used to develop treatments that specifically target the factors identified as standard OCD treatments have been shown to have little effect (Abramowitz et al, 20013; Rufer et al 2006). Multiple case studies using a modified version of CBT, based on the cognitive-behavioural model of hoarding, focusing on problems with emotional attachment, beliefs about possessions, and decision-making have been successful in reducing both the clutter and hoarding-based distress (Cermele, Melendez-Pallitto, & Pandina,2001). Further refinements to this treatment style were assessed in an open trial. The intervention was delivered by clinicians who focused on enhancing

motivation, improving organization and decision-making, and included cognitive and exposure methods to reduce acquiring, improve discarding, and remove clutter. While the high dropout rate remained similar to hoarding patients receiving OCD treatment, there were significant improvements in post-trial assessments. Depending on the measure used, around 50-60% of people who completed the program reported clinically significant improvements (Tolin, Frost, & Steketee, 2007).

This is consistent with the findings of a randomized control trial comparing patients receiving the modified CBT with patients on a waitlist. They found that improvement from the treatment was significantly greater than the waitlist on most hoarding severity measures with moderately large effect sizes, even after only 12 weeks (Steketee, Frost, Tolin, Rasmussen, & Brown, 2010).

The current research considers the patient's perceptions of the effectiveness of similar modified CBT treatments offered by the Making Space Project run by We Care, Bristol. The program has two components, a 1:1 home visit service, and a case-worker-facilitated support group.

Many of the successful uses of cognitive-behavioural interventions rely on home visits at least once per month, with one study piloting 'marathon sessions' where the therapist travelled to the patient's home for approximately 3 hours to assist with clearing (Steketee, Frost, Tolin, Rasmussen, & Brown, 2010). At Making Space, the 1:1 home visits are undertaken by either volunteers or caseworkers (referred to as 'visitors') and can be done weekly or fortnightly depending on the client's need. The visits involve supporting the client in de-cluttering, organising, and cleaning their home with a focus on reducing the overall number of items. Throughout, the visitor will offer compassion and support while also challenging unhelpful ways of thinking that can lead to further acquiring or reluctance to discard items. This research aims to assess the perceived effectiveness of home visits by volunteers and caseworkers rather than trained therapists or clinicians. This is a

cheaper and more practical alternative to the previously discussed treatments, which are both uncommon and in extremely high demand and are therefore mostly inaccessible.

Making Space also offers a support group based on an interactive client workbook designed by Tolin, Frost, and Steketee (2014), for brevity this is referred to as 'the workbook'. The authors include one of the main developers of the cognitive behavioural model and so the workbook is based on ideas backed by a wealth of research evidence (Woody, Kellman-McFarlane, & Welsted, 2014). They break the disorder down into factors that reduce hoarding ('the good guys'), and factors that increase or maintain hoarding ('the bad guys') including various questionnaires, goal-setting exercises, organisation plans, behavioural experiments, spaces to record thoughts and beliefs, cognitive techniques, and a list of interventions learned during treatment (Muroff, Bratiotis, & Steketee, 2011). Making Space offers a twice-monthly meeting, incorporating the workbook, focusing on providing a safe and accepting place for people to discuss their issues with hoarding while helping to reframe thought processes by sharing feelings and coping strategies with other hoarders. They also aim to have individual check-ins of each person's progress, goals, and struggles during the session.

The present research considered the question "What are the service users' experiences and perceptions of the effectiveness and utility of the treatments offered by Making Space?" with the aim of establishing themes (i.e. repeated patterns of meaning) regarding participants' perceptions of their own treatment. I chose to focus on the participant's perception of the effectiveness of the interventions rather than more objective measures, such as the volume of items removed, because of the historically low retention in treatments for hoarding. It has been identified that people suffering from hoarding disorder often struggle to engage with homework assignments and fail to complete treatment programmes (Williams & Viscusi, 2016). One possible way to encourage patient buy-in is to involve them in the development of their treatment, taking their feedback into account and tailoring the program to the needs of the users. Making Space identified an opportunity to use the

findings from this research to establish the perceived effectiveness of the program and therefore make adjustments that increase the likelihood of completion.

Method

Design

This was a qualitative study involving semi-structured interviews using open questions to prompt rich, detailed answers about the participant's experiences of the treatment programs and their perceptions of its effectiveness. Ethical approval was obtained through the University of Bristol (Approval Code 13013).

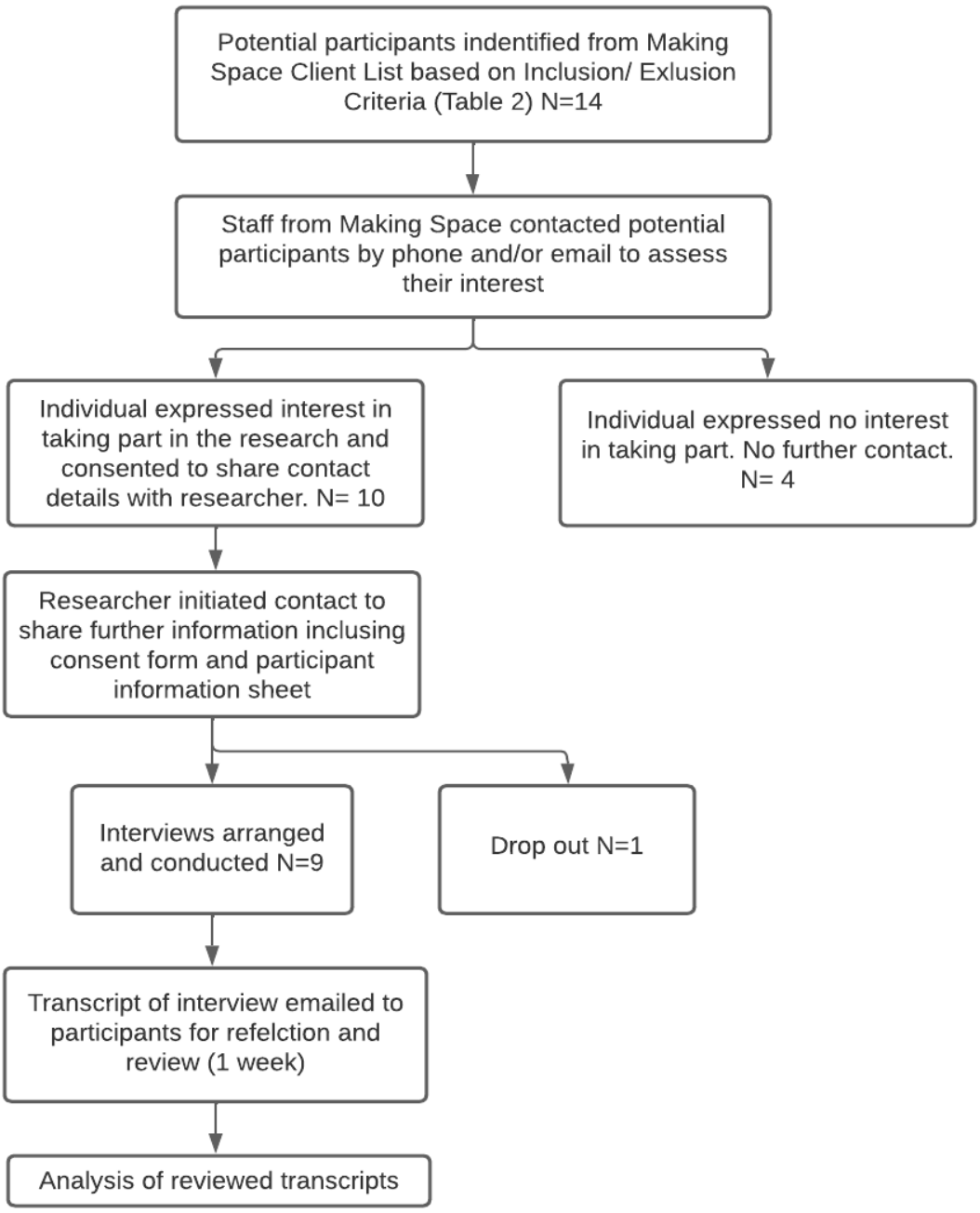
The interviews were predicted to last 1 hour though no time limit was imposed, allowing interviews to continue if the participant felt there was more to be said. This was to ensure participants left the interview feeling like they had every opportunity to make their voice heard and to avoid feelings of being interrupted or cut off which is particularly important when engaging with a group who are often stigmatised and silenced. Responses were coded and analysed using Reflexive Thematic Analysis (Braun and Clarke, 2022).

Participants

People first language should be used when discussing mental health disorders to reduce stigmatisation and maximise individualisation, especially when discussing hoarding due to the poor perception of 'hoarders' in the media. It may be more appropriate to use the label 'person who suffers from collection issues' depending on the preference of the individual involved. Person-centred language was used during the interviews, except with people who preferred to self-identify as hoarders, but for brevity the terms hoarder and service-user will be used throughout this report.

Participants (N=9) were drawn from the Making Space client list and interviewed (Male= 4, Female = 5) either at the Making Space offices or by telephone (Figure 1).

Figure 1
Movement of Participants



All participants receiving home visits had their homes assessed using the Clutter Image Rating Scale (CIRS) by a caseworker though participants attending the support group did not. The CIRS is an image-based rating scale where clients, family members, clinicians, or independent

assessors compare rooms in the home to the image scale to assess the volume of clutter. Making Space recognises this as a slightly flawed system as many homes have varying levels of clutter in different rooms with some rooms being relatively clear and yet one or two rooms being inaccessible. However, it is still useful as an indicator of the average level of clutter in a home, with good internal consistency and test-retest reliability while also proving sensitive to treatment effects (Frost, Steketee, Tolin, & Renaud, 2008). Making Spaces' full referral and assessment process is detailed in Appendix A and a copy of the assessment form is included in Appendix B.

Figure 2
Example Clutter Image Rating Scale (CIRS) in a Bedroom

1 2 3

4 5 6

7 8 9

In order to protect the anonymity of the participants in a small sample, age and ethnicity will not be shared though non-identifying demographic data is included in Table 1. All participants met the inclusion criteria (Table 2).

Table One
Demographics of Participants

Pseudonym	Type of Support Received	Average Clutter Index Rating	Gender
Augustus	Home Visits	6	M
Baltazar	Support Group	-	M
Cyrus	Home Visits	8	M
Doris	Support Group and Home Visits	4	F
Eileen	Support Group	-	F
Frances	Home Visits	3	F
Gladys	Home Visits	4	F
Herbert	Support Group and Home Visits	4	M
Ingrid	Support Group	-	F

Table Two
Inclusion Criteria

Inclusion Criteria	Exclusion Criteria
Fluent in English	Sporadic or infrequent engagement with the service
Over 18 years old	Serious drug or alcohol abuse
Referred to Making Space due to issues with collection, hoarding and/or acquiring	Serious and ongoing psychosis
Have an average CIRS of 3+ or a CIRS 0f 4+ in at least one room	
Regularly attending the support group or regularly receiving home visits (at least once per month)	
Currently utilising the service or completed their treatment allocation no more than 6 months prior to interview	

Saturation, or informational redundancy, is the point where no new codes or themes can be generated from the data. While there is no minimum number of participants set by the APA, a recent review suggests that in most cases saturation can be achieved from 9 interviews (Hennink & Kaiser, 2022) though this is far from standardised with some researchers suggesting saturation can be achieved after 8 interviews (Constantinou Georgiou & Perdikogianni, 2017) and others suggesting as many as 24 might be necessary (Hennink, Kaiser & Marconi, 2017). This uncertainty makes it difficult to establish saturation in advance and is the fundamental issue that causes Braun and Clarke (2013) to express a general dislike for the idea of saturation in Reflexive Thematic Analysis. Their argument is that saturation is often used as a post hoc justification and is a holdover from positivist ideas that meaning exists in the data and not the researchers' interpretations of it. In this study, I decided to set a minimum of 5 interviews and a maximum of 15 based more on the practicality of a single, student researcher rather than any prediction of when saturation might be achieved in accordance with Braun and Clarke's recommendations. Due to the small sample pool, data collection was stopped at 9 interviews and, although full saturation was not achieved, enough common themes were generated to justify the research.

Procedure

Interviews were arranged following an initial contact from Making Space staff to assess interest. If the service user expressed a willingness to take part then their contact details were passed to me for further arrangements.

Following an explanation of the withdrawal process and receiving informed consent, participants confirmed they met the inclusion criteria. There was a short explanation of my history as a volunteer visitor with Making Space with my impartiality reiterated. Discussion topics were explained (Table 3) and participants were reminded of their right not to answer any question they found invasive or preferred not to discuss. The interviews took between 50 minutes and 1 hour 20

minutes with some participants answering more questions due to their use of both the support group and home visit service.

Table Three
Discussion Topics

Topic	Questions/ Probes
Introduction	Introduce self, explain format, explain consent, withdrawal and anonymity.
Demographics	Age, gender, live alone/ CIRS
Onset of hoarding	How long hoarding? Initial trigger? Experience of homelessness?
Support Group (if applicable)	How regular is attendance? How long attending? What is useful? Development of program. How could it be improved? Relationships between support group attendees Relationship with co-ordinators Logistical preferences- size of group, length? Feelings before/during/after group Outcomes of group- decreased acquiring? Decluttering?
Home visits (if applicable)	How long have been receiving visits? How frequently? Caseworker or volunteer? What is useful? Discarding increased/acquiring decreased? What could be improved? Relationship with visitor? Feelings before/during/after visit? Is outcome as expected? More or less?
Waiting list experience	How long spent on the waiting list? Access any support while on the waiting list? Feelings while on waitlist? Improve mood or not? What can be done to improve this experience?
Other treatment	NHS- CBT therapy? Counselling? Outcome of other treatment

A link to an anonymous questionnaire was provided after the interview to check that participants felt able to be open and honest while speaking to me. This was included due to the potential bias introduced by interviewing some participants in the Making Space offices and my previous work with the service.

Analysis

Interviews were conducted over a period of three weeks with transcription beginning as soon as the first interview was completed. Audio recordings were transcribed manually to produce accurate verbatim records of interviews. Transcriptions were completed orthographically to fully reflect how participants expressed themselves during interviews. It is not possible to provide an entire example transcript and still preserve anonymity from the staff at Making Space, so a small section of a fully anonymised transcript is available instead (Appendix C).

Once each interview was transcribed, it was emailed to the participant for their review. This was to facilitate further reflection and allow participants time to include details they had forgotten, amend statements that didn't come across as they intended, or remove anything that they felt was inaccurate. Participants were each given one week to amend their transcripts which some chose to do.

The researcher familiarised themselves with the data set several times, listening to the recordings to fully understand tone and inflection, and annotating this on the transcript as appropriate. Initial observations were recorded in a notebook along with reflections and notes to improve the flow and quality of later interviews. Initial coding was completed in NVivo (QSR International, 2022) to capture and label features that seemed relevant to the research question. This involved multiple rounds of coding and re-coding before the final codes were used to generate themes. These are broader patterns of meaning that could be collected under one heading and were reworked several times involving splitting, combining, and discarding until a convincing story was

developed that addressed the research question. Due to the exploratory nature of this research, an inductive approach was used as there has been no previous research or theory surrounding patients' experiences of this type of hoarding treatment.

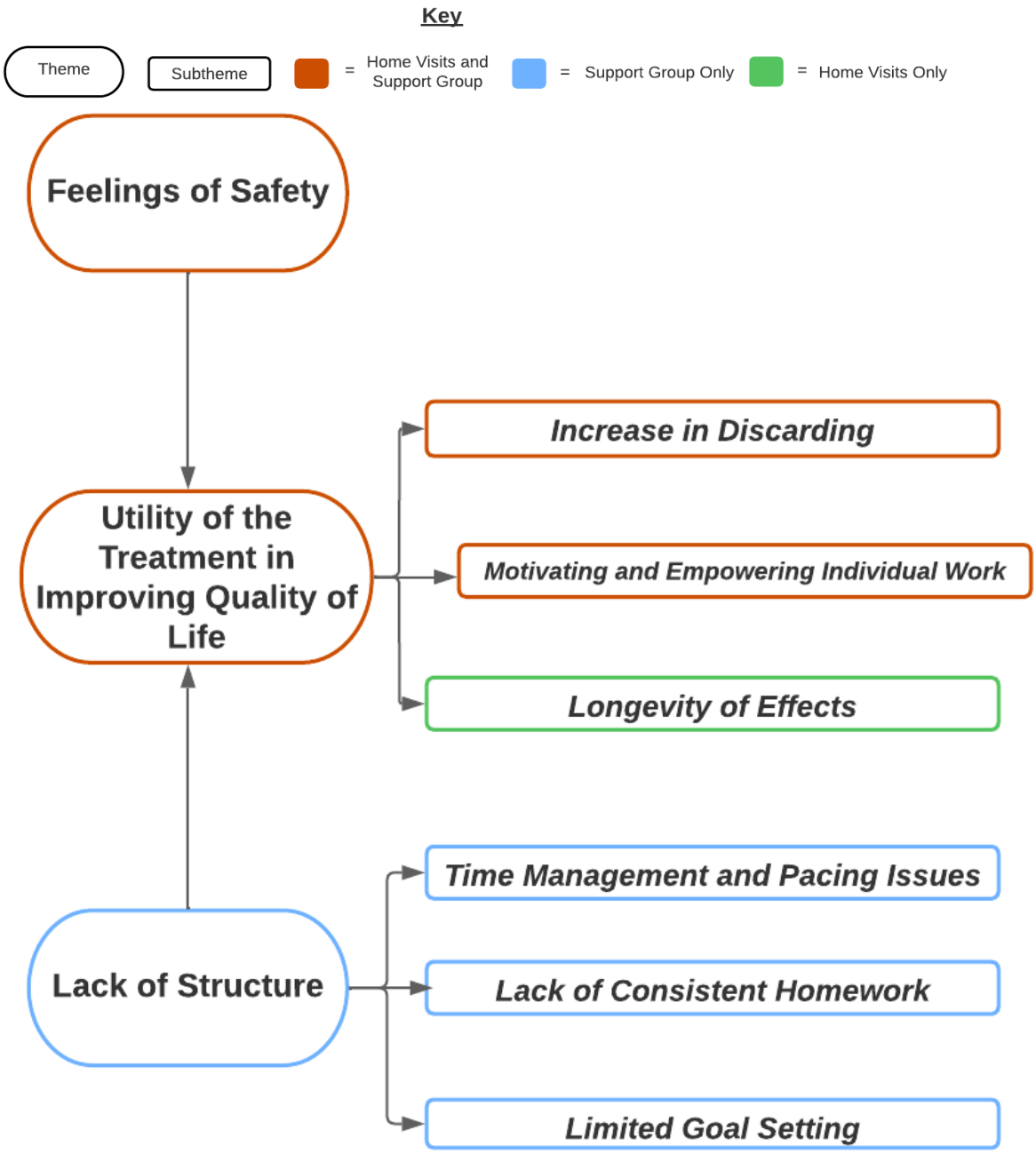
Researcher Positionality

In Reflexive Thematic Analysis the themes and the researcher's interpretation of the data are intrinsically linked, it is impossible to provide an 'objective' analysis of the data as the researcher is an integral part of the process of identifying themes. As themes are not passively 'discovered' but are instead found through the researcher's analysis, it is impossible to remove the bias to achieve an objective understanding. Therefore, it is important to reflect on my own role in the charity as a volunteer for home visits and any previous conceptions I held about the service. While I generally had positive opinions of the programs, a bottom-up approach allowed me to use the participant responses to generate codes and themes which maximised the voice of the participants. As someone who does not suffer from hoarding issues, nor does anyone in my family, there was no personal, emotional history to draw on which did make me more of an 'outsider' to this disorder. In some ways, this was a benefit because it prevented my emotional biases from influencing the themes but perhaps the study might have benefited from a researcher who was more fully able to relate to participants and appreciate the real-world consequences of hoarding disorder.

Results and Discussion

Five themes have been identified though only three will be discussed here. The remaining two themes consider ways to expand the service and the necessity of additional support, going slightly beyond my research question which considers only the experiences of the present Making Space program (See Appendix D for full themes). The three relevant themes and associated subthemes are illustrated in Figure 2.

Figure 2
Thematic Map



Feelings of Safety

This theme explores participants' feelings of safety within the support group and when inviting visitors into their homes. Participants discussed feeling "like somebody cared" and that "it's all quite supportive" with all participants reporting positive feelings in this area.

Home Visits. There was a generally positive opinion of all of the visitors, they were "tolerant", "nice", and "very, very wonderful" during the home visits and provided a non-judgmental and supportive service.

> We really developed a good relationship. I felt like I wasn't being treated like a patient or like I had an illness or something. We genuinely used to get on and chat about other things and that sort of made me feel like we were sort of doing it together rather than her coming to sort of fix me. So, you know, it felt very respectful. (Frances)

Visiting someone's home can be an intrusive event for anyone, for people who hoard the intrusion can feel substantially worse with feelings of guilt and shame being common in the literature (Chou et al, 2018; Brien, O'Connor, & Russell-Carroll, 2018). The importance of a "respectful", non-judgmental home visitor cannot be overstated here as even the smallest indications of shock or blame can lead to the patient disengaging with the service and becoming unwilling to attempt decluttering the future (Tinlin, 2022).

It is also important that service users do not feel pressured into discarding more than they are comfortable with. Participants reported that the visitors were understanding of their needs, Cyrus feels his visitors "take notice of what I say as well, if I am uncertain about something or I'm unhappy about something then I say and they follow what I say" and did not put undue pressure on him to discard items. Augustus agrees with this stating "I can't really criticise it. I think it was nice, laid back, not too pressured. If it was trying to force a bigger throw away outcome out of it, then I'd criticise".

> I was never forced to do anything. I mean, sometimes I was gently encouraged and that would work. I didn't feel like I had to do anything. So when I ever threw something out, whenever anything left, I felt like it was my decision…. I don't think I ever felt pressured in a bad way (Frances)

When items are removed without the full knowledge and consent of the service user then it is likely that the areas will not remain clear and new clutter will be acquired to fill the space (Andersen, Raffin-Bouchal, & Marcy-Edwards, 2008). These behaviours also damage the trusting relationship between the service user and visitor which can lead to a reluctance to invite them back into the home, more strained interactions, and ultimately disengagement from the service. At the far end of this extreme are cases where house clearances are forced which consistently often 'worsen symptoms and lead to recidivism' (Fleury, Gaudette & Moran, 2012 pg 159). The Making Space service seems to have successfully avoided the potential problem of forcing too much discarding. Though it is possible that faster progress could have been made with a more aggressive approach, the findings from this research would indicate that the service users are happy with the pace set as it allows them more control and a less stressful experience which is also likely to increase retention and adherence to the treatment program.

Support Group. There was also a generally supportive atmosphere created by the facilitators of the support group whose careful direction "gives that safety in the group. I think there's a great bottom line of respect." with participants remarking that "I certainly like everyone in the group" and "I think they're all really lovely". Participants want to continue attending the group as they are provided with a welcoming environment; Ingrid credits this to the facilitators "I think because the leaders provide that safe situation and they work together, you can tell that they're coming from the same place".

There is a wealth of research evidence that highlights the positive effect of regular support group attendance on treatment outcomes for everything from weight loss (Orth et al, 2008) to alcoholism (Laudet, 2008). Developing these feelings of safety are crucial when engaging a population that has been found to struggle to establish social relationships with others and often cope with this anxiety with behavioural avoidance (Medard & Kellet, 2014). In order to encourage regular attendance at the support group and reduce the drop-out rates, Making Space needed to focus on

creating a safe space where participants felt like they were understood. This allows service users to focus on progressing through the workbook without self-censoring due to a fear of judgment or criticism. The findings from the present study would suggest that they have achieved this aim, arguably one of the most significant aspects of creating a support group, as without regular attendance, further benefits cannot be achieved.

Utility of the Treatment in Improving Quality of Life

This theme explores the effectiveness of the treatment in improving the quality of life of the service users in three subthemes; 'Increase in discarding', 'empowering and motivating individual work', and 'longevity of effects'.

Increase in Discarding

Home Visits. Overall participants receiving home visits reported a significant decrease in the amount of clutter in their homes. For some participants the impact of Making Space has been huge, one participant had been living in his car prior to receiving support as he wasn't able to enter his flat due to the volume of clutter; "It's helped me enormously….at least I'm in my own home now". Other goals have included "to get the lounge to the point that for Christmas, I could eat Christmas dinner off the table", to clear out the bedroom "in order to get the bedroom decorated." and to clear a section of a room to "get to the fireplace in time to put the Christmas tree up". These goals have been successfully achieved over a period of months and while participants still reported a lot of work left to do, they are understandably proud of what has been achieved in their homes; "The amount of stuff that's gone out is amazing, really, every week more stuff goes out". Augustus reported being "delighted in terms of the way we managed to work through the room we did. And we got some other things on the way, like a clear staircase to get to the clear room"

> It has helped me reduce the density of my home. I can see over the table, I can walk around the table, there are chairs at the table I can sit on. I can actually get into my armchair and eat meals in my armchair. I can play the piano (Herbert).

De-cluttering does get easier as more is organised or discarded with Cyrus remarking “it’s getting down to a much more manageable proportion”. Steketee and Frost (2006) suggest that as service users practice their decision-making skills then it becomes faster and less stressful, speeding category creation and allocation which is the foundation of the de-cluttering process (e.g. sell, donate, store, or display). This is supported by the lived experience of the service users who suggest that both decluttering and organising are skills that can be learned, practiced, and improved with help from their visitors. Gladys reported that “I learned a few things from her as well. I learned it's quite easy sometimes just to tidy the muddles just have tidy piles of stuff instead of a heap” with Doris learning the importance of consistency rather than bursts of effort; “I think it's a consistency of knowing for those two hours, I was going to be decluttering something” (Doris).

Support Group. While the support group offers less hands-on support, service users have still reported that they find it useful in tackling their issues with hoarding and increasing their discarding. Participants suggest that the support group plays a valuable role in forcing accountability; “I find it kind of keeps me on track” and provides an “incentive” to get the work done. There is also an agreement that the support group encourages participants to keep up with de-cluttering and not slip back into behavioural avoidance; “It is the first time that I've actually been able to keep facing the problem”. By providing emotional support, accountability, and “normalizing” the condition, the support group allows participants to move away from their feelings of hopelessness and develop more resilience to keep trying to discard.

> One of the things that the group does is interpret a different emotion by taking my negative emotion of shame and guilt and the sense of overwhelm, and I can't, and I'm stuck and the

> hopelessness….and going, and I'm okay with this, because it’s a disorder, this is a mental health problem. (Herbert)

The cognitive-behavioural model suggests that a classic avoidance pattern is common including behavioural aspects such as slow-paced discarding and churning (constant movement of items from one place to another without ever discarding them) as well as cognitive aspects such as perfectionism. The support offered by Making Space seems to have some utility in breaking this cycle by having regular sessions encouraging accountability to either the group or the visitor which prevents denial. They also discuss the use of tactics such as churning and the issues surrounding perfectionism to further encourage independent decluttering at home.

Motivating and Empowering Individual Work

This subtheme links with the cognitive-behavioural idea that de-cluttering and decision-making are skills that can be taught, practiced, and improved. Both during and after receiving support from Making Space, service users feel empowered to make changes themselves. This is coupled with a surge in motivation before the home visits or support group which means that there is meaningful work being done outside of the scheduled sessions.

Home Visits. Prior to receiving a home visitor, participants were “just overwhelmed with everything, and I just didn't know where to start.”. Cyrus reported difficulty starting “I did try to get some clearing done. I did find it was a bit difficult. It was a bit overwhelming to be honest.” With others discussing a “lack of motivation” to try. However, once participants had begun the treatment program and were expecting a weekly or fortnightly visit, they were much more motivated to undertake individual cleaning alone whereas before they wouldn’t have tried.

> So last night, I tried to mop the floor of the kitchen. It did not go well. Even with a Karcher steam cleaner I ended up with streaks of lemon all over the floor. Very, very badly done. But the difference is when I get home this afternoon, I'll try it again. Previously, I would have given up because I would have felt overwhelmed (Herbert)

Participants reported that their visitors empowered them to continue to do the work alone which they wouldn't have felt able to tackle previously due to feelings of overwhelm and hopelessness. Frances reflected on the emotional impact of the home visits "I feel empowered, so that I could do more of this work myself now…that's their legacy they've left with me"

They also reported using the home visits as a deadline by which they must have done some organising. Several references were made to the common social convention of people cleaning before their domestic cleaner visits so as not to disappoint them or be embarrassed of their home; "If you get a cleaning lady…. then you spend the day before tidying up". Herbert remembered that he "used to tease my grandma that she'd tidy up before the cleaner came out but now, I do the same with [visitor] because I don't want to let her down".

This is consistent with Lock and Latham's (2012) theoretical explanation for the effectiveness of deadlines (such as a home visit) with their goal-setting theory of motivation. Their interpretation would be that when the service user and visitor work together to set a small but meaningful goal to be achieved by the next visit (e.g. shred a pile of paperwork) they provide a level of extrinsic motivation that is more successful than relying on the service users intrinsic motivation alone. People with hoarding issues generally have low intrinsic motivation so the creation of an external motivation factor is key to breaking the cycle of failed attempts to begin decluttering (Worden, DiLoreto & Tolin, 2014). It also breaks the cycle of perfectionism which is a common cognitive distortion amongst hoarders identified by research into the cognitive-behavioural model (Frost & Hartl, 1996)

Support Group. Similar to the home visits, participants have reported that having the support group scheduled gives them a fixed point to work around rather than a "never-ending series of tomorrows". Ingrid stated "The fact that I know I'm going back to a group makes me think right I'll do some shredding today" suggesting that the support group puts a small amount of manageable pressure on the participants to encourage them to have achieved something to feedback to the group.

Eileen agrees with this and believes the group “stops me from just giving up which I think I've got great desire somewhere to just give up on everything”.

However, the support group was criticised for not being structured enough to offer true accountability with set goals and consistent check-ins on progress. This is explored further in the third theme ‘Lack of clear structure’.

Longevity of Effects

This subtheme considers whether the positive effects of the service last when the home visits stopped. The support group is currently available on an ongoing basis and so the longevity of the effects cannot be known. Most participants involved in this study were still receiving support from Making Space, however, those who had finished or were close to finishing their home-visit treatments did express concern for the future of their decluttering efforts. They mainly expressed that the work will be much harder and slower without help from the visitor.

> But I think it's, since I haven't had that support, that I am aware that I have to do it on my own, which is fine. But then I am so much slower… my brain just reacts differently when I've got somebody in the room, than if I'm doing on my own (Doris)

Despite these concerns, on the whole, participants expressed confidence that they will be able to continue making positive changes as they “can tackle bits now” and “feel like I can do this by myself”. The transparency in the inner workings of the service, including the length of the waitlist, gave participants the ability to understand that visitors were needed elsewhere and meant that they “never felt abandoned. I felt I thought I'd come to an end”.

The overwhelming feeling from the participants at or nearing the end of their home-visits allocation was one of gratitude, “I felt like I was blessed” (Frances), and a sense of being ready to try the work alone. Gladys agrees stating “I just think they were so helpful. They were so helpful to me. And I got to start helping myself now” and with Cyrus adding “I’ve benefited from it, to say the least, I am grateful for that”.

However, there are critical gaps in the research considering the longitudinal effects of interventions. There have been no follow-ups on existing treatments including those based on the cognitive behavioural model such as the program explored in the current study. This is a recommended area for future research with follow-ups after an extended time-period being required to assess the longevity of the treatment benefits.

Lack of Structure

The third theme applies only to the support group. Despite the overall positive opinions expressed of both the home visits and support group, there was some criticism of the "quite unstructured" nature of the support group. Three subthemes have been identified here, a lack of timekeeping, a lack of consistent homework, and limited goal setting.

Time Management and Pacing Issues

Many participants expressed frustration with the lack of time management within the sessions, they felt this had knock-on consequences in the group's ability to meaningfully utilise the session to progress through the workbook as well as limiting their ability to hold themselves accountable to the group.

One common complaint is the 'check-in' process at the beginning of the session extending into the time allocated to work directly from the workbook with participants reporting "it just went on too long". Participants agree that "[There is a] lot of independent storytelling…. the stories are often very engaging and whatever, but I've not always felt that they are taking the group forward".

While there is an agenda displayed throughout the session (See appendix E) participants expressed a desire to have stricter timekeeping to prevent "drift" and ensure that meaningful work could be achieved in every session; Baltazar suggests "You should have an agenda. You should have some timings down and you should sort of drive through". He believed that sticking to an agenda would facilitate stricter time limits and support their efforts for greater discipline within the group.

Herbert also thinks “we could be more disciplined in sort of in the opening round of sharing, we could probably set a shorter time limit [with an agenda]”.

Participants also expressed some frustration at the pace they moved through the workbook due to the limited session time they spend on it. Unfortunately, the pace of the sessions is impacted by the mixed ideas as to the structure of the group, either as a timed program from which a service user would graduate having completed the workbook and covered all aspects of the treatment program or as a continuous drop-in service with no real end-state. Participants expressed that they would prefer a structured, time limited group as “after a certain duration I'd like to think that at some stage, I could manage it alone” without needing the support group. Herbert also stressed the importance of endings and not relying on the support group for life stating that “the timeframe is almost arbitrary, but you need to end. But the end goal needs to be set at the beginning.” (Herbert)

However, there has not been a definitive end date set and the drop-in nature means that many people do not attend every session. There is an issue with the method of data collection here as I interviewed participants who were regular attendees. On the whole, they agree that a time-bound program would be better, though it is possible that some of the service users I did not interview would prefer a support group that is more fluid due to their sporadic attendance. This lack of consistent attendance by some service users means that timekeeping and pacing can be problematic as some elements of the work need to be repeated, “I feel some of the chapters I've probably done twice”, which can leave regular attendees frustrated.

Lack of Consistent Homework

Participants expressed a desire to use the workbook more, particularly when setting homework. The use of homework was encouraged by participants as it helps accountability and makes it more likely that participants will engage with decluttering and the workbook outside of the support group session. Eileen believes that “if you've not been set homework, the [work]book maybe

doesn't get opened very much. If at all" so would appreciate more homework to help her engage outside of the session.

> But whether you do the homework as soon as you get it, or you do it just before you have to give it in. You do it. You think I've got to clear something today so that I've got something to tell them. I think that would be probably motivating (Baltazar)

Homework or between-session learning is considered a crucial part of cognitive behavioural therapies and also plays a supporting role in most other psychotherapies (Kazantzis & Ronan, 2006). Completion of homework tasks is a strong predictor of successful completion of treatment, possibly because it indicates a high level of 'buy-in' to the program and therefore a higher motivation to finish (Rees, McEvoy, & Nathan, 2005). Without consistency in setting homework tasks, it is impossible for service users to be consistent in completing it which limits the utility of the program and can leave participants feeling demotivated between support group sessions.

Limited Goal Setting

While goal setting has been successfully used in the home visit service to improve motivation and empower service users, participants expressed a desire to set more goals in the support group. They identified a need for both overarching goals for the entire time they attend the support group and smaller goals between each session as the group is "kind of meandering…because we haven't been setting very clear goals".

> I think I would probably have begun the group by setting some SMART goals and saying: Why are you here? What do you want to achieve? What is the timeframe in which you want to achieve it? (Herbert)

Doris believes that goals would be likely to motivate her to complete more decluttering because she would want to avoid feeling "annoyed at myself". She believes "If I had achieved [the goal], I would feel I have accomplished something and I think I would achieve if I wrote it down and spoke to the group".

Previous research indicates that hoarders can struggle to set achievable goals without support, often setting unrealistic or vague goals such as ‘clear out the kitchen’ (Gilliam & Tolin, 2010). However, with appropriate support, goal-setting and goal review have been incredibly effective for the vast majority of clients undertaking treatment based on the cognitive behavioural model (Turner, Steketee, & Nauth, 2010; Bratiotis, Woody, & Lauster, 2019). More broadly, goal setting has been used to great success when tackling weight issues, addiction, and other interventions that involve significant lifestyle change (Pearson, 2012; Urschel, 2009). The findings of the present study, backed by existing research, suggest that the Making Space program would greatly benefit from clearer goal-setting routines.

Limitations and Future Research

The conclusions drawn by this study are limited by the sampling method. As all participants were drawn from the client list of Making Space, they were people who were actively seeking and engaged with treatment. I did not include participants who dropped out from treatment meaning that the sample could be biased towards the program as they have continued to utilise the service. Future research should consider including participants who dropped out of treatment programs in order to get the full breadth of perspectives in an attempt to improve retention.

Despite these sampling limitations, all participants reported that they felt that they could be open and honest with the researcher during a post-interview anonymous survey. This indicates that despite the sensitive nature of the topic, participants felt able to be truthful without fearing judgement.

A measure of how engaged participants have been could have been useful to this research, for example, a record of cancelled home visits, missed support group sessions, or incomplete homework assignments. This could then be compared with the perceived effectiveness of the treatment in order to assess if participants who ‘buy-in’ to the program and engage to the fullest are also participants who perceive the most benefit. This evidence could then be used to assess the need for interventions

used to increase ‘buy-in’ such as photographs, attendance rewards, and social incentives such as sponsorship programs.

Additionally, quantitative research would be useful to gain a more objective look at the actual effectiveness of treatment (in terms of items discarded) to support these findings about the perceived effectiveness of treatment. While the perception of service users is vital for retention, it is also important to consider the overall utility of service for reducing clutter.

Finally, a comparison of the volunteer-based Making Space service with more traditional CBT methods would be useful in assessing the necessity of a trained therapist/ psychologist. The potential reduction in the cost of services is attractive but must be balanced with a potential lack of continuity and reduced ability for volunteers to address underlying issues and traumas. Further research is needed to firmly establish what volunteers could be appropriately utilised for without the support of a qualified psychologist, in order to avoid reliance on under-qualified mental health support for hoarding disorder.

Conclusion

Overall, this research is a useful indication that the Making Space program is generally well-regarded by service users. They feel that the service is safe, non-judgemental, and doesn’t put too much pressure on them while also recognising the utility of the service in supporting their efforts to discard. Participants report feeling more motivated and empowered but, despite optimism from service users reaching the end of their treatment, there is little evidence to assess the longevity of these positive effects. Furthermore, participants feel the support group would benefit from more structure including better timekeeping, goal setting, and more regular homework in order to reach its full potential as a tool for accountability. These findings are useful to the Making Space program and any future cognitive-behavioural treatments for hoarding disorder as it highlights the need for a supportive and structured environment. This research also demonstrates that a non-judgmental

service that doesn’t put overt pressure on service users to discard or force extreme clear-outs can have real benefits in reducing symptoms without causing distress.

Future research should focus on assessing the longitudinal effects of cognitive-behavioural interventions like Making Space and the potential pitfalls of a volunteer-based service while also considering more objective measures of utility and effectiveness.

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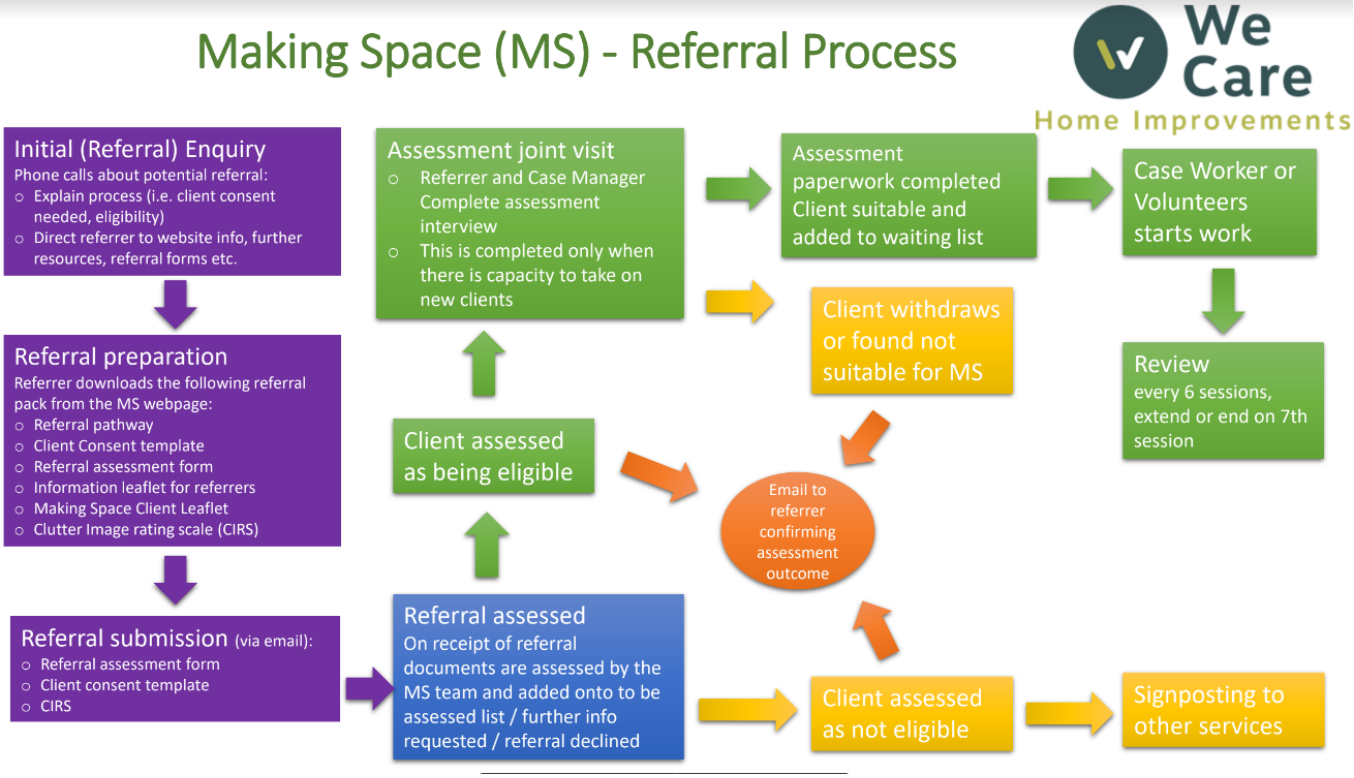
Appendix A

Referral and Assessment Process Flowchart (Provided by Making Space)



Appendix B

Abridged Making Space Assessment Form (Provided by Making Space)

Note: In order to protect their privacy, I did not access participants assessment forms though all were assessed suitable for support by Making Space. This means that all participants fit one or more of the criteria detailed on this form and/or have difficulty with one or more of the 'activities for daily living'. All participants demonstrated that their hoarding has a substantial impact on their quality of life and/or mental health.

Cluttering Problems

Front / Back / Internal (stairs) access:

The clutter prevents essential works to the home from being carried out: Yes ☐ No ☐

The clutter prevents discharge from hospital: Yes ☐ No ☐

The clutter prevents a move to more appropriate accommodation: Yes ☐ No ☐

Fire Risk:

Falls History:

The clutter obstructs essential pathways / constitute a tripping hazard: Yes ☐ No ☐

Falls in the last 6 months:

Risk of Eviction: Yes ☐ No ☐

Environment Health Involvement: Yes ☐ No ☐

Pests: Yes ☐ No ☐

Activities of daily living				
Please indicate to what extent clutter interferes with the client's ability to do the following				
Activity of daily living	N/A	Can do	Can do with difficulty	Unable to do
Prepare food				
Use refrigerator				
Use stove				
Use Kitchen Sink				
Eat at table				
Move around inside the house				
Exit home quickly				
Access Toilet				
Access bath / shower				
Access bathroom sink				

Answer door quickly				
Sit in Sofa / Chairs				
Sleep in bed				
Clean the house				
Do Laundry				
Find Important things (e.g. bills)				

Mental Health and Wellbeing

Do you feel the number of possessions in your home is problematic for you?

Thinking about your home environment, is anything causing you distress at the moment?

What are your priorities for change?

If your living environment were different, what could you then do? what could you no longer do?

Smoke alarm		
Is there a working smoke alarm?	Yes ☐	No ☐
If no, do you give permission for Making Space to make a referral for you to Avon Fire & Rescue?	Yes ☐	No ☐
Urgent Repairs		
Are there any obvious repairs that need carrying out at the property	Yes ☐	No ☐
If yes, please indicate the needed repairs:		

Appendix C
Extract of Transcript

Note: Due to the small nature of the sample and familiarity of the Making Space staff with the participants, in order to ensure total anonymity only a carefully selected section of one transcript is provided to demonstrate type of transcription.

Line	Transcript
1	**Interviewer**: So how… how do you feel during meetings?
2	
3	[25:02] **Participant**: Ah well, this is the important thing. So the meeting, the group
4	is really, really good at making me feel accepted and having a hoarding disorder. I
5	don't feel shame I don't feel stigma about having hoarding disorder I feel okay, this is
6	normal. There are other people who have this to actually work with this.
7	
8	**I**: Hmmm, yeah.
9	
10	**P**: And then in that broad acceptance, you can, you can accept unconditionally. If I
11	can unconditionally accept and not feel shame and not feel guilty and not feel stigma
12	then I am more likely to take action. Okay? And that's what the group helps with. I
13	come away from the group feeling okay. Whereas I wake up in the morning, walk
14	into my lounge and go shit send for the National Guard. Someone has been in here
15	again [laughs]. No, I live alone. It was me. The group makes me feel less
16	overwhelmed. And more able to take action.
17	
18	**I**: Okay, that's good. So when [visitor name] visits before [their] visits, do you feel
19	like you're able to be motivated before [they] arrives?
20	
21	[26:17] **P**: This is kind of a great question, because I used to tease my grandma, that
22	she'd tidy up before the cleaner came out. And I do the same with [visitor name].
23	Because I don't want to let [them] down. I know, [they're] giving up [their] time to
	help me. So if I mess things up between [their] visit, and we go backwards, then I try
	and get back on top of it before [they] arrives.

Appendix D

Additional Themes

Theme	Detail	Quotes
Necessity of Additional Support	A fourth theme identified was a necessity for additional mental health support prior to or concurrently with the Making Space service. Participants discussed a need to be in the right headspace so external mental health support might be useful for that. Participants also identified that concurrent mental health support such as counselling or other 'talking' therapies might be useful while receiving the home visits to help deal with the emotions it brings up.	"The reason you hold on to stuff is for a psychological reason, isn't it? So if you're not dealing with that, as well? How could you possibly improve?" (Frances) "I'm just wondering if it would be good as any other like, you know, services if they should be going at the same time because I think the decluttering itself is something very different to talking about the why you need decluttering" (Doris)
Ideas to Expand the Service	Participants were eager to discuss ideas to expand the service that go beyond improving the service that is already provided (ie. addressing the lack of structure in the support group). This theme is beyond the scope of this study but have been included here for possible future research and development. • Sponsorship programs such as in Alcoholics Anonymous by recovered hoarders • An additional service focusing on maintaining the cleared space for those who are further on in their journey. A 'next step' to aim for- • Normalising the disorder through education for relevant parties (e.g. housing officers, firefighters) delivered by recovered hoarders • Creation of a 'Friends and family' support group	"I'm passing on the gift I've been given…. pass on what you have been taught and sponsor and bring in a new round and be the helpers" (Herbert) "I'd like another branch of how does one maintain the free space that one makes" (Doris) "Take the knowledge into the academic and the professional communities so that people who are on training programmes to be a fire officer or housing officer or a social worker or a counsellor or a psychotherapist or psychologist, meet people with hoarding disorder and they share their experiences" (Herbert) "But I can see that it affects my wife's life because she really doesn't… she hates it" (Baltazar)

Appendix E
Example Agendas for Support Group Meeting

Unstructured Agenda Currently in Use

Time	Task
10:30	Arrival
	Check-in
	Book work
	Break
	Book work
	Meditation
12:30	End of session

Suggested Improved Agenda Based on Analysis of Participant Interviews

Time	Task
10:30- 10:45	Arrival
10:45- 11:05	Check-in- Questions about homework reading Were last week's goals achieved? Share before/after photos of goal if possible.
11:05- 11:30	Book Work- Exercise from current chapter
11:30- 11:45	Break
11:45- 12:05	Book Work- Discuss outcome of exercise.
12:05- 12:15	Set homework and write down individual's goal for next two weeks.
12:15- 12:20	Meditation
1220- 1230	Check out- Three words to describe how you are feeling now

Note: This example agenda is included for the benefit of readers who may wish to set up a similar service or as a possible data-driven alternative for Making Space.