

# **Aftermath of an explosion: Lived experiences of compulsive hoarders**

By

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# ABSTRACT

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**Background:** This study aimed to explore the experiences of people who compulsively hoard and how they make sense of their own hoarding behaviour (HB).

Research studies have revealed that people with hoarding typically collect and keep items due to their aesthetic appeal, utility, and strong emotional attachment to them resulting in clutter and limiting living spaces. This study aims to explore the lived experiences of individuals with hoarding disorder (HD).

**Objective:** The objectives of this study were to explore: (i) what persons with hoarding behaviour perceived as the causal triggers of their behaviour; (ii) the impact of living with a hoarding behaviour on their quality of life; (iii) the coping strategies adopted by individuals who hoard, and (iv) to identify available support strategies and recommendations.

**Design:** A qualitative approach following the principles of Interpretative Phenomenological Analysis (IPA).

**Setting:** Depending on the participants' preferences, three interviews were conducted at the participants' homes whilst two interviews were held in a public space.

**Participants:** Five participants with compulsive HB consisting of two females and three males

**Methodology:** A total of five participants with compulsive HB were recruited and interviewed using a simple semi-structured interview format, designed for the purposes of the study. The resulting transcribed interviews were analysed using interpretive-phenomenological analysis.

**Results:** Three super-ordinate themes emerged: 'Unearthing the roots of HB', 'Aftermath of an explosion' and 'Reclaiming spaces, restoring lives.' In the first super-ordinate theme 'Unearthing the roots of HB', the participants explained how their HB could have been triggered by poverty, attachment needs, expected behaviour and loss of a close family member. The second super-ordinate theme 'Aftermath of an explosion' focused on the impact of HB. Participants explained how their HB affected them emotionally, functionally, psychologically, spirituality, physically and their interpersonal relationships (participants

spoke about the impact of HB on the relationships with their family members and friends). The third super-ordinate theme 'Reclaiming spaces, restoring lives' explored the strategies used by participants to try to cope with their HB.

**Conclusion:** This study provides new insights into the significant reliance on HCP among individuals with HB, broadening our understanding of the necessary support systems in the context of hoarding. While HCP support can be beneficial, it is crucial to implement it in a manner that respects the autonomy and needs of the patients. Individuals with HB should be empowered to make their own decisions. The findings of this study and their implications aim to provide HCP with a better understanding of the impact of living with HB and the coping strategies employed. This understanding can contribute to the development of appropriate interventions, as suggested by the researcher conducting this study.

**Key words:** 'Hoarding', 'Lived experiences', 'Hoarders', 'obsessive compulsive disorder', 'Qualitative', 'Decluttering', 'Hoarding behaviour'

# DEDICATION

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# ACKNOWLEDGMENTS

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# List of abbreviation

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<b>IPA</b>	Interpretative Phenomenological Analysis
<b>CINAHL</b>	Cumulative index to Nursing and Allied Health Literature
<b>NGOs</b>	Non-Governmental Organisations
<b>HD</b>	Hoarding disorder
<b>ADLs</b>	Activities of Daily Living
<b>HCP</b>	Health care professionals
<b>QoL</b>	Quality of life
<b>CBT</b>	Cognitive behavioural therapy
<b>MI</b>	Motivational interviewing
<b>HB</b>	Hoarding behaviour
<b>CSM</b>	Common sense model
<b>FREC</b>	Faculty Research Ethics Committee
<b>PEO</b>	Population, Exposure, and Outcome
<b>UOM</b>	University of Malta
<b>CASP</b>	Critical Appraisal Skills Programme
<b>SD</b>	Standard deviation
<b>UK</b>	United Kingdom
<b>DSM-5</b>	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
<b>CMHTs</b>	Community Mental Health Teams

# Chapter 1: Introduction

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## 1.1 Background to the study

Hoarding behaviour (HB) can affect individuals across various stages of life and it often begin in childhood or early adulthood (Ayers et al., 2010; Grisham et al., 2006; Storch et al., 2011). The people who fall into this category are most likely to be single, have never been married, have experienced trauma as children, have lived in a cluttered and disorganised home or have lost a loved one as well as having a family history of hoarding or suffer from obsessive compulsive disorder (OCD) (Millanta, 2017).

Hoarding is associated with various other disorders such as autism, dementia, OCD, depression, anxiety, and schizophrenia (Steketee & Frost, 2014b). The most prevalent comorbid conditions in Hoarding disorder (HD) seem to be mood and anxiety disorders. According to Frost, Steketee, et al., (2011), 50.7% of participants with HD were found to have comorbid major depressive disorder, while 24.4% had generalized anxiety disorder, and 23.5% had social anxiety disorder.

According to the American Psychiatric Association (APA), (2013), the estimated prevalence of HD is estimated that around 2 to 6% of the world's population. A United Kingdom (UK) epidemiological study conducted by Nordsletten et al. (2013) suggested a prevalence rate between 1.3% and 1.5%, indicating that approximately 868,358 to 1,001,952 individuals in the UK may meet the criteria for HD. Although the study was conducted only in London, the sample was diverse, including people from various ethnic and socioeconomic backgrounds, thus enhancing the survey's representativeness. It is important to consider that these figures do not account for individuals who experience difficulties with HB or clutter but do not meet the criteria for HD. The prevalence rate reported by Nordsletten et al. (2013) is likely an underestimate due to several factors identified by the authors. These factors include social isolation and past issues such as the risk of eviction, which may have deterred individuals with HD from being identified and participating in the study. The reluctance of these

individuals to engage with unknown researchers further contributes to the potential underestimation of prevalence.

Therefore, while the prevalence estimates indicate that over half a million individuals in the UK may have HD, the actual scale of the problem could be even larger. This is supported by a recent meta-analysis by Postlethwaite et al. (2019), which examined prevalence studies with sample sizes over 1000 participants from Europe, Singapore, and Australia. The meta-analysis suggested a pooled prevalence rate of 2.5%.

Clinically significant hoarding can lead to distress and impairment, as indicated by the diagnostic criteria for HD outlined by the APA, (2013). Hoarding symptoms, such as excessive acquisition, difficulty discarding, and clutter, have been found to impact various aspects of functioning and cause impairment (Ong et al., 2015). For instance, studies have shown associations between difficulties in discarding and impairment (Rodriguez et al., 2013), as well as challenges in performing daily living tasks due to clutter (Frost et al., 2013). The inability to discard old or worn-out objects has been identified as a significant predictor of lower mental and physical health scores, decreased social functioning, and greater impairment in work roles due to emotional problems (Rodriguez et al., 2013). Severe hoarding poses risks such as fire hazards and infestations of rodents and insects when spaces become too cluttered to be effectively cleaned (Brakoulias & Milicevic, 2015).

Unsatisfactory sanitary conditions, including the presence of mold, can lead to health issues, particularly for children who are particularly vulnerable (Tolin et al., 2017). However, these conditions can also affect everyone living in hoarded homes, including the individuals who hoard. Clutter can create tripping and falling hazards, and in extreme cases, individuals who hoard have been found dead under fallen clutter (Brakoulias & Milicevic, 2015).

Other adverse outcomes may include eviction and the removal of pets or children from the hoarded environment (Tolin, Frost, Steketee, et al., 2008). Hoarding also has significant implications for families and the broader community. The families of individuals who hoard often undergo feelings of being marginalized, experiencing depression, and feeling disempowered. In certain instances, hoarding can even lead to family breakdown (Wilbram et al., 2008). Although it is probable that these behaviours have been present for centuries, research in this area has significantly intensified over the past 25 years.

In the subsequent section, an overview of the local mental health system and the available services in Malta will be presented.

## **1.2 The Local Scenario**

Garrett, (2017). estimated that up to one in every 25 senior citizens hoard in Malta, and the issue tends to worsen with age. This figure indicates that, as of 2016, around 3,165 senior Maltese had hoarding issues (Garrett, 2017). These individuals often go unnoticed as they do not perceive their HB as problematic. Usually, they are only identified when referred to the authority Garrett, (2017).

Support for people with HD and their families is limited in Malta. However, Mental Health Services offer assistance to individuals with chronic and acute mental illnesses, including hoarding, and their families through Outreach mental health services in the community and community mental health teams (CMHTs).

In the Mental Health Strategy for Malta 2020-2030, it was mentioned that the aim of these services is to provide mental healthcare activities away from hospitals. The CMHTs consist of several health care professionals (HCP) such as doctors, psychiatrists, social workers, psychiatric nurses, psychologists, and occupational therapists, working together to offer holistic and comprehensive services to people in the community who suffers from mental health diseases. The purpose of these services is to provide care, treatment, and therapeutic intervention in the home environment and the wider community, enabling individuals to cope with and manage their mental health issues and lead a productive and socially fulfilling life.

There are seven community mental health clinics and three outreach teams that support people with mental illness and their families, covering all parts of Malta. The state runs these community clinics, providing a wide range of services to meet the individual needs of people with mental illness in their communities. Additionally, there are three Outreach teams in the community: Cospicua, which covers the south of Malta, Floriana, covering the centre of Malta, and Mtarfa, covering the north of Malta.

The Outreach teams work with people who have serious mental illnesses that require intensive interventions. At Outreach, key workers interact with service users to manage illnesses and symptoms (treatment), offer guidance and practical help with activities of daily living, engage in rehabilitation, and provide support for recovery. The aim of Outreach key

workers is to ensure continuity of care, early interventions to prevent deterioration, prevent admissions to psychiatric hospitals, and reintegrate service users into the community.

Outreach teams carry out intensive interventions with people who hoard by using various methods such as introducing risk or harm reduction strategies, assisting them with decluttering, monitor compliance to treatment and by building a therapeutic relationship with the service user to promote positive change.

In addition to government services, there are also Non-Governmental Organizations (NGOs) that provide different services in the community for people with mental health problems. Some of these NGOs include Richmond Foundation and Foundation for Social Welfare Services (FSWS). Both services empower individuals and help them become responsible, integrated, and productive members of society who value life as a resource for self-actualization. These two NGOs have worked with several hoarders in the community and have assisted with decluttering and providing support for to improve their quality of life (QoL) by promoting mental wellbeing and addressing the prevention of mental health problems. However, there are no government services or NGOs in Malta that specialize on hoarding, therefore the services for hoarding still need to be improved.

### **1.3 The Present Study**

This study aims to contribute to the existing literature by exploring the lived experience of people who hoard in Malta. The qualitative approach selected to guide this study is Interpretative Phenomenological Analysis (IPA). The researcher chose this approach to understand the participants inside perspectives and experiences. This approach explores how each individual makes sense of their own HB. By using this approach, the researcher can gather in-depth insights into the participants' problems and create new ideas for research (Bhandari, 2023). Additionally, being hermeneutic, the researcher can interpret the experiences in-depth.

Data were collected through individual semi-structured in-depth interviews. This approach can provide more detailed information regarding the participants' life experience to explain complex issues. Therefore, the study aims to develop an understanding of the lived experiences of individuals who compulsively hoard in Malta. The objectives of the study are to determine: (i) what persons with HB perceived as the causal triggers of their behaviour; (ii)

the impact of living with a HB on their QoL; (iii) the coping strategies adopted by individuals who hoard, and (iv) to identify available support strategies and recommendations.

The following section delineates the significance of the study.

## **1.4 Significance of the Study**

The decision to conduct a qualitative study emerged as this design enables the researcher to extract in-depth information and explore the following research question set for this study: "What are the lived experiences of people who compulsively hoard in Malta?". I embarked upon this research topic due to the limited understanding of HD in Malta. Being employed as a community nurse specializing in psychiatric care, I realised that a lot of patients hoard and that this was more common than one would think. This observation prompted me to delve deeper into the lived experiences of individuals affected by HB, with the aim of enhancing HCP ability to provide support to these individuals and gain insights into the underlying reasons for hoarding and its impact on their overall QoL. As a HCP, I encounter notable challenges when working with individuals with HD. These individuals often possess a strong desire for control, making it difficult to engage in the process of discarding items, as many possessions hold sentimental value for them. Moreover, assisting them in acquiring new coping mechanisms to facilitate the release of their belongings is a time-consuming endeavour. In order to enhance my comprehension of such individuals I conducted an extensive review of the existing literature. However, upon reviewing the extracted articles, I observed a lack of qualitative research specifically focusing on the experiences of individuals who hoard. The available literature focused mostly on the experiences of family members or HCP working with individuals who hoard. Consequently, there exists a research gap regarding the qualitative exploration of the experiences of people directly affected by HD. The aim of this study, therefore, is to address this gap in both international and local literature and contribute valuable insights into the experiences of individuals who hoard.

By conducting this study, I aspire to shed light on the specific needs of individuals with HD. This knowledge can subsequently be utilised to help the HCP to understand these needs, so they can support them more affectively and include them more in care planning.

Additionally, since no local studies have been conducted to explore this phenomenon, this research endeavour will give voice to the experiences of individuals in our local context.

Through understanding and exploring the beliefs of the participants, HCP can deliver person-

centred care, leading to positive outcomes such as improved care experiences and a sense of well-being for individuals with HB.

## **1.5 The Dissertation Structure**

The structure of this dissertation is as follows: Chapter one provides an introduction and rationale for the choice of the topic. Chapter two presents a critical discussion of the literature retrieved. Chapter three offers a detailed description of the research method used. Chapter four presents the analysis of the data collected through semi-structured interviews and my interpretations. Chapter five presents a discussion of the findings of this study with reference to the existing literature. Chapter six concludes the dissertation by describing its strengths and limitations and providing recommendations for future research.

# Chapter 2: Literature review

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## 2.1 Introduction

This chapter describes the theoretical framework and search strategy applied to identify the extant research on the experiences of individuals who hoard in Malta. A comprehensive search using several electronic databases was conducted. The findings and main methodological issues identified from the included studies are also discussed and critiqued in this chapter.

The process of gathering pertinent literature concerning the objective of this investigation is impacted by the specific criteria for inclusion and exclusion that were established. A more comprehensive explanation of these criteria can be found in the subsequent section.

## 2.2 Inclusion and Exclusion Criteria

The question addressed in this chapter is: What are the lived experiences of adult hoarders? To establish the studies included in this review, the Population, Exposure, and Outcome (PEO) approach developed by Khan et al. (2003) was utilized. Table 2.1 provides an overview of the criteria employed to determine which studies were included or excluded.

Table 2.1 – Inclusion and Exclusion criteria for the present literature review.

<b>PEO</b>	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Population	Adults aged 18 years and above who hoard.	Participants aged less than 18 years since the study focuses on adults.
Exposure	Participants with HB.	Participants who are not hoarders.
Outcome	QoL; coping strategies.	Experiences other than coping or QoL.

The researcher developed search strategies for electronic databases after applying the inclusion and exclusion criteria. The search strategy is explained in greater detail in the following section.

## 2.3 The Search Strategy

To ensure a comprehensive and unbiased literature search, a variety of electronic databases were employed (Randolph, 2009). The University of Malta (UoM) electronic databases, including Academic Search Complete (EBSCO), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE (ProQuest), PubMed, and PsychInfo, were thoroughly examined. However, it is important to note that the restriction to English-language articles may have introduced language bias, potentially missing non-English publications (The Cochrane Collaboration, 2011). To supplement the search, the reference lists of identified full-text articles were reviewed for additional relevant literature. Primary sources were prioritized as they provide direct evidence pertaining to the research question, while secondary sources were consulted only when primary sources were unavailable. The search spanned from 1994 to 2023, as research on the topic was available during this time period. The search was conducted between March 2022 and October 2022. The search terms employed are outlined in Table 2.2.

Table 2.2 – The search terms used in the search strategy.

<b>PEO</b>	<b>Population</b>	<b>Exposure</b>	<b>Outcome</b>
Search terms	“Patient*” OR “People” OR “Person*” OR “Individual*” OR “Hoarder*” OR “Client*” OR “User”	“Hoarding*”	“Lived experiences” OR “Coping” OR “Impact on the quality of life”

Using the search terms "Hoarding\*" AND "Lived experience" OR "Coping" OR "Impact on the quality of life" yielded 2,561 hits. To focus on the specific research question, the terms were combined using "or" and "and".

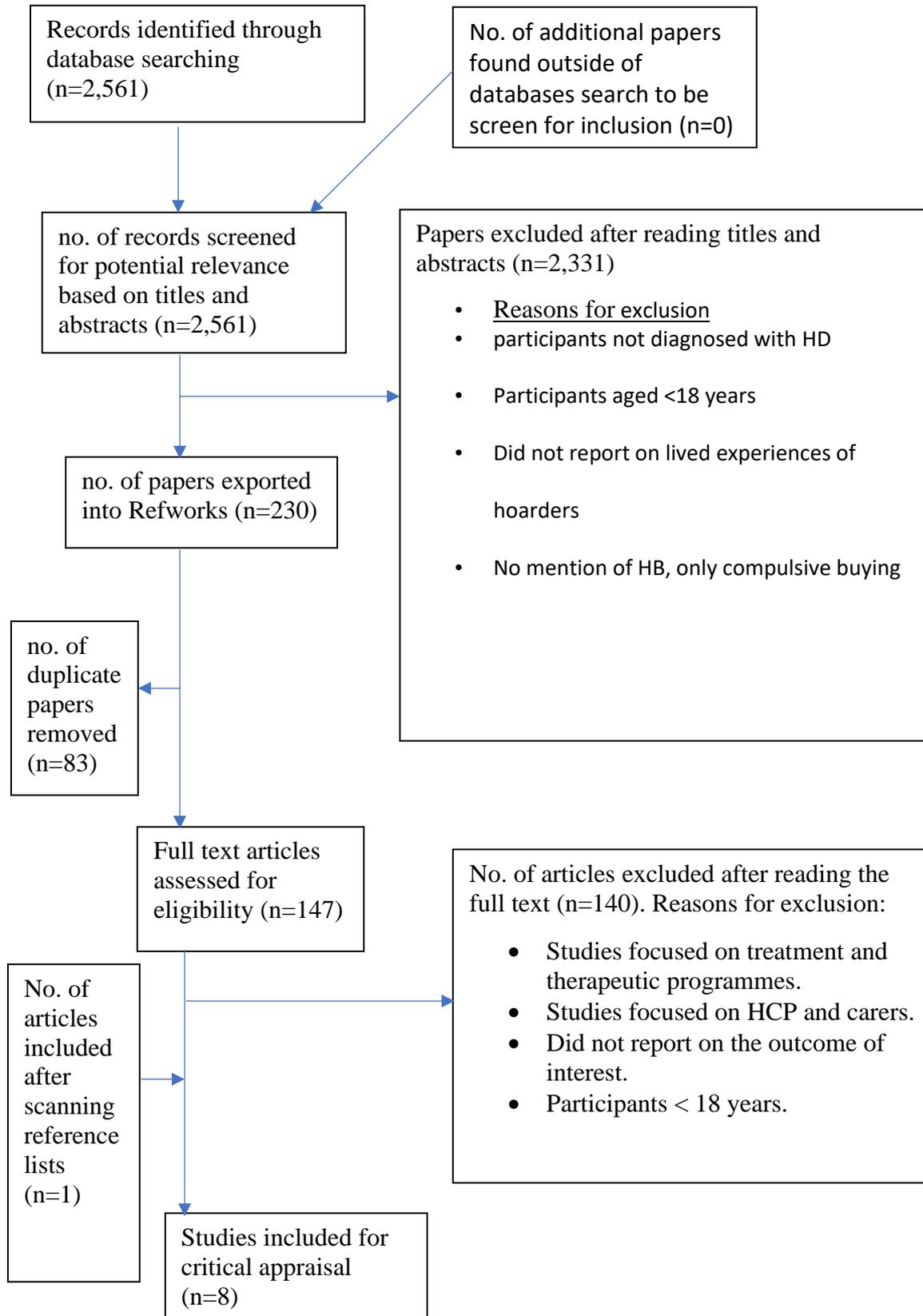
The next section describes the screening process undertaken, which identified the relevant studies.

## **2.4 Identification and Screening of Studies**

The selection process for including publications in this review followed the guidelines outlined in the PRISMA framework (Moher et al., 2009). Figure 2.1 presents the flow diagram describing the screening process based on Moher et al. (2009). At this phase, 2,561 articles were screened based on their titles to determine eligibility. In cases where titles were unclear, the abstracts were assessed. After excluding papers that were not pertinent to the topic of interest, 230 relevant papers remained. Due to the difficulty of establishing eligibility solely based on titles and abstracts, the full texts of these papers were examined. The reasons for excluding irrelevant papers were as follows: 1) papers not written in English; 2) unavailability of the full text; 3) absence of individuals with hoarding behavior (HB) in the papers; and 4) lack of focus on adults. The relevant papers were exported into bibliographic software (Refworks), and any duplicates were eliminated.

At this point, a total of 8 studies were incorporated into this review for critical appraisal. The studies were conducted in the United Kingdom (2), Ireland (2), Singapore (2), Australia (1), and Canada (1). The literature search yielded 8 papers in which the research targeted adult individuals with HB. I thoroughly re-read these papers to conduct a critique of the studies. HD has been receiving greater attention recently due to increased research into the issue. This literature review explores the lived experiences of individuals who hoard, as reported in the selected studies. It will begin by briefly describing the definition of hoarding, followed by a review of the literature based on the triggers of HB, the impact of HB on individuals, and exploring different coping strategies.

Figure 2.1- Flow diagram describing the screening process based on Moher et al. (2009).



The following section provides a critique of the studies extracted.

## **2.5 A Critique of studies on individuals with HB**

### **2.5.1 QoL studies**

Ong et al. (2015) conducted a systematic review of the existing literature on the functioning and QoL in individuals who hoard. The authors aimed to compile research on how hoarding affects numerous elements of an individual's functioning and QoL, such as social, occupational, and psychological functioning, as well as to identify knowledge gaps in the extant literature. The authors conducted a systematic literature search using several electronic databases, including ProQuest, PsycINFO, PubMed, and Science Direct, as well as a reference list of relevant articles. They included 37 studies in the final analysis, most of which were cross-sectional and used self-report measures. The number of articles chosen provide a considerable amount of evidence on the relationship between hoarding and QoL, increasing the generalizability of the researchers' findings and strengthening their conclusions. The authors used clear inclusion criteria to identify relevant studies, enhancing the quality of their review.

As per the study's title, the authors performed a systematic review by conducting a thorough search of relevant databases to identify studies that used standardized measures such as the Saving Inventory-Revised, Saving Cognitions Inventory, and the UCLA Hoarding Severity Scale. These measures have been used by researchers and clinicians and focus on the three distinct dimensions of hoarding outlined in the DSM-5. Such measures were used to evaluate hoarding cases, assess functioning and QoL in individuals with HD. This study highlights the importance of using standardized measures to assess the impact of hoarding on functioning and QoL. Standardized measures are crucial in research as they provide a consistent and reliable way to measure the same construct across different studies, making it easier to compare and combine results from different studies.

The review is well-structured, with a clear introduction, methods section, and results section. The authors provided a critical analysis of the studies included in the review and discussed the implications of the findings. One limitation is that the review only included studies published in English, which may result in the exclusion of relevant studies published in other languages (The Cochrane Collaboration, 2011). The research question was clearly stated and

justified since the authors identified the population, intervention, and outcome in the methodology. They identified these by using specified search terms when searching the literature such as "hoarding" AND "disability," "hoarding" AND " QoL." The papers were appraised for methodological quality, and the authors summarized the findings using a narrative synthesis approach.

Despite these limitations, the review provided important insights into the functioning and QoL of individuals with HD. The findings suggest that HD has a significant impact on individuals' daily lives and underscores the need for effective interventions. The authors also highlight the need for further research to better understand the mechanism underlying the relationship between HD and functioning and QoL.

In conclusion, the systematic review conducted by Ong et al. (2015) suggests that individuals with HD experience greater impairment in daily functioning, particularly in social and occupational aspects, compared to individuals in the general population or those with OCD, after controlling for psychiatric comorbidities, age, and gender. These findings highlight the importance for clinicians to assess and address the functional and QoL effects of hoarding in their patients, and the need for future research to identify effective interventions that may improve the functionality and QoL of individuals with HD.

The qualitative study by Orr et al.(2019) employed a unique approach by directly examining the perspectives of individuals who hoard to investigate the meaning of clutter and hoarding in relation to culture, agency, and well-being. The authors used a rigorous ethnographic methodology, including in-depth interviews, participant observation, and document analysis, to gain rich and detailed data on the experiences and meanings of HB. The study's findings shed light on the complex factors that influence HB, such as cultural and social factors, individual agency, and personal meaning-making, and have important implications for interventions that consider the cultural and individual contexts of hoarding.

The study addresses the question of how individuals understand the behaviours that led to their classification as "hoarders" by state agencies intervening in such situations. Although many of the participants' experiences occurred before the official creation of HD, they were still labelled as "hoarders" by agencies at a time when the diagnosis was being flagged and implicitly influencing practice.

Additional thematic analysis was conducted, but this time, the focus was not solely on the relevance of the interviewees' statements to the topic, but on new themes that surfaced from the interview data itself, as opposed to the initial framework. The study's analysis concentrated on the themes that emerged from the codes associated with the nature of hoarding. As a result of this approach, the research identified four key themes that described the discourses employed by the participants.

In the first theme – 'notions of value and waste' - participants related the value of things in terms of use value to themselves, such as hobbies or knowledge contained in the items. In this context, the respondents also rejected the label 'hoarder,' instead distinguishing between 'collection,' 'clutter,' and 'rubbish.' They also rejected the meaning of 'regardless of value' in the DSM-5, both questioning the definition of 'waste', recalling times where mending and recycling was necessary and commonplace, and critiquing the modern 'throwaway society'. Participants described the positive feelings and happiness that keeping things would bring in this category.

In the second theme – 'connections with sociality, relationships, and/or loss' - some admitted that having too many items prevented them from having social contacts, others stated that they did not need social contacts, particularly if it meant conforming to societal norms and pressures. Others believed that their possessions would facilitate social contacts by allowing them to anticipate and respond to the requirements of others. Other meanings were assigned to early deprivation and death experiences.

In the third theme – 'physical constraints' - participants described health conditions or practical challenges, such as a lack of time and space, that limit their ability to achieve more order. In the last theme – 'mental health' - some participants acknowledged HD as a treatable mental health condition, encouraging them to seek help, whereas others claimed that an official definition demonstrated how 'normal' HB was, ignoring the potential risks for themselves or others associated with HB.

Moreover, participants discussed how personal events, such as childhood scarcity or trauma, influenced their hoarding. The emotional meaning of clutter was also described by the participants, with many of them stating that their items had a profound emotional resonance and signified a sense of self or identity. The participants discussed their struggles with possession management and how clutter had a negative impact on their well-being and QoL. Furthermore, participants described their HB as both a source of comfort and a source of

distress. They also discussed the role of culture and social norms in shaping their attitudes towards hoarding, with some feeling stigmatized and misunderstood by others. Finally, the participants talked about their agency regarding hoarding, noting the difficulties they had in changing their habit and managing their possessions. Orr et al. (2019), indicated a need for more compassionate and person-centred methods to assist patients with HB.

The authors concluded that hoarding is a complicated and nuanced phenomenon influenced by personal, societal, and cultural factors. They argue that gaining a better grasp of the meanings of clutter and hoarding from the perspective of persons who hoard themselves could lead to more effective interventions and assistance for people having a HD. The study emphasizes the necessity of person-centred approaches that include specific experiences and views of people who hoard.

Subramaniam et al., (2020), conducted a qualitative study aimed at exploring the lived experiences of individuals with HD. The study sought to understand and describe the patterns and reasons for hoarding, experiences with decluttering, and the impact of HD on significant others and society, within the context of a multi-ethnic urban Asian country. A purposive sampling method was used to recruit 12 participants with HD, including five males and seven females. The average age of the subjects was 56.7 years ( $SD = 14.5$ ), and the bulk of the participants (91.7%) were of Chinese ethnicity, unemployed (58.3%), single or married (41.7% each), and with secondary level education (41.7%). The age of onset of HD was 43.9 years ( $SD = 22.3$ ), ranging from 12 to 75 years.

The study recruited participants from January 2017 to June 2018, through clinicians at the Institute of Mental Health (IMH), a tertiary psychiatric institution in Singapore, as well as through stakeholder recommendations from the Agency for Integrated Care (AIC) and Housing and Development Board (HDB). Participants with HD were either diagnosed by their clinicians or identified by community workers using the clutter image rating scale (Frost, Steketee, Tolin, & Renaud, 2008), which was associated with reports of hoarding related distress or functional impairment. Participants in the research were over the age of 21, could converse in English or one of the local languages (Chinese, Malay, or Tamil), and were deemed clinically stable and capable of conducting the interview by the clinical team. Recruitment was halted when data saturation was achieved.

One of the study's strengths is the use of an interpretive approach, in which the researchers focused not only on the psychological model of the disorder, but also recognized that social

reality is shaped by lived experiences and social contexts, and thus best understood through participant interpretation (Elliott & Timulak, 2005). The authors conducted semi-structured interviews with participants to learn about their hoarding experiences, beliefs, and attitudes toward hoarding, as well as the effect of hoarding on their daily lives. Participants were asked to describe in-depth how the behaviour began and establish a timeline for the disorder's progression and the impairment or consequences associated with it. The authors provided a detailed description of their method to data collection and analysis, which improves the study's transparency and rigor.

Another strength of the research is that it focuses on the experiences of individuals with HD in Singapore. The findings of this research are significant in improving knowledge of HD and its management in the Singaporean community. Although people who hoard seem to have a strong emotional attachment to their possessions, there has been limited research on the individual's personal experience of hoarding. Qualitative studies suggest that there is still much to learn about the person who hoards. There is a significant gap in our understanding of the hoarder's perspective.

Although the clinical characteristics of HD are similar, it is also acknowledged that there may be differences in the phenomenology of the disorder due to ethnocultural differences (Shaeffer, 2012), indicating the need to research the disorder in a variety of populations. In relation to this, the present study addresses this gap by exploring the experiences of a Maltese population of persons who hoard and within a Maltese contextual culture.

Another limitation is that, since the referrals were made by service providers, no quantitative screening measures of hoarding or structured clinical interviews were employed by the research team to confirm the diagnosis of HD. The researchers were additionally not given access to any medical records, so the clinical judgment of psychiatrists and community workers was used to confirm the diagnosis of HD. Therefore, it is conceivable that some of the participants who were referred by community workers had clinically significant hoarding that was a comorbidity of another mental illness. However, detailed narratives seem to indicate that the onset of hoarding was primary in nature.

Nine main themes were elicited from the study, namely types of hoarded items, sources of hoarded items, ways of storing/arranging hoarded items, help-seeking/treatment contact, reasons for hoarding, experience with decluttering, impact upon family, community, and self, restricting HB and insight. In addition to this, several participants reported that relationship

issues and decluttering caused low moods and anxiety. Individuals with hoarding disorder may have described more negative experiences with decluttering due to the observable pressure on them to take immediate action to resolve the issues resulting from their hoarding, after being recognized as having hoarding disorder by a clinical or community team. Furthermore, participant narratives included traumatic life events experienced as a child or adult, such as unexpected mortality, parental abuse and neglect, and other traumatic life events. Some participants explicitly linked their HB to a traumatic event in their lives, while others did not.

Another limitation of the study is the potential for researcher bias. The authors acknowledged that their own attitudes and beliefs about hoarding may have affected the study design and data gathering process. To overcome this limitation, the authors used a qualitative approach, which provides for a more open-ended exploration of participants' experiences. This helps to ensure the credibility and trustworthiness of the study. However, the authors did not provide a detailed description of their data analysis method, that may limit the study's transparency.

Despite these limitations, the research is well-organized, with a concise introduction, methods section, and results section. The authors analysed the results critically and discussed the implications for future study and clinical practice.

The study's findings are consistent with earlier studies on HD and highlight the significant impact of hoarding on people's everyday lives. The study found that HB were associated with several factors, including traumatic life events, social isolation, loneliness, and lack of control. The hoarders also reported feeling overwhelmed, ashamed, and embarrassed by their HB, which prevented them from seeking help. Some participants reported that their HB were linked to their cultural beliefs and practices. The study also offers important insights into the beliefs and attitudes of people suffering from HD, which could help to create more effective interventions. The research emphasizes the need for a more comprehensive and integrated approach to the treatment of HD.

Another qualitative study was carried out by Mulligan Rabbitt, O'Connor, and Brien (2023) to investigate the experiences of people who hoard and their relationship to their possessions. One strength of the study is the use of a phenomenologically oriented qualitative research design, that enabled a deep exploration of participants' experiences and perspectives. The researchers explored the experiences of 14 participants with HB. A national news outlet's online story that was posted online was used to recruit participants. The study's overall goal

and the research subject were briefly described in the article. Within a week of being released, it had 22,730 views. Adults over the age of 18 were invited to contact the researcher personally to express their interest in participating in the study and/or to ask more questions. Fifty-six individuals contacted the researcher to express interest in taking part in the study. These prospective participants were then called and invited to a quick screening interview. Furthermore, the research employed a hybrid methodology that included a descriptive phenomenological strategy informed by Giorgi (2012) and a psychoanalytic research interview proposed by Cartwright (2004). The combination of these two methods were perceived as facilitating a deeper understanding of participants' experiences.

The interview questions were open-ended with minimal interventions as recommended within Giorgi's (2012) descriptive phenomenological psychological interview method. This study provides important insights into the emotional and psychological factors that contribute to HB, as well as the effect of societal stigma on hoarders. The data analysis was divided into two sections. The first step was carried out in accordance with Garza's (2004) account of thematic moment-by-moment analysis based on Giorgi's work (2012). The second stage was guided by a psychoanalytic technique based on Cartwright's (2004) Psychoanalytic Research Interview. This perspective offered a valuable framework for understanding the emotional attachment that individuals with HD have to their possessions and the impact of early childhood experiences on their HB.

Three main themes emerged from this process: Firstly, "It's not yours. It's mine"; secondly, "Keeping within the walls"; and thirdly, "Sorting through." These themes reflect the creative and inventive ways participants related to hoarded material. The participants described their emotional attachment to objects—which they connected with emotions of security, familiarity, and comfort—was discovered to be the most important component in their hoarding tendency. Hoarding's relational component was also highlighted, with participants using their possessions to uphold bonds with others or recall happy memories.

Another major topic was the perception of control, with individuals saying that their HB gave them a sense of power over their surroundings. Also, it was discovered that the participants' experiences of guilt and stigma connected to hoarding were influenced by social norms and cultural expectations.

The study emphasizes how intricate HB is and how it ties to the psychological and emotional experiences of those who engage in it. The results discussed in this study may serve as a

potential starting point for considering the significance of hoarding for individuals and identifying a respectful and beneficial approach in clinical engagement. The current methods frequently involve removing the hoard or a portion of it through well-intentioned and professional planning, but based on the findings of this research, these approaches may not be helpful and could even be harmful. Taking away a person's primary coping mechanism without providing an adequate and tolerable substitute might leave them psychologically exposed and vulnerable. Thus, an approach to hoarding that involves a more comprehensive and compassionate understanding of the hoard and the person who hoards may be beneficial.

The researchers did not examine other significant aspects of HD, such as the impact of hoarding on everyday functioning, but instead, focused primarily on the emotional and psychological factors underlying HB. Moreover, the authors acknowledge their biases and assumptions, that enhances the transparency and rigor of the study. The use of psychoanalytic theories and methods may pose some limitations, as they may not be applicable to everyone who hoards. Overall, this study's contribution to the literature on HB depends on the rigor of the research methodology, the relevance of the psychoanalytic theories, and the insights gained from the subjective experiences of individuals who hoard. Further research is needed to confirm and extend the study's findings and to develop effective interventions and treatments for HB.

The research has significant clinical implications, emphasizing the importance of developing trust and rapport with individuals who hoard to create effective interventions. The results also highlight the importance of understanding hoarding as a complex emotional and psychological phenomenon, rather than just a problem of clutter and disorganization. Overall, this study adds to the literature on hoarding by providing important insights into the subjective experience of people who hoard, as well as the emotional and psychological factors that contribute to HB.

In their 2010 study, Kellett, Greenhalgh, Beail, and Ridgway investigated the subjective experiences of individuals who suffer from compulsive hoarding and how they make sense of their HB. Eleven participants (3 males and 8 females) who had engaged in hoarding throughout adulthood were selected to participate in semi-structured interviews that were analysed using interpretative phenomenological analysis (IPA). This approach allowed the researchers to gain a rich and nuanced understanding of the lived experiences of individuals with HD. The sample size was determined in accordance with recommendations for best

practices in qualitative research (Turpin et al., 1997), which is adequate for the research purposes. The sample's age varied from 26 to 63 years (mean age = 38.41, SD = 12.5 years), and seven of the sample's eleven participants were single. Participants were sought out and self-selected through OCD Action, a UK charity that offers support, guidance, and information to those with OCD. Only one participant was awaiting psychodynamic psychotherapy and in touch with psychiatric services at the time of the study. The study included a diverse group of people with HD, with men and women of various ages. The researchers purposively selected a reasonably homogenous group of 11 participants who were particularly motivated to discuss the personal and emotional impact of hoarding. Although the sample was dominated by female participants, previous research has shown that people who hoard are more likely to be female. The fact that the sample was recruited from a self-help organization may limit the generalizability of the results, but it may have also facilitated the research process, as participants were accustomed to describing their plights, dilemmas, and stresses through repetition. However, the sampling technique may unintentionally deter potential study participants with high levels of shame due to the concealment associated with compulsive hoarding.

The study could have been arguably strengthened by screening participants using clinical interviews conducted by trained mental HCP and validated hoarding assessments, to further ensure that clients were compulsive hoarders. However, a strength in this research was that, to the extent possible, the interviews followed the interests, concerns, and experiences of the participants and encouraged participants to describe in depth and detail the process of compulsive hoarding and their thoughts and feelings concerning their HB.

Four super-ordinate discrete but interacting themes emerged from the participants' experiences. These include: (1) childhood factors; (2) the participants' relationship to their hoarded items; (3) cognitive and behavioural avoidance of discard; and (4) the impact of hoarding on self, others, and the home environment. Participants expressed feelings of shame, anxiety, and depression. Most participants experienced adverse effects such as social isolation and stigma by society. Two participants described hoarding bodily products including hair, blood, and faeces. The majority of participants described that HB emerged in childhood and adolescence before expanding in scope and range over adult life. Moreover, the study participants reported enduring significant challenges when it came to ridding themselves of their belongings, which was closely linked to their emotional attachment to the items they hoarded. The findings indicated that there were two main types of avoidance

strategies used by the participants: behavioural and cognitive. The behavioural sub-categories included repeatedly handling their possessions, reluctance to part with their belongings, and behavioural avoidance. The cognitive sub-categories included a desire for perfectionism and indulging in fantasy.

Many participants gave examples of how efforts to reduce clutter consistently resulted in failure to discard. Churning was described as a common behavioural avoidant procedure, with an associated sense of futility that discard efforts rarely resulted in any sizeable reduction in the amount of clutter. Another issue mentioned relating to behavioural avoidance was the slow rate of discard. One participant stated, "Forty years let's say that may seem a long time to many people, but to me I don't think it's that long to clear everything, when you think about it. Considering the pace, I mean that's what I'm judging by. You know the pace at which I'm shifting things" (Kellett, Greenhalgh, Beail, and Ridgway, 2010, p. 148).

Participants reported feeling encompassed by the clutter around them, with this sensation of entrapment relating to both psychological and physical characteristics. Another theme that emerged from the negative impact on the self was the belief that chronic and prolonged hoarding had the ability to alter a person's sense of self and identity.

Participants frequently discussed the effects of compulsive hoarding on family, friends, and neighbours. Finally, in terms of effects, participants mentioned the influence of hoarding on the physical environment of the house. One of the participants expressed, "In the past, I used to be able to find things quite easily amongst this terrible, terrible mess, but I can't anymore because it's got too bad. Got out of hand" (Kellett, Greenhalgh, Beail, and Ridgway, 2010, p. 149).

In conclusion, the current study has provided a detailed exploration of the experiences of 11 persons with their inability to discard and the effect hoarding has on their lives and physical environment. The aim of the study was not to test previously hypothesized associations between hoarding variables, but rather to describe in detail the phenomenology of compulsive hoarding. Many of the results from the existing quantitative evidence base on hoarding were echoed by the qualitative methods used, especially the Frost and Hartl (1996) cognitive behavioural model, and suggested extensions to the model in terms of schema, trauma, and attachment issues. Researchers and clinicians continue to face significant challenges with compulsive hoarding (Maier, 2004; Steketee and Frost, 2003), particularly in developing an

evidence-based biopsychosocial formulation of the disorder (Bystritsky, 2006), and further developing and thoroughly evaluating targeted treatment approaches.

Andersen et al., (2008) used a focused ethnographic research design as the method of exploration. The ethnographic method was chosen specifically to reveal the experiences of acquiring and owning excess because it was critical to look beyond hoarding as pathology and toward the experiences that hoarded possessions produced for their owners. Ethnography is a type of qualitative study that involves looking, listening, and asking questions (Roper & Shapira, 2000). The study design was called "focused ethnography" because it was conducted on a small scale and concentrated on a specific group of people to be studied within a single context, with a small number of participants (Speziale & Carpenter, 2003). The interpretive approach and focused design's objectives, according to the investigator, were to describe and interpret words and actions. The aim of this study was to investigate a deeper understanding of emotional issues that underpin HB by older people in order to guide the practice of HCP who care for such clients in the community.

The study sample included eight older adults who received home care and who were identified as exhibiting compulsive HB. They were all over the age of 65 and self-identified as hoarders. Participants were recruited using local newspaper advertisements and flyers in public places, and they were interviewed about their HB, motivations, and experiences.

The analysis of the interviews showed various themes concerning the participants' reasons for hoarding. The reasons to accumulate or acquire excess included freedom from anxiety, feeling connected and socially engaged, feeling needed by others, feeling proud and productive, and feeling in control.

Many of the participants stated that they had a deep sentimental tie to their possessions, with their goods reflecting memories of loved ones, prior experiences, or significant life events. For some individuals, hoarding was a strategy to maintain a link to the past and a sense of self-identity. Others reported hoarding as a means to prevent feelings of loss or abandonment, with items providing comfort and stability. Several of the participants saw their possessions as useful and were hesitant to get rid of things that they might use in the future.

Finally, some participants reported avoiding decision-making around their possessions as a reason for hoarding. This was frequently associated with worry or difficulty surrounding the

decision to let go of things, with participants experiencing a sense of uncertainty or loss of control when confronted with the idea of disposing of objects.

According to the authors, HB in older individuals is a complicated and multifaceted phenomenon that is shaped by a range of factors. They argue that understanding the motivations behind HB is critical for designing effective interventions and assistance for those suffering from hoarding condition. The study emphasizes the need for person-centred approaches that include hoarders' specific experiences and motives, as well as the need for more research to guide best practices in working with older adults who hoard.

Thew and Salkovskis (2016) conducted an evaluation of the literature on hoarding among older people over 55 years old. The aim of this study was to determine the extent to which the older adult hoarding literature may be confounded or overly influenced by age-related factors such as problem chronicity, cognitive function, or demographic characteristics, and to consider the implications for theoretical and empirical work in hoarding. The authors reviewed the literature in relation to the following questions: hoarding among older people, and how does this fit with the idea of 'anxiety burnout'?

The researchers searched the literature using electronic databases such as Medline, APA PsycNet, Scopus, National Library for Health, Web of Knowledge, Cochrane, and Google Scholar to identify relevant studies. The year of publication was not set as a search criterion due to the relative recency of the field. Papers had to have undergone peer review and could include observational studies, reviews, case studies or series, or conceptual/theoretical papers. Search terms incorporated accepted synonymous words or phrases to minimize the risk of missing relevant material. Mesh terms were also used. Forty-five studies were chosen to be reviewed. The studies assessed hoarding using a variety of approaches, including self-report questionnaires, clinician interviews, and home visits.

The literature relevant to hoarding in later life was reviewed in relation to a set of questions placing hoarding in a lifespan developmental context. Efforts to identify and control for factors relating to age or problem chronicity were minimal, and a key future direction is the identification of younger samples of people who hoard. In this study, the researchers focused on identifying more clearly the processes that drive the acquisition and retention of excessive amounts of material.

The most important details in this text are the difficulty discarding possessions, a perceived need to save items, clutter in active living areas, and significant distress or functional impairment. Cognitive-behavioural approaches suggest that hoarding is driven by beliefs about the nature of possessions, their value, and the purpose of saving, and that these beliefs may have become exaggerated or biased over time. Measures such as the Saving Cognitions Inventory (Steketee, Frost, and Kyrios, 2003) have been used to show differences in beliefs between those who hoard and those who do not. Studies have begun to explore hoarding development and maintenance from a range of perspectives, including cognitive-behavioural, attachment, genetic, and neuropsychological approaches.

In conclusion, the reviewed literature provides effective descriptions of the presentations, difficulties, and management of hoarding issues in older adults. However, there is a lack of high-quality empirical studies, as well as an insufficient emphasis on the motivating beliefs and cognitions that may reflect the core psychopathology of this mental health difficulty. As a result, the power of this literature to influence conceptual and theoretical understandings of hoarding, and thus clinical interventions derived from these, is limited.

Older adults frequently make up a significant proportion of hoarding research studies, almost certainly because their clutter is more severe, making them simpler to identify. There is a real risk that findings and related theorizing may be misleading because they may be unduly influenced by aging-related and chronicity-related confounds that may have nothing to do with the core psychopathology underlying hoarding problems. This is because efforts to identify and control for age-related factors are uncommon in the literature. Given that the average age of hoarding onset is believed to be in adolescence, research on a broader age range, especially younger people, is likely to avoid these confounds and better develop our understanding of what can be a lifelong and disabling condition.

The next section focuses on studies relating to early environment, attachment, and trauma.

### **2.5.2 Early environment, attachment, and trauma**

Chia et al. (2021) conducted a systematic and thorough review that investigated the link between hoarding symptoms and three potential vulnerability factors. The review analysed studies to examine the association between hoarding symptoms and interpersonal attachment,

early family environment, and traumatic or adverse life events. The review explored the relationship between hoarding and traumatic experiences from various angles. The studies examined the relationship between overall hoarding severity and exposure to traumatic or stressful life events throughout a person's lifetime, childhood adversity, and short-term adverse events. Chia et al.'s review established a connection between the cumulative exposure to trauma, adverse childhood experience, and short-term stressful life events with hoarding severity. Overall, the results suggested that traumatic experiences from various contexts may influence the severity of hoarding.

The researchers searched through electronic databases such as PubMed, PsycINFO, and Scopus to find papers without any restrictions on the date of publication. The review included 39 studies that utilized self-report questionnaires and clinician interviews to examine hoarding, interpersonal attachment, early family environment, and trauma.

The authors concluded by discussing the clinical implications and limitations of these findings and proposed new directions for future research. However, a limitation of the review is that most of the included studies were cross-sectional, and only one repeated-measures study was identified. Due to the lack of experimental or longitudinal research, it is challenging to establish causal relationships between the examined factors and hoarding symptoms. Additionally, it is not clear whether interpersonal attachment, early family environment, and traumatic life events may act as vulnerability, precipitating, or maintaining factors for HD. The review identified methodological limitations such as the reliance on retrospective self-reporting of past events that may be influenced by memory and perceptual biases. Furthermore, variability in the assessment and definition of hoarding symptomatology may impact the generalization of the findings.

The authors conclude that a deeper knowledge of attachment, early family environment, and trauma in hoarding may aid in the development of more effective treatments for this disorder. The review emphasizes the importance of interventions that address the underlying emotional and psychological factors that contribute to hoarding, such as high levels of anxiety sensitivity and low distress tolerance, which may lead them to seek comfort and safety in objects when human attachments are uncertain. Another area of interest is the connection between hoarding and stressful life events and trauma. Chia et al. (2021) conducted a review of studies on this topic and found that hoarding was associated with both the frequency and

intensity of traumatic events, including those that meet the criteria for post-traumatic stress disorder (PTSD), as well as non-criteria A stressful life events.

Lastly, the authors emphasized the importance of early interventions that address the impact of family environment and trauma on people's beliefs and attitudes toward possessions.

## **2.6 Conclusion**

This literature review discusses the lived experiences of individuals with HD, examining their perceived impact, support, and coping mechanisms. The review retrieved 8 studies, all with hoarders as study participants. The critique of literature highlights a gap in knowledge regarding the lived experiences of individuals with HB living in Malta. As a result, the present research study aims to provide an in-depth account of the lived experiences of hoarders in Malta.

The critical discussion underscores that the majority of the studies identified demonstrate the impact of HB on individuals' QoL, coping mechanisms, and emotions. Additionally, the studies indicate the need for more research to guide best practices when working with hoarders. The methodology of the study is presented in the following chapter.

# Chapter 3: Methodology

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## 3.1 Introduction

This chapter provides a comprehensive description of the planning stages and methodology utilized in this study. The selected research methodology was based on enabling the exploration of the lived experiences of the participants. To address the research question, the study utilized IPA, as outlined by Smith et al. (2009), and the details are presented in this chapter. Furthermore, this chapter provides an overview of the data gathering and analysis techniques employed. Additionally, the ethical considerations and methodological rigor of this study are discussed.

## 3.2 Aims, objectives and research question

The research question addressed in this study was, "What are the lived experiences of individuals who hoard in Malta?" The primary aim of this study is to gain an understanding of the lived experiences of individuals who compulsively hoard in Malta. To achieve this objective, the following objectives were identified: (i) what persons with HB perceived as the causal triggers of their behaviour; (ii) the impact of living with a HB on their quality of life (QoL); (iii) the coping strategies adopted by individuals who hoard, and (iv) to identify available support strategies and recommendations.

The subsequent section presents the operational definitions used in this study.

## 3.3 Operational Definitions

The term "experience" in this study pertains to the events, emotions, and situations encountered by individuals living with HB. It encompasses their past and present encounters

with HD. Furthermore, a hoarder is a person who experiences persistent difficulty discarding or relinquishing possessions, regardless of their actual value, due to a perceived need to save them or a fear of losing them.

### **3.4 Research Designs**

When conducting nursing research, there are three primary research approaches: mixed, qualitative, and quantitative methodologies. The researcher has selected the qualitative method to explore the research question, which involves the collection and analysis of non-numerical data. This approach enables the researcher to comprehend the personal viewpoints and experiences of the participants in-depth. By utilizing this method, the researcher can gather detailed information about the participant's experiences and generate new research ideas (Bhandari, 2023).

In contrast, quantitative research involves gathering and analysing data in a numerical form using statistical processes (Bhandari, 2023). Its goal is to create knowledge and develop an understanding of society (Allen, 2017). On the other hand, mixed methods research involves gathering and analysing both qualitative and quantitative data in the same study (Shorten & Smith, 2017). However, neither approach can provide a thorough exploration and analysis of the lived experiences of individuals who hoard. In contrast, qualitative approaches can offer a more profound understanding of such participants' experiences. By providing participants with the opportunity to express their experiences, we can gain insights into what it is like to live with HD.

#### **3.4.1 Research Paradigm**

The set of beliefs that guide action is known as a research paradigm. Paradigms represent a worldview (Guba & Lincoln, 1994). According to Creswell and Poth (2018), researchers take positions to direct their research, and these positions are called paradigms. A research paradigm comprises ontology, epistemology, and methodology (Creswell & Poth, 2018). Ontology is concerned with the question, "What is reality?" In the context of the researcher,

this means understanding whether there is a definite reality to the researcher's topic. Epistemology is the study of knowledge, and it focuses on the question, "How is it possible to know reality?" Finally, methodology is concerned with the question, "How does the researcher discover reality?" A distinct perspective is known as axiology, which pertains to the researcher's ethical standards and values (Creswell & Poth, 2018; Mingers, 2003). Axiology encompasses the researcher's values and perspectives throughout the process of generating knowledge (Kafle, 2011). In this study, the researcher explicitly delineates the objectives and biases of the research, as well as providing insights into her personal background and reflections regarding the study (Creswell & Poth, 2018). These positions contribute to a comprehensive understanding of knowledge and how it relates to our own perspectives and the methodologies we employ to attain it.

### **3.4.2. Interpretative Frameworks**

When researchers undertake a qualitative study, they apply paradigms within the interpretive frameworks they use. As a result, key stances in interpretative frameworks utilized in qualitative research include ontology, epistemology, axiology, and methodology (Denzin & Lincoln, 2011). Social constructivism, also known as interpretivism, refers to a philosophical perspective in which individuals strive to comprehend the world they inhabit (Denzin & Lincoln, 2011). According to this perspective, individuals construct subjective meanings based on their experiences. In the context of social constructivism, researchers aim to rely on the perspectives of the participants, exploring the intricacies of their views and interpretations, recognizing the existence of multiple viewpoints and meanings. These arbitrary interpretations are frequently created by an individual's interactions with others. In constructivism, meaning patterns are developed inductively by the researcher. Additionally, the researcher interprets the results, and this interpretation is influenced by the researcher's background and experiences (Creswell & Poth, 2018). Therefore, in interpretivism, the researcher connects with the individuals being investigated in order to eventually obtain their perspectives on reality. This allows the researcher to understand the experience from the perspective of those who live it (Appleton & King, 2002).

Phenomenological studies are an example of research that embodies the constructivist paradigm (Creswell & Poth, 2018). The scope of this study is to explore the lived experiences of people with HB in Malta.

The following section describes various types of qualitative designs and the rationale for selecting the design used in the present study.

### **3.5 Qualitative Research Designs**

The researcher chose the qualitative method to explore the study question, which involves collecting and analysing non-numerical data. The strategy was used to comprehend the personal viewpoints and experiences of the participants, enabling the researcher to explore the lived experience of individuals with HD in Malta in-depth. Various research methodologies such as grounded theory, ethnography, and phenomenology are used in qualitative research. Grounded theory was developed in 1967 by Glaser and Strauss in California, where the researcher creates theory based on individuals who have undergone similar processes, actions, or interactions. In ethnography, the researcher spends an extended time being immersed in the community being studied, and describes and interprets the shared patterns of values, behaviours, beliefs, and language. The roots of ethnography can be traced back to the field of anthropology in the early 20th century.

However, the present study aimed to comprehend and investigate the actual experiences of people with HB in Malta. Therefore, IPA, as outlined by Smith et al. (2009), is the research approach that would be most effective in answering the research question. The researcher used this method to examine how each person interprets this significant life event and to learn how these people explain their own HB. According to Smith et al. (2009), IPA is founded on three important branches of the philosophy of knowledge, namely phenomenology, hermeneutics, and idiography.

IPA provides the researcher with the chance to delve deeply into the participants' experiences. As the study aimed to explore the in-depth perspective of the individual, the researcher had the opportunity to experience everyone's story within their unique context. Furthermore, adopting a hermeneutic approach enables the researcher to delve deeply into the

interpretation of all the experiences at hand. The following section describes the three theoretical underpinnings of IPA, which are phenomenology, hermeneutics, and idiography.

## **3.6 Philosophical Underpinnings of IPA research**

Smith, Flowers, and Larkin (2009) introduced the concept that Interpretative Phenomenological Analysis (IPA) is a form of hermeneutic phenomenology, prioritizing interpretation over the mere description of phenomena. In this approach, the researcher aims to comprehend how participants perceive the world from their own perspectives. According to Smith et al. (2009), conducting research using IPA is an effective means to achieve this understanding, which is why the researcher opted for IPA as the primary research design. Smith et al. (2009) also emphasized that IPA, as a hermeneutic phenomenology, places greater emphasis on interpretation rather than the characterization of phenomenological aspects.

By adopting the IPA methodology, the study granted participants the opportunity to express their first-hand experiences, providing them with a voice. Such a level of participant engagement would not have been possible through a quantitative approach. Furthermore, as a staff member within a mental health facility, fully setting aside personal beliefs and assumptions during the analysis of participants' experiences with HB would have posed a significant challenge.

In fact, being hermeneutic, IPA acknowledges that throughout the data analysis stage, researchers can utilize their own beliefs, assumptions, and personal experiences to interpret results (Smith et al., 2009). Therefore, IPA made it possible for the current researcher to actively take part in the interpretation process. The researcher was inductive and grounded in the data when using IPA. Phenomenology, hermeneutics, and IPA idiography are the three main branches of philosophy covered in the following sections (Smith et al., 2009).

### **3.6.1 Phenomenology**

Phenomenology is another approach that focuses on exploring participants' experiences and encouraging them to narrate their experiences from their own perspectives. Hence, the goal of

this approach is to produce a subjective description of the experience rather than attempting to produce an objective record of the experience itself (Pietkiewicz & Smith, 2014).

According to Husserl (as cited in Koch, 1995), the use of phenomenological reductions can result in an objective description of participants' experiences. This idea is also referred to as "bracketing" in philosophical writing. The researcher hence puts the focus of the study in brackets, utilizing phenomenological reductions to set everything else aside and put the emphasis on the participants' lived experience (Larkin et al., 2006). This is the only way the participants' lived experience can be truly understood. Therefore, researchers should try to set aside their biases during the data collection stage.

To identify my own preconceptions and beliefs, I kept a reflective diary throughout the study process, as advised by Smith et al. (2009). Then, throughout the data collection stage of this study, I made sure that these preconceptions and beliefs did not influence the participants' answers to the interview questions.

### **3.6.2 Hermeneutics**

According to Smith et al. (2009), hermeneutics refers to the theory of interpretation. In the context of Interpretative Phenomenological Analysis (IPA), it is closely linked to the understanding that the interpretation of an individual's experience can only be achieved through a collaborative process involving both the participant and the researcher (Smith, 2011). Smith (2011) further argues that experience requires a process of interaction and interpretation rather than being directly produced from the participant. In this procedure, the researcher engages in a double hermeneutic, in which the researcher analyses what the participant is saying, to make sense of the experience the participant is trying to make sense of.

Schleiermacher, Heidegger, and Gadamer are the three philosophers on whom IPA's hermeneutics theory is based. Heidegger's phenomenology served as the foundation for this study because it was designed to examine something that might be concealed (Smith et al., 2009). For IPA researchers, this phenomenological presentation offers a helpful framework for thinking about the data analysis. In this instance, the only appropriate method of seeking any hidden meanings in the text is by interpreting the text itself (Debesay et al., 2008). To allow the genuine and accurate meanings of the experience to emerge, this calls for a careful reading of the text during which the researcher must be conscious of their biases. In fact,

within this study, I was constantly questioning both my own prior knowledge and the veracity of the findings.

### **3.6.3 Idiography**

Idiography is a significant factor in shaping IPA. Idiography focuses on the specific individual. As IPA aims to investigate in-depth details, thorough examination of each case is critical. IPA is idiographic as it allows for a comprehensive investigation of each case until saturation is attained. Once the researcher has reached a degree of saturation in one case, they then proceed to the next. A cross-case analysis is only conducted after achieving a degree of saturation. This approach enables similarities and differences among the transcripts to emerge (Shinebourne & Smith, 2010).

The IPA approach is dedicated to comprehending and interpreting how a particular experience, relationship, or event has been perceived by individuals in specific circumstances. Additionally, it contextualizes participants' experiences and offers comprehensive knowledge of their world. According to Smith et al. (2009), IPA hypothesizes that the experience of Dasein is connected to the phenomenon and not to the individual's traits. Nevertheless, individuals can offer a distinctive personal perspective on their relationship with the phenomenon under investigation.

In the upcoming section, the study will outline the specific sampling methodology and criteria for inclusion.

## **3.7 Sampling Technique and Inclusion Criteria**

The primary objective of IPA research is to offer a comprehensive understanding of an individual's experience (Smith et al., 2009). Therefore, it is crucial for the researcher to carefully select participants who are likely to provide in-depth and focused information on the research topic (Walsh & Downe, 2006). It is advisable to opt for a homogeneous sample comprising individuals who possess direct knowledge of the phenomenon under investigation. As argued by Clearly et al. (2014), selecting a purposeful sample consisting of individuals currently undergoing the experience being examined would enable the researcher to gather credible and authentic experiences.

For this study, a total of five participants were recruited, in accordance with the inclusion and exclusion criteria specified in Table 3.1. To be eligible, participants had to be at least 18 years old and have hoarding behaviour (HB).

Table 3.1 Inclusion and Exclusion Criteria of Participants

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
People with HB.	People without HB.
Living in the community setting.	Not inpatient.
Living in Malta.	Not living abroad.
Over the age of 18 years	Under the age of 18 years.

The following section delineates the recruitment process

### **3.8 Recruitment Process**

The participants in the study were recruited through an intermediary, and the sample was purposefully chosen. The recruitment of potential participants involved contacting people with HB. Prior to initiating the research, I provided a comprehensive overview of the research project to the intermediaries, as detailed in Appendix A. The recruitment of participants for this study involved the participation of three intermediaries who serve as charge nurses in outreach teams. Using the inclusion criteria as a guide, the intermediaries reached out to potential participants. An information letter explaining the study process (see Appendix B) was sent to interested participants by the intermediary. The potential participants were made aware that participation was completely optional and that they were free to withdraw from the study at any moment without having to provide a reason. This ensured that the potential participants could decide without feeling coerced.

The researcher was unaware of anyone who was approached but declined to participate, since they were contacted by the intermediary. People who expressed interest in participating sent their contact details to the intermediary and were then contacted through a phone call by the researcher. After the researcher made contact, she explained the nature of the study and answered any queries that the participants had. Furthermore, the researcher scheduled an

interview with those participants who were interested in taking part in the study. During the initial meeting, the participants were asked whether they had any further queries requiring clarification, following which they were invited to consent to participate (see Appendix C). The researcher ensured that participants were informed about the confidentiality of the information shared and guaranteed that their personal identities would remain anonymous. The following section presents specific information about the participants chosen, in accordance with the inclusion criteria outlined in section 3.7.

### 3.9 Demographic Data of the Participants

Data collection began in July 2022 and extended until January 2023. The participants in this study constitute a relatively homogeneous sample, comprising individuals with (HB) residing in Malta. The recruited participants consisted of two males and three females. Their ages ranged from 40 to 63 years, with an average age of 54 years. The demographic characteristics of the participants with HB are presented in Table 3.2. The duration of their hoarding experiences varied from 4 to 25 years. At the time of the interviews, one participant was employed, while the remaining participants were either unemployed, receiving social benefits, or pensioners. All participants were single. In order to protect their identity and confidentiality, no additional information concerning the participants' demographic details is provided. The subsequent section will delineate the process of data collection.

Table 3.2 Demographic data.

<b>Pseudonym</b>	<b>Age/Years</b>	<b>Employment status</b>	<b>Marital status</b>
Maria	40	Unemployed	Single
Anna	62	Pensioner	Single
Jane	53	Employed	Single
Anton	63	Pensioner	Single
Theodore	52	Unemployed	Single

The following section furnishes details regarding the data collection instrument employed, along with information concerning the research setting and the pilot interview conducted.

## **3.10 Data Collection**

The most popular method for gathering data when utilizing IPA is to conduct semi-structured interviews with participants. Semi-structured interviews are very useful to obtain a complete picture of the participants' experiences and they offer guidance to the interviewer to ensure that the research question is adequately addressed (Smith & Osborne, 2003). Semi-structured interviews, as opposed to questionnaires, offer far greater flexibility, enabling the researcher to explore any new areas that come up during the interview and, hence, produce better data (Griffiths, 2009). The researcher used this method to collect the data. The participants were questioned in an open-ended manner. Under no circumstances was the participant's response shaped to meet the needs of the researcher.

The researcher also had to be a good listener and let the participants speak. It was crucial that the location selected for the interview fostered comfort for the participant. To have a comprehensive understanding of these interviews, it was essential to record them and later transcribe them (Neubauer et al., 2019). Additionally, due to time limitations, the researcher chose to conduct semi-structured interviews with a guide, which was considered a valuable approach to ensure effective interviews (Langdrige, 2007).

### **3.10.1 Interview Schedule**

IPA suggests the use of an interview guide to establish a general framework for the interview and anticipate potentially sensitive topics. However, merely having an interview schedule does not guarantee a high-quality interview. To gain deeper insights into participants' experiences, researchers must fully engage with them, actively listen, and ask probing questions. Failure to do so may result in insufficient data for meaningful analysis (Smith et al., 2009). Furthermore, Smith et al. (2009) recommend creating an interview schedule as a helpful approach to guide novice researchers in qualitative thinking. Developing an interview schedule enables the researcher to consider the topics to be covered during the interview and address any potential challenges, such as question wording or sensitive subjects (Smith, 2008). In this study, the researcher designed an interview guide (see Appendix C) containing six open-ended questions focusing on the participants' hoarding experiences. In addition to this, it also focused on their coping strategies, emotions, and their expectations of future and

current support relating to their HB. The questions were created after conducting a literature review and were specifically created with the aim of this study in mind.

The interview focused on asking the participants to describe and reflect on aspects of their experience with hoarding. The interview started with a direct open-ended question: “Can you please share with me your experience of how you started hoarding?”. Asking this question first invited the participants to consider how their HB started, and this experience could then be discussed with me openly. The following questions then inquired more deeply into various aspects such as the impact of hoarding on their QoL, the participant’s feelings, thoughts, and reactions, their coping strategies, and the support that they received or wished to receive during this experience. Prompts were used to encourage the participants to talk more about a subject (example: “Can you tell me more about this?” or “And how did you react to that?”). This made it possible to thoroughly explore the experiences while ensuring that probes were not leading (Rapley, 2001; Smith, 2008). The prompts were not practiced before the actual interviews as they came out naturally during the interview.

To accommodate the bilingual nature of Malta, where both Maltese and English are official languages, the researcher created versions of the interview guide in both Maltese and English. The researcher used only the Maltese version of the interview at the participants request as they were more at ease to do the interview in their mother-tongue. The audio recordings of the interviews were verbatim translated from Maltese to English by a professional translator.

The interviews were carried out in different locations that were selected by the participants. Three interviews were conducted in the participants’ homes, and two interviews in a quiet corner in a coffee shop. The participants selected the time that was suitable for them. These measures ensured that the participants had the opportunity to feel more comfortable talking about their experiences. The interviews lasted between 30 to 60 minutes. The next section provides further details about the pilot study and the actual interviews.

### **3.11 Pilot Work**

Qualitative inquiry often utilizes pilot work to prepare for a study, and face-to-face interviews are considered an effective means of gaining insight into the experiences of those living the phenomenon under investigation (Smith et al., 2009). Before beginning the actual study, a pilot interview was conducted with a male participant. The pilot lasted for 45 minutes and was helpful in allowing the researcher to practice asking interview questions. The questions

were not changed after the pilot, but the transcript was reviewed with the academic supervisor who recommended the use of prompts during the interview to obtain more in-depth data. The findings from the pilot study did not provide in-depth data for analysis and its findings were not included in the final analysis of the study.

The next section outlines the data analytic procedures applied in this study.

## **3.12 Data Analysis**

Smith et al. (2009) outline a systematic and structured procedure for analysing the data gathered. This method is guided by an open mindset and a desire to immerse in the data in order to extract the meanings attached to the participants' experiences. There are six steps that make up this process, which are listed below.

### **Step 1: Reading and re-reading.**

First, to familiarize oneself with the participant accounts, the interview transcripts were read while listening to the audio recordings (Smith et al., 2009). Any pauses or emotions that the participants expressed were documented while listening to the tapes because these can be crucial when evaluating the data (Rapley, 2001). I read the transcripts numerous times to enable me to immerse myself in the data collected.

### **Step 2: Initial noting.**

At this point, statements that seemed interesting or relevant were underlined, and on the right margin, exploratory comments were typed. Three categories of comments—descriptive, conceptual, and linguistic—were generated from the initial notes as explained in the findings.

### **Step 3: Developing emergent themes.**

This step entails concentrating on the exploratory comments to identify emergent themes. As a result, the data is organized to reduce volume. This procedure involved breaking down statements from the original interview transcript into sub-themes. By grouping related statements together, patterns between the sub-themes were discovered. The themes included the analyst's interpretation as well as the participant's words and thoughts. Therefore, the emergent themes reflected a chronological process of description and interpretation.

#### **Step 4: Searching for connections across emergent themes.**

In this step, the process involves categorizing emergent themes and developing overarching themes. The analyst thoroughly examined the transcripts, noting similarities and differences, and identified the overarching themes that emerged as significant concerns among the participants. Additionally, the analyst paid attention to contextual or narrative elements within the transcripts to establish connections between the emergent themes, thereby obtaining a more comprehensive understanding of the participants' lived experiences.

#### **Step 5: Moving to the next case.**

Following the analysis of one interview transcript, the next step was to move on to the next participant's transcript and repeat the four steps outlined above. As Smith et al. (2009) advised, I did my best to set aside as many of the ideas that emerged from the analysis of the first participant's transcript as possible while working on the second. This pattern continued in subsequent cases.

#### **Step 6: Looking for patterns across cases.**

Following the analysis of all interview transcripts, the superordinate themes and main themes identified for each case were thoroughly reviewed. This review led to the creation of a comprehensive Master table encompassing the superordinate themes and themes for all participants, as described in Chapter 4. The researcher employed an inductive approach to data analysis, allowing patterns and themes to naturally emerge from the gathered information. Moreover, the supervisor provided an audit of the superordinate themes and sub-themes during the analysis stage, and discussions with the supervisor were conducted to ensure the coding system accurately captured the findings of the transcripts.

The following section addresses the ethical issues that arose during my research.

### **3.13 Ethical Issues**

It is critical to address a number of ethical considerations related to doing research. The principal ethical problems addressed in this study were those of self-determination, maintaining confidentiality and protection from harm. The sections that follow discuss the ethical issues that were considered at various stages of this study.

### **3.13.1 Recruitment**

There is a possibility of coercion during participant recruitment (Rebar et al., 2011). The participants were recruited from the community. Since I work in the community there was a risk of coercion, but this was prevented by conducting my study in a different Outreach setting from that in which I worked. To ensure that participants did not feel pressured to take part in the study, intermediaries were used to recruit them. Additionally, the intermediaries did not disclose any information about individuals who declined to participate in the study.

### **3.13.2 Informed Consent**

IPA may cause ethical issues for the researcher. Smith et al. (2009) stated that while conducting such research, it is critical to obtain participant consent for both data collection and data analysis, especially when collecting quotes from what was shared in the interviews. Before obtaining this consent, it is critical to provide the participants with a detailed explanation of what is required of them. As a result of this, the participants were given an information letter. The information letter explains the study to ensure that they understand how this study is going to be carried out and to make an informed choice. Furthermore, an explanation of the participant's rights to withdraw from the study was provided if they chose to participate. Another ethical issue is how certain ideas and feelings may cause distress to the participants, so the researcher must ensure that the participant is referred to a psychologist for the required help. In addition to this, details of a psychologist were provided in case any participant feels distressed during the interview.

A written consent form was given to the participants who wanted to be involved. The participants of the study were given a clear assurance that their participation was entirely voluntary and that they had the freedom to withdraw from the study at any point. They and their relatives would not experience any negative consequences from this. It was made sure that participants had enough time to determine whether or not to participate in the study before being asked to sign the consent form (Appendix B).

### **3.13.3 Pseudonymity and Confidentiality**

As stated by Rebar et al. (2011), strict measures were taken to ensure confidentiality throughout the study. Participant identities were kept confidential, and no information was linked to any specific individual. All transcripts and recordings used in the study were securely stored in a locked cabinet during the research period and were subsequently destroyed upon completion of the research. Only the researcher had access to the data, although the supervisor and examiners may have been granted access for verification purposes. Pseudonyms were used to protect participants' anonymity, and personal data was stored separately from the transcripts. Audio recordings and transcripts were stored on the researcher's password-protected and encrypted personal computer. Hard copies of the materials were stored in a locked cupboard during the research period and will be destroyed once the study is concluded.

### **3.13.4 Minimizing Harm**

The researcher has a responsibility to minimize any potential harm (Parahoo, 2006). Therefore, prior to obtaining consent for the interview, an information sheet was provided to the participants, outlining the risks and benefits of the study. These risks and benefits were also discussed verbally with the participants, as recommended by Garthwaite (2008). Additionally, as part of the consent process, participants were informed about the possibility of experiencing uncomfortable emotions and anxiety during the interview. They were assured that if such feelings arose, they could access the services of a psychologist at no additional cost (see Appendix F). The information letter provided all the necessary details about the professional help available. Importantly, participants had the right to decline answering any questions they were uncomfortable with, and if they chose to withdraw from the study, all collected data would be securely destroyed.

## **3.14 Quality and Trustworthiness**

According to Smith et al. (2009), qualitative research should be assessed using its own criteria. In addition, Smith et al. (2009) advise utilizing Yardley's (2000) criteria to evaluate

IPA's trustworthiness and quality. Yardley (2000) suggests the following four factors to guarantee quality and trustworthiness.

### **3.14.1 Sensitivity to Context**

Ensuring sensitivity to context involves assessing whether the research findings accurately capture the true essence of the data collected from participants. To achieve this, two techniques were employed. Firstly, as recommended by Smith et al. (2009), a significant number of verbatim extracts were included in the study to support the arguments presented, giving participants a voice and allowing readers to evaluate the proposed interpretations. This approach enhances sensitivity to context by directly showcasing participants' perspectives. Secondly, to further enhance sensitivity to context, Yardley's (2000) suggestion was followed. This entails the researcher possessing a comprehensive understanding of the relevant literature related to the research topic and being familiar with the foundations of the research methodology employed. By presenting the findings alongside the relevant literature, a contextualized approach is ensured.

However, it is important to note that readers may not always share the same interpretations as the researcher, as Interpretative Phenomenological Analysis (IPA) allows both the researcher and the reader to bring their own preconceptions to the analysis, which may influence their individual perspectives.

### **3.14.2 Commitment, rigour, transparency, and coherence**

Commitment, rigor, transparency, and coherence encompass the expectations for thoroughness in data collection, analysis, and reporting in research (Yardley, 2000). In this study, the research process was described with utmost clarity, providing rational explanations for all decisions and actions taken (Garthwaite, 2008). Following Garthwaite's recommendation, the use of a field journal throughout the study greatly supported this clarity. The field journal served as an informal repository of notes, capturing personal feelings, thoughts, ideas, biases, feedback, and gathered information. Documenting these thoughts and ideas in the reflective journal proved immensely valuable as they facilitated the writing of this thesis. They increased awareness of the influences on data interpretation, the researcher's relationship to the research topic and participants, demonstrating reflexivity throughout the text (Parahoo, 2006). Reflexivity, as described by Parahoo, involves the ongoing process of

reflecting on the researcher's values, preconceptions, behaviour, and presence, as well as those of the participants, which can influence the interpretation of responses. Jootun et al. (2009) stated that reflexivity enhances the credibility of research and should be an integral component of any qualitative inquiry.

### **3.14.3 Impact and quality**

The credibility of a study is supported when it provides intriguing findings that are relevant to the study's purpose and contribute to the reader's understanding (Smith et al., 2009). This study aimed to fill the existing gap in knowledge regarding the specific sample under investigation, specifically focusing on individuals living with hoarding disorder (HB). Being a novel researcher, I also needed the research supervisor's direction to carry out this study. The research supervisor guided me in ensuring that I followed the standards of trustworthiness and quality.

The following section describes how reflexivity was conducted.

## **3.15 Reflexivity**

The reliability, accountability, and transparency of qualitative research are enhanced through reflexivity (Finlay, 2009). Additionally, the process of reflexivity involves paying systematic attention to the context of knowledge, particularly the effect of the researcher at each stage of the research process (Cohen & Crabtree, 2006). Furthermore, reflexivity helps the researcher recognize any prejudices and assumptions she may have that could unwittingly be introduced into the study. As part of the study, a reflexive journal was maintained to document any preconceived notions. The journal also recorded logistics, decisions, and the reasoning behind them. Personal reflections and interests related to the study were also documented.

However, having some background in the topic of inquiry could potentially limit the study because there is a chance that the researcher's biases could affect how the results are interpreted (Bishop & Shepherd, 2011). According to the description in the paragraph that follows, this might have occurred in the current study.

I have been a nurse at Outreach (psychiatric community) for the past four years. I had several opportunities to work with patients with HB. Hence, before conducting this study, I had some

understanding of the difficulties that these patients face. Bishop and Shepherd (2011) stated that having experience within the same research field can be seen as a paradoxical influence. It might improve the study by making it simpler for the researcher to establish a good relationship with the participants (Bishop & Shepherd, 2011).

In fact, I feel that I managed to build a strong relationship with some of the participants as they felt that they could trust me. However, having some background in the topic of inquiry could potentially limit the study because there is a possibility that the researcher's biases could affect how the results are interpreted (Bishop & Shepherd, 2011). I saw that the participants were at ease discussing their experiences throughout the interviews, and they expressed that they found it helpful to share their experiences with a person who is not judgemental. This satisfied me because prior to the interviews, I was preoccupied that the participants would consider the interviews as a waste of time.

My perception was that such individuals struggle a lot when they are living in the community. They are usually misfits in society and very often judged and left alone. My belief was that they refuse help and tend to push people away for fear of being judged. In addition to this, I also thought that due to their cluttered environment, they tend to avoid staying at home. I felt helpless during the interviews because I could not refer them to any services which support HB since there is no such service available in Malta. I was inquisitive regarding how they managed to cope in their daily life, hence why I decided to carry out such a study.

During the interviews, I expressed empathy and acknowledged the participants' emotions as they shared their detailed experiences. I was particularly struck by the wide range and intensity of emotions expressed, such as anxiety, loneliness, worry, guilt, shame, frustration, and profound sadness, which were commonly shared by most participants when discussing their challenging experiences. This deepened my understanding of the lived experience of individuals with hoarding disorder (HD). Although I anticipated that the interviews could potentially trigger distress, I found that this was not the case.

Throughout the interviews, I made a conscious effort to differentiate between my professional role as a nurse conducting one-on-one sessions and my role as a researcher collecting data for the study. The most challenging aspect was the need to maintain a clear distinction between these two roles and refrain from discussing the participants' issues from a

nursing perspective. I recognized the importance of keeping these roles separate and ensuring that my focus remained on the research objectives during the interviews.

In order to target my professional development, I practice reflexivity. After each interview, I recorded my thoughts and ideas in a reflective diary, which helped me clear my mind and prepare for the next interview. While the diary was useful for understanding the results, discussing my analysis with my supervisor was also beneficial. As a novice researcher, her encouragement prompted me to delve deeper into the transcripts and fully grasp the meanings and concepts conveyed by the participants.

The need for support and the lack of awareness about hoarding deeply resonated with me. As a nurse, I feel compelled to take action to address these issues. One way I hope to do so is by introducing non-governmental organizations that involve volunteers to assist individuals struggling with hoarding.

In conclusion, this chapter has provided an overview of the research topic, the methods used to collect data, and the findings that will be discussed in the following chapter.

### **3.16 Conclusion**

This chapter outlined the primary research topic, as well as the tools and methods used to gather data to accurately answer the research question. The research findings from the study are presented in the next chapter.

# Chapter 4: Findings

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## 4.1 Introduction

This chapter presents the findings related to the personal experiences of individuals who struggle with hoarding. The data analysis followed the procedure outlined by Smith et al. (2009). From the participants' experiences, three overarching themes and several emergent themes were identified. Table 4.1 provides an overview of the superordinate themes and themes across the cases. For this study, I will present the relevant themes, superordinate themes, and my interpretations that address the central question of this research.

To ensure that the participants' voices are represented, I have included several short excerpts from the interview transcripts, as suggested by Smith et al. (2009). By including these excerpts, I aim to enhance readers' understanding of the participants' experiences and uphold the credibility of this study. To protect the participants' identities, pseudonyms have been used throughout this chapter. The following pseudonyms were assigned to the participants: Maria, Anna, Jane, Anton, and Theodore. Table 3.2 presents demographic details such as sex, marital status, age, and employment for these participants. Their ages ranged from 40 to 63 years old, with Jane being the only participant currently employed, while the others are either pensioners or receive social benefits. All participants were single.

All interviews were conducted in Maltese as per the participants' request. The excerpts presented in this chapter are in the original Maltese version. These Maltese excerpts were then translated into English by a professional translator, and another professional translated the English versions back into Maltese for comparison. This process, known as back translation, ensures the accuracy of translations (Sousa & Rojjanasrirat, 2011). According to WHO recommendations (2020), the main considerations in this process are conceptual and societal equivalence.

Excerpts from the interviews are italicized, enclosed in quotation marks, and labelled with the corresponding pseudonym. When portions of the excerpts are omitted for editorial purposes, ellipses ("...") are used. The researcher occasionally introduced words into the excerpts to

improve coherence, and such words are enclosed in square brackets. Nonverbal actions or body language displayed by the participants, such as laughter or emotional reactions, are indicated by descriptions of the actions enclosed between asterisks (e.g., laughter).

Before presenting the themes that emerged from the participants' experiences, it is important to discuss certain linguistic components used by the participants during the interviews.

Paying attention to the language employed by participants is recommended by Smith et al. (2009) as it contributes to a better understanding of their lived experiences. The following section describes the linguistic components identified in the participants' transcripts.

## 4.2 Linguistic Components

During the analytic process, it was noted that the participants frequently used repetitive words in the same sentence. According to Nevalainen et al. (2008), repetitions in statements are used when the individual wishes to emphasize a point.

For example, in the following excerpt, it is possible that Anton used repetition to emphasise the emotional impact of hoarding. This repetition relays a strong message that the participant is overwhelmed with his current situation and claims that he feels attached to his possessions even though he described his possessions as clutter.

*“Mhux hekk hux...imbarazz, imbarazz... norbtu qalbna ma’ dik ix-xi ħaga.”*(Anton, p. 2, line 25)

*“That’s what it is... clutter, clutter... we get attached to an item.”*

Anna used repetition to emphasise that hoarding is clutter and that without the assistance of others, her situation is out of control. She displayed a lot of emotions when explaining that her friends are passing away and hence, she is losing people in her life who used to accept her clutter.

*“imbarazz, imbarazz...ħeqq jaċċetawni l-ħbieb għax il-ħbieb nagħżilhom... U l-ħbieb qegħdin imutuli! Hallini jaħasra (\*biki\*.)”*  
(Anna, p.2, line 35-36)

*“Clutter, clutter... my friends accept me because I choose them (people who accept her clutter) ... but my friends are dying! Leave me alone (\*crying\*.)”*

On the other hand, Jane used repetition to emphasise that clutter has limited her house space and that the clutter is making her lose her mind.

*“Qas għandi aktar spazju fid-dar... qed niġġennen b’dawn il-karti kollha se jġennuni...”* (Jane, p.3, line 62)

*“I do not have any more space at home... I am going crazy with all these papers; they are going to make me go crazy...”*

However, Theodore used repetition to emphasise that he was all alone and had no contact with any of his relatives. Theodore was brought up without a family and throughout the years he learnt to be independent and now believes that he does not need support from anyone.

*“U l-familja x’familja? M’għandi kuntatt ma’ ħadd. Wara li mort l-istitut qatt ma rajtu iżjed lil missieri.”* (Theodore, p.2, line 48-49)

*“Family what family? I don’t have any contact with them. After I was placed in an orphanage, I never saw my father.”*

Metaphors are another linguistic component noted in the recordings of the participants. The metaphors used by the participants aided comprehension of the participants' lived experiences. Metaphors assist participants to articulate their feelings in a manner enabling communication of their experience to others.

Maria described that her life was much better now than it used to be because she is now receiving support from health professionals. She mentioned that she used to feel ashamed about her home situation and used to struggle to get organised and to cope with activities of daily living. In the following statement she emphasised that her house was filled with clutter using the word bomb.

*Qabel kont nistħi mis-sitwazzjoni tad-dar kif kienet u kont insibha diffiċli ħafna biex nagħmel l-affarijiet tad-dar... Kienet qisha waqgħet bomba bl-imbarazz li kien hawn...”* (Maria, p.3, line 102-104)

*“Before I used to feel ashamed about my home situation and I used to struggle a lot to do house chores... it was like a bomb exploded in my house due to the huge amount of clutter...”*

Another rhetorical device that was noted was the use of hyperbole, which in the example below possibly serves to emphasize the fact that Jane faces a challenge to access her bed due to the enormous amount of clutter.

*“Imma biex naċċessa s-sodda tiegħi rrid      “However, to access my bed I need to jump  
nagħmel l-obstacles (\*tidħaq\*)”.* (Jane, p.3, *obstacles (\*laughter\*)”.*  
line 70)

The following section presents the superordinate themes extracted from the participant data. Table 4.1 lists the themes and super-ordinate themes elicited from the experience of individuals with HB.

Table 4.1: Themes and super-ordinate themes extracted

<b>Super-ordinate Themes</b>	<b>Emergent Themes</b>
<b>Unearthing the roots of HB</b>	<ul style="list-style-type: none"> <li>• From scarcity to necessity</li> <li>• Lack of human attachment</li> <li>• An accepted way of life</li> <li>• Grieving family loss</li> </ul>
<b>Aftermath of an explosion</b>	<ul style="list-style-type: none"> <li>• Unveiling the Emotional Toll of HB</li> <li>• Daily life struggles</li> <li>• The psychological depths of Hoarding</li> <li>• Clutter souls</li> <li>• Physically Trapped in chaos</li> <li>• Affected connections</li> </ul>
<b>Reclaiming spaces, restoring lives</b>	<ul style="list-style-type: none"> <li>• Support from HCP</li> <li>• Support from family and friends</li> <li>• Exerting personal control</li> </ul>

The following section presents the first superordinate theme with accompanying excerpts.

## 4.3 Unearthing the roots of HB

This section discusses the participants' perceptions of causal triggers for HB. The findings indicate that some participants perceived poverty as a trigger, while two others perceived the loss of a loved one as a potential trigger. Another participant, Anton explained that he was raised in a hoarding environment, which for him represented normality. Furthermore, one participant, Theodore emphasized the significance of attachment needs in human development. It is believed that when individuals do not have their interpersonal attachment needs fulfilled, they may try to fulfil those needs through alternative methods, such as acquiring objects and attaching themselves to them.

### 4.3.1 From scarcity to necessity

The theme provides details regarding the participants' fear of experiencing poverty and hence why they hoard.

Maria described how her HB may have been triggered by poverty, as she was deprived of most things. She described how she experienced poverty throughout her childhood. At the age of five, her parents separated, and her father left the family. This impacted Maria's family in various domains including financially. She feared experiencing poverty again and not being able to provide for her son and emphasized that she did not want to be like her mother by neglecting her child. For Maria hoarding provided her with a sense of security and a safeguard against poverty.

*“Kemm-il darba kont immur l-iskola mingħajr lunch u t-teachers kienu jindunaw u kienu ġieli jġibuli l-ikel magħhom. Il-ħwejjeg kienu jkunu dejjem maħmuġin jew imqattgħin sakemm ma kontx naħsilhom jiena, allavolja ma tantx kont naf naħsilhom ta' dik l-eta...Meta bdejt nikber, bdejt ninduna kemm huma importanti l-affarijiet peress li qatt ma kelli xejn. Meta bdejt nikber, bdejt nibza' li se nerga' nitlef kollox*

*“I would go to school without lunch and the teachers would notice this and sometimes they would bring me food. My clothes were always dirty or torn unless I washed them myself...When I got older, I realized how important things were since I lived in poverty. I was afraid of possibly losing everything once again and passing through that poverty again...I don't want my son to*

*u nerġa' ngħaddi minn dak il-faqar... Ma nixtieqx li t-tifel tiegħi jgħaddi milli għaddejt jien... Ma rridx inkun bħal ommi.*”  
 (Maria p.1, lines 6-15) *experience what I experienced... I don't want to be like my mother.”*

Hence, as demonstrated by Anton, items are kept as a precaution - just in case they are needed in the future and the individual is unable to buy them at the time.

*“Mhux ezatt ingemma tgħid għandi kaxxa ha nħalliha hemm għax jaf niġi bzonnha hux.”* (Anton, p.1, line 15) *“It's not exactly collecting, it's more like if I have a box, I leave it there just in case I need it.”*

During the interviews the participants also talked about the impact of neglect on their HB.

### **4.3.2 Lack of Human Attachment**

The theme presents details regarding how participants developed attachment to their possessions as they could not develop human attachment. One of the participants developed attachment to his possessions since he could not develop human attachment due to neglect in his childhood.

Theodore explained that he lost his mother while giving birth to him, and his father deserted the family due to his alcohol addiction. Consequently, he was sent to an orphanage from a young age. Theodore described forming a 'bond' between himself and the objects he hoarded, such as comics. These items replaced the bond that he could not have within a family context. Theodore vividly and emotionally recalled the trauma that he experienced when a nun threw away his collections, using words such as 'angry,' 'sad,' and 'alone' to describe the event. For him these collections represented stable items that he could bond or attach with. He explained that he learned to suppress his emotions because he had experienced trauma after trauma, including abandonment, loss, and unresolved grief. He never dealt with these traumas and neglect, and for him, losing or throwing away items meant reliving his traumas.

*“Darba ma ninsiha qatt is-soru dahlet fil-kamra u ħaditli kollox kulma kont ikkolezzjonajt u ramithomli. Niftakar qaltli li fil-kamra ma kienx hemm post għal dal-ħmerijiet u li l-gwardarobba qiegħda hemm għal ħwejjeġ mhux għall-imbarazz. Niftakar dak il-ħin ħassejt rabja u dwejjaq kbar u ħassejtني waħdi aktar minn qatt qabel.”*

(Theodore p.1, lines 12-15)

*“I will never forget the time when a nun came into my room and took everything I had, all my collections and she threw them away. I recall that she told me there was no place in the room for such silly things and that the wardrobe is there to store clothes and not clutter. I still remember how angry and sad I felt, and I felt alone more than ever.”*

For him, hoarding provided him with emotional attachment since he could never develop it with other people due to neglect.

In addition to neglect, some participants spoke about the impact of their family environment on their HB. This is presented in the following section.

### **4.3.3 An accepted way of life**

If someone shows signs of hoarding, it could be due to their upbringing in a hoarding environment during childhood. Children tend to imitate the habits of their parents, and as they grow up, they are more likely to exhibit HB themselves. As adults, children may either continue the HB learned in childhood or develop minimalism as a way of rejecting their past living situation.

Anton mentioned that he was raised in an environment of hoarding, and therefore, hoarding represented normality for him. Anton explained that hoarding was a common behaviour in his family, with both his parents and siblings, especially his mother, collecting things and never discarding anything. For Anton, this behaviour was normal, and he never questioned it. He stated that his mother hoarded due to her fear of loss, which motivated her to hold onto items in case they might be useful in the future.

*“ Ommi hekk kienet id-dar, kaxxa ma narmuhiex nerfgħuha qed tifhem. Konna minn dejjem hekk jiġifieri, trabbejt hekk.”*

(Anton, p.1, lines 8-9)

*“My mother was like this at home, a box we wouldn't throw it away, but we would keep it, do you understand? We were always like this you know; I was raised like that.”*

The following section describes how losing someone close can trigger HB in some individuals.

#### 4.3.4 Grieving family loss

Participants differed regarding when they began their HB. Some participants reported starting to hoard items during childhood, while others began later in life following the loss of someone dear to them. Anna's HB began during her childhood. However, her sister used to assist her in controlling this behaviour. When her sister passed away four years ago, there was no one to control her HB, and after a while, it got out of hand, triggering her HB again.

*“... bdiet mill-mewt ta’ oħti għax ħadt l-imbarazz tat- tifel u għibthom id-dar. Minn dejjem ingemma l-imbarazz kont imma oħti kienet tarmili l-affarijiet. Meta mietet ma baqax min jikkmandani u hekk hux.” (Anna p.1, lines 5-7)*

*“... it [HB] started from my sister’s death because I took my son’s clutter and brought it home. I always collected useless items but by sister used to throw them away. When she died, there was no one telling me what to do.”*

Another participant, Jane, described how she started hoarding after she lost her mother at the age of forty. She mentioned that she was very close to her mother and that hoarding was triggered by this traumatic loss. Jane described feeling emotionally drained and unable to cope with discarding things, including possessions that belonged to her parents, because they had sentimental value for her.

*“Wara li mietet, ħassejtni imkissra emozzjonalment u ma nafx fejn se naqbad nitfa rasi. Ma kellix biżżejjed saħħa biex noqghod naghżel l-affarijiet tagħha u naħseb x’sa nżomm u x’sa narmi..... spicċajt b’munzelli ta’ karti, gazzetti, irċevuti u kotba u jien naf ftit minn kollox insomma... ħafna imbarazz hux... imma ma*

*“After her death, I felt emotionally destroyed and overwhelmed. I did not have enough energy to sort her stuff and to think what I should keep or throw away ... I ended up with piles of papers, newspapers, receipts, books. I don’t know a bit of everything...a lot of trash you know... but I didn’t want to throw anything away as they*

*ridt narmi xejn peress li jaf niġi bżonnhom u hafna minnhom kienu ta'ommi u ma xtaqtx narmijom.*” (Jane p.1, line 11-1)

*could come in handy, and most items belonged to my mum, and I didn't want to throw them away.”*

The following section outlines the impact of HB on the participants quality of life.

## **4.4 Aftermath of an explosion**

A bomb explosion it leaves a huge impact on each individual that includes, the psychological, emotional and physical aspect amongst others. Therefore, HB was associated with an explosion of a bomb by Maria because it had a significant impact on various domains of an individual's life, such as their relationships, social and work activities, and other essential areas of functioning. Serious hoarding can result in severe outcomes, including health and safety hazards such as fire hazards, tripping hazards, and violations of health codes.

### **4.4.1 Unveiling the emotional toll of HB**

This theme presents details regarding the emotional impact of HB.

All participants indicated that the primary reason for keeping their collections was for security due to future needs or scarcity situations. For others, collecting things helped them to cope with their fears of losing a part of themselves or with keeping the past alive. Their belongings offered a safe haven, where they felt secure and at ease. Some participants described feeling ashamed and embarrassed about their behaviour and living in a cluttered setting, while others were proud of their HB. Most participants perceived an obvious connection between their clutter and their identity.

For Anna, hoarding provided feelings of safety, security, and comfort. She mentioned that her possessions make her feel “covered” which meant keeping items represented security over an uncertain future. Many participants, gathering and collecting objects had evolved into a pastime that offered a sense of safety, security, and comfort.

*“I feel comfortable hux, il-feeling li I am covered hux... inħossni safe, insakkar u norqod.” (Anna p.3, line 59)*

*“I feel comfortable, the feeling that I am covered makes me feel safe...I lock the door and sleep.”*

Theodore stated that HB did not affect his emotions negatively because he enjoyed it since it kept him busy.

*“Ma jaffetwanix ta’! Għalfejn għandu jaffetwani? Jien kuntent kif jien, almenu nsib x’nagħmel u nżomm busy, għax ma tkunx taħdem tad- dwejjaq ta’.” (Theodore p.3 lines 76-77)*

*“It doesn’t affect me! Why should it affect me? I am happy the way that I am, at least I can keep myself busy since being unemployed is quite depressing.”*

However, another three participants described that HB affected their emotions in a negative way, and they wanted to change to improve their quality of life. Jane described that she is not proud of her possessions and that she felt shame and guilt and wished to manage her clutter better. She added that she had tried several times to manage her clutter, but she had failed. She emphasized that she hates decluttering because it made her feel very lonely since she would be at home alone. She described decluttering as a punishment because she explained how depressing and boring it is.

*“Nistħi ħafna mis-sitwazzjoni tiegħi... Meta ma nkunx id-dar, inħossni guilty li ma kontx hemm u qgħadt nissortja l-karti u nqattagħhom biex narmihom... Ippruvajt nagħmel hekk diversi drabi, iżda vera xi haġa depressing u boring. Jekk noqgħod id-dar waħdi nilgħab mal-karti vera nħossni lonely... Vera hija xi haġa li nobgħod nagħmel, inħossni qishom ikkastigawni... imma mbaġħad inħossni guilty għax mhux qed nagħmel hekk...” (Jane, p 5 lines 126-129)*

*“I feel very ashamed of my situation. When I am not at home, I feel guilty about not being there and going through my papers and tearing them to throw them away... I have tried to do this several times, but it is very depressing and boring. Staying home alone, and sorting papers makes me feel very lonely. I really hate doing it; it feels like a punishment but then I feel guilty because I am not doing it...”*

Another participant (Maria) described that she feels guilty when she needs to discard something and that she is not capable of doing it. She emphasized that she dislikes it when people tell her she has a lot of unnecessary items. Maria believed that such persons did not understand her and could not appreciate her experiences of living in poverty and being emotionally attached to her possessions. Maria explained that having clutter provided her with security.

<p><i>“Vera nħossni guilty jekk ikolli bżonn narmi xi haġa, ma jirnexiliex nagħmila u vera nobgħod meta n-nies jgħiduli li għandi wisq affarijiet għax hadd ma jifhem kif tħossok meta ma jkollok xejn. Għalija li jkolli l-affarijiet kollha li qed tara madwari, tħisser sigurtà...”</i> (Maria p.1, lines 20-22)</p>	<p><i>“I feel so guilty If I need to throw anything away, I just cannot do this and I hate it when people tell me that I have too many things because no one understands what it feels like when you have nothing. For me having all these things that you are seeing around me, means security...”</i></p>
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#### 4.4.2 Daily life struggles

Participants explained how they carry out their ADLs by following specific procedures and routines. They spent time thinking and planning their tasks before engaging in any activity, often relying on elaborate routines to do so. These routines helped them organize their daily activities. Furthermore, participants reported various functional impairments resulting from their HB, including narrowed passageways and obstacles that impeded their movement in their homes. The accumulation of items also resulted in an increased risk of pest infestations. Two others described the difficulties that they faced when moving furniture or belongings in and out of their homes due to restricted passageways. Jane shared a personal experience that exemplifies this situation.

<p><i>“Biex naċċessa s-sodda tiegħi rrid nagħmel l-obstacles *dahq*... Irrid noqgħod immexxi l-piles ta’ karti li għandi minn fuq is-sodda u nitfagħhom hdejn il-bieb tal-kamra tas-sodda kull filgħaxija għax inkella ma jkollix biżżejjed spazju fejn nimtedd. Imbagħad</i></p>	<p><i>“To access the bed, I need to jump over obstacles *laughter*... I need to move piles of papers from my bed and every night I need to place them near the door outside my bedroom because otherwise I will not have enough space to lie down. Then every</i></p>
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*filghodu qabel ma mmur ghax-xoghol,  
nerga' npoggi l-karti fuq is-sodda halli  
nkun nista' nohrog mill-kamra tieghi...*

(Jane p.3, lines 70-73)

*morning before I go to work, I have to place  
the papers back on the bed so I will be able  
to leave my room..."*

Anna described that she takes a long time to peel onions and potatoes due to the huge amount of clutter, and that it is not always possible to cook. In addition, she explained how most of the time she eats takeout due to the clutter. She explains how the only room in her house that is not cluttered is the bathroom, because she needs to shower, and therefore cannot have clutter there. She explained that if she cannot cook, she can eat takeout but when it comes to showering this must be done only at her house, hence the need to keep her bathroom without any clutter.

*"Indum biex inqaxxar il-patata u l-basal  
habba l-imbarazz. Mhux dejjem inkun nista'  
nsajjar ma nsajjarx sikwit, hafna drabi  
niekol minn barra...heqq u rrid ninhasel. Ix-  
shower mhux ha nhalliha bl-imbarazz, irrid  
ninhasel hux." (Anna p.3 lines 44-45)*

*"It takes time to peel potatoes and onions  
because of clutter. I can't always cook, I  
don't cook often, I often eat outside...and I  
need to bathe. I cannot leave the shower  
with the clutter; I need to bathe."*

Furthermore, Anna described how she needs to step on things to access her bed. The excerpt below illustrate how even moving around her house requires effort. Not being able to move freely around her house made it harder to get things done as explained in the excerpt above.

*"Ikolli nirfes fuq l-affarijiet biex nacçessa s-  
sodda imma x'tagħmel."(Anna p.3, line 53)*

*"I need to step on things to access the bed  
but there is nothing you can do."*

Anton described how he does not enjoy living in a cluttered environment and is aware that such an environment is unhealthy. He also feels ashamed because the house is not just cluttered, but dirty as well. He described how he never cooks because the kitchen is very dirty, thus he always buys takeout. He explained that when he sees dirt, it puts him off, however, he does not have any motivation to clean.

*“Ma tkunx kuntent hux għax fiha ħafna traskuraġni...ma nħossnzx komdu, id-dar pulita u nadifa sabiħa... ikollok kollox organizzat fil-kxaxen l-aħjar hux għax inkella tal-mistħija hux u nistħi l-aktar għax maħmuġa... Biex insajjar ma nsajjarx għax jien niekol minn barra però hemm il-ħmieġ hux kullimkien trab... idejjaqni imma... imma... ma jkollix aptit noqgħod innaddaf.”*  
 (Anton p.2 & p.5 lines 29-106)

*“You won't be happy because it contains a lot of carelessness... I don't feel comfortable, the house is nice when it is neat and tidy...it is best to have everything organized in the drawers...I don't cook because I eat take-outs however there is a lot of dirt and dust everywhere... it bothers me... but I don't have the motivation to clean.”*

Unlike the other participants, Theodore, who loved his clutter, had a less structured routine, and spent most of his time away from home. He described how he is currently living in his garage because the rooms in his house are full of clutter and last summer, he had a cockroach infestation. In addition to this, Theodore explained how he does not cook and eats takeout. Most participants do not cook at home and prefer to eat out or order takeaway.

*“Il- kurituri mimlijin imbarazz u diffiċli taċċessa l-kmamar sakemm ma timxix fuq l-affarijiet. M'għandiex aċċess għal-kċina, allura ma nużahiex għax mimlija imbarazz u maħmuġa, niekol minn barra. Is-sajf li għadda ntlejt bil-wirdien u kelli nċempel lil dawn tal-Comtec għax bdew jidħluli fil-kamra tas-sodda u ovjament ma rridhomx jitiġħu fuqi waqt li rieqed \*daħq\*!”*  
 (Theodore p.3, lines 65-67)

*“The corridors are full of clutter and it's difficult to access the rooms unless you walk over stuff. I don't have access to the kitchen, I don't use it, it's dirty and full of clutter, I eat from outlets. Last summer I was infested with cockroaches, and I had to contact Comtec because they were entering my bedroom and I don't want them [cockroaches] crawling on me while asleep \*laughter\*!”*

#### **4.4.3 The psychological depths of hoarding**

Some participants reported the psychological distress that they faced while residing in cluttered homes. This can serve as an example of how their living conditions affect their

everyday lives, and not as conclusive proof of the existence of these situations. Anna described feeling cognitively overwhelmed when she needed to make decisions. She explained that she becomes anxious and depressed when she had to think about managing her possessions, including organising, clearing, discarding, and sorting. Anna believed that thinking about discarding or getting rid of her belongings caused her great discomfort. She acknowledged that her anxiety was a contributing factor in maintain hoarding, and she refrained from discarding her belongings because it was a stressful process.

<p><i>“Meta nigi biex naħseb xi rrid inżomm jew narmi jaqbduni d-dwejjaq u l-anzjetà. Hemm wisq imbarazz, qas naf minn fejn se naqbad nibda biex niżbarazza...” (Anna p.2, lines 29-30)</i></p>	<p><i>“When I need to think about what possessions I am going to keep or discard I feel sad and anxious. There is too much clutter, I don’t know from where I should start to clear up.”</i></p>
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Maria explains that her house situation did not always affect her negatively, but it depended on the day and her mood. She mentioned that even though she might be having a good day, she could still feel a bit overwhelmed with her situation, but she managed to cope with this feeling. She also emphasized that when she is in a bad mood, she felt very overwhelmed when she thought about her home situation. Moreover, she felt that was failing as a mother because of her house being cluttered and dirty. This feeling could further trigger her depression, which made the situation more difficult when it came to decluttering because she would lose focus and motivation.

<p><i>“Jiddependi fuq il-ġurnata, jekk ikolli ġurnata tajba jaf inħossni xi ftit overwhelmed imma inħalliha tgħaddi normali bħal l-oħrajn però jekk ikolli burdata ħażina u naħseb fis-sitwazzjoni tad-dar naqa’ ħażin ħafna u nħossni li qed infalli bħala omm.” (Maria p.,4 lines 84-86)</i></p>	<p><i>“It depends on the day, if I am having a good day, I may feel a bit overwhelmed, but I let it go by normally pass by normally like others but if I am in a bad mood and I think about my situation at home, it can ruin my day, I get very sad and feel like I am failing as a mother.”</i></p>
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Jane described that in her younger years, she used to feel secure surrounded by all her possessions and was not concerned about her behaviour. However, as she got older, her home

situation became more difficult to manage and got out of control. She mentioned that she used to manage to find anything within her clutter, but nowadays it is not possible due to her memory not being as sharp as it used to be.

*“Ma kontx noqgħod naħseb fuqha... għax kont inhossni safe imdawra bl-affarijiet u jekk kont niġi bżonn ta’ xi karta partikolari kont insibha mill-ewwel... Imma issa m’għadniex insibha ta!... Qabel kont naf kollox fejn kien u l-imbarazz ma kien idejjaqni xejn imma issa li qed nixjieħ, qed insibha aktar diffiċli għax il-memorja tiegħi m’għadhiex bħal ma kienet.”* (Jane p.1, lines 20-23)

*“I never used to think about it...I felt safe among this stuff and knew that if I ever need a certain paper, I will find it straight away. But now I don’t manage to find it!... Before, I knew where everything was and clutter did not bother me but as I am getting older, I am finding it more difficult as my memory is not the same as it was.”*

Despite having good insight and being aware of the need to change her lifestyle, Jane found it extremely challenging to declutter. When HCP advised her to declutter, she felt that she was not capable of doing it on her own, as it exhausted her. She stressed that there is a significant amount of clutter, and when she thought about it, she became overwhelmed and gave up. Furthermore, when becoming overwhelmed she tended to have bed seeking behaviour or she escaped her problems by going out.

*“...ġili tiġi n-nurse jew is-social worker u jgħiduli li għandi bżonn nisbarazza u biex noqgħod inqatta’ l-karti li ma rridx ha nkun nista narmihom... però inhoss li ma nistax nagħmilha waħdi din il-ħaġa...wisq exhausting, hemm wisq affarijiet, naqta’ qalbi allura jew naqbad u mmur fis-sodda jew nitlaq ‘il barra...”* (Jane p.2, lines 31-33)

*“...Sometimes the nurse and social worker come to visit and they tell me that I need to declutter and to tear up the papers that I don’t need so that I can throw them away... but I feel that I am not able to do it on my own... it’s too exhausting, there are too many things, I give up so I tend to go to bed or go out...”*

Furthermore, Jane explained that decision making on what to hoard gave her an opportunity to feel in control.

*“L-aktar karti, junk mail, irċevuti, basktijiet tal-plastik u kaxxi. Dawn qatt ma narmihom. Heqq ifhem ma narmihomx għax jekk narmihom, inħossni anzjuża u ħazin...li ma narmihomx inħossni li għandi kontroll...” (Jane p. 2, lines 37-38)*

*“Mainly it’s papers, junk mail, receipts, plastic bags and boxes. I never throw away any of these. I do it because if I don’t do it, I feel anxious and bad, keeping them gives me a sense of control.”*

Theodore's attachment to his possessions differed from the other participants in the study. He did not experience feelings of loneliness, isolation, embarrassment, or distress related to his belongings. In fact, he felt enthusiastic about his clutter and viewed it as a source of entertainment or occupation. When space became limited, he tends to sell items which do not have a meaning to him, or which are duplicates. He survived on hoarding.

*“U xi kultant nagħmel xi naqra lira ‘l hemm u ‘l hawn minnha l-ħaġa ukoll hux so għalfejn għandi nħossni ħazin jew nistħi? Almenu naqla xi ħaġa. Kieku niġġennen ma nagħmel xejn irrid inżomm on the go inkella moħħi jiġġennen.” (Theodore p. 3, lines 79-80)*

*“Sometimes I make money out of it, so why should I feel upset or ashamed of this? At least I am earning something... otherwise I will go crazy if I am not doing anything, I need to keep myself busy or else I will go mad.”*

Theodore further explained that he was selective when selling items by retaining those items that were most significant to him. However, selling items through his garage was one of the few opportunities to make extra cash. He views his belongings as resources that could be sold or bartered for something else, as he stated below:

*“Jien nagħżel x’inbiegħ. Jekk ikun oġġett għal qalbi ma nbiegħhux għax ikun ifisser xi ħaġa għalija...u jekk ma jkunx oġġett importanti għalija nipprova inbiegħ hux naqla lira żejda.” (Theodore p. 2, line 34-35)*

*“I choose what to sell. If the item is close to my heart, I don’t sell it because it has a meaning for me ... but if it is not an important object to me, I will try to sell it maybe I can earn some extra cash.”*

#### 4.4.4 Clutter souls

This theme presents details regarding the spiritual impact of HB.

Hoarding may be a spiritual manifestation of an inability to let go and a search for meaning. Most participants believed that their identity had been shaped by their clutter and inability to complete simple daily tasks. Engaging in various activities and occupations enabled individuals to fill their day with purpose, establish a sense of identity and existence, and contribute to their community, facilitating adaptive interactions with their environment. When people constructed their identities, they acquired the necessary contexts to lead meaningful lives, which in turn contributed to their overall well-being.

Two participants (Jane and Theodore) emotionally described how they identified themselves as "collectors," while people labelled them as hoarders. Jane disclosed her deep attachment to her belongings and her self-identification as a "collector." She asserts that being a collector is an inherent part of her identity, something she has been and will always be, leaving no room for hope that her behaviour could be altered.

*“Hafna nies qatghu qalbhom minni u anka jien qtajt qalbi, inhossni li ma nistax nissepara ruhi mill-affarijiet u ma nista’ ninbidel qatt, din jien u rrid ngħix biha allavolja taffettwali l-ħajja ta’ kuljum.”*

(Jane p.6, lines 154-155)

*“Many people gave up on me including myself, I feel that I can never part from my items and that I can never change, this is who I am, and I have to live with it even though it’s affecting my daily life.”*

On the other hand, Theodore described how the clutter was an important aspect of his identity. He would not know who he was or what to do without his clutter. He felt proud of who he has become and of his self-identification.

*“Xejn ma jien proud bil-kollezzjonijiet li għandi. Dak qisu parti minni u kulhadd jafni ta’ li jien. Dik ma rridx inbidilha.”*

(Theodore p.3 line 77) (Theodore p.3 line 77)

*“I am very proud of my collections. They are part of me, and everyone knows me for who am I. I don’t want to change it.”*

Theodore identified himself as a "collector", stating that he had been collecting items from a young age, but his living environments limited the extent of his hoarding. In addition, he also described how his possessions were considered as his protective factor which have protected him from suicide when he felt lonely and depressed.

*Minn dejjem kont nikollezzjona l-affarijiet u nemmen li dawn il-kollezzjonijiet żammewni ħaj u żammewni għaddej meta inħossni waħdi u bid-depression.”* (Theodore p.1, line 19). *“I’ve always been collecting things and I believe that these collections have kept me alive and kept me going when I felt alone and depressed.”*

Another participant, Maria, explained that she did not have the ability to let go of things, and all her possessions hold a significant meaning to her.

*“Meta n-nies jgħidu li jien għażżiena jew maħmuġa, ma inħossnix tajba, imma ma nafx kif nagħmel is-sitwazzjoni aħjar għax kulma għandi għandi bżonnu jew ifisser xi ħaga għaliġa.”* (Maria p. 4, lines 80-81) *“When people point out that I am lazy or dirty, it doesn’t feel good, but I don’t know how to improve my situation because everything that I have, I need or has a meaning.”*

All participants indicated that clutter had a significant impact on their self-identity, and their sense of self was formed by their identities as "collectors." The experiences of the participants highlighted the personal meaning that the clutter held for them

#### **4.4.5 Physically trapped in chaos**

This theme presents details regarding the physical impact of HB.

Participants reported various physical dangers resulting from their HB, including health risks arising dangerous hazards that came with living in run-down housing. The accumulation of items also resulted in an increased risk of falls and fires for three participants. Jane shared a personal experience that expressed concerns about the potential risk of fire.

*“Jekk alla ħares qatt xi darba jkun hemm nar, nahraq id-dar kollha u jien magħha...”* *“If God forbid there is a fire, the whole house will burn down and myself with it.”*  
 (Jane p.3, line 70)

In addition, Jane also mentioned that she has reached a point where she needs help with decluttering because her house has become much more hazardous to her. Last year, she experienced two falls and had to be taken to the hospital, which led to her realization that her clutter was putting her safety at risk.

*“Peress li għandi ħafna imbarazz, irrid noqgħod attenta li ma niżloqx jew naqa’ f’xi ħaga. Is-sena l-oħra waqajt darbtejn u spiċċajt Mater Dei...”* *“Since I have a lot of clutter, I have to be careful not to trip or bump into something. Last year I fell twice, and I ended up at Mater Dei [hospital]...”*  
 (Jane p. 1, lines 25-26)

Theodore mentioned how last summer he had an infestation of cockroaches at his house, and to avoid them crawling on him during sleep, he claimed that he "had emigrated" to his garage, where he is sleeping on a mattress and using the garage bathroom since he does not have hot water in his house. This affects Theodore's physical health as his garage is not well-ventilated and sleeping on a mattress could lead to back pain and other physical health problems.

*“Mis-sajf li għadda ‘l hawn qbadt norqod fuq saqqu fil-garaxx u nuża l-kamra tal-banju hemmhek ukoll għax tad-dar m’għandhiex miżhun fiha apparti li kif taf, ma tantx hemm fejn tiċċaqlaq. Allura qbadt u emigrajt għall-garaxx \*dahq\*.”* *“Since last summer I started sleeping on a mattress in my garage and I use the bathroom there as well because at home I don’t have hot water and as you know there isn’t much space to move around. So, I emigrated to the garage \*laughter\*.”*  
 (Theodore p.3, lines 72-74)

Furthermore, Anton mentioned that he is always tired and has no energy to clean or declutter. The low energy level has decreased his ability to engage in organizational and discarding tasks in his home. He described how having less energy has made duties such as sorting, making decisions, and discarding objects more difficult throughout the years.

*“Dejjem ngħidilhom lin-nurse iva iva issa nagħmel, issa nagħmel u f’moħħi vera jkolli hekk li rrid nagħmel imma ma nagħmel xejn ghax ma jkollix energija u saħħa.” (Anton p. 6, lines 126-127)*

*“I always tell the nurse yes yes I will do it I will do it and in my mind I really picture that I will do it but then I do nothing because of apathy and lack of energy.”*

#### **4.4.6 Affected connections**

The participants highlighted how their cluttered environments had a negative impact on their social interactions and relationships with others. Some participants found the clutter so overwhelming that they felt ashamed to invite anyone over, while others experienced strain in their relationships due to the clutter. These feelings of shame and guilt resulted in many participants feeling isolated and alone.

Jane spoke about her relationships with other people and explained how these relationships were influenced by her cluttered home. She described how she struggled to maintain relationships and has a limited social network. Her only friends are her colleagues who are not aware of her HB and her cluttered home environment. Therefore, Jane expressed that she could not show her true identity to them. In fact, Jane confided that she was embarrassed to show anyone her home apart from the HCP and her aunt. She emphasised that she missed her mother, who passed away, as she was a person with whom Jane could be herself.

*“Jien single u qatt ma kelli partner. Hadd m’ghadu jiġi jżurni apparti s-social workers, in-nurses jew iz-zija. Ommi kienet l-aqwa ħabiba tiegħi... kemm nimmisjaha...konna nagħmlu kollox flimkien. Iz-zija taf bis-sitwazzjoni tiegħi u ppruvat tgħinni diversi drabi però xi drabi nħossha li tinvadili l-privatezza tiegħi, u nispiċċaw nargumentaw. L-uniċi ħbieb li għandi huma l-kollegi tiegħi u kif diġà*

*“I am single and never had a partner. No one visits anymore apart from social workers, nurses and my aunt. My mother was my best friend, I miss her so much- we used to do everything together. My aunt knows about my situation and tries to help me several times, however at times I feel that she invades my privacy, and we end up arguing a lot. The only friends I have are my colleagues and as I already told you they are not aware of my home situation.”*

*ghidtlek ma jafux is-sitwazzjoni tad-dar tiegħi.*” (Jane p. 4, lines 96-100)

The feelings experienced by Maria were very intense and conveyed a sense of loneliness and isolation even from close family members who judged her.

<i>“Jien dejjem waħdi anke t-tifel bilkemm ikellimni għax jgħid li jien maħmuġa... din ħajti, tipprova tagħmel il-gid imma qatt ma jirnexxilek iġġibha tajba. Kulhadd jabbandunak...”</i> (Maria p.3, line 49-50)	<i>“I am always alone even my son barely speaks to me because he says that I am filthy... this is my life you try do good but you never get it right. Everyone abandons you...”</i>
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When asked about her friend's relationship, she revealed that she no longer invites people over due to her fear of being judged for having a cluttered home and questioned why she lives this way. She believed that her friends would visit only to scrutinise the mess, rather than to spend time with her.

<i>“Darba ġibt ħabiba mill-knisja u ġiġhma wara ġie xi ħadt u qalli li qalet kemm jien maħmuġa u għazziena ħabba l-imbarazz li hemm u ħlift fuq ħajti li ma nerġa nistieden lil hadd id-dar. Waqqgħatli wiċċi l-art mal-ħbieb tal-knisja. Jien m’jiniex għazziena, forsi vera għandi ħafna imbarazz id-dar imma ma jfissirx li jien għazziena... għalhekk ma nistieden lil hadd id-dar għax kulhadd irrid jiġġudika...ma jifhmukx.”</i> (Maria p. 3, lines 60-64)	<i>“Once I invited a friend from church and a week later someone told me that she was saying how dirty and lazy I am because of the clutter and I swore on my life that I will not invite anyone to my house. She embarrassed me with my friends, I am not lazy I may have a lot of clutter in the house... but it doesn’t mean I am lazy... That is why I don’t invite friends in my house they are so judgmental...they don’t understand you.”</i>
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On the contrary, two participants, Anna and Theodore, are open to having company at their homes. Anna mentioned that she does not mind inviting people over because she does not feel ashamed of the state of her house.

*“Le le ma niddejjaqx indaħħal nies id-dar, ma nisthix, le m’jiniex mistħija għax Alla dik id-dar provda u dik hi.” (Anna p. 2, line 42)*

*“No no I don’t mind inviting people over to my house, I am not embarrassed, no I am not embarrassed because that’s the house God provided and that is what it is.”*

Furthermore, Theodore described how he has never been able to maintain a relationship with a partner due to the clutter, as they have always been judgemental and opposed to it.

*“Dejjem kienet diffiċli jkolli tfajla, għax dejjem jikkumentaw fuq l-affarijiet. Joqogħdu sejr in x’tambihom dawn l-affarijiet kollha? Għandek ħafna mbarazz id-dar, għalfejn għandek dan l-injam kollu fil-kamra tas-sodda? Bla bla bla... Qatt ma setgħu jifmhuni u jaċċetawni kif jien” (Theodore p. 2, lines 46-50)*

*“It has always been difficult for me to have a girlfriend... They always commented about my stuff; ‘Do you really need all this stuff? there’s so much clutter in your house, why do you have all this wood in your bedroom?’ Bla bla bla... They could never understand me and accept me as I am.”*

The next section focuses on strategies used that assist participants to strive to cope with hoarding and the support that they receive and their recommendations.

## **4.5 Reclaiming spaces, restoring lives**

This theme presents details regarding the way the participants strived to cope with the challenge of hoarding.

Attempting to overcome hoarding is a separate process, in which individuals who struggle with managing their possessions aim to find new ways of attachment and living without succumbing to problematic HB. This includes resisting the urge to acquire more goods, seeking formal and informal help, and, in some cases, establishing a life outside of hoarding. The latter was particularly significant for those participants who had a lengthy history of struggling to manage their belongings and required the establishment and adjustment of new ways of functioning and identities.

### 4.5.1 Support from HCP

At the time of the interview, all participants were receiving or had received a service from HCP of some kind to assist them in managing their everyday life.

Anton described how he is now managing to make decisions when it comes to discarding and has learned this process through the help of HCP. He claimed that, at times, he still finds it difficult to discard certain items because he feels attached to them and is afraid that he will regret it. He still has difficulty with acquiring but compared to the rates at which he previously acquired, he suggests that he is, in fact, making improvements.

*“Li ikolli narmi hux... eżempju meta tmur tixtri ituk baskett tal-plastik, nerfa erba forsi nigi bżonnom imma il-bqija narmi... Pero issa armejt ħafna affarijiet filfatt armejt izejjed, armejt ċertu affarijiet li kelli bżonnom bħal żraben u hekk. Jigi l-carer jgħidli armi armi u hu għallimni narmi u armejtom pero wara li armejtom ċertu affarijiet idispjaċini li armejtom... għaġilt.”*

(Anton p. 4, lines 71-74)

*“Whatever I have I discard it... for example when you go shopping, they give you a plastic bag, I keep four maybe they will come handy and the rest I will discard them... Now I have discarded most of my possessions in fact I discarded more than I should have, I threw away certain things which I needed like shoes etc. The health care worker comes and tell me to throw away things and he taught me how to discard and I did discard them however after I threw them away, I regreted it... I took a fast decision.”*

Jane explains that she finds it difficult to resist temptation alone, but with the support of her aunt and health professionals, she manages to organize her papers and discard what she does not need. She requires however continuous prompting when it comes to discarding and resisting temptation because she finds it very difficult to do such process.

*“Meta z-zija jew is-social worker u nurse jżuruni, jinkuraġġuni biex noqgħod nagħzel il-karti li rrid u li ma rridx u narmijhom.*

*“When my aunt, social worker or the nurse visit me, they encourage me to shred papers I don't need and discard them. I find it very*

*Insibha diffiċli ħafna li nagħmel dan waħdi.      difficult to do this on my own. I need  
Għandi bżonn lil xi hadd jimmotivani...”      someone to motivate me...”  
(Jane p.6, linew 134-136)*

Jane described how she had received enough support throughout her life when it comes to hoarding. She explained how she finds HCP very supportive, especially when they take their time to listen to her problems even though they do not understand her.

*“Naħseb irċevejt biżżejjed sapport f’ħajti...      “Well, I had several different health  
Ifhem kelli ħafna tobba u professjonisti      professionals in my life including social  
f’ħajti jien naf, social workers, nurses,      workers, nurses, psychiatrists and  
psikjatri, psychologists.... Insib sapport      psychologists... I do find support in these  
f’dawn in-nies speċjalment meta joqogħdu      people especially when they are there to  
jisimghuni allavolja kultant ma jifmhuniex      listen to me even though sometimes, they do  
ta. Imma almenu meta ma nkunx qed      not understand me but at least when I am  
inħossni sew nista’ nikkuntatjahom u jkunu      feeling unwell, I can contact them, and they  
hemm għalija.” (Jane p. 6, lines 147-149)      are there.”*

Jane recommended that HCP listen and try to understand the mental state of individuals who are trying to get out of their comfort zone and declutter. This is because this step can create a lot of anxiety and emotions. If health professionals push too much or become frustrated, it can negatively affect this very sensitive situation from an emotional point of view. On the other hand, it is important for HCP to help set realistic goals that are achievable, as it can be motivating even if, in their eyes, it's just a small target.

*“Għandi bżonn lil xi hadd jimmotivani...  
 Huwa importanti li ma jisfurzawnix biex  
 narmi l-affarijiet tiegħi imma billi jagħtuni  
 l-isparju tiegħi għax meta jagħmluli  
 pressure u deadlines biex nagħmel xi haġa  
 niġi overwhelmed u jaqbadni panic attack...  
 Allura jeħtieġ li nagħmel l-affarijiet bil-mod  
 bil-pass tiegħi. Meta nħares lejn l-imbarazz  
 li għandi nħossni stressjata imma mbaġhad  
 nagħti lili nnifsi mument biex naħseb u  
 nipprova ngiegel lili nnifsi biex niżbarazza.  
 Xi drabi anke għaxar minuti jinħassu  
 qishom siegħa imma nipprova nagħmel goal  
 u nlaħħqu.” (Jane p.6, lines 134-140)*

*“I need someone to motivate me... It’s  
 important that they don’t force me to throw  
 away my stuff but give me my space because  
 when they place pressure on me to do  
 something with a deadline, I get  
 overwhelmed and suffer panic attacks. So, it  
 needs to be done in small steps at my pace.  
 When I look at all my stuff, I feel stressed  
 but then I give myself a moment to think and  
 I try to push myself to clean up. Sometimes  
 even 10 minutes [of clearing up] feels like  
 an hour, but I try to set a goal and try to  
 achieve it.”*

Maria described that, nowadays, with the help of HCP, she is managing to make decisions and organize her clutter by grouping her stuff and sorting them into categories. She explained how one nurse assisted her with assembling shelves to organize her kitchen and living room stuff. Maria recommended that when a health professional insists on the need to throw away items, it makes it harder to do so. Instead, what would work better is to help with organizing the clutter. This could be done by having the HCP suggest areas where furniture could be installed or where items could be placed or help with categorizing different things. Sometimes the clutter is there because it is very disorganized, not just because it must be thrown away.

*“Huma għalmuni kif norganizza l-affarijiet  
 tiegħi. Sempliċiment ma stajtx inkampa iżda  
 bl-għajjnuna ta’ dawn in-nies, irnexxieli  
 nagħmel id-dar aktar komda... Kien hemm  
 nurse għenitni narma xi xkaffi biex inkun  
 nista’ norganizza l-affarijiet tal-kċina u tas-  
 salott. Is-sena li għaddiet bdejt norganizza*

*“They [HCP]taught me how to organize my  
 stuff. Before I couldn’t cope but with the  
 help of these people, I managed to make the  
 house more comfortable... One nurse  
 helped me assemble some shelves so I could  
 organize the stuff in my kitchen and living  
 room... The past year I started to organised*

*l-affarijiet li għandi f'kategoriji u rnexxieli my staff into their own categories and I  
nbiddel l-imbarazz f'ordni... Vera napprezza managed to turn the clutter into order... I  
x-xogħol li jagħmlu.” (Maria p.5, lines 104- appreciate a lot the work they do.”  
109)*

Anna explained that currently, she is receiving support from HCP, but she gets overwhelmed when there are more than two nurses involved. She expressed that they took control over the situation and left little room for her to take decisions on what to keep or discard.

*“Dawn l-erba’ nurses li jiġuni rridhom “I would like these four nurses that come to  
jibqgħu jiġu, imma ma nlahħaqx magħhom assist me to continue coming but I don’t  
għax jibdew jgħidu ‘narmulha ta’ manage to keep up with them as they start  
narmulha’ ... Nixtieq jiġu tnejn tnejn għax saying ‘let’s throw away her things, let’s  
nagħja hi. Jew pereżempju jgħinuni ngorr l- throw them away’ ... I would like that only  
affarijiet u hekk biex immur narmihom u two will come because I get tired. Or for  
jerggħu lura jwassluni lura bil-karozza.” example they assist me with carrying things  
(Anna p. 4 line, 84-87) drive me back home.”*

Theodore explained how he received support from his psychiatrist and is compliant to his psychiatric treatment but would not want anyone to judge him. He did not accept people judging him as he was not doing anything wrong. He explained how he managed to cope on his own and his recommendation was to let him live the life that he lived, one where he caused no harm to himself or to others.

*“Hafna min-nies ma jaħsbuhiex hekk. Jekk “Most people don’t think that way, if for  
għalihom mhux tajba jfisser li ħażina u li them it’s not good it means that it’s bad and  
rrid ninbidel għalihom għax ma that I need to change for them because they  
jogħgobhomx hekk. Mhux se npaxxiàom don’t like it, I won’t give them that pleasure  
imma u diġa għidt lill-psikjatra li nirrifjuta and I have already told my psychiatrist that  
din it-tip ta’ għajjnuna. Jien nara it- tabib I refuse such help. I see a psychiatrist every  
kull ftit xhur u nieħu il mediċina u few months and take my treatment but that’s*

*daqshekk... Jien imdorri ngħix hekk u mux se ninbidel.*” (Theodore p.4, lines 100-104)      *it... I am used to living this way and I will not change who I am.”*

#### **4.5.2 Support from family and friends**

Participants did not receive much support from their friends and family when it came to decluttering and assisting with their HB. Most participants described how they do not have a family which supports them and only have a few friends who support them. In addition to this it was noted that most support was received from HCP rather than family and friends.

Anna's HB began during her childhood. When her sister was alive, she used to be very supportive and used to control her HB by discarding her things and not letting her hoard but after her sister passed away her hoarding got out of hand.

“Minn dejjem ingemma l-imbarazz kont imma oħti kienet tarmili l-affarijiet. Meta mietet ma baqax min jikmandani u bdejt inżomm kollox.” (Anna, p.1, lines 5-7)      *“I always used to hoard but my sister used to throw everything away. When she passed away there was no one to control me and I was keeping everything.”*

Jane described how her aunt is very supportive but can be very controlling at times and she feels that at times she invades her privacy. Due to this her aunt cannot be as supportive as she wants to be because they end up arguing.

“*Iz-zija taf bis-sitwazzjoni tiegħi u ppruvat tgħinni diversi drabi però xi drabi nħossha li tinvadili l-privatezza tiegħi, u nispiċċaw nargumentaw.*” (Jane p.4, line 92-94)      *My aunt knows about my situation and tries to help me several times, at times I feel that she invades my privacy, and we end up arguing a lot.”*

Theodore explained how his friends are aware of his situation, and they have accepted it. Sometimes, they even encourage his HB but never assist him with decluttering. While he has many friends, he does not have any family.

*“Shabi jafuha s-sitwazzjoni tiegħi u m’għandhom l-ebda problema biha, anzi jinkuraġġuni għax il-ħin kollu ġejjin u sejr in il-garaxx b’xi haġa. U l-familja x’familja? M’għandi kuntatt ma ħadd. Wara li mort l-istitut qatt ma rajtu iżjed lil missieri.”*  
 (Theodore p.2, line 46-48)

Moreover, Maria explained that her only support system was her neighbour apart from HCP. She mentioned how her neighbour assisted her with decluttering and is always there to help. Maria stated how her mother passed away and she has no family to support her.

*“Jien waħdi, in-neighbour vera qalba tajba, u dejjem tiġi tiprova tgħina nisbarazza ftit u isaqsini għandiex bżonn xi haġa... Ommi mietet meta kelli għoxrien sena, alura m’għandiex familja biex jappoġġjawni.”*  
 (Maria p.2 lines 38-39)

### 4.5.3 Exerting personal control

The process of deciding which items to keep and throw away and arranging the remaining ones in a suitable manner (which some participants referred to as organizing) may appear simple at first. However, there were numerous obstacles that hindered people from successfully completing these tasks. Participants explained how they wanted to make their own personal decisions when it came to discarding.

Anna explained how she chooses what to hoard and that she manages to discard certain items on her own. She recommended that she should be the one making her own personal decisions before discarding items, and that the HCP should be just a guide. She suggested that HCP must be assertive but not too imposing or bossy, while also not leaving her entirely free to take her own decisions.

*“Nixtieq nara jien x’qed jarmu għax bħal paperwork ma tistax taqbad tarmi. Biex ma noqgħodx indewwimhom, nagħmilhom go files fuq xulxin u nagħmilhom gol-kaxxi u mbagħhad noqgħod narahom jien xi rrid u ma rridx. Imma għandi x’nagħmel eh. Irrid nara l-paper work kollu li hemm qabel ma narmi. Ma nixtieq li n-nurse tindaħalli żżejjed imma lanqas thallini libera, tikmandani xi ftit imma ma rridhiex titla’ fuq rasi dik hi”.* (Anna p. 5, lines 89-93)

*“I want to see what they are discarding because paperwork you cannot just discard it. In order not to keep them waiting, the paperwork I will sort them in files and in boxes and then I go through them to see what I want to keep or not. But I have a lot of things to do, I need to go through all the paperwork before I discard any. I don’t want the nurse to interfere too much in my life but at the same time I don’t want to be left completely free to make my own decisions. I need the nurse to guide me as long as the guidance doesn’t become a command.”*

In Theodore's case, he mentioned that he thinks about what he already owns before buying something and asks himself whether he truly needs it. However, he contradicted this by saying that this thought only lasts for a few seconds until he decides that one of his friends needs it or that he can buy the new item and give the old item he already owns to his friend.

*“Perkażu jien inħobb ħafna l-arloggi għandi minn kull tip id-dar. Li jeħlu mal-ħajt biex nifthemu, digital tal-alarm, tal-cuckoo, bir-radio u kalendarju magħhom u jien naf daqs x’hemm. Imma qabel niddeċidi x’nixtri ngħid għandi minn dawn diġà għandi bżonn iehor? Ħafna mid-drabi dal-ħsieb ma jdumx wisq, ftit sekondi kollox qabel ma niddeċiedi ngħid eżempju sieħbi jrid wiehed ara ħa nixtrihulu jew jekk vera jogħgobni lil sieħbi ntih wiehed milli diġà għandi u jien inżomm il-ġdid.”* (Theodore p. 4, lines 89-94)

*“For example, I love clocks, I have all types of clocks at home; wall clocks, digital clocks those with the alarm, cuckoo, with the radio and calendar and much more...but before I decide to buy it, I be like ‘I already have a lot of clocks at home do I really need this one?’ Most of the time that thought lasts only for a few seconds before I make a decision and decide ‘my friend wants one, so let me get it for him’ or if I really like it, I give him one that I already own and I keep the new one.”*

Anton described how now he is managing to make decisions and discard on his own. He claimed that currently he has been doing well with discarding and explained how next Wednesday his occupational therapist assistant will be visiting him and he would like to declutter his room on his own before she visits.

*“Sejjer tajjed bħalissa... Eżempju nhar l-Erbgħa ġejja l-occupational therapist assistant u nixtieq li nkun żbarazzajt il-kamra qabel ma tiġi hi.” (Anton p. 8, lines 151-152)*

*“I am doing well now... Now I’ve started discarding alone for example, next Wednesday the occupational therapist assistant is coming, and I would like to clear my room before she comes.”*

## **4.6 Conclusion**

This chapter presented three super-ordinate themes which emerged from the analysis of data collection from the participants. The first super-ordinate theme, “Triggers to HB” described poverty, attachment needs, expected form of behaviour and loss of a close family member. The second super-ordinate theme “The explosion of a bomb” described the impact of HB on their quality of life. The final super-ordinate theme “Trying to overcome hoarding”, incorporated aspects of strategies used to resist temptation, making personal decisions as well as the support they receive and their recommendations. Hence, this chapter provided an insight into the lived experiences of individual HB. The dialogue between the findings, the literature and theory will be presented in the next chapter.

# CHAPTER 5: DISCUSSION

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## 5.1 Introduction

The discussion chapter engages in a discussion of the existing literature, the study's findings, and my interpretation in light of the Common-Sense Model (CSM) (Leventhal et al., 1980).

The findings of the present study which are discussed in this chapter focuses on the lived experiences of people with HB. All the five participants (three females and two males) in this study had HB. This enabled the researcher to explore the perceptions of these participants. The study's findings and their implications are explored in light of extant research. My personal interpretations as a researcher are also considered through an interpretation of the findings and current literature, as recommended by Smith et al. (2009).

In developing this understanding, this study aims to contribute to the extant literature by exploring the following objectives- (i) what persons with HB perceived as the causal triggers of their behaviour; (ii) the impact of living with a HB on their quality of life; (iii) the coping strategies adopted by individuals who hoard, and (iv) the identification of available support strategies and recommendations.

This chapter summarizes the study's findings and discusses them in connection to previous research and literature. Table 5.1 contrasts the findings from research articles extracted and described in the literature review with findings emanating from the current study.

Additionally, in order to facilitate comparison between these findings, the findings drawn from the retrieved literature are aligned opposite to those obtained in my study, when they correspond. In those cases, where findings were only identified in the foreign studies or in my side alone, the text was listed under one subheading in the following table.

Table 5.1 – Comparison of the findings presented in the literature review and findings of the present study.

<b>Findings extracted from papers cited in the literature review</b>	<b>Findings from the present study</b>
Participants with HB experiences:	The following themes emerged under the superordinate theme <b>Unearthing the roots of HB:</b>
<ul style="list-style-type: none"> <li>• Individuals acquire and hoard possessions as a way to exert control over their environment, ensuring a sense of security and protection against uncertainty (Mulligan-Rabbitt et al., 2023; Chia et al., 2021; Subramaniam et al.,2020).</li> </ul>	<ol style="list-style-type: none"> <li>1. <i>From scarcity to necessity</i>- Keeping possessions symbolizes a sense of security and a safeguard against poverty.</li> </ol>
<ul style="list-style-type: none"> <li>• The accumulation of possessions serves as a way for individuals to fill emotional voids caused by trauma and to avoid confronting their pain, (Neave et al. 2016).</li> </ul>	<ol style="list-style-type: none"> <li>2. <i>Lack of human attachment</i>- One participant developed a strong emotional attachment to his possessions due to a lack of secure interpersonal relationships in his childhood.</li> </ol>
<ul style="list-style-type: none"> <li>• Six individuals indirectly mentioned a familial predisposition that could have contributed to their hoarding behavior, while a few others discussed a family member who enabled their hoarding tendencies. (Subramaniam et al. 2020; Chia et al. (2021).</li> </ul>	<ol style="list-style-type: none"> <li>3. <i>An accepted way of life</i>- One participant grew up in a cluttered household where hoarding was considered normal. This highlights the impact of early environmental factors on the development of hoarding tendencies.</li> </ol>
<ul style="list-style-type: none"> <li>• Hoarding may begin after a significant loss (Subramaniam et al. 2020; Rudnick, 1981)</li> </ul>	<ol style="list-style-type: none"> <li>4. <i>Grieving family loss</i>- Losing a family member may have triggered HB for two participants. They describe how their hoarding started after they lost a close family member.</li> </ol>

<p>Participants with HB experiences:</p>	<p>The following themes emerged under the superordinate theme <b>Aftermath of an explosion</b>:</p>
<ul style="list-style-type: none"> <li>• Participants described negative emotions such as distress, feeling wretched, worried, angry and helplessness (Subramaniam et al. 2020)</li> <li>• Accumulating possessions can generate pleasurable, comfort and prideful emotional states. (Chia et al. 2021; Mulligan-Rabbitt et al., 2023; Caldwell et al., 2010; Grisham et al., 2009; Keefer et al., 2012). These studies highlight the feelings of sadness, shame, and guilt related to HB, often leading individuals to hide or conceal aspects of themselves or their homes (Taylor et al. 2019; and Kellett et al., 2010).</li> </ul>	<p>1. <i>Unveiling the emotional toll of HB</i>- Three participants felt guilt, overwhelmed, lonely, and embarrassed regarding their cluttered homes. While two other participants felt happy and proud of their possessions. Hoarding gave them a sense of security, safety, and comfort.</p>
<ul style="list-style-type: none"> <li>• The participants described their struggles in performing daily tasks, as even simple activities like preparing a meal or going to bed required significant effort due to the need to navigate obstacles and move piles of items (Kellett et al. 2010).</li> <li>• Hoarding has a notable negative impact on daily functioning (Ong et al., 2015; Orr et al., 2019).</li> </ul>	<p>2. <i>Daily life struggle</i>- The participants faced daily struggles, with even simple tasks like cooking or sleeping requiring significant effort due to obstacles and clutter. These challenges left them physically and emotionally drained. The disorganized and cluttered environment hindered their movement and obstructed daily activities. Some participants felt overwhelmed and trapped by the clutter, finding it difficult to locate things.</p>
<ul style="list-style-type: none"> <li>• Generalized anxiety disorder and social anxiety have been found to co-occur with hoarding (Frost, Steketee, et al., 2011).</li> <li>• Decluttering is associated with significant distress and anxiety (Subramaniam et al. 2020).</li> </ul>	<p>3. <i>The psychological depths of hoarding</i>- Participants described feelings of distress, being overwhelmed, and anxious. When faced with decisions about what to discard, they felt mentally overloaded. Managing their possessions, such as organizing, clearing, discarding, and sorting, triggered anxiety and depression. Most participants felt that hoarding</p>

	<p>provides them a sense of control. One participant struggled with memory and had difficulty finding things.</p>
	<p>4. <i>Clutter souls</i>- Participants feel their clutter and difficulty completing tasks have shaped their identity. Some identify as collectors and believe they can't change their identity. Others attach personal meaning to their possessions and struggle to let go. One participant views his possessions as a protective factor against suicide.</p>
<ul style="list-style-type: none"> <li>• Hazardous living conditions in rundown housing posed health risks, including fire hazards, home deterioration, hygiene concerns, and falls Orr et al. (2019).</li> <li>• Participants described health considerations as a physical constraint, including lack of energy and mobility issues (Orr et al., 2019).</li> </ul>	<p>5. <i>Trapped in chaos</i>-Hoarding posed physical dangers for participants, with health risks from hazardous living conditions in rundown housing. The accumulation of items increased the risk of falls, fires, and poor ventilation. One participant cited lack of energy as a barrier to decluttering.</p>
<ul style="list-style-type: none"> <li>• Significant impact of hoarding on social isolation and limited social interactions (Garza &amp; Landrum, 2015, Subramaniam et al. 2020).</li> <li>• Individuals who hoard felt shame and stigma when others visiting their homes failed to understand their HB (Kellett et al.'s 2010).</li> </ul>	<p>6. <i>Affected connections</i>- Participants acknowledged that cluttered environments had a detrimental impact on their social interactions and relationships. The overwhelming clutter caused feelings of shame, making it difficult for some to invite people over and leading to strain in relationships. Consequently, many participants experienced isolation, guilt, and fear of judgment.</p> <p>However, two participants expressed no shame about their cluttered homes, which did not affect their friendships.</p>

<p>Participants with HB experiences:</p>	<p>The following themes emerged under the superordinate theme <b>Reclaiming spaces, restoring lives:</b></p>
<ul style="list-style-type: none"> <li>• Participants receiving support from HCP (Orr et al. 2019; Frost et al., 2013).</li> <li>• Adopting person-centred approaches when addressing HB in older individuals is important. Recognizing their autonomy, understanding their unique judgments and tolerance levels, and avoiding forced interventions that disregard their personal significance can contribute to more effective and compassionate interventions (Andersen et al. 2008)</li> </ul>	<ol style="list-style-type: none"> <li>1. <i>Support from HCP-</i> The findings of the present study suggest that increasing the number of healthcare professionals (HCP) to assist with organizing and discarding possessions may not be effective and can potentially exacerbate tensions. It was advised that HCP should avoid pushing too hard to prevent frustration. Effective support involves HCP being good listeners and understanding the participants' mental state during decluttering assistance. Setting realistic goals is important to avoid disappointment. One participant expressed a preference for minimal HCP involvement, preferring to see his psychiatrist once a month for psychiatric treatment.</li> </ol>
<ul style="list-style-type: none"> <li>• Most participants shared their experiences of family members attempting various interventions, including offering advice, pressuring or nagging them, seeking external support, or even forcefully disregarding their decisions (Subramaniam et al. 2020).</li> </ul>	<ol style="list-style-type: none"> <li>2. <i>Support from family and friends-</i> Most participants mentioned that their families did not provide adequate support, and only a few friends offered assistance. It was evident that the loss of a supportive family member, as in one participant case, or interference in decision-making, as experienced by another participant, can negatively impact the support individuals receive. On the other hand, one participant stated that his friends enable his HB by giving him more items without invading his privacy or pressuring him to discard.</li> </ol>

<p>HB are driven by a desire to maintain control and prevent interference from (Warren &amp; Ostrom, 1988; Frost et al., 1995)</p>	<p>3. <i>Exerting personal control</i>-. The study suggests that frustrations can be reduced by organizing care in a way that allows the client to have long periods of uninterrupted time to themselves and make their own decisions about what to discard.</p>
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The present study's findings offer an in-depth exploration into the experiences of individuals who compulsively hoard in Malta. These findings add meaning and significance to some of the results obtained from the relevant literature. For instance, two quantitative studies (Ong et al., 2015; Orr et al., 2019 retrieved in the literature review revealed that hoarding has a notable negative impact on daily functioning. However, the present study goes further by providing a detailed account of how hoarding specifically affects their everyday lives.

Furthermore, as there is limited existing literature on the coping strategies employed by individuals living with HB, this study makes a valuable contribution to the extant literature by providing insight into their coping strategies.

Consequently, due to the scarcity of relevant literature on this topic, this chapter primarily focuses on comparing the findings from the present study with those of research conducted among individuals with HB. This is because unlike the case for persons living with HB, there are a considerable number of studies which have explored the experiences of HCP working with individuals with HB or their family members experiences.

The chosen theoretical framework for discussing the findings of this study was the Common-Sense Model (CSM) developed by Leventhal et al. (1980). This model was selected because it recognizes the presence of a threat, which, in this study, pertains to a health threat of being diagnosed with having a HB. The following section provides an overview of the Common-Sense Model (CSM).

## 5.2 The Common-Sense Model

The Common Sense Model (CSM) proposed by Leventhal, Meyer, and Nerenz, (1980) suggests that when individuals encounter a new health threat, they try to interpret it by constructing cognitive representations of the threat. These cognitive representations are influenced by both lay information about the threat and the previous experiences of others who have faced a similar threat (Petrie & Weinman, 2006). Additionally, cultural, social factors and media also play a role in shaping these perceptions (Diefenbach & Leventhal, 1996). These cognitive representations guide individuals in developing coping strategies aimed at mitigating the risks associated with the threat (Leventhal, Brissette, & Leventhal, 2003). There are six main components comprising these cognitive representations:

**Identity of the illness:** This refers to the label assigned to the illness (e.g., hoarding disorder) and the symptoms associated with it (e.g., excessive accumulation of clutter hindering room accessibility).

**Cause of the illness:** This pertains to the perceived cause or origin of the illness (e.g., trauma).

**Timeline:** This represents the individual's belief about the duration of the illness (e.g., acute or chronic).

**Consequences of the illness:** This encompasses the perceived impact of the illness on daily life.

**Cure/control:** This relates to the individual's perceived belief in the possibility of curing or managing the condition, as well as their perceived control over it.

**Illness coherence:** This refers to the individual's perceived understanding and knowledge about the condition (Leventhal et al., 1997).

Furthermore, according to the CSM (Leventhal et al., 1980), individuals also experience an emotional response to the perceived threat and develop coping plans aimed at reducing this emotional response. Moreover, individuals continually evaluate the effectiveness of the coping strategies they employ (Petrie & Weinman, 2006).

In the present study, the perceived threat for the participants revolved around living with a HB, as indicated by statements such as "*When I need to think about what possessions I am*

*going to keep or discard, I feel sad and anxious"* (Anna, p.2, line 29). Therefore, the interview questions in my study were designed to explore the participants' experiences of living with this HB and how they coped with it.

The following section presents the triggers of HB.

### **5.3 Past triggers of HB**

The present study delves into the experiences of individuals who have gone through traumatic events in both their childhood and adult lives. These events include unexpected deaths, challenging family environments, parental neglect, and poverty. Such experiences have resulted in attachment needs and a fear of limited resources among the participants. Previous research by Grisham et al. (2006) also established a significant connection between HB and traumatic events, with a substantial portion of their sample reporting a stressful life event at the onset of hoarding symptoms. Similarly, Tolin et al. (2010) found that HB could be triggered by a past traumatic event that individuals struggled to cope with, leading to the emergence of symptoms during or shortly after the event. This emotional attachment to possessions and the associated beliefs, such as perceiving possessions as a form of self-protection, contribute to the development of HB.

Furthermore, the accumulation of possessions serves as a way for individuals to fill emotional voids caused by trauma and to avoid confronting their pain (Neave et al., 2016). Interestingly, previous studies exploring the correlates of hoarding disorder have also highlighted the connection between the onset of hoarding disorder and chronic stress or significant life events (Morgado et al., 2015; Shaw et al., 2016).

The participants in this study described investing considerable time in hoarding activities, planning, and expanding their hoards as a way to reinforce a sense of security. They held onto their possessions tightly due to an underlying sense of threat, believing that their belongings were at risk and could easily be lost or taken away if not protected within the hoard. For instance, one participant, Maria, hoarded possessions as a response to childhood experiences of resource scarcity and to avoid experiencing poverty again. Hoarding provided her with a sense of security and acted as a safeguard against potential future deprivation. Another participant, Anton, explained that he kept his possessions as a precaution, anticipating a future need for them when he might be unable to purchase them. This finding aligns with the notion that individuals acquire and hoard possessions as a way to exert control over their

environment, ensuring a sense of security and protection against uncertainty (Mulligan-Rabbitt et al., 2023; Chia et al., 2021). Additionally, as per the CSM (Leventhal et al., 1980), it is proposed that individuals react emotionally to perceived threats and develop coping strategies aimed at mitigating these emotional responses. Furthermore, the individual consistently evaluates the effectiveness of the coping mechanisms employed, as noted by Petrie and Weinman (2006). For instance, individuals who perceive a greater sense of control tend to experience reduced levels of anxiety, providing them with a feeling of security and safeguarding against uncertainty. Not to mention studies in consumer and marketing domains have also observed an increase in consumer hoarding during periods of perceived uncertainty or threat, such as economic crises or pandemics (Shoham et al., 2017; Yuen et al., 2020). Likewise, Subramaniam et al. (2020) found that HB was driven by a desire to mitigate future uncertainties by storing duplicate or triplicate items that individuals believed might become unaffordable or unavailable in the future. This behaviour aligns with the "risk minimization theory" (McKinnon et al., 1985), which suggests that hoarding serves as a strategy to minimize potential future risks.

In hoarding, similar to other contexts, there is a tendency to rely on inanimate objects as a way to cope with the experience of loss (O'Connor, 2014). Loss is frequently encountered in HB, and qualitative research suggests that holding onto possessions allows individuals who hoard to avoid confronting the painful reality of what they have lost (Andersen et al., 2008). Some research studies have indicated that hoarding may begin after a significant loss (Rudnick, 1981). It is possible that the hoard represents an attempt to regain what has been lost, providing a tangible means of dealing with loss and an alternative response to the impermanence of things in life (O'Connor, 2014).

The present study expanded on the findings of Mulligan Rabbitt, O'Connor, and Brien (2023) by suggesting that HB may be triggered by the loss of a close family member. These authors explained how in hoarding there is a tendency to rely on inanimate objects as a means of coping with the experience of loss. Hoarding often involves encounters with various forms of loss, and qualitative research indicates that holding onto possessions enables individuals who hoard to avoid confronting the distressing reality of their past losses. Some studies have indicated that HB may begin after a significant loss. It is plausible that the hoarded items serve as an effort to regain what has been lost, providing a tangible approach to address loss and offering an alternative response to the impermanence of things in life. Two participants, Anna and Jane, in the present study explained how they started hoarding after the death of a

close relative. Furthermore, Anna described how her sister used to control her HB before she passed away, but now she has resumed hoarding and it has become uncontrollable. This finding aligns with Subramaniam et al.'s (2020) study, where a participant mentioned a newfound sense of freedom to collect without anyone nagging at her *"My mom is not in the house, that's one factor, so there's freedom. Freedom for me to collect and there's nobody going to nag at me"* (p. 460). Anna and the participant in Subramaniam et al.'s study felt both a sense of freedom. Both Anna and the participant in Subramaniam et al, (2020) associated the absence of control with the ability to collect items without interference, implying that external nagging previously restrained her hoarding tendencies. This perspective of freedom to be oneself without external control was also evident in a qualitative study by Granger (2020), where several participants described receiving informal support from their family or friends, which helped them regulate their HB.

In the present study Theodore's account of developing a strong emotional attachment to possessions due to a lack of secure interpersonal relationships resonates with previous research. According to John Bowlby, the attachment theory in childhood focuses on the emotional bonds between infants and caregivers. It suggests that early attachments impact a child's development. Infants seek closeness and security from caregivers and responsive caregiving is crucial for healthy attachment formation (cherry,2023). The quality of attachment determines various attachment styles namely: secure, insecure-avoidant, insecure-anxious/ambivalent, and disorganized/disoriented. Such as attachment patterns shape beliefs about self and relationships. For instance, secure attachment leads to confidence and exploration. Insecure-avoidant children are reported to become self-reliant, while insecure-anxious/ambivalent children display clinginess. Disorganized/disoriented attachment arises from severe neglect or abuse. Attachment patterns affect emotional regulation, social interactions, and adult relationships. Secure attachment fosters self-esteem and trust, while insecure attachment can lead to difficulties in relationships.

The systematic review by Chia et al. (2021) supports the idea that excessive attachment to inanimate objects in hoarding can compensate for the absence of security in personal connections. When human relationships are perceived as rejecting or unreliable, objects offer a substitute source of reliability, as they can be entirely controlled by their possessor. Keefer et al. (2012) provided experimental evidence by demonstrating that recalling instances of unreliable close others leads to stronger attachment to objects. Yap et al. (2020) further

established a positive association between loneliness, hoarding symptoms, and object attachment, providing support for the "compensation hypothesis."

The phenomenon of children forming intense attachments to comfort objects echoes Winnicott's (1953) concept of transitional objects. While most children outgrow this attachment, persistent object attachment beyond childhood has been linked to lower interpersonal attachment security (Stagg & Li, 2018). These findings suggest that similar dynamics may be present in hoarding disorder. However, as noted, additional empirical research is necessary to establish a definitive link between object and interpersonal attachment in relation to hoarding (Mathes et al., 2020).

Anton's experience of growing up in a cluttered household where hoarding was considered normal highlights the impact of early environmental factors on the development of hoarding tendencies. Chia et al. (2021) posits that experiences of disorganization or the absence of effective role models for organizing possessions can shape an individual's relationship with objects and contribute to hoarding. Additionally, the reinforcement pattern observed in Anton's childhood, and additionally as described by Calamari and colleagues (2012), likely intensified his HB and cognitions over time. The sense of things "getting out of hand" when the person's age limits their ability to sort or categorize possessions as reported in other case reports Thew and Salkovskis (2016), further emphasize the impact of environmental factors.

The role of the family in HB is substantiated by Subramaniam et al. (2020), who found familial vulnerability to be a contributing factor in several participants. The presence of a family member who enabled HB further exemplified the influence of the family environment on HB. This was exemplified by a participant stating, "*Yes, my grandma collected a lot*" (Subramaniam et al., 2020, p. 460). Genetic factors, non-shared environmental factors, and common environmental factors were identified as potential contributors to the variation in hoarding traits by Hombali et al. (2019). However, it is crucial to note that these findings require replication in larger samples and specifically in individuals diagnosed with hoarding disorder to validate their significance.

## **5.4 Participant Impact and Emotional Responses to HB**

This section focuses on the impact of HB on the participants, encompassing both negative and positive aspects. In the present study, several factors were found to have a significant impact on the participants, including emotional, functional, psychological, spiritual, physical, and interpersonal factors. The results align with a fundamental principle of the CSM, which highlights the personalized nature of illness representations. As outlined in the CSM (Leventhal et al., 1980), individuals' cognitive perceptions of an illness are predictive of their practical and emotional reactions to a health threat, including the level of distress they experience. The emotional representation of illness encompasses emotions such as depression, anxiety, and anger that are associated with the specific illness (Diefenbach & Leventhal, 1996). Even when individuals share the same illness, they can have distinct emotional representations of their condition, resulting in varying emotional responses (Petrie & Weinman, 2006).

### ***5.4.1 The emotional impact***

The study findings also align with a study by Subramaniam et al. (2020), where the authors emphasized the substantial impact of hoarding on individuals' daily life, affecting themselves, their family and friends, and the community. The negative emotional experiences expressed by most participants in the present study, such as guilt, overwhelm, loneliness, and embarrassment regarding their cluttered homes, are consistent with findings from two studies (Kellett et al., 2010; Taylor et al., 2019). These studies highlight the feelings of sadness, shame, and guilt related to HB, often leading individuals to hide or conceal aspects of themselves or their homes. Furthermore, Maria explained how she feels guilty when she considers discarding something, which supports the findings of Chia et al. (2021) that individuals who hoard experience intense negative emotions (e.g., grief, anxiety, guilt) when faced with the prospect of parting with their possessions, leading to avoidance of discarding to alleviate distress. Additionally, Yap et al. (2020) discovered a positive association between loneliness and hoarding symptoms, with attachment to objects mediating this relationship, further supporting the "compensation hypothesis."

The present study also delves into the positive emotions associated with HB. Two participants, Anna and Theodore, expressed happiness, pride, excitement, comfort, and safety as positive emotions related to their hoarding tendencies. These positive emotions serve as

encouragement for them to continue hoarding, as identified by Chia et al. (2021), who found that accumulating possessions can generate pleasurable and prideful emotional states, further motivating individuals to acquire and save more. However, it is essential to recognize that these positive emotions are not universal among participants and may vary depending on individual experiences.

#### ***5.4.2 The functional impact***

The cluttered homes observed by the researcher during the interview visits reflect the findings of Kellett et al. (2010), where homes were excessively cluttered, making them unusable for their intended purposes. The participants described their struggles in performing daily tasks, as even simple activities like preparing a meal or going to bed required significant effort due to the need to navigate obstacles and move piles of items. These physical challenges left the participants physically and emotionally drained. The lack of organization and cluttered environment hindered their movement and obstructed daily activities. The participants' experiences resonate with previous research, highlighting the difficulty in finding things among clutter, feeling overwhelmed, and trapped by it.

The present study revealed that participants relied on routines and procedures to accomplish tasks and organize their activities. These routines helped them navigate their hoarded environments and engage in daily occupations. This finding aligns with the literature in occupational therapy, which emphasizes the importance of constructing effective and meaningful habits and routines to enable individuals to fully engage in everyday occupations. Lack of skills and suitable daily routines negatively impact participation in occupations. However, the excessive focus on decluttering, as mentioned by Gibson (2015), may neglect the emotional needs and concerns of individuals, leading to significant psychological distress.

One participant humorously described the need to navigate obstacles and move piles of papers from their bed every night just to have enough space to lie down. Some participants mentioned resorting to eating out or ordering takeaway instead of cooking at home. When asked about how they organized their collected items, most participants mentioned storing them on tables, kitchen tops, piled on the floor, or clustered in a disorganized manner, which obstructed their movement. None of the participants arranged their collected items in an organized way. These participants engaged in daily coping mechanisms to manage their clutter. They resorted to hoarding as a means of dealing with negative experiences like loss

and trauma. However, their HB led to additional losses, preventing them from fully enjoying and living their lives to the fullest. Additionally, one participant, Theodore, shared his experience of having a cockroach infestation in his cluttered house last summer, which led him to "emigrate" to his garage. Despite the challenges they faced each day, the participants managed to perform most tasks at home, although they found them complicated compared to what might seem simple to others. For instance, one participant (Jane) managed to work full-time, two others cared for their children (Maria and Anna), while two participants (Theodore and Anton) had less structured routines and spent more time outside their homes.

### ***5.4.3 Psychological impact***

In this study, participants reported experiencing psychological distress while living in cluttered homes. They described feelings of distress, being overwhelmed, and anxious. When faced with decisions about what to discard, they felt mentally overloaded. Managing their possessions, such as organizing, clearing, discarding, and sorting, triggered anxiety and depression. The thought of getting rid of their belongings caused them great discomfort. Anxiety was identified as a contributing factor in maintaining HB, as participants refrained from discarding their possessions due to the stress it caused. The study identified decision-making and discarding as significant sources of anxiety, which aligns with previous research findings (e.g., Grisham & Barlow, 2005). In addition to these aspects, participants also described other forms of anxiety. Anna, Jane, and Maria highlighted the relationship between HB and attachment anxiety and social anxiety, explaining how hoarding could both trigger and alleviate anxiety symptoms. Previous studies have reported a co-occurrence of hoarding with generalized anxiety disorder and social anxiety (Frost, Steketee, et al., 2011).

Furthermore, participants (Anton, Maria, and Anna) shared their experiences of how depression impacted their ability to effectively manage their possessions and contributed to the worsening of their hoarding tendencies. These insights provide a better understanding of how anxiety and depression can influence HB by driving the acquisition of items, reducing motivation and energy to address clutter, and impeding the ability to discard. These observations shed light on the relationship between depression, anxiety, and hoarding, addressing the question raised by Frost, Steketee, et al. (2011) regarding whether depression and anxiety cause hoarding or are a consequence of it. The participants' detailed accounts, such as Anna's description of how her hoarding escalated due to anxiety and depression, offer a deeper understanding of how comorbid conditions can contribute to and exacerbate HB. It

is possible that experiences of anxiety, depression, and trauma create a detrimental cycle in relation to hoarding.

Locating items within a cluttered environment poses a significant challenge for individuals dealing with HB. Participants, such as Jane, described how their memory became less reliable over time, making it harder to find things they once knew the location of. This was illustrated by Jane's statement: *"I never used to think about it...I felt secure among this stuff and knew that if I ever needed a certain paper, I would find it right away. But now I struggle to find it!...Before, I knew where everything was, and clutter didn't bother me, but as I am getting older, I find it more difficult because my memory is not what it used to be"* (Jane p.1, lines 20-22). This struggle to find items despite having a general sense of where they are adds to the frustration and stress associated with clutter. Millanta, (2017) also found that finding things in a cluttered environment was a major challenge for participants, requiring considerable effort and time. This is exemplified by the phrase *"I cannot tell you where it is. I have no memory of what happened to it. You need a friggin' homing pigeon device on it like an alarm..."* (Millanta, 2017).

#### **5.4.4 Spiritual impact**

The study highlights the case of Theodore, who expressed enthusiasm for his clutter and viewed it as a source of entertainment and occupation. Contrary to common experiences, Theodore did not feel loneliness, isolation, embarrassment, or distress related to his clutter. Instead, he identified hoarding as a significant part of his identity. Additionally, he mentioned occasionally selling belongings that held no personal meaning to him in order to make extra money. Theodore emphasized the significance of hoarding to him, as it kept him occupied and prevented feelings of madness. This finding aligns with previous research by Andersen et al. (2015), which found that some participants expressed pride and productivity in their HB.

The discussion surrounding spirituality and hoarding, as presented by Jane and Theodore, provides valuable insights into the intricate relationship between HB and personal identity. Both participants expressed that their clutter and possessions were integral parts of who they are. Jane expressed a deep attachment to her belongings and identified herself as a "collector," while others labelled her as a hoarder. She believed that being a collector was an intrinsic aspect of her identity, indicating little hope for changing her behaviour. This

sentiment resonates with previous research by Kellett et al. (2010), which found that individuals with chronic hoarding tendencies often blurred the boundaries between their sense of self and their possessions, leading them to primarily identify themselves as hoarders. However, this study offers a fresh perspective by highlighting hoarding as an occupation that contributes to an individual's occupational identity without being their sole identity. In other words, while Jane and Theodore identified themselves as collectors, they also engaged in various activities and occupations that gave them a sense of purpose, self-establishment, and contribution to their community. Recognizing hoarding as one aspect of an individual's identity rather than their entire identity could be a significant step in addressing hoarding-related problems and facilitating positive psychological change. Orr et al. (2019) similarly noted that participants tended to primarily identify themselves as "hoarders" rather than individuals experiencing hoarding-related problems. The fusion of identity with the presenting problem has been observed in other disorders as well, such as bulimia nervosa, schizophrenia, and substance misuse. This suggests a broader phenomenon where individuals come to identify themselves primarily through the lens of their presenting problem. This is in agreement with the CSM (Leventhal et al., 1980) which states the identity dimension reflects the symptoms and label given to the illness or condition. Future research in the field of hoarding should delve deeper into these identity issues, potentially through naturalistic longitudinal studies or treatment intervention studies. By understanding the dynamics of identity shift and its role in achieving lasting positive psychological change, researchers and practitioners can develop more effective strategies for intervention and treatment.

Jane and Theodore emphasized in the present study that they cannot change who they are and their HB. They also stated that they could never part with their possessions because of the meaning they hold for them. The beliefs and emotional attachments that the participants hold towards their possessions contribute to the motivation to save and make it challenging for them to discard items. The research conducted supports the notion that individuals with hoarding difficulties have strong emotional connections to their belongings, finding emotional comfort and a sense of safety in them. These findings align with the work of Yap and Grisham (2020), which shed light on the beliefs driving HB.

Understanding the deep emotional attachment individuals with HB have towards their possessions is crucial for developing interventions that address the underlying motivations and provide alternative coping mechanisms. By addressing the emotional needs and

providing support in finding comfort and security through means other than hoarding, it may be possible to help individuals gradually let go of unnecessary belongings.

Moreover, Theodore described how his possessions served as a protective factor, providing solace and preventing thoughts of suicide when he felt lonely and depressed. While existing literature has primarily discussed the risks associated with hoarding, such as forced clearance and its link to suicide (Frost & Steketee's, 2010), this study sheds light on hoarding as a potential protective factor. Steketee & Frost, (2014b) have advised against enforced clearances under any circumstances, as they are highly traumatic, erode trust, and can contribute to reluctance to seek support. Understanding the role of hoarding as a coping mechanism and source of emotional comfort can inform more nuanced and compassionate interventions.

In conclusion, the discussion presented by Jane and Theodore provides valuable insights into the intricate relationship between HB and personal identity. Recognizing hoarding as an aspect of an individual's identity rather than their entire identity could have important implications for treatment and intervention. Future research should explore the dynamics of identity shift and develop strategies that address the emotional attachments and beliefs driving HB, ultimately aiming to facilitate positive psychological change and improve treatment outcomes for individuals with hoarding difficulties.

#### ***5.4.5 Physical impact***

The present study's findings shed light on the various physical dangers associated with HB, emphasizing the need for intervention and support. The participants reported a range of physical risks resulting from their HB. Hazardous living conditions in rundown housing posed health risks, including fire hazards, home deterioration, hygiene concerns, and falls, as noted by Orr et al. (2019). These risks not only affect the hoarder but also others living in the hoarded environment, underscoring the urgency for intervention when necessary.

In addition to the general risks, specific physical dangers were highlighted by the participants. Anna and Jane expressed concerns about falls, which can be attributed to the accumulation of items. Jane also mentioned the potential risk of fire, indicating the hazards associated with overcrowded spaces. Theodore, although not mentioning specific physical dangers, described living conditions that negatively impact his physical health. Sleeping on a

mattress in a poorly ventilated garage and lacking hot water in his house can lead to back pain, poor sleep quality, and other physical issues.

The presence of rodents, insects, and poor sanitary conditions in cluttered spaces was also mentioned, indicating the potential health problems associated with severe hoarding. These findings align with the research conducted by Brakoulias and Milicevic (2015), who highlighted infestations and unsanitary conditions as consequences of severe hoarding. Mould, in particular, can pose health risks, especially for children, as noted by Tolin et al. (2017).

In a study conducted by Orr et al. (2019), participants discussed how health considerations served as physical limitations, such as experiencing a lack of energy and mobility issues. The decline in mobility affected their ability to reach high cupboards, while the lack of energy made them feel overwhelmed with limited time to address their belongings (Eckfield & Wallhagen, 2013). While a previous study (Orr et al., 2019) indicated that physical constraints played a minor role in the impact of hoarding, Anton specifically attributed a significant portion of his hoarding behavior to his lack of energy. All participants in the current study appeared physically exhausted, and one participant (Anna) faced mobility difficulties. These findings build upon the results of Eckfield and Wallhagen (2013), which focused on an older age group, suggesting that deteriorating health can influence HB not only in older individuals but also in a broader age range. When considering comorbid factors and treatment approaches for hoarding, it becomes important to specifically address the effects of decreased mobility, decreased energy levels, and physical pain.

#### ***5.4.6 Impact on relationships***

Another significant aspect highlighted in the study is the impact of hoarding on relationships. All participants reported difficulties in maintaining connections, with strained or non-existent relationships with family members and friends. Participants felt disrespected and often isolated themselves from others due to perceived criticism of their hoarding and pressure to clean and discard.

Jane, the only participant with a good relationship with her aunt, still had frequent arguments with her aunt over decluttering. Jane never had a partner and lacked close friends, except for colleagues who were unaware of her HB, causing her embarrassment in inviting them to her

house. She mentioned that only healthcare professionals and her aunt visited her nowadays because she felt ashamed of her cluttered home. Maria expressed feelings of loneliness, with her son barely speaking to her due to considering her living conditions as filthy. She also refrained from inviting friends over out of fear of judgment. In contrast, two participants, Anna and Theodore, were open to having company at their homes, as they did not feel embarrassed about their living conditions and were not afraid of being judged. The participants in the present study expressed feelings of loneliness, embarrassment, and shame regarding their hoarded living conditions, resulting in a reluctance to invite others into their homes. These sentiments align with previous research, highlighting the impact of hoarding on social isolation and limited social interactions (Garza & Landrum, 2015).

Attempts to remove hoarded items may be perceived as rejecting the individual themselves, leading to further conflict and strained relationships. Children living with parents who hoard face daily struggles, feeling generally unhappy and finding it difficult to make friends due to embarrassment and shame about their home's condition, as found by Tolin et al., (2008).

Garza and Landrum (2015) reported strained relationships within families due to the perception of hoarding as off-putting, repellent, or disgusting, and attempts to remove hoarded items may be seen as rejecting the individual themselves. Family members may also feel embarrassed to invite others to their home, affecting relationships outside the household. Children of individuals with HB may also experience bullying if their messy and unsafe living environment becomes known at school, leading to embarrassment in inviting others home (Tolin et al., 2008). Furthermore, when family members intervene in hoarding situations to reduce clutter, it often leads to further conflict and strained relationships (Wilbram et al., 2008).

Lastly, in their studies on caregivers and family members of individuals who hoard, Wilbram et al. (2008) and Sampson (2013) both highlighted the evident disruption to family and social relationships. This breakdown and loss of relationships affected both parties involved. Sampson (2013) discovered that family members of individuals with HB expressed feelings of sadness, loss, and grief over the deterioration of once-meaningful relationships. Eleven out of twelve participant caregivers in Sampson's study (2013) described feeling hurt as the individuals with HB often prioritized their possessions over maintaining relationships with their family members. Additionally, Kellett et al.'s (2010) findings from their study on the lived experience of being a hoarder discussed how individuals who hoard felt shame and stigma when others visiting their homes failed to understand their HB. This may lead them to

actively avoid inviting people into their homes, further contributing to relationship breakdown. Furthermore, Sampson (2013) reported that a lack of understanding regarding HB resulted in negative feelings towards the family member who hoarded.

## **5.5 Coping strategies adopted by people with HB**

The study's findings provide valuable insights into the coping strategies adopted by individuals with HB. Participants in the present study emphasized the importance of support systems, including HCP, family, and friends, in helping them cope with the challenges associated with their HB. While participants acknowledged the value of support from HCP, they also expressed the need to be in control and make their own decisions regarding discarding possessions. Making decisions about what to keep, discard, clean up, or recycle posed a significant challenge for participants. It was found that some participants felt pressured by HCP to make decisions about discarding, which added to the complexity of the process.

The study revealed that four participants heavily relied on the support of HCP, which had not been prominently discussed in existing literature that focused more on support from family and friends. This finding contributes new insights into the significant dependence on HCP among individuals with HB, expanding the understanding of the support systems needed in the context of hoarding.

The experiences shared by the participants highlighted the importance of HCP listening attentively and trying to understand the mental state of individuals attempting to declutter. The process of discarding can trigger anxiety and evoke strong emotions, and participants emphasized the need for sensitive and empathetic support from HCP. It was noted that pushing too much or showing frustration could have a negative impact on the already sensitive emotional state of individuals with hoarding difficulties. Instead, setting realistic and achievable goals, even small targets, was found to be motivating for participants.

The participants also provided suggestions for how HCP could provide assistance. Jane recommended that HCP assist in understanding the mental state of individuals stepping out of their comfort zone and decluttering. Maria suggested that instead of simply telling patients to discard items, HCP could help in organizing the clutter by suggesting suitable areas for

furniture placement or assisting with categorization. This approach recognizes that sometimes the presence of clutter is due to disorganization rather than a need for everything to be discarded.

Individual preferences regarding the extent of support from HCP were also evident. Anna expressed feeling overwhelmed when there were too many nurses involved and recommended that they allow her to make her own decisions regarding what to keep or discard. Theodore, on the other hand, preferred support only from his psychiatrist and declined assistance from other HCP for decluttering. His recommendation was to respect his autonomy and allow him to live the life he chose as long as he caused no harm to himself or others.

Discussions regarding help-seeking behaviours among individuals with hoarding difficulties were also addressed. Existing literature suggests that older adults with hoarding problems rarely seek direct assistance for their condition, often coming to the attention of services through other agencies or community complaints (Chapin et al., 2010). In a study by Kim et al. (2001), the distribution of referrals was as follows: 73% came from other agencies, 21% originated from direct complaints, 3% were made by service delivery workers, and the remaining 3% were self-referrals. Many individuals do not perceive their hoarding as problematic, viewing it as a lifestyle choice or normal behaviour (Franks et al., 2004, p.80). Lack of storage space is commonly identified as a problem when the issue is acknowledged (Thomas, 1998). The literature frequently reports reluctance to voluntarily seek treatment (Thomas, 1998, p.52), particularly when individuals do not find their living conditions distressing, even if others perceive them as cluttered or unsanitary. This resistance to intervention can result in fines and threats of prosecution from agencies on public health grounds (Reinisch, 2009; Lee & LoGiudice, 2012; Koenig et al., 2013). Feelings of shame and embarrassment about their living conditions can also delay help-seeking, and a trusting relationship with a healthcare professional appears to be necessary for individuals to seek direct assistance (Koenig et al., 2013).

In terms of intervention, the prevailing view in the literature is that multi-agency and interdisciplinary collaboration is recommended as the most effective approach. However, there is currently a lack of studies comparing different models of intervention. To address the potential influence on the time gap between the onset of hoarding and treatment, it is advisable to conduct additional research on the stigma associated with hoarding, the effects of

media programming on public attitudes and treatment expectations, and the obstacles that hinder individuals from seeking help (Thew and Salkovskis,2016).

The findings of the study conducted by Orr et al. (2019) shed light on the perspectives of participants regarding the helpfulness of support workers in addressing HB. Participants reported that support workers who actively participated in sorting and discarding possessions alongside them were found to be most helpful. These workers provided practical guidance and advice, relieving individuals from overthinking ethical considerations regarding disposal. This highlights the significance of these perspectives expressed in the interviews and emphasizes the material nature of hoarding and its consequences.

Approaches that fail to understand the material nature of hoarding and its impact may impede effective interventions and hinder collaboration between HCP and individuals seeking help. Therefore, it is crucial to adopt approaches that are responsive and based on negotiation, as they hold greater potential for success. This focus on meaning and personal significance serves as a valuable correction to existing approaches, providing a more holistic understanding of HB (Braye et al., 2014).

In the present study, participants reported limited support from their friends and family when it came to decluttering and addressing their HB. Most participants mentioned that their families did not provide adequate support, and only a few friends offered assistance. The absence of support from family and friends can further isolate individuals struggling with hoarding difficulties. It was evident that the loss of a supportive family member, as in Anna's case, or interference in decision-making, as experienced by Jane, can negatively impact the support individuals receive. On the other hand, Theodore stated that his friends enable his HB by giving him more items without invading his privacy or pressuring him to discard. HCP were highlighted as a significant source of support for participants. HCP, along with a supportive neighbour in Maria's case, played a crucial role in providing assistance with decluttering. However, it was mentioned that increasing the number of HCP to assist with organizing and discarding may not be effective and can even exacerbate tensions. Instead, it was recommended to organize care in a way that allows individuals to have uninterrupted time and make their own decisions regarding what to discard. This approach respects their autonomy while still providing support.

Previous researchers have presented conflicting suggestions regarding improving living conditions for individuals who hoard possessions. Steketee et al., (2001) found that removing clutter without involving the elderly person was ineffective and often led to re-cluttering in cleared areas. They argue against involuntary cleaning as a solution. In contrast, Frost and Hartl, (1996) propose starting with significant removal of possessions to create a liveable home environment and then helping the client develop skills to maintain a manageable number of possessions and sufficient living space.

Caring for older people in the community who hoard is challenging due to their hoarding beliefs, personality traits, and associated psychopathology. Engaging these individuals in treatment is difficult, as they often come to clinical attention due to the impact of their behaviour on others (Steketee et al., 2001).

The findings of the present study suggest that increasing the number of HCP to assist with organizing and discarding possessions may not be effective and can potentially exacerbate tensions. Instead, the study suggests that frustrations can be reduced by organizing care in a way that allows the client to have long periods of uninterrupted time to themselves and make their own decisions about what to discard. This approach recognizes the importance of autonomy and empowerment for individuals struggling with HB. It is essential for HCP to strike a balance between being assertive and providing guidance while avoiding being too demanding or intrusive. This approach aligns with the participants' perspectives and promotes a collaborative and supportive environment.

The findings of the present study are consistent with a qualitative study conducted by Andersen et al., (2008). Andersen et al.'s research emphasizes that older people with HB have different judgments and tolerance levels compared to the majority of older individuals. They tend to perceive order in disorder and may not recognize the presence of clutter, garbage, and filth in their living spaces. This understanding highlights the importance of considering the unique perspectives and beliefs of older hoarders when addressing hoarding issues.

Addressing hoarding issues in individuals cannot be solely achieved by imposing societal standards of cleanliness and tidiness. Forcing involuntary cleaning or item removal can have detrimental effects, leading to emotional breakdowns and a sense of loss of control and self-efficacy. Older individuals with HB may experience various negative emotions such as stress, loss, defeat, and exhaustion when their personal possessions are taken away. These interventions can also give rise to new psychological threats, including diminished

confidence, self-esteem, fear of theft, feelings of vulnerability, worthlessness, homelessness, disconnection from others, and insecurity.

Moreover, in the present study most participants revealed that they want to be the one in control to make their own decisions regarding discarding. One participant (Jane) revealed that hoarding provided her with a sense of control over her possessions. This observation aligns with previous research suggesting that HB are driven by a desire to maintain control and prevent interference from others (Warren & Ostrom, 1988; Frost et al., 1995). Hoarding allows individuals to make decisions about their belongings, offering a sense of autonomy and personal control. The need for autonomy and choice is emphasized by participants who express a desire to be involved in decision-making processes rather than having others intervene in their lives.

The importance of building trust over time is underscored by the experiences of individuals with hoarding issues, who may have encountered stressful and traumatic interventions from others (Steketee & Frost, 2014a). Establishing a positive working relationship that respects autonomy, choice, and personal growth is crucial. Concerns related to autonomy and control are also evident in the desire for control expressed by hoarding participants in studies conducted by Brien et al. (2018). Recognizing and addressing these concerns can contribute to a more effective and supportive approach to addressing HB.

Overall, the present study's findings, along with the supporting evidence from Andersen et al. (2008), emphasize the importance of adopting person-centred approaches when addressing HB in older individuals. Recognizing their autonomy, understanding their unique judgments and tolerance levels, and avoiding forced interventions that disregard their personal significance can contribute to more effective and compassionate interventions. Further research and collaboration among healthcare professionals are essential to develop tailored approaches that respect the individual's beliefs and needs while promoting a safe and healthy living environment.

## **5.6 Conclusion**

The upcoming chapter will provide a brief overview of the current study and emphasize its strengths and limitations. It will also present a set of recommendations that address the implications derived from the findings discussed earlier.

# CHAPTER 6: Conclusion

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## 6.1 Introduction

This chapter provides a brief summary of the research study carried out among people with compulsive hoarding behaviour in Malta. This chapter also presents the strengths and limitations of the study. Recommendations for clinical practice and future research are also be presented.

## 6.2 Summary of the Research Study

While research on HB has been widely investigated by many researchers, it was noted that research in this area is still non-existent locally. Moreover, international research is mostly focused on the impact of HB or the lived experiences of HCP working with patients with HB or of their caregivers. Therefore, it can be argued that the presents study contributes to extant literature by exploring how persons who are compulsive hoarders strive to cope with this behaviour It was this lack of research about different coping strategies regarding HB that inspired this present study with the aim of exploring the lived experiences of individuals living with HB.

Moreover, I aimed to provide a voice for this group of participants, who until now have lacked the opportunity to voice their experiences and concerns. Semi-structured interviews were used to gather data from a purposive sample of 5 participants (two males and three females) who are diagnosed with HD. The data were analysed using IPA as described by Smith et al. (2009). Three super-ordinate themes emerged: 'Unearthing the roots of HB,' 'Aftermath of an explosion' and 'Reclaiming spaces, restoring lives.' The themes extracted were then discussed and compared with the extant literature in light of the CSM framework (Leventhal, et al., 1980). In the first super-ordinate theme 'Unearthing the roots of HB, the participants explained how their HB could have been triggered by poverty, attachment needs, expected behaviour and loss of a close family member. The second super-ordinate theme 'Aftermath of an explosion' focused on the impact of HB. Participants explained how their

HB affected them emotionally, functionally, psychologically, spirituality, physically and their interpersonal relationships (participants spoke about the impact of HB on the relationships with their family members and friends). The third super-ordinate theme ‘Reclaiming spaces, restoring lives’ explored the strategies used by participants to try to cope with their HB. These strategies include support from HCP, support from family and friends and exerting personal control. Such support could assist or hinder the process, and it was important for the HCP to have empathy, understanding, and awareness of the underlying issues in hoarding when patients seek formal support, although this could be challenging to obtain. Such interventions must be implemented in a way that respect the participant’s needs and autonomy. In addition to this participants explained how they want to be in control to take their own decisions and do not want other people to make decisions for them.

## **6.3 Strengths and Limitations**

This section outlines the strengths and limitations of this research study.

### **6.3.1 Strengths**

This study had a number of strengths which are listed below:

- This is the first local study to investigate the lived experiences of people with HB in Malta. The findings of this local study may also contribute to the scarcity of worldwide literature on this subject. This study has extended the findings of the studies retrieved in the literature review by providing an in-depth account on the triggers of HB, the impact of HB, as well as contributed to existing knowledge by providing insight into a number of coping strategies used by people with HB.
- In keeping with IPA methodology, this study used a relatively homogeneous sample of five adult participants to provide an in-depth analysis of the lived experiences of people with HB. The use of in-person interviews assured confidentiality. This strategy allowed participants to express their feelings, hence providing a ‘voice’ to these participants. A pilot interview with one participant was conducted prior to the start of the official interviews. This gave the researcher an opportunity to determine the

coherence of the interview guide, provided details in relation to the potential duration of the interview, and enabled me to practice my interviewing abilities.

- The researcher attempted to reduce the possibility of bias. As a result, a reflective diary containing the researcher's reflections before, during, and after the research project was kept. In addition, to decrease the potential of researcher bias, the researcher's academic supervisor conducted minor audits of the data analysis.

### **6.3.2 Limitations**

The limitations of the present study included:

- The author's lack of experience in conducting phenomenological research and being a novice researcher in IPA could be considered a limitation. Additionally, this was the author's first-time conducting interviews. However, the author was able to build confidence by conducting a pilot interview.
- All the interviews were conducted in Maltese, as it was the participants' preferred language and mother tongue. To ensure accurate translations, a professional translator was employed, but some profound meanings or metaphorical phrases may not have exact equivalents in English. To reduce this limitation, the excerpts are presented in both Maltese and English languages.
- Qualitative research does not provide generalizable findings. Thus, the findings may not be a representation of all the people with HB in Malta. However, the aim of the present study was not to collate generalisable data but rather in-depth data.
- IPA aims to grasp the fundamental nature of the phenomenon under investigation, which entails collecting a comprehensive account of it (Smith et al., 2009). However, there is a possibility that participants may not accurately recall specific details from their past experiences. The researcher acknowledged this as a limitation and used

prompts during the interviews to assist participants to voice their experiences. Despite this limitation, the study provides a comprehensive description of a topic that has not been extensively researched.

- The participants' responses may have been influenced by social desirability bias, as they may have been hesitant to provide completely honest answers for fear of negative repercussions. To reduce this bias, the researcher emphasized confidentiality, assured participants that there were no right or wrong answers and maintained a non-judgmental stance during the interviews. Furthermore, conducting this study served as a learning opportunity for the researcher in both the research field and the topic.

My learning experience is pointed out in the following section.

## **6.4 My learning Experience**

I will outline my learning experience during the execution of this research study by employing Bloom's Learning Theory (Bloom et al., 1956).

As a novice researcher, undertaking this study has enhanced my understanding of phenomenological research, the techniques involved in conducting in-person interviews, and the ethical considerations that come with conducting a research study. Furthermore, I have acquired a deeper understanding of the experiences of individuals with HB.

Conducting this study has made me aware about the importance and significance of understanding the underlying meanings in participant's words, rather than interpreting them literally. Through this experience, I have also gained insight into why patients use certain language features like metaphors and repetitions in their speech and how this understanding can assist professionals in their interpersonal skills. Additionally, I have come to understand that patients may not always be capable of expressing their emotions and difficulties openly, underscoring the importance of exploring their lived experiences.

Through this study, I have come to realize the significance of consulting the existing literature to gain a deeper understanding of the experiences of patients. Moreover,

maintaining a reflective journal throughout the research process has enhanced my analytical abilities. I now understand the significance of examining how my own assumptions and values can impact the data collection and analysis procedures, as well as my interactions with participants. I have developed my ability to synthesize information by learning how to identify emerging themes from the interview transcripts and then creating overarching themes from those emergent themes. After reflecting on my performance after each interview, I noticed a gradual improvement in my interviewing skills as I was able to apply my previous experiences to guide the conversations. Furthermore, I became more proficient in evaluating my own work as time progressed. Initially, when I presented my work to my supervisor, there were numerous corrections and aspects that required modification which I had not noticed. However, with time, my critical skills developed, enabling me to identify areas that needed improvement before submitting my work for feedback.

The following sections list recommendations emanating from the findings of this study.

## **6.5 Recommendations for clinical practice**

The following are recommendations for clinical practice:

- The participants' need for support with practical, emotional, and psychological aspects of hoarding highlights the complexity of this issue. Hoarding cannot be solved simply by cleaning up the clutter. Instead, it requires collaborative strategies and interventions. One recommendation is to involve multidisciplinary teams, including social workers, doctors, occupational therapists, psychologists and nurses, to address hoarding effectively. Participants primarily received support from HCP, emphasizing the importance of professional training in delivering holistic care for hoarding. Training HCP can equip them with the necessary knowledge to assist patients without causing distress. There is a lack of local support services and NGOs specifically focused on hoarding. Another recommendation would be to utilise peer support groups focusing on HB because locally they do not exist, and it would be helpful for

such individuals as they can feel supportive and not judged. The study's suggested strategies can be valuable additions to clinicians' toolkit for addressing hoarding.

- Understanding the strong emotional attachment individuals with HB have toward their possessions is crucial for developing interventions that target underlying motivations and provide alternative coping mechanisms. By addressing emotional needs and helping individuals find comfort and security through non-hoarding means, it may be possible to gradually reduce unnecessary belongings.
- Viewing hoarding as part of an individual's identity, rather than their entire identity, is an important step in addressing hoarding-related problems and promoting positive psychological change. Future research should explore identity dynamics and develop strategies to address emotional attachments and beliefs driving hoarding, ultimately improving treatment outcomes.
- It was noted that participants do not receive enough support from their families and friends. Some of them mentioned that they fear that people will judge them. Therefore, it is highly recommended to educate their support system as well as to increase the awareness of HB within the public. Raising awareness about the services can be accomplished by utilizing social media platforms, educational programs in the media, and distributing informational leaflets to caregivers.
- Participants emphasized the importance of attentive listening and understanding the mental state of individuals during decluttering attempts. Discarding items can trigger anxiety and strong emotions, requiring sensitive and empathetic support from HCP. Pushing too much or expressing frustration can negatively impact individuals with hoarding difficulties, while setting realistic goals and achievable targets proved motivating for participants.
- Instead of simply instructing patients to discard items, HCP could assist in organizing clutter by suggesting suitable furniture placement or aiding in categorization.

Recognizing that clutter may stem from disorganization rather than a need to keep everything is essential.

- Increasing the number of HCP to assist with organizing and discarding possessions may not be effective and can potentially increase tensions. Allowing patients uninterrupted time to make their own decisions about what to discard and maintaining their autonomy and empowerment are crucial. HCP should strike a balance between being assertive and providing guidance without being too demanding or intrusive, fostering a collaborative and supportive environment.
- Forcing involuntary cleaning or item removal can have detrimental effects, leading to emotional breakdowns and a loss of control and self-efficacy. Negative emotions such as stress, loss, defeat, and exhaustion may arise when personal possessions are taken away, along with psychological threats like diminished confidence, self-esteem, fear of theft, vulnerability, worthlessness, homelessness, disconnection, and insecurity.
- In cases where extremely dirty, dusty, or pest-infested items need to be cleared, there is a need for specialized cleaning companies trained in the psychology of hoarding, such as ‘Steri-Clean’ in America. In Malta, HCP are currently the only available service for decluttering, although it is not typically considered part of their role to clean. Thus, such companies are greatly needed in Malta to meet the high demand for such services and protect HCP from unhygienic environments.
- It is essential to develop practice guidelines for HCP to assist individuals in need of help. These guidelines should outline the specific process and occupational domains that HCP can focus on when working with patients with hoarding tendencies. It is crucial for these guidelines to cover both community and inpatient settings and incorporate other effective approaches such as providing HCP with training in cognitive behaviour therapy (CBT) for hoarding, which is considered one of the best practices when working with patients with HB, as recommended by Steketee & Frost (2014b).

## 6.6 Recommendations for Future Research

- One approach for studying the experiences of individuals with HB is to conduct a longitudinal study where participants are followed from diagnosis onward, with follow-ups at 6 and 12 months. This would provide a detailed understanding of how their perceptions may change over time.
- Several participants in this study shared significant traumatic events or hardships from their past that influenced the development and maintenance of their HB. Evidence from a study on younger adults suggests that stressful life events and transitions, such as employment or financial problems and changes in relationships, are associated with more severe hoarding symptoms, as well as depression and anxiety. Further examination of this area is needed to understand the course of HB across different stages of life. To enhance research in the future, similar studies could be conducted on younger patients or specific age groups to create a more homogeneous and robust study population.

It is important to note that this study was limited to a small number of participants and the findings cannot be generalized to all individuals with HB. Therefore, a larger study with the same design could explore the perceptions of a larger sample from different locations, cultures, and with various comorbidities. Comparing these findings would expand our knowledge of the strategies people employ to manage their daily lives and the challenges they face in a cluttered environment.

- Future research should delve into the dynamics of identity shift and develop strategies that address the emotional attachments and beliefs driving HB. The ultimate goal is to facilitate positive psychological change and improve treatment outcomes for individuals struggling with hoarding difficulties. There are two potential implications here: a need for aftercare for people who hoard to develop ways of functioning in their home which allow them to manage their living spaces, and the importance of developing an identity which does not involve hoarding

- It is recommended that HB receive specialized training to assist patients with decluttering. Therefore, it is advisable to provide both undergraduate and postgraduate training in this specific area. As well as to educate HCP when they are still studying to become professionals.

## **6.7 Conclusion**

The objective of this study was to deeply understand the experiences of individuals living with HB. By utilizing IPA, the study achieved an original contribution to the knowledge and research on hoarding, despite the small sample size. The narratives of five participants were shared, focusing on the triggers of HB, its impact on various aspects of their well-being (emotional, functional, psychological, physical, spiritual, and interpersonal), and the coping strategies they employed.

This study provides new insights into the significant reliance on HCP among individuals with HB, broadening our understanding of the necessary support systems in the context of hoarding. While HCP support can be beneficial, it is crucial to implement it in a manner that respects the autonomy and needs of the patients. Individuals with HB should be empowered to make their own decisions.

The findings of this study and their implications aim to provide HCP with a better understanding of the impact of living with HB and the coping strategies employed. This understanding can contribute to the development of appropriate interventions, as suggested by the researcher conducting this study.

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# Appendix A: Intermediary letter

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18th April 2022

Mr [REDACTED]

Charge nurse

Mental Health Services

**Re: Research Study: “Aftermath of an explosion: Lived experiences of compulsive hoarders”.**

Dear Mr [REDACTED],

My name is Michelle Elise Demanuele, I am a staff nurse currently working at Mount Carmel Hospital. I am presently reading for a Master of Science degree in Mental Health Nursing at the University of Malta. As part fulfilment of my study requirements, I am expected to conduct a research study. I intend to explore the lived experiences of people who compulsively hoard in Malta. This will be done by conducting an in-depth audio-recorded interview with five to ten patients who compulsively hoard. The duration of this interview is expected to be about 1 hour. The inclusion criteria for my research are adults i.e., eighteen years and over and who are interested in sharing their experience of hoarding. I am requesting that you approach potential participants and provide them with an information letter describing the present study. Those individuals who are interested in participating can then contact me directly on the contact details provided in the information letter. The data collected from this study will solely be used for research purposes and all the data will be stored in an encrypted format. Confidentiality will be maintained during data collection and data analysis. It is anticipated that data collection will commence by June 2022 and any personal data will be destroyed on completion of this study. I am aware that I must strictly adhere to ethical guidelines, especially relating to informed consent and confidentiality and that I must consult with my research supervisor, Prof. Josianne Scerri, throughout the research process. Moreover, I will be seeking approval for this study from the University Research Ethics Committee. Your support for this research project is greatly appreciated. If you wish to clarify any issues about this research project, you can contact me on [REDACTED] email: ([REDACTED]) or my supervisor Prof. Josianne Scerri on [REDACTED] (email: [REDACTED]).

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Michelle Elise Demanuele

Researcher

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Prof. Josianne Scerri

Dissertation Supervisor

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Mr [REDACTED]

Charge Nurse

# Appendix B: Information letter and consent form

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## Participants` Information Sheet

### Aftermath of an explosion: Lived experiences of compulsive hoarders

Dear Participant,

My name is Michelle Elise Demanuele and I am currently reading for a Masters Degree in Mental Health Nursing at the University of Malta. As part of my course requirements, I am conducting a research study entitled, "*Aftermath of an explosion: Lived experiences of compulsive hoarders.*" The aim of this study is to develop an understanding of the experiences of the individuals who compulsively hoard to understand and describe the patterns and reasons for hoarding, experiences with decluttering and the impact of hoarding disorder on significant others and society in the context of Malta. Your participation in this study would help us gain a better understanding about hoarding and its impact on these individuals, this may assist in the improvement of practice and also to raise awareness about hoarding in Malta. Furthermore, all data collected from this research shall be used solely for the purpose of this study.

With this letter I am inviting you to participate in this study. Your participation will be greatly appreciated. If you agree to participate, you will be expected to take part in an interview with myself regarding your experience. The interview will take approximately an hour and will be held at a time and place most suitable for you. I will ask for your consent on whether I may audio record the interview and transcribe the interview (written down as it has been spoken) before its commencement. **You are not obliged to answer all the questions and may withdraw from the study at any time without giving a reason.** Furthermore, withdrawal from the study will not have any negative repercussions on you and any data collected will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been

anonymised). I can assure you that confidentiality will be maintained throughout the study and that your identity and personal information will not be revealed in any publications, reports or presentations arising from this research. All data collected will be pseudonymised meaning that the transcripts will be assigned codes and that this data will be stored securely and separately from any codes and personal data. This data may only be accessed by the researcher. The academic supervisor/s and the examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. The coded audio-recordings, and transcripts will be stored on the researcher`s personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard.

In the event that you feel distressed due to participation in the interview, the service of a Psychologist Ms. [REDACTED] will be available at no financial cost on your part. You can contact Ms [REDACTED] on [REDACTED] or by email on: [REDACTED]

Participation in this study is completely voluntary and you are free to accept or refuse to take part without giving a reason. A copy of the information sheet and consent form will be provided for future reference. As a participant, you have the right, under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning you to be erased. Once the study is completed and the results are published, the data will be retained in anonymous form. Any personal details will be destroyed by August 2023.

This study has been approved by the Research Ethics Committee of the Faculty of Health Sciences at the University of Malta.

Thank you for your time and consideration. Should you have any questions or concerns do not hesitate to contact me on [REDACTED] or by email on: [REDACTED] or my supervisor Prof. Josianne Scerri on [REDACTED] or by email on: [REDACTED]

Yours Sincerely,

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**Michelle Elise Demanuele**

Researcher

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**Prof. Josianne Scerri**

Research Supervisor

# Participant Consent Form

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## **Aftermath of an explosion: Lived experiences of compulsive hoarders**

I, the undersigned, give my consent to take part in the study conducted by Michelle Elise Demanuele. The purpose of this document is to specify the terms of my participation in this research study.

1. I have been given written and verbal information about the purpose of the study and all questions have been answered.
2. I understand that I have been invited to participate in an interview, in which the researcher will ask questions to develop an understanding of the experiences of the individuals who compulsively hoard to understand and describe the patterns and reasons for hoarding, experiences with decluttering and the impact of hoarding disorder on significant others and society in the context of Malta.
3. I am aware that the interview will take approximately one hour.
4. I understand that the interview is to be conducted in a place and at a time that is convenient for me.
5. I am aware that this interview will be audio recorded and transcribed (written down as it has been spoken).
6. I am aware that the transcripts will be coded and that this data will be stored securely and separately from any codes and personal data.
7. I am aware that the researcher is the only person who has access to this data. The academic supervisor/s and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes.
8. I am also aware that the coded audio-recordings and transcripts will be stored on the researcher's personal computer that is password protected and in an encrypted format. Any material in hard-copy form will be placed in a locked cupboard and kept until results are published.

9. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.
10. I also understand that I am free to accept, refuse or stop participation at any time without giving any reason. This will have no negative repercussions on myself and that any data collected from me will be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised).
11. I also understand that my contribution will serve to help us gain a better understanding about hoarding and its impact on these individuals, this may assist in the improvement of practice and also to raise awareness about hoarding in Malta.
12. If I feel that the interview has distressed me in any way, Ms [REDACTED] psychologist will be available to provide a service at no financial costs on my part. Distress may be present since talking about the experience might cause emotional distress.
13. I understand that under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, I have the right to access, rectify, and where applicable ask for the data concerning me to be erased.
14. I also understand that once the study is completed and results are published the data will be retained in anonymous form. Any personal details will be destroyed.
15. I will be provided with a copy of the information letter and consent form for future reference.
16. I have read and understood the points and statements of this form. I have had all the questions answered to my satisfaction, and I agree to participate in this study.

Participant: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

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**Michelle Elise Demanuele**

Researcher

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**Prof. Josianne Scerri**

Research Supervisor

# Appendix B: Maltese Version

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## Formula ta' Kunsens tal-Parteċipanti

### **Aftermath of an explosion: Lived experiences of compulsive hoarders**

Jien, hawn taht iffirmat/a, nagħti l-kunsens tiegħi biex nieħu sehem fl-istudju mmexxi minn Michelle Elise Demanuele. L-għan ta' dan id-dokument hu li jiġu speċifikati t-termini tal-parteċipazzjoni tiegħi f'dan l-istudju ta' riċerka.

1. Jien ingħatajt informazzjoni miktuba u verbali dwar l-għan tal-istudju u l-mistoqsijiet kollha twiegħbu.
2. Nifhem li se nkun qed nipparteċipa fi studju, fejn ir- Riċerkatriċi ħa tinvestiga u tesplora xi tfisser l-esperjenza għal persuna li tbagħti b' diżordni ta' "hoarding" u x' impatt thalli din id-disordni fuq nies ohra u s-socjetà fil-kuntest ta' Malta.
3. Naf li l-intervista se jieħu madwar siegħa.
4. Nifhem, li l-laqqgħa se ssir f' post u ħin konvenjenti għalija.
5. Jien konxju/a li r-risposti tiegħi se jkunu qed jiġu rrekordjati permezz ta' tagħmir awdjo u se jinkitbu r-risposti fuq formuli apposta.
6. Naf ukoll li se ssir kodifikazzjoni tad-data u din se tinzamm separatament mill-informazzjoni personali.
7. Naf ukoll li r-Riċerkatur / Riċerkatriċi hu/hi l-uniku/a persuna li se jkollu/jkollha aċċess għal din l-informazzjoni, filwaqt li s-Supervizur/a akkademiku/a (jew is-Supervizuri akkademiċi) u l-eżaminaturi se jkollhom aċċess għal data kkodifikata biss. Is-Supervizuri akkademiċi u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika.
8. Barra min hekk, naf li l-awdjo rrekordjat u d-data se jinħażnu fuq il-kompjuter personali tar-Riċerkatur jew Riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u

li hi protetta b'password. Barra minn hekk, naf li l-materjal stampat se jitqiegħed f'post sikur u se jinżamm sakemm joħorġu r-riżultati.

9. Naf li l-identità tiegħi u l-informazzjoni personali mhuma se jinkixfu mkien fit-teżi, fir-rapporti, fil-preżentazzjonijiet u/jew fil-pubblikazzjonijiet li jistgħu jirriżultaw minnha.
10. Nifhem ukoll li jien liberu/a li naċċetta, nirrifjuta jew inwaqqaf il-partecipazzjoni f'kull ħin bla ma nagħti raġuni. Dan mhux ħa jkollu riperkussjonijiet negattivi fuqi. Nifhem ukoll li la darba nirtira minn dan l-istudju, l-informazzjoni miġbura se tithassar. Id-data se tinħażen b'mod anonimu kemm-il darba jkun impossibbli li tithassar (eż. jekk diġà kienet anonimizzata).
11. Nifhem ukoll li l-kontribuzzjoni tiegħi ser isservi biex dan l-istudju jista' jgħin biex ikollna aktar għarfien dwar dwar l-“hoarding” u l-impatt tiegħu fuq dawn l-individwi, dan jista' jgħin fit-titjib tal-prattika u wkoll biex iqajjem kuxjenza dwar l-hoarding f'Malta. Kull informazzjoni miġbura tintuża biss għall-għan jew l-għanijiet ta' dan l-istudju.
12. Madanakollu, jekk inħoss li l-istudju ħoloqli diffikultà u nixtieq li niddiskuti x'qed inħoss, naf li [REDACTED] psikologista se tkun qed tipprovdi servizz ta' għajjnuna mingħajr ħlas min-naħa tiegħa peres li jista jinholoq certu dwejjaq dwar li wiehed qed jitkellem dwar l-esperjenza tiegħu.
13. Nifhem ukoll, li skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti rilevanti tar-regolamenti msemmija, jiena għandi d-dritt li naċċessa, nirretifika, u fejn japplika nitlob sabiex tithassar id-data li tikkonċernani.
14. Naf ukoll li meta jintemm l-istudju u r-riżultati jkunu ppubblikati, l-informazzjoni personali miġbura tithassar.
15. Fl-aħħar nett, naf ukoll li se ningħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex inkun nista' naċċessahom fil-futur.
16. Jien qrajt u fhimt il-punti u d-dikjarazzjonijiet f'din il-formula. Inħossni sodisfatt/a bit-twegibiet li ngħatajt għall-mistoqsijiet li kelli, u qed naċċetta minn jeddi li nipparteċipa f'dan l-istudju.

Partecipant: \_\_\_\_\_

Firma: \_\_\_\_\_

Data: \_\_\_\_\_

\_\_\_\_\_  
Michelle Elise Demanuele  
Ricerkatriçi

\_\_\_\_\_  
Profs. Josianne Scerri  
Supervisura

# Formula ta' Informazzjoni għall-Parteċipanti

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## Aftermath of an explosion: Lived experiences of compulsive hoarders

Għażiż/a Parteċipant/a,

Jiena Michelle Elise Demanuele, fil-preżent qed insegwi Masters Degree F' Mental Health Nursing fi hdan l-University of Malta. Bħala parti mir-rekwiżiti tal-kors, qed nagħmel riċerka bit-titlu, *“Aftermath of an explosion: Lived experiences of compulsive hoarders”*. L-għan ta' dan l-istudju hu li ninvestiga u li nesplora xi tfigħer l-esperjenza għal persuna li tbaġhti b' diżordni ta' “hoarding” u biex nifem u niddekrivi l-mudelli u r- raġunijiet għall-“hoarding”, kif ukoll l-esperjenzi tagħhom meta jigu biex jarmu u jizbaraw u l-impatt li thalli din id-disordni fuq nies ohra u s-socjetà fil-kuntest ta' Malta.

Is-sehem tiegħek f'dan l-istudju jista' jgħin biex ikollna aktar għarfien dwar l- “hoarding” u l-impatt tiegħu fuq dawn l-individwi, dan jista' jgħin fit-titjib tal-prattika u wkoll biex iqajjem kuxjenza dwar l-hoarding f'Malta. Kull informazzjoni miġbura tintuża biss għall-għan jew l-għanijiet ta' dan l-istudju.

Bħala parteċipant/a inti se tintalab tiegħu sehem f' intervista sabiex nesploraw l-esperjenzi tiegħek. Jekk taċċetta li tiegħu sehem inti tintalab sabiex tiltaqa' mar-riċerkatriċi. L-intervista se tiegħu madwar siegħa u ssir f' post u f'ħin li jkun konvenjenti għalik.

M'intix obligat/a li twieġeb il-mistoqsijiet kollha u tista' twaqqaf l-intervista fi xħin trid mingħajr ma tagħti l-ebda raġuni. Dan mhux ha jkollu riperkussjonijiet negattivi fuqek u l-informazzjoni li tingabar mingħandek tithassar. Id-data se tinħażen b'mod anonimu kemm-il darba jkun impossibbli li tithassar (eż. jekk diġà kienet anonimizzata).

Sakemm m'għandek l-ebda oġġezzjoni, ir-risposti tiegħek se jiġu rrekordjati bl-awdjo. Nassigurak li se tinżamm il-kunfidenzjalità matul l-istudju kollu u l-identità tiegħek u kull informazzjoni personali miġbura mhuma se jiġu żvelati mkien fit-teżi, ir-rapporti, il-prezentazzjonijiet u/jew il-pubblikazzjonijiet li jistgħu jirriżultaw minnha. Kull tagħrif miġbur se jiġi psewdonomizzat, jiġifieri id-data kollha se tkun protetta permezz ta' sistema ta' kodiċi u miżmuma separatament mill-informazzjoni personali.

Ir-riċerkatriċi biss ser ikollha aċċess għall-informazzjoni miġbura, filwaqt li s-superviżura akkademika u l-eżaminaturi se jkollhom biss aċċess għal data kkodifikata. Is-Superviżura u l-eżaminaturi jista jkollhom bżonn aċċess għall-informazzjoni miġbura għal skop ta' verifika.

L-awdjo rrekordjat u d-data kollha se jinħażnu fuq il-kompjuter personali tar-riċerkatriċi permezz ta' kodifikazzjoni tad-data (data encryption) u li hi protetta b'password. Barra minn hekk, il-materjal stampat se jinqafel f'post sigur.

F'każ li tħoss li l-intervista ħolqitlek diffikultà u tixtieq li tiddiskuti x'qed tħoss ma' professjonist/a mill-qasam tal-kura tas-saħħa, [REDACTED] psikologista se tkun qed tipprovdi servizz ta' għajjnuna mingħajr ħlas min-naħa tiegħek. Biex tagħmel kuntatt mas-sinjura [REDACTED] ċempel fuq [REDACTED] jew ibgħat fl-indirizz elettroniku [REDACTED]

Il-parteciċipazzjoni tiegħek f'din l-intervista hija għażla għal kollox volontarja u inti ħieles/ħielsa li taċċetta jew tirrifjuta li tiegħu sehem mingħajr ma jkun hemm konsegwenzi fil-konfront tiegħek. Se tingħata kopja tal-ittra ta' informazzjoni u tal-formula ta' kunsens sabiex tkun tista' taċċessahom fil-futur. Barra minn hekk, skont ir-Regolamenti Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali li timplimenta u tispeċifika aktar il-provvedimenti rilevanti tar-regolamenti msemmija, inti għandek id-dritt li taċċessa, tirretifika, u fejn japplika titlob sabiex titħassar id-data li tikkonċerna lilek. L-informazzjoni personali kollha se titħassar hekk kif jintemm dan l-istudju ta' riċerka u jkunu ppubblikati r-riżultati miksuba sa Awissu 2023.

Dan l-istudju ġie approvat mill-Kumitat għall-Etika fir-Riċerka fi ħdan il-Fakultà tax-Xjenzi tas-Saħħa fl-Università ta' Malta.

Grazzi ħafna tal-ħin u s-sehem tiegħek f'dan l-istudju. F'każ li jkollok xi mistoqsijiet jew tixtieq tiċċara xi ħaġa, tista' ċċempilli fuq [REDACTED] jew tibgħatli email fuq [REDACTED]. Tista' wkoll tikkuntattja lis-Supervizura Profs. Josianne Scerri fuq [REDACTED] jew billi tibgħat email fuq [REDACTED].

Dejjem tiegħek,

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Michelle Elise Demanuele  
Riċerkatriċi

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Profs. Josianne Scerri

# Appendix C: Interview schedule

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## INTERVIEW SCHEDULE

**English Version: Interview Guide**

**Duration: 1 hour**

### **Aftermath of an explosion: Lived experiences of compulsive hoarders**

- 1) Can you please share with me your experience of how you started hoarding?
- 2) What items do you hoard and why do you do it?
- 3) How does this affect you in your daily life? That is regarding your family, friends, activities of daily living, work, how you deal with others, leisure activities etc.
- 4) How does this behaviour affect your feelings, thoughts, and reactions?
- 5) Can you describe any helpful means of coping with this hoarding behaviour?
- 6) Can you share your experiences of any support that you receive or would like to receive relating to your hoarding behaviour?

# Appendix C: Maltese version

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## Verżjoni bil-Malti

### Gwida Għall-Intervista

#### Tuwl tal- intervista: Siegħa

#### **Aftermath of an explosion: lived experiences of compulsive hoarders**

- 1) Tista 'jekk jogħġbok taqsam miegħi l-esperjenza tiegħek ta' kif bdiet din l-imġieba ta 'hoarding?
- 2) X'oġġetti iġemma u għaliex tagħmel dan?
- 3) Dan kif jaffettwak fil-ħajja tiegħek ta' kuljum? Dan rigward il-familja tiegħek, il-ħbieb, l-attivitajiet tal-għajxien ta' kuljum, ix-xogħol, kif tmur ma' haddieħor, aktivitajiet ta' divertiment eċċ.
- 4) Din l-imġieba kif taffettwa s-sentimenti, il-ħsibijiet u r-reazzjonijiet tiegħek?
- 5) X' jghinek tkampa ma' din l-imġieba ta 'hoarding?
- 6) Tista' taqsam l-esperjenzi tiegħek ta' kwalunkwe appoġġ li tircievi jew tixtieq tircievi b'rabta mal-imġieba tal-hoarding tiegħek?

# Appendix D: Permission from hospital management

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26th April 2022

██████████

██████████

██████████

██████████

## **Re: Research Study: Aftermath of an explosion: Lived experiences of compulsive hoarders**

Dear Dr ████████,

My name is Michelle Elise Demanuele, I am a staff nurse currently working at Mount Carmel Hospital Outreach zone 3. I am presently reading for a Master of Science degree in Mental Health Nursing at the University of Malta. As part fulfilment of my study requirements, I am expected to conduct a research study. I intend to explore the lived experiences of people who compulsively hoard in Malta. This will be done by conducting an initial in-depth audio-recorded interview with five to ten informal patients. The duration of the interview is expected to be about 1 hour. The inclusion criteria for my research are adults i.e., eighteen years and over and who are interested in sharing their experience of hoarding. I am aware that I must strictly adhere to ethical issues especially related to informed consent and confidentiality, and that I have to consult my research supervisor, Prof. Josianne Scerri throughout the research process. Moreover, I will be seeking ethical approval from the University Research Ethics Committee. Participants will be recruited with the assistance of intermediaries namely, three charge nurses working Outreach teams. The intermediary will approach potential participants and provide an information letter explaining the nature of the present study. Any individual who is interested to participate can contact me on the details provided in the participant information letter. I am therefore asking your kind permission to allow me to access participants in the manner described. Your support for this research study is greatly appreciated. Whilst thanking you in advance, should you require further details regarding my study, please do not hesitate to contact me

on [REDACTED] (email: [REDACTED]) or my supervisor Prof. Josianne Scerri on [REDACTED] (email: [REDACTED]).

Yours Sincerely,

\_\_\_\_\_

Michelle Elise Demanuele

Student Research Supervisor

M.Sc Mental Health Nursing Student

\_\_\_\_\_

Prof. Josianne Scerri

\_\_\_\_\_

Dr [REDACTED]

Chief Executive Officer

# Appendix E: Ethics approval

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Research Ethics HEALTHSCI [REDACTED].mt>

8 Aug 2022,  
09:06

Dear Michelle,

I am pleased to inform you that UREC-DP has reviewed the application in caption, which was found to be consistent with the University of Malta Research Code of Practice.

Approval is therefore granted.

I wish you good luck with your studies.

Sincere Regards,

[REDACTED]

FREC Secretary

University of Malta

**Faculty of Health Sciences**

[REDACTED]

[REDACTED]

# Appendix F: Psychologist Agreement Letter

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19<sup>th</sup> April 2022

## Psychologist Agreement Letter

I, Ms [REDACTED] declare that research study ‘Aftermath of an explosion: Lived experiences of compulsive hoarders’ was described to me in detail by the researcher Ms Michelle Elise Demanuele. As a professional psychologist, I understand that the study participants may experience some psychological distress during the interview for which support may be needed. In view of this, they will be offered the opportunity to be referred to me for counselling. This would incur no financial cost to the participants or researcher.

Thanking you for your co-operation and availability,

Name of Researcher: Michelle Elise Demanuele

Contact Details [REDACTED]

Email: [REDACTED]

Researcher’s Signature: \_\_\_\_\_

Research Supervisor: Prof. Josianne Scerri

Contact details: [REDACTED]

Email [REDACTED]

Research Supervisor Signature: \_\_\_\_\_

Psychologist’s Name & Surname: [REDACTED]

Contact details [REDACTED]

Email [REDACTED]

Psychologist Signature: \_\_\_\_\_

# Appendix G: Authenticity and research ethics form

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L-Università  
ta' Malta

FACULTY/INSTITUTE/CENTRE/SCHOOL of Health Sciences

## DECLARATIONS BY POSTGRADUATE STUDENTS

Student's Code [REDACTED]

Student's Name & Surname Michelle Elise Demanuele

Course Masters in mental health nursing

Title of Dissertation Aftermath of an explosion: Lived experiences of compulsive hoarders

### (a) Authenticity of Dissertation

I hereby declare that I am the legitimate author of this Dissertation and that it is my original work.

No portion of this work has been submitted in support of an application for another degree or qualification of this or any other university or institution of higher education. I hold the University of Malta harmless against any third party claims with regard to copyright violation, breach of confidentiality, defamation and any other third party right infringement.

### (b) Research Code of Practice and Ethics Review Procedures

I declare that I have abided by the University's Research Ethics Review Procedures. Research Ethics & Data Protection form code [REDACTED]

As a Master's student, as per Regulation 77 of the General Regulations for University Postgraduate Awards 2021, I accept that should my dissertation be awarded a Grade A, it will be made publicly available on the University of Malta Institutional Repository

[REDACTED]

Michelle Elise Demanuele

Signature of Student

Name of Student (in Caps)

6/6/2023

Date