

Research Article

“Making It Easier to Live, You Know?” A Qualitative Study of the Impact of Hoarding Behaviours and Social Networks on Older People’s Supported Housing Decisions

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The decision to move from independent to supported housing is a key life decision. Research focusing on the potential barriers to transition to supported housing for people with hoarding behaviours and the impact of social networks on the decision-making process is scarce. 16 participants, including 4 participants with hoarding behaviours, took part in in-depth semistructured interviews providing information about their social networks, support received, their perceptions of supported housing, and their decisions made. Relatives and friends were the most widely reported networks of support for discussing supported housing options for participants both with and without hoarding behaviours. Three key themes were extracted from the dataset: Before the Move: Crisis and Stigma; During the Move: Possessions and Support; and After the Move: Supported Housing = a Bright Tomorrow. The data revealed stigmatised and negative perceptions of supported housing prior to moving, with a crisis event initiating the move in most cases. For people with hoarding behaviours, existing life traumas proved an additional barrier. All participants reported “moving day” as an acutely stressful event, and participants with hoarding behaviours reported greater stress and anxiety over possessions. All moved participants reported living in supported housing as a positive outcome. Three key considerations are apparent: awareness raising to combat stigmatised perceptions of supported housing; targeted support during the moving process to manage and pre-empt problems; promoting supported housing as a positive environment and making participants, and their networks aware, potentially reducing the perceived impact of the move. Further research with a larger, and more socially and geographically diverse sample of individuals with and without hoarding behaviours, is recommended to further explore these considerations.

1. Introduction

The desire to remain in our own homes, or age in place, is supported by many drivers. These include both policies which view it as a cost-effective solution to the problems associated with increased admission to institutional care [1] and personal and psychological connections to home by individuals who are seen to increase wellbeing and independence [2]. However, most of us will find that, as we age, our living and accommodation needs will change, and this means that our connection to our homes can both

impede and support our ability to age within them [3]. Moving home or downsizing due to declining mobility can be challenging. This is especially the case for older people who hoard (PwH). According to the American Psychiatric Association [4], hoarding disorder (HD) is characterised by the excessive accumulation of items; a marked difficulty in discarding those items; severe cluttering of living spaces which prevents their intended use; and clinically significant distress or impairment in normal functioning. HD is a chronic condition, which emerges in middle to late adolescence and becomes more problematic with age [5]. The

prevalence of HD has been estimated at around 2.5%, making it more common than disorders such as schizophrenia and OCD [6], though some researchers have reported a higher incidence of up to 6% [7]. While to some observers, it may simply represent an eccentric but harmless lifestyle choice; in recent years, such behaviours have become increasingly associated with poorer social and economic outcomes, increased marginalisation and deprivation, an increase in health problems, and a greater risk of accident-related injuries [8–13]. The fact that such behaviours all place additional strain on the suitability of people's homes further reinforces the impacts of housing as social determinant of health and wellbeing [14].

PwH report experiencing higher levels of material deprivation, crime, and physical/sexual abuse as children, with the number of traumatic life events (TLEs) correlating with hoarding severity [15, 16]. They also report that they have experienced a greater number of different types of traumas, more frequent traumatic experiences, and more symptoms of posttraumatic stress [15, 16]. Not surprisingly then, most studies assessing comorbidity in hoarding report high rates of depression, at significantly higher rates than comparable OCD groups [17, 18]. Rates of anxiety are also reported to be significantly higher in HD, especially for generalised anxiety disorder and social phobias [19]. For example, in a clinical sample of 217 individuals diagnosed with HD, Frost et al. [20] found comorbidity rates of around 50% for major depressive disorder and rates of 23.5% and 24.4% for social phobia and generalised anxiety disorder, respectively. Whether depression/anxiety predates hoarding behaviours and influences their development or whether the hoarding behaviours and their negative impacts on the individual and their environment leads to greater anxiety/depression remains to be evaluated.

The number of PwH seeking treatment or support is low [21] with high dropout rates when it comes to engaging with support interventions [22]. This is exacerbated by the stigmatisation of HD as a poorly understood condition [23–25] with self-stigma associated with reduced willingness to engage with treatment [26] difficulties trusting others without feeling judged [27] with negative impact of help-seeking behaviours [28]. Talking about hoarding is therefore extremely challenging and can have an impact of PwH engagement with both agencies and researchers when it comes to addressing quality of life issues faced by individuals with HD.

As the key symptom of hoarding (i.e., excessive clutter) can take many years to reach a level where impairment in daily functioning becomes problematic, it is no surprise that hoarding appears to be a particular challenge for older people, as they may have spent many years accumulating possessions. Research on older PwH reveals that hoarding severity increases with age and outcomes are particularly poor [29]. Hoarding in the elderly is particularly associated with increased social isolation, higher levels of depression, and deficits in executive function, memory, and attention, which can make the symptoms even harder to address [30].

HD impacts not only the individual and their families but also the wider community and particularly those

agencies and individuals who work with PwH on a regular basis. In one survey of organisations who address hoarding behaviours, it was found that hoarding costs on average around £15,000 per annum due to increased staff time, clean-up costs, and legal expenses [31]. The same survey found that the cost to an emergency service was around £100,000 per annum. Housing providers bear the brunt of hoarding behaviours. In one survey of a city council in England, interviews with housing officers revealed the highly complex nature of hoarding cases, with a fine balance between enforcing tenancy rules and meeting the complex and diverse needs of the person involved [25]. This problem is exacerbated by the lack of multiagency approaches to what is a highly complex health and community problem [32].

A key decision facing an individual and the organisations that support them relates to transitioning from independent living to supported housing. When a person is no longer able to cope with living in their current home, then supported housing is an increasingly popular option. It is a service model that combines independent living with the addition of community-based support [33]. It is commonly associated with older people who can no longer physically maintain a larger multistorey property, perhaps with additional outdoor spaces, and provides additional security in the form of onsite health and personal care, meals, and community activities [34]. Research studies on the benefits of supported housing demonstrate that it offers stability of tenure, increased safety, reductions in hospitalisation and homelessness, and improved quality of life (see [33]). However, the current research study has been focussed on individuals with a psychiatric illness (such as schizophrenia), an addiction, or are homeless [35, 36], and there is limited evidence in relation to people living with a persistent mental illness such as HD.

The decision to move from independent to supported housing can be a very difficult one to make, as the person is giving up their perceived “independence” [37, 38] and perhaps a family home filled with positive memories and sentimental associations. Even though research has considered the benefits of providing supported housing from the perspective of severe mental illness/homelessness [39, 40], there is much less research studies focusing on the potential barriers to transition in people with less severe mental illnesses, such as hoarding.

Considering an individual's social support networks and the type of support received is also crucial in being able to understand the ways in which they may make decisions about supported housing. The research study has demonstrated the positive impacts of support from family, friends, and neighbours on healthy ageing [41, 42] as well as wider community engagement to combat loneliness and isolation [43]. Further investigation of how such support enables an older person to arrive at decisions to move into supported housing is also a key to consider potential future support interventions when the time comes to make the move.

Considering a move from independent to supported housing in people with hoarding behaviours might be particularly interesting because these individuals develop extremely strong attachments to inanimate objects [44].

This, combined with their pronounced inability to discard items, might make such a decision (which invariably involves downsizing) particularly difficult for them. The aim of this research study was to better understand the potential barriers and enablers faced by older people with hoarding behaviours in considering and/or making the transition to supported housing. We did this by gathering the views of older people who are considering the transition or who have made it recently. We also sought to consider what prompted or supported older people to move or consider moving and to provide practical recommendations which might make this difficult transition period less stressful in future.

2. Methods

2.1. Study Design. This study represents the findings of a nested qualitative evaluation taken from within a mixed methods study exploring social support networks in people with and without hoarding behaviours experiencing the transition from independent to supporting housing. In-depth semistructured qualitative interviews were conducted to explore older people's attitudes towards and experiences of supported housing in the north east of England and the impact of hoarding behaviours and social networks on decisions made regarding supported housing choices.

2.2. Ethical Approval. The study received ethical approval from University REC (Ref: 29397).

2.3. Participants' Eligibility. Participants were eligible if they were aged 50 years or above and, at time of study participation, living in the north east of England (Tyne and Wear; County Durham, Northumberland; Teesside). Participants were also required to either be currently considering, or being asked to consider, supported housing at the time of taking in the study or to have moved into supported housing within the previous 6 months. As we wanted to specifically assess the transition to supported housing in PwH, being self-identified as such also formed part of the eligibility criteria.

2.4. Identification and Approach. Participants were recruited through direct e-mail or telephone call to social housing providers and older people's organisations and via promotion of the project on social media, Facebook, and Twitter. Participants were offered a £10 Love2Shop gift voucher per research visit to participate. The research team worked in partnership with a local authority housing team based in the north east of England to identify the best approach to the study. The research team was also supported by a project advisory board comprising hoarding specialists, social housing providers, and older people's organisations to maximise the recruitment strategy, and how to make best practical use of the research findings.

2.5. Data Collection. The study involved an initial 1-hour visit with each individual participant either in their home or mutually agreed location. Initial quantitative demographic

data were collected using Network Canvas [45] software regarding how people's networks influenced the person's decisions about supported housing. The Savings Inventory Revised (SI-R) [46] was used to collect baseline information about the individual's hoarding behaviours.

In addition, semistructured interviews were conducted, focusing on a series of open-ended questions concerning participants' expectations of supported housing; experiences or perceptions of the advantages and disadvantages of supported housing; the impact, real or anticipated, of supported housing on their social and personal networks; the impact of possessions and how the participant felt about them, on their decisions to move; their expectations or experiences of the moving process; the level of information that they had about supported housing either currently or prior to moving and the gaps in information or support experienced; and any final advice they would like to share for any other person either moving or thinking about moving into supported housing. The average interview length was 18 minutes 19 seconds (maximum = 52 minutes 32 seconds; minimum = 11 minutes 08 seconds).

Participants' informed consent was taken via the first demographic data collection visit and recorded on the Network Canvas interview proforma (an "I agree" box was ticked to indicate study consent at the beginning of the survey). Further consent was collected as an audio recording at the beginning of the interview during the second study visit. Interviews were audio only recorded using a TASCAM DR.42 voice recorder and transcribed manually by one researcher (CMM) who carried out all home visits and interviews. One person chose to take part via a telephone call for their first visit, followed by a Microsoft Teams recorded interview due to self-isolation due to potential COVID symptoms. Due to a pause in face-to-face data collection as per university COVID regulations (eased September 2021), one person took part via a telephone call in August 2021, and a further person preferred to have their first meeting via telephone and met the researcher in person for the follow-up interview.

As data collection took place whilst COVID-19 public health restrictions remained in place for much of the UK, a full risk assessment was carried out prior to each visit to minimise the risk of harm for participants or researchers due to the risk of COVID-19 infection. The researcher undertook COVID-19 lateral flow tests prior to each visit, with each participant being contacted before the visit to check that they did not have any symptoms that may present as COVID-19. Face-to-face data collection was permitted from September 2021 as per university easing of restrictions for research data collection activities.

Given the nature of the research and the sensitivities of the subjects (i.e., considering supported housing and hoarding behaviours), the researcher was transparent in discussing the aims and objectives of the research in detail (e.g., how the research aims to help others in a similar situation in the longer-term). Time was taken for the participant to decide whether they wished to be interviewed at home or at a location that was familiar to them or where they felt comfortable (e.g., meeting room in their local library).

Meeting places were mutually agreed with locations chosen which allowed for privacy and to minimise disruption. In cases where the participant wished to meet at home, a meeting space was agreed beforehand that, given COVID-19 restrictions, provided ventilation. Participants were also reminded that they had the choice to skip any questions that they did not wish to answer. Each participant was reminded that all data would be anonymised, and they were given a unique code so that they could remove their consent to take part, and consequently their data, pre-publication should they wish to do so.

2.6. Data Analysis. The researcher who had conducted all data collection visits (CMM) made notes and regularly discussed anonymised content with the other researchers, with regular additional reporting to the project advisory board. All recordings were transcribed verbatim and coded manually in Microsoft Word using inductive thematic analysis and the six-step process outlined by Braun and Clarke [47]. The interviewer grouped together similar content from across the dataset to generate codes from repeated content across the data. A smaller sample set of 5 interviews were uploaded to Nvivo 12 analysis software [48] and were counter-analysed by another member of the research team (PH) to cross-reference codes generated. Both researchers independently coded the data, cross-referencing on all codes generated to both ensure consistency of topics and keywords across the dataset, repetition, data saturation, and to ensure greater accuracy of findings as opposed to one author's subjective experiences.

3. Results

3.1. Participant Demographics and Social Network Overview. Initial data collection visits took place between August and December 2021. A total of $n = 16$ older people took part in the study (11 = women; 5 = men). Of the population sample, $n = 4$ people were self-identified as having hoarding behaviours and scored 41 or above indicating clinical levels of hoarding on the Savings Inventory Revised (SI-R) (see Table 1 for more details).

Participants reported the following types of support received as per the social health-related functions of social support framework [49] (see Tables 2 and 3).

Most of the support received was from relatives not living with the individual (e.g., adult children and grandchildren; siblings, and cousins). This was the case for participants with and without hoarding behaviours. People with hoarding behaviours reported receiving no support from a spouse or partner and no support from neighbours. Most participants also reported having discussed the option of supported housing with their relatives (Table 3).

3.2. Interviews. Participants agreed to a follow-up interview which took place during September 2021–January 2022. Data analysis and themes generated an initial set of 102 codes across 4 subsections: supported housing, possessions, hoarding behaviours, and impact of COVID-19. On further

inspection of the data, an initial thematic structure was generated involving a total of 16 subthemes across 4 sections (see Table 4).

Further analysis of the data conducted by two of the researchers (CMM and PH) generated 3 final themes: (1) Before the Move: Crisis and Stigma; (2) During the Move: Possessions and Support; (3) After the Move: Supported Housing = a Bright Tomorrow. Each theme will now be discussed in turn, and the implications for individuals with hoarding behaviours and social networks will be discussed.

3.3. Before the Move: Crisis and Stigma

3.3.1. Crisis. A crisis episode is a period in an individual's life where major life transitions can impact on a person's psychological, physical, and emotional capacities to be able to cope with and manages the challenges they are presented with. In the context of ageing, examples such as falls, declining mobility, or declining ability to manage a household budget can lead to a crisis episode, whereby an older person is forced to consider supported housing. It is often a crisis event (e.g., a fall) that can lead to a matter of urgency in considering housing decisions. Both the concept and lived experience of increased physical frailty can force an individual to get to "crisis point" where they face adverse health outcomes in large part because of their declining ability to manage their current home environment. Participants in this study reported that some form of crisis had facilitated their move, or consideration of a move, to supported housing, rather than such decisions being made preventatively. Declining physical mobility was widely reported, resulting in the need to move to accommodation that could better suit their needs. Participants reported that getting to crisis point in declining mobility was the main reason that supported housing was discussed with relatives and professionals prior to moving.

"Number one was secure. That was the main thing. And {...} that I would be independent but have back-up. Because I've got brittle bones and I fall over a lot. So, it's a good thing that, you know, there are people I can call and rely upon." (Female, aged 68, PwH)

Two participants who were previously renting in the private sector also reported that they were forced to move due to private landlord deciding to sell the property:

"...we were actually forced into the situation when...our landlord gave us notice. Said he wasn't going to renew our contract anymore. So we were forced to make the decision of what we were going to do." (Male, aged 77, non-hoarder)

Participants also talked about the expediency of moving decisions in themselves being experienced as a crisis. The prospect of "moving day" was widely reported as an acutely stressful event and, in many cases, an almost insurmountable barrier to moving in itself:

"Very stressful. Which it was.... I nearly backed out." (Female, aged 57, non-hoarder).

TABLE 1: Interviewee demographics $n = 16$ (network canvas first visit).

	People with hoarding behaviours ($n = 4$)	People without hoarding behaviours ($n = 12$)
Mean age	61.75 years (SD 10.81, range 49–73)	70.0 years (SD 7.03, range 57–77)
Gender		
Female	$n = 4$ (100%)	$n = 7$ (58%)
Male	$n = 0$ (0%)	$n = 5$ (42%)
Ethnicity		
White British/Irish	$n = 3$ (75%)	$n = 12$ (100%)
Not recorded	$n = 1$ (25%)	$n = 0$ (0%)
Current supported housing tenancy type		
Sheltered accommodation (flat or apartment)	$n = 2$ (50%)	$n = 9$ (75%)
Sheltered accommodation (bungalow)	$n = 1$ (25%)	$n = 2$ (17%)
Council house	$n = 1$ (25%)	$n = 1$ (8%)

TABLE 2: Participant support networks $n = 16$ (network canvas first visit).

Sources of support network	People with hoarding behaviours ($n = 4$)	People without hoarding behaviours ($n = 12$)
Spouse/partner	$n = 0$ (0%)	$n = 2$ (17%)
Relatives	$n = 4$ (100%)	$n = 10$ (83%)
Friends	$n = 4$ (100%)	$n = 8$ (67%)
Neighbours	$n = 0$ (0%)	$n = 4$ (33%)
Professional support	$n = 2$ (50%)	$n = 3$ (25%)

One participant stated that she also experienced the “crisis” of deciding “right there and then” as to whether she wanted to accept a flat, adding a time critical pressure to deciding.

The prospect of downsizing, packing, and physical moving from one location to the other was also widely presented as a crisis. Moving day was stressful for both single people and couples within our sample:

“I think a younger person could’ve handled it better than we did, but we-we were really on our nerve’s ends, we were fighting day in and day out with each other, we just – it was just...terrible.” (Female, aged 75, non-hoarder)

This was also the case for participants with hoarding behaviours, with one participant reflecting on the impact of moving in the context of leaving behind a home that you may have lived in for a substantial period:

“Very stressful...but, saying that, I do have a lot of friends that would help, so...But I think moving’s stressful anyway, plus it’s leaving...it’s like leaving yer old place behind, which I know is gonna be hard, ‘cos I’ve lived there a long time, seventeen year.” (Female, aged 57, PwH).

In corroboration with the previous literature, the participants with hoarding behaviours in this study reported a multiplicity of crises or traumatic life events (TLEs) occurring simultaneously, with several additional crises’ factors reported in addition to mobility decline. Domestic abuse, financial difficulties, memory decline, and neighbour harassment were indicated as factors that resulted in their decision to move into, or consider, supported housing. In

reporting neighbour harassment as a key factor, one participant who had recently moved talked about the advantages of supported housing:

“...the biggest advantage for me was living somewhere where I had my own front and back door, and I was away from neighbours that were actually, basically, wanting...-making me self-harm. And were actually...hurting my life.” (Female, aged 49, PwH)

This presents an interesting perspective in terms of considering how older adults who hoard interact with their neighbours, with many PwH experiencing lower levels of social support and with the repercussions of hoarding for the immediate living environment (e.g., dwellings with shared entrances or communal spaces), can bring PwH into direct conflict with their neighbours, which can in turn exacerbate social isolation and stigma experienced by hoarding individuals.

Financial difficulties were also identified as a main factor in considering moving, particularly for hoarding participants, many of whom were already struggling. Supported housing would ensure moving to a smaller home and therefore not cost as much:

“Well, for me at the minute I can’t afford where I am....I’ve got two spare bedrooms and I’m paying bedroom tax and it’s quite a lot of money.” (Female, aged 57, PwH)

This raises questions about the disproportionate difficulties that PwH have in managing personal finances due to a range of potential factors often associated with hoarding symptomologies including difficulties with executive

TABLE 3: Types of peer support received $n=16$ (network canvas first visit).

	Spouse/partner ($n=2$)	Relatives ($n=14$)	All participants ($n=16$)	Neighbours ($n=4$)	Professional support ($n=5$)
			Friends ($n=12$)		
Emotional	$n=1$ (50%)	$n=14$ (100%)	$n=12$ (100%)	$n=3$ (75%)	$n=3$ (60%)
Tangible	$n=1$ (50%)	$n=12$ (86%)	$n=5$ (42%)	$n=2$ (50%)	$n=4$ (80%)
Informational	$n=1$ (50%)	$n=9$ (64%)	$n=7$ (58%)	$n=3$ (75%)	$n=5$ (100%)
Discusses supported housing	$n=2$ (100%)	$n=13$ (93%)	$n=6$ (50%)	$n=4$ (100%)	$n=5$ (100%)

TABLE 4: Initial subthemes across 4 sections.

(1) Before the move	(2) During the move	(3) After the move	(4) Additional challenges for people with hoarding behaviours
Our needs change as we age Getting to crisis point Stigma attached to supported housing Anticipating the stress of moving day	Struggling with belongings Reciprocal family ties Importance of professional support Continuing community links	Supported housing = a bright tomorrow Information I had wished I had before and during the move Impact of COVID-19	Additional challenges Professional support Need for peer support Support from family in managing the stress After the move: what now?

function (e.g., compulsive shopping and easily sourcing paperwork to pay bills) and, for older people who hoard, the disproportionate financial insecurities experienced because of chronic mental ill health experienced over a long period of time. This in turn has the potential to reduce the financial resources that older people with hoarding behaviours have when it comes to relocating to more suitable accommodation. Just one of the participants with hoarding behaviours reported hoarding as a trigger for considering supported housing, stating that they thought moving to a smaller space meant they would have to dispense with and not accumulate new items. As per the previous literature, there was a low prevalence of help-seeking by PwH for their hoarding behaviours, which raises further questions about the extent to which individuals themselves understand the severity of their symptoms and hoarding disorder remaining a poorly understood issue by both hoarders and professionals alike.

3.3.2. *Stigma*. Considering the move into supported housing can challenge the notion of personal independence when faced with declining capacities to manage daily tasks. This can be exacerbated by preconceived perceptions of what supported housing may entail. Internalised ageism can be a key factor, with prevailing beliefs that to not remain physical or cognitively independent is somehow a personal failing. Participants reported stigma and negative perceptions of supported housing as a barrier to moving. Such perceptions made managing the changes to their housing needs difficult. Stereotypical views of what accommodation for “old people” would entail were repeatedly reported:

“And I know there’s a huge stigma.... really.... still as er {sic} you know: “where do you live?” “Oh, in sheltered housing” “Oh-you must be so old!” (Female, aged 65, non-hoarder)

Such perceptions were held by both the individuals themselves and their peers:

“I just thought it would just be like lots of old folks sitting round tables and singing...talking.” (Male, aged 75, non-hoarder)

This serves as a reminder of the extent to which both ageism and public perceptions of supported housing acts as a barrier to when it comes to supported housing decisions, compounded by the value that is placed on independence or the maintenance of it. Perceptions of supported housing are also arguably substantially mismatched with supported housing options that are currently available, as opposed to the prevailing “nursing home” model that dominates the shared public imagination of what supported housing necessarily entails. Fear of perceived loss of independence due to moving into supported housing acted as a key barrier and delayed the decision for most participants:

“I think in years gone by, I think...if somebody said, “oh, where’s Jonny gone? I’ve never seen him,” “oh, he’s gone into sheltered accommodation.” He’s done...he’d be

forgotten...like somebody going into the workhouse!” (Male, aged 77, non-hoarder)

These perspectives arguably suggest that both public and older people’s perspectives of supported housing are on balance negative and associate supported housing with a reduction of autonomy and independence, as opposed to supported housing being an opportunity to the longer-term maintenance of a person’s autonomy and wellbeing. It also serves as a reminder of the connection between home and identity, where a person can “be oneself” and the perceived loss of identity when moving from one’s own home to supported housing.

Older people with hoarding behaviours face the additional challenges of the stigmatisation of hoarding when it comes to stigma in this context: not only are they dealing with the need for supported housing but also the shame and stigma associated with hoarding behaviours.

3.4. *During the Move: Possessions and Support*

3.4.1. *Possessions*. The practical implications of downsizing at a later stage in life will inevitably mean that difficult decisions need to be made about what items to keep and what to discard. In most cases, individuals who move into supported housing will be moving into a dwelling that, to be more manageable, will be smaller in size.

Faced with the reality of downsizing, participants reported considerable stress regarding choosing which possessions to keep and which to discard and preparing them for removal.

In most cases, individuals who move into supported housing will be moving into a dwelling that, to be more manageable, will be smaller in size, meaning that, for very practical reasons, beloved items (e.g., family furniture) had to be discarded:

“Had to get rid of a lot of stuff but that-you knew, you just had no room for....But that’s the choice you make to downsize. But yeah, it makes a deal of having to leave some stuff, you know?” (Female, aged 70, non-hoarder)

Participants both with and without hoarding behaviours reported extreme stress in discarding items, often in the haste of moving and the moving day having a substantial short-term adverse impact on close family relationships.

Participants with hoarding behaviours reported substantial anxieties about maintaining agency in making decisions about items for keeping and discarding and who would have access to their possessions during the process. Progress was slow and only possible with the support of family members or professionals who supported hoarding participants to make the decisions themselves in deciding which items to keep and which to discard:

“And I mean, she {housing officer} actually said to me it {the process of moving to supported housing} wasn’t gonna be pleasant. The other thing she said was “I will not come in

here and take away any of your stuff. That has to be your decision.” (Female, aged 49, PwH)

This quote is a reminder of the vital importance of supporting individuals who hoard to maintain choice and agency over the moving and downsizing process, often at a time when they feel their sense of agency could be compromised.

Other participants with hoarding behaviours in our sample delegated the decision-making process over possessions to family members when it became too overwhelming:

“That was the hardest. That was just....just givin’ things - I-I couldn’t of give them away. (Participant’s daughter) waited till I moved....I didn’t mind so much taking them to the charity shop...I didn’t mind them going to the charity shop as long as I wasn’t there....But (name of daughter) I left it all to them.” (Female, aged 73, PwH)

This quote is a reminder of the complexities of the relationships that people with hoarding behaviours may have with their items, and the level of cognitive functioning required to be able to plan and organise items in a systematic way, which can be a challenge for many people who hoard, and compounded with, in some cases, declining memory or cognitive function due to ageing.

3.4.2. Support. Support networks play a key factor in supporting individuals to make important life decisions. The importance of family and professional support before and during the moving process could not be overstated, with all participants reporting that they would not be able to either consider moving or have made the move without the emotional, tangible, and informational support of either close family or professionals (including housing officers, social workers and sheltered accommodation managers, and wardens). Utilising the 3 types of social support (i) emotional, (ii) tangible, and (iii) informational in the context of social support as identified by Schaefer et al. [49], the study identified several examples of each of the 3 types of support in turn. It is important to stress that, in many cases, the 3 types of support occurred simultaneously and were key to participants both decision-making processes about moving and decisions made on practical decisions throughout the moving process and going forward.

(1) Emotional Support. Supported housing had the opportunity to also provide peace of mind for families and to therefore enhance the support that family members were able to give. This provided a great deal of emotional assurance for participants themselves, who were safe in the knowledge that supported housing assisted their family members to also get the support they needed:

“I can get in touch with wor (participant’s daughter) and them, but I mean, they’re at work. And stuff like this and it’s not like they can take weeks off, days off (to provide support).” (Female, aged 73, PwHW).

Three out of the four participants with hoarding behaviours shared positive experiences of professionals working with professionals longer, or going further, than what was strictly specified in their working role. For example, one participant reported considerable emotional support from a local authority housing officer before, during, and after moving working over an extended period to get help her to a point where she was able to move:

“I knew it (moving) would be incredibly stressful. I, well I guessed it would be incredibly stressful...I knew it would take its toll on me....again if I hadn’t had my housing officer...there were times when I would’ve cracked. (Female, aged 49, PwH)

(2) Tangible Support. There were substantial examples of tangible support from professionals in supporting individuals to move into supported housing, especially for individuals for who no family support was available. This included sourcing items to help them settle into their new accommodation:

“...it was unbelievable, ‘cos it took me two hours to move. The lady down there {Supported Housing Warden} she went down to {local community furniture service}...she went down there, saw the lady, picked all the things I would need.arranged, er, the removal van, and within 2 hours that was me moved. It was unbelievable.” (Male, aged 57, non-hoarder)

Support for one participant with hoarding behaviours came from a combination of their social worker and a financial wellbeing charity worker, and the two participants with hoarding behaviours reported support from family members, with a further participant reporting support from the police in fleeing a situation of domestic abuse into supported accommodation.

(3) Informational Support. There was substantial evidence of professionals going above and beyond their roles in providing tangible support, which proved invaluable, (e.g., help with welfare advice and benefit applications) not only during the moving process but also going forward:

“The warden in here. She’s been fantastic, Really good...she did help me a lot and I think, the other thing about moving is all the claims and everything ...for....housing and for different things like that and it seems – it takes a long time, when you’re waiting for pension credits and things like that to come through, and I worry, and she knew I worried.” (Female, aged 74, non-hoarder)

They serve as a reminder of the potential for positive outcomes if a more holistic approach is taken (e.g., practical, and emotional support) in professionals (e.g., wardens) supporting an older adult to adapt to new life in supported housing.

The findings illustrate that the dynamics of support networks for the older people involved in this study were multifaceted and varied whereas there was evidence of emotional family support for some individuals, supported housing options also provided a lifeline of support for family members who often had to manage a range of other commitments simultaneously alongside their ageing parents change in housing needs. This indicated that supported housing options could be beneficial for the family as a whole, and this was keenly felt by some participants who did not wish to be a “burden” on their adult children or grandchildren. Professionals on the other hand provided a range of different types of support, often beyond the official scope of their role, and in way that demonstrated that they understood the complexities and sensitivities of the moving process for an older person. This was particularly the case with one participant with hoarding behaviours, who, without long-term support from her housing officer, would not have been able to move. This illustrates the longer-term needs of older people who hoard in terms of not only managing the stress and anxiety precipitated by moving home, but also the longer-term needs of those individuals going forward.

3.5. After the Move: Supported Housing = a Bright Tomorrow

3.5.1. *Bright Tomorrow.* All participants who had moved stated that they were glad that they had done so, with many of them wishing they had moved at an earlier stage. Participants reported that supported housing had provided them with much needed support and adaption to their living conditions, whilst being able to maintain a high level of independence:

“But certainly, make the move. You know? ‘Cos it is a help. You’ve got things you can do in here, pull a button, pull a thingy, touch wood we’ve never had to – to do anything like that, but yeah, support housing – is good for that.” (Female, aged 70, non-hoarder)

This was further enhanced by the additional choices that they had in terms of connecting with others. Choice was also an important aspect of life after moving, especially in respect of combatting loneliness and isolation:

“I would say go for it. Don’t let other people’s opinions put you off. Because it is—it’s wonderful. You know, if you want to make friends, {sic} I’m not a one for that, I like my own space. And I like to be on my own. But, you know, if you like company, if you like to play bingo and whatever...it’s there. You know, you don’t have to go out and seek it. You—you’re not alone. You don’t have to be alone.” (Female, aged 65, non-hoarder)

Being able to continue being independent whilst having support in the background if they needed it was also an important factor. In addition, participants talked about the importance of supported housing in terms of combatting loneliness and isolation:

“It (supported housing) is advantage all the way because it gets rid of that loneliness. If a person feels lonely...where they’ve been living, and they want to meet people, coming into a place like this is ideal.” (Male, aged 77, non-hoarder)

Several participants (including one with hoarding behaviours) talked specifically about their supported or sheltered housing scheme as being a community, with an element of development of new social networks post-move within the scheme or supported housing they had moved to:

“Do it! The first day I moved in, there was a card through my door from one of the residents. And she made me feel very welcome with what she’d written. And she’s in her 90s. She made it sound so nice, and at the bottom “p.s. we have a scrabble club at 1.30 on Saturday” So now I’m part of the scrabble club!” (Female, aged 68, PwH)

Several participants shared their frustrations regarding the lack of information and their own lack of understanding about supported housing. Being better informed about the realities of supported housing may have enabled participants to have better navigated the stigma and misconceptions related to social housing, as well benefitting from the built-in support to help individuals maintain their autonomy and wellbeing for longer:

“I think if people were aware of . . .the social benefits, I think that would encourage people.....’cos a lot of people think, “oh, it’s giving up my independence,” but I think if more people knew about the social benefits, they would be more inclined to go.” (Female, aged 58, non-hoarder)

This was not helped by the lack of opportunities to meet other residents at a scheme beforehand to get their views on the accommodation and the scheme:

“...ask whether, if they could, have a look at a flat which is currently occupied. To see what can be done. Which may help them to make their mind up. ‘Cos if they don’t have a look, they may never get past the first hurdle.” (Male, aged 77, non-hoarder).

COVID-19 was also a hindrance, as many recently moved participants had not been able to view a property before moving and did not, due to national lockdown regulations, receive the normal level of support in settling into supported accommodation:

“we didn’t have people to come and help us in any way, really, it was something we had to do on our own and it wasn’t like you could just phone somebody and they would come out and see yer...But that was understandable, with {sic} COVID. We understand that, but it meant that the move was made little bit tougher...” (Female, aged 70, non-hoarder)

3.5.2. Need for Ongoing Support from Peers and Professionals.

Several participants were keen to stress that lack of peer support in terms of supporting them to make an informed decision. For people with hoarding behaviours, there is also currently little opportunity to meet other people with hoarding behaviours who had been successfully moved, and this is problematic for people with hoarding behaviours in the lack of demonstrating what could be possible:

“Well, I would like to talk - ‘cos I don’t really know anybody else with a hoarding issue that’s done it. You know, that’s moved. So that - I think that would be really helpful, to know other people have managed it successfully.” (Female, aged 57, PwH).

Participants with hoarding behaviours also talked about their ongoing support needs once they had moved, especially when it comes to managing possessions and their living environment. One participant talked about the positive mental wellbeing aspects of feeling supported in their new supported housing and away from their previous environment that they perceived as having a negative impact on their mental health when it came to not being able to immediately find a specific item of sentimental values:

“I’ve actually been able to process that. At the flat (previous home), I would’ve just been a complete mess.” (Female, aged 49, PwH)

Another participant with hoarding behaviours talked about still working through the process of sorting through their belongings:

“They put the boxes in the bedrooms, and stuff like that. And left me to sort them out. Touch wood, I’m getting nearer to most of them sorted....and put away (Female, aged 73, PwH).

The ongoing support of people who hoard in supported housing appeared to depend very much on the goodwill of dedicated individual professionals and therefore not always necessarily consistent across the board in terms of what support people have access to.

In summary, most participants reported that their decision to move into, or to consider supported housing, was precipitated by a crisis event (e.g., declining mobility). Interestingly, there was little divergence between participants with hoarding behaviours and participants who do not hoard in terms of the stress and anxiety they faced when discarding possessions during the moving process. The main discrepancy was to do with the continuing needs of participants with hoarding behaviours in terms of their ongoing support needs to navigate additional traumas (i.e., domestic abuse, neighbour harassment, financial difficulties, and memory decline), and the specific type of additional support the participants with hoarding behaviours needed in being able to navigate or consider the moving process. All participants in the sample who had moved had reported stigma associated with supported housing, with one participant

with hoarding behaviours who had not moved stating that she would like to connect with peer support (i.e., other hoarders) in being able to arrive at her decision.

4. Discussion

The aim of this research study was to better understand the potential barriers and enablers faced by older people with and without hoarding behaviours in considering and/or making the transition to supported housing. All participants in this current study stated that a crisis event forced them to consider supported housing, with additional traumatic life events (TLEs) playing a significant role for all participants with hoarding behaviours. The previous research study on the benefits of supported housing has typically focussed on severe psychiatric conditions, addictions, or the homeless [33, 50, 51], and an exploration of the wider impact of supported housing on mental health [52]. However, whilst there are several studies that focus on older people’s perceptions of supported housing [37, 38, 53], there is currently a gap in the literature focusing on older people with hoarding behaviours and their support needs in the context of supported housing. When it comes to stigma, there is a considerable gap in the literature examining the stigma experienced by PwH in the context of hoarding and supported housing and how both types of stigmas combined affect PwH specifically. The findings of our study arguably support the previous literature regarding the stigmatisation of HD [23–25]. For example, if self-stigma results in low engagement with treatment [26], it could be suggested that discussing one’s support needs in the context of supported housing would also be extremely difficult. The older PwH in this current study were able to discuss their supported housing needs that they shared with people who do not hoard (e.g., declining mobility), but found it much more difficult to define what their supported housing needs may be in the context of their hoarding. This appears to support the current literature around PwH seeking support for other services other than hoarding, and not feeling able to trust services when it comes to talking about hoarding specifically [27].

In our study, 16 participants took part in semistructured interviews providing information about their social networks, support received, and their perceptions of supported housing. All 12 nonhoarding participants had discussed supported housing with their relatives. People with hoarding behaviours reported regular support from a mixture of relatives, friends, and care professionals. This is consistent with the previous literature in terms of reflecting the types of support that individuals received when considering supported housing [42, 49]. This in turn directly impacted participants’ decisions to move. As examples from our study, emotional and tangible support both from relatives and professional were crucial in being able to consider supported housing (e.g., contacting supported housing providers, help with discarding items, and packing belongings). Informational support was a key component of the support provided by professionals in assessing supported housing options. Shared decision-making with both family and

professionals was evident in terms of participants reporting that they felt respected and listened to throughout the moving process, resulting in positive outcomes. For professionals, this is a key component of good practice with positive outcomes consistent with previous findings [54, 55]. However, support networks across participants in this study varied, and many depended on either supportive family members or exemplary professionals (e.g., supported housing wardens) prepared to “go the extra mile.” Comprehensive approaches to community support and multi-agency approaches are needed in supporting older people who are isolated such as community-focused support. However, the current picture in the UK is inconsistent, based on a “postcode lottery” and increasing reliance on the not-for-profit sector [56].

The moving process itself, together with dealing with belongings, and stigma about social housing, all had a substantial impact on participants’ decisions to move. People with hoarding behaviours particularly struggled with the prospect of losing agency over their possessions. There were substantial concerns that items would be either discarded without them knowing, or them not being able to find items later. One participant found the prospect of discarding possessions so stressful, that they delegated the entire task to family members. Perceived loss of decision-making over possessions was a source of anxiety, and formed a psychological barrier to moving, corroborating previous literature [27, 44, 57]. People with hoarding behaviours also experienced additional, and long-term, traumas, corroborating the previous research study that describes the complexities that need to be addressed when supporting PwH [15]. Further research is recommended to explore potential associations between previous trauma and the retainment of possessions in the context of supporting PwH to move home.

The results arguably suggest that social networks do have a meaningful impact on the decisions made by older people regarding supported housing, in accord with the previous research study [42, 49]. Attitudes towards supported housing were also influenced by stigma, and preconceptions about what supported housing entailed, which is consistent with the previous literature [37]. For example, people who think that “moving into a home means being old etc.” and perceived loss of autonomy and independence is widely supported by the previous literature [37, 38, 53]. Crucially, there were widely held perceptions of supported housing indicating loss of autonomy and independence, again consistent with previous research study [38]. Additional challenges of moving, dealing with possessions, and the need for support from both family and professionals were also key influences. For older PwH, additional challenges around agency in respect of possessions, additional crises faced, and the importance of long-term relationships with trusted professionals were keys to their decisions regarding supported housing. To date, there is very little literature available regarding the impact of decision making about possessions on levels of anxiety for people with hoarding behaviours specifically in the context of moving home, and this warrants further investigation from the point of view of supporting older people affected.

In terms of the complexities of the needs of people with hoarding behaviours, there are several factors that need to be addressed. Taking a trauma-informed approach (e.g., as in [25]) to support someone with hoarding behaviours to move home requires a consistent approach over a long period of time which is very difficult if there is a tight turnaround as to accommodation availability. In most cases, participants reported that they had to make a “there-and-then” decision about taking sheltered or supported accommodation on offer due to the demands on the accommodation available. This is stressful and, for many people with hoarding behaviours, prohibitive.

In terms of social networks, none of the hoarding participants reported seeing or having support from neighbours. It is a small sample size, but the extent to which people with hoarding behaviours feel connected with their local community or neighbourhood warrants further investigation. Participants with hoarding behaviours accessed crisis services (e.g., financial support services, housing support, and police) which then led to a discussion about supported housing as an option. Only when professional support was put in place did they then receive support both for their difficulties with hoarding, and with considering a move to supported housing.

In terms of the study implications and practical recommendations which might make this difficult transition period less stressful in future, three key considerations are apparent. Firstly, the negative perception of the move is a contributor to people making crisis-based decisions to move, rather than being preventative. This can be the stigma of the supported housing itself, or the perceived lack of support in managing possessions and logistics. Awareness raising is required to combat this. Secondly, the move itself represents a peak of stress and has a negative impact on people leading up to it. This can lead to them wanting to delay the move, which if left unchecked over time may further exacerbate poor living conditions (e.g., worsening mobility decline). Targeted support is needed during the moving process to manage it and pre-empt problems. Finally, the environment awaiting the participants was found to be supportive and community-based, all of which contributes to addressing the tensions above. Ensuring that participants, and the social networks supporting them, are aware of this will help reduce the perceived impact of the move. This suggests that supported housing can be a suitable option for people with hoarding behaviours as it provides additional support that they may not receive living alone in the community.

There were key limitations to this study, and we acknowledge that these affect the applicability of our findings. The study was carried out during COVID-19 restrictions, meaning that recruitment opportunities were limited. Many of the organisations working with older people were already stretched and in crisis response mode, so did not have the capacity to advertise the opportunity amongst their service users. Given the stigma attached to hoarding, people with hoarding behaviours are a seldom heard population, combined with the additional comorbidities that make both people hoarding, and older hoarders, shielding and

potentially, understandably concerned about contracting COVID-19. The result was a small sample size, where people without hoarding behaviours far outnumbered people who were hoarding. In addition, we acknowledge that the sample lacked geographical and cultural diversity, which may impact on transferability of the findings to other sectors and communities. There are likely to be various social and cultural factors which could influence decisions relating to housing transition which we were unable to capture. In addition, the people who comprised the final sample were those who were willing and able to take part in the study, and to talk at length about their personal experiences and mental wellbeing.

There is clearly a bias to this sample as there are likely to be many more people with and without hoarding behaviours whose voices were not heard in this research, either due to lack of awareness about the project, or due to personal reticence. It is possible that such people have quite different perceptions and experiences of the transition to supported housing. Finally, we note that our study comprised a “snapshot” of current lived experiences of housing transition but lacks a longitudinal perspective.

An additional factor to consider relates to the comorbidities typically associated with HD, namely, anxiety and depression. We did not explore these in detail during the interviews, being mindful of not triggering negative emotional states and causing undue distress. However, it is likely that negative emotional states influence decisions relating to housing transition, as it is known that such states influence poor decision-making in psychiatric conditions such as eating disorders, addiction, and schizophrenia [58]. Deficits in executive functioning are consistently found in older people with mood and anxiety disorders [59] but we are unaware of how emotional states may specifically influence housing choices in people who hoard. We note the reported links between anxiety and cognitive processes (including decision-making) in hoarding cohorts [60] and so it is likely that emotional states may well have played a role in the decisions relating to housing choices. This clearly requires further investigation.

Finally, the term “supported housing” was often defined differently across organisations who supported us to recruit participants (e.g., some social housing providers described a sheltered bungalow as independent housing, others as supported, but many as sheltered housing). The difference in terminology potentially impacted on how the opportunity to take part was interpreted and disseminated. Most participants had also moved into supported housing within the previous 6 months, resulting in them being asked them about their experiences retrospectively. This has the potential for recall bias errors, with a margin of error for recalling events accurately or omission of important or interesting details. In addition, participants did at least have some form of support network, indicating that the current study did not reach more isolated individuals, and therefore and assessment the needs of older people with more complex needs are not included.

Future research is necessary to address these limitations. A larger and more culturally diverse sample size, drawn from

different social backgrounds and geographical locations, would provide better opportunities to explore the impact of hoarding behaviours on the decisions to transition to supported housing. Studies could track such individuals through the whole transition process, awareness, decision-making, the move itself, and postmove, to better understand the barriers, facilitators and the importance of social and professional support networks. This would, for example, shed light on whether hoarding behaviours had improved or worsened during the transition process. In addition, it would be beneficial to explore the experiences of front-line professional staff (e.g., wardens, housing officers, and social workers) as this would allow for a much more in-depth understanding of what support older people have, and what support they may need, when making the transition to supported housing. Further research considering practical interventions in challenging the stigma and promoting the benefits of supported housing, whilst also addressing the specific needs of older people with hoarding behaviours, is also recommended.

5. Conclusion

Through a process of semistructured interviews, this study explored the impact of hoarding behaviours and social networks on older people’s attitudes towards supported housing. The study established that discussing the prospect of moving into supported housing with relatives and friends was the key in supporting older people to make the move. Support professionals were also crucial in enabling the moving process. Crisis and declining mobility were the main catalysts for making the move, and this was further exacerbated for people with hoarding behaviours who faced additional life challenges (e.g., financial difficulties and neighbour harassment). None of the participants with hoarding behaviours identified support with their hoarding as being a key decision to move. All participants described the process of moving as an acutely stressful event, and participants with hoarding behaviours faced additional stress over agency and decision-making related to retaining and discarding possessions. The stigma related to perceptions of supported housing was also a key barrier. All moved participants reported that the outcome of moving into supported housing and were keen to see more interventions to challenge stigmatising perceptions of supported housing. Challenging negative perceptions of supported housing, managing, and pre-empting the challenge of moving day, and tailoring support and allowing longer time for individuals with hoarding behaviours to support them in making the transition is recommended. We note that while not directly relevant to this study, there is now growing evidence that multiagency approaches to manage hoarding behaviours can be very effective [32, 61]. Due to the barriers we have identified in relation to housing transition, the role of multiagency teams drawn from relevant professional agencies (e.g. housing, social care, and mental health support) would be invaluable in drawing up best practice guidelines to ensure that people with and without hoarding behaviours are provided with appropriate advice and

support before, during, and after the transition process to reduce the associated negative perceptions and experiences.

Data Availability

The data used to support the findings of this study are available at https://osf.io/n2ze6/?view_only=6e9bfd7c8aa2468db1cf3ed9867286c8.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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