Navigating the multi-dimensional landscape of self-neglect practice: An ethnographic study exploring social workers' experiences.

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Declaration of Ownership:

I hereby declare that this thesis has not been, and will not be, submitted in whole or in part to another University for the award of any other degree.

Signature:..Maria Brent.....

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Abstract

This thesis presents an ethnographic study of local authority social workers' experiences of working with people who self-neglect. Self-neglect has been brought into focus in England with the implementation of the Care Act 2014 and its Statutory Guidance, which identifies self-neglect as a category of abuse and neglect within safeguarding adult procedures. This change requires local authorities to assess whether self-neglect concerns meet the safeguarding criteria under s.42 of the Care Act, with social workers often taking the primary role in this process. However, few studies explore how social workers experience this work. This empirical study contributes to remedying this knowledge gap by being alongside social workers undertaking home visits and asking them how they experience working with self-neglect in the following contexts: the law and policy framework that informs self-neglect work, organisational responses, multi/interagency working, and the impact of self-neglect work on the social workers themselves.

A thematic analysis of the findings identified that social workers' experiences of self-neglect work are multi-faceted. Their work is located within a practice framework that requires them to navigate a multi-dimensional landscape of law and policy, organisational and multi/inter-agency expectations, professional values, and personal relationships. This often contradictory interface can result in ethical challenges for social workers who struggle to meet managerial demands in what they describe as a 'case management' model that can deny them time to build the critical relationships needed in self-neglect work. The findings identified that social workers could be adversely affected by the sensory and emotional impact of self-neglect work, but they struggled to recognise or articulate this in professional supervision. The evidence from this study suggests that social workers need a safe space to explore the sensory, emotional and ethical impact of self-neglect work, and these impacts need to be understood by managers, partner agencies and more broadly within organisational and community settings to ensure social workers gain the appropriate support in this growing area of practice.

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Glossary of terms

CA	Care Act
CF	Compassion Fatigue
DH	Department of Health
DHSC	Department of Health and Social Care
LA	Local Authority
MCA	Mental Capacity Act
MSP	Making Safeguarding Personal
SAB	Safeguarding Adults Board
SARs	Safeguarding Adult Reviews
SCRs	Serious Case Reviews
SI	Symbolic Interactionism

Chapter One. Introduction

1.1 An overview

This thesis explores how social workers experience working with adults who self-neglect. The motivation for this topic is two-fold. First, my own experience as a local authority social worker working with people who self-neglect has had a profound impact on me. I wanted to make sense of my own experience and understand how other social workers experience this work. Second, since 2015 self-neglect has been identified as a category of abuse and neglect within the Statutory Guidance to the Care Act 2014 (Department of Health and Social Care (hereafter DHSC), 2022). The introduction of self-neglect into the Statutory Guidance has placed a duty on local authorities to respond to concerns of self-neglect where previously self-neglect sat outside of adult safeguarding procedures as there was no third party involved. Local authority social workers have a primary role in assessing concerns of self-neglect and I am interested in how they are experiencing these changes and how, if at all, the changes have affected their practice.

There is a growing recognition of the complexity and challenges of self-neglect work in England (Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Orr, Preston-Shoot and Braye, 2019; Martineau et al., 2021) and its increasing presence in Safeguarding Adults Reviews (SARs) (Martineau et al., 2019; Martineau and Manthorpe, 2020; Preston-Shoot, 2019; 2021; Preston-Shoot et al., 2020). It is suggested that 20% of social workers' caseloads involve self-neglect when working with older people or those affected by mental health issues (Barnett, 2018), but few studies explore social workers' direct experiences of this work. Rare examples include Day, McCarthy and Leahy-Warren (2012); Doron, Band-Winterstein and Naim (2013); Braye, Orr and Preston-Shoot (2014) and Mason and Evans (2020). There is also limited attention given to what interventions are effective; some examples include Brown and Pain, (2014) and Anka et al. (2017). This scarcity has resulted in a mounting call for research that explores this growing area of practice (James Lind Alliance, 2018).

This thesis partly addresses this call by undertaking an ethnographic case study that explores how social workers experience and make sense of self-neglect work. The participants are 10 social workers based in Adult Community Teams in five different authorities working with adults with mental capacity who self-neglect. The data was collected by observing social workers undertaking home visits and conducting interviews with them before and after the visit to explore their experiences. Social workers were also asked how law, policies and procedures that guide self-neglect work affect their practice within their organisation. My own reflections on the home visits and interviews were captured using a reflective diary.

This introductory chapter explains my motivation for undertaking this thesis, which as explained, is twofold. My own practice experiences have been a catalyst to explore how other social workers experience working with self-neglect, and in the next section I share a personal case study from practice to illustrate my experiences. My second motivation for undertaking this thesis is to explore how social workers experience working with the legal and policy framework that informs self-neglect work following the implementation of the Care Act 2014 and supporting Statutory Guidance (DHSC, 2022). Chapter Two provides an overview of the legal and policy framework that informs self-neglect work to provide a context for this discussion. This introductory chapter concludes by setting out the overall structure for the remainder of this thesis and summarises what each chapter intends to address.

1.2 A personal perspective

A key motivator for undertaking this study is my own practice experience. Before my current role as a social work academic, I worked for fifteen years as an Adults Community Social Worker, which

included working with people who self-neglect. One woman I worked with, whom I will call Mary, had a profound emotional impact on me. Mary was self-neglecting her personal care and home environment and working with her uncovered a range of emotions that left me feeling overwhelmed and with questions that, years later, I am still trying to reconcile. I can vividly recall the details of my first home visit to her over 20 years ago.

Mary was in her late 70s, living alone on the top floor of a small, terraced house. She had been referred to the adults' community team due to the neighbours' complaints of an offensive smell emitting from Mary's flat, and I had been allocated to undertake an assessment. Mary had lived in the area all her life. Her husband had died five years ago and they had no children. She suffered from a painful skin condition, cellulitis, which affected her mobility, and now struggled to get out of her flat. On my first visit, I remember standing at Mary's front door and being overwhelmed by the smell. The downstairs neighbour, a young mother, opened the front door holding her baby. I explained I was visiting Mary and the neighbour became very upset and started to shout at me, saying how the stench from Mary's flat was ruining her life. The neighbour blamed me, social services and housing for allowing Mary to live like this. I tried to remain calm but remember feeling apprehensive as I walked up the stairs to Mary's flat and the stench increased. I was worried about what I would be presented with as I knocked on her front door. To my relief, an older woman opened the door with a welcoming smile. She was appropriately dressed, wearing an apron, and her hair was brushed, but her clothes were extremely dirty. I distinctly remember her apron. I could just make out the flower design through the layers of ingrained dirt. I remember thinking she had an apron that was supposed to keep her clean, but it was filthy. She invited me in and as I walked through the hallway my feet were sticking to the carpet due to the layers of dirt. I could see an accumulation of plastic bags piled up in the corridor. I remember thinking it might be faeces as the stench was so overwhelming. Mary invited me into her kitchen and offered me a seat and a cup of tea. I was presented with a microcosm of normality among the dirt and the stench. A teapot, cups and saucers were set out on a small table with two heavily stained seats. Mary offered me a seat and I surreptitiously slipped my bag underneath as I sat down

to protect my clothes. I tried to hide this from Mary so as not to offend her. I politely declined the tea and made an excuse that I had just had a drink with lunch. Mary was open and willing to engage, and we quickly built a good rapport. She explained that she had problems since her husband died and could not get out due to her health issues. Mary also explained that her bathroom was now so cluttered that she could not use it anymore and 'went to the loo' in plastic bags, which I could see were piled up in the corridor and the bathroom. Whilst I was there, Mary excused herself, left the room, and returned around 10 minutes later, clutching a Sainsbury's plastic bag and tying a knot in it. Like a photograph etched in my mind, I remember the image of her sitting in front of me with the bag on her lap. I remember thinking, I am sure Mary has just defecated in that bag and now she is sitting opposite me with the bag in her lap, drinking her cup of tea as if nothing was out of the ordinary. The façade of normality was a barrier to me asking her directly if she had defecated in the bag. At that moment, I remember feeling completely overwhelmed. I could not process what I was experiencing in terms of the sensory overload, the sights, smells and emotions, what my role was, what decisions I needed to make and what action I needed to take. I returned to my team and shared my story with colleagues to try to make sense of what had happened. Retelling my story helped, but it did little to alleviate the internal feelings of shock, helplessness, and concern. I remember feeling bewildered and thinking, 'How can it be right that a woman like Mary could live like that?' I had come into social work to try to support people. I was deeply troubled that all I could do was walk away and leave her in this state, in filth, isolated, at risk and vilified by her neighbours. After this initial visit, I continued to work with Mary for several weeks. We built up a trusting relationship and I tried to encourage her to accept support, but she consistently declined. This work was prior to the introduction of the Mental Capacity Act 2005. However, Mary had mental capacity and was not showing any evidence of a mental health disorder, although it was suspected she might have been depressed following the death of her husband. Unfortunately, Mary had a stroke and was admitted to a nursing home and my work with her ceased.

I worked with many complex and challenging cases over the years, but the feelings Mary evoked are still vivid and, to some extent, unresolved. As I became more experienced, I developed practical

coping mechanisms when going on home visits, i.e., using my trusted plastic-covered handbag to discreetly sit on during some home visits as the chairs were often soiled; however, these practical strategies masked a much deeper emotional reaction. Some conditions were so extreme that I would feel emotionally shaken and physically drained during and after the visit, and my feelings and thoughts were often confused and conflicted. It was hard to try to listen and respect the person's views and remain non-judgemental whilst feeling at times like a helpless bystander, shocked and overwhelmed by the person's level of self-neglect. Although I received professional supervision, I did not have the opportunity to explore these experiences in any meaningful depth. I sometimes felt ashamed and embarrassed to talk openly to colleagues about my visceral physical and emotional reactions to these situations. As a social worker, I believed I should be professional, toughen up, and get on with the job. When I did share these experiences with colleagues and heard their stories of working with self-neglect it provided some release. It gave me a sense that I was not alone in experiencing these feelings and situations that were often hard to comprehend and so far removed from anything I had experienced before. This experience, and others working with self-neglect, have motivated me to undertake this study to try to make sense of my own experiences and to understand how other social workers experience self-neglect work.

1.3 Structure of the thesis

This introductory chapter explains my motivation for undertaking this study, supported by a case study from practice. This is followed by Chapter Two, which provides an overview of key legal and policy drivers that inform self-neglect work. As explained, I am interested in exploring how social workers experience the legal and policy framework that informs self-neglect work, and this chapter provides a context for this exploration.

Chapter Three presents a literature review that aims to establish what we know about social workers' experiences of working with self-neglect. The chapter begins by explaining my methodological approach for undertaking this literature review, followed by material that provides a background context for understanding self-neglect and an explanatory framework for this study. This chapter then progresses to consider specifically empirical research that answers my research question and explores how practitioners experience the organisational context, multi/interagency working, and the impact of working with self-neglect. These themes are drawn on to develop my research questions, which provide the overall framework of this thesis.

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Chapter Four explains the methodological approach I took. It explains the rationale for employing a qualitative, ethnographic approach, drawing on Symbolic Interactionism as a theoretical framework. The practical steps I undertook to collect the data are explained, alongside consideration of this approach's limitations and ethical considerations.

Chapter Five presents a thematic analysis of the findings. These are drawn from the interviews and direct observations of social workers undertaking home visits to people who self-neglect and include my observations and reflections on undertaking this fieldwork.

Chapter Six discusses the findings in relation to the key themes identified in the literature review in Chapter Three. Using Symbolic Interactionism as an analytical lens, suggestions are made regarding how social workers make sense of the multi-dimensional and sometimes conflicting relationships within self-neglect work. This chapter also considers surprise findings that did not appear to have been explored in the literature. It explains how undertaking new reading and using the analytical lens of Goffman and Facework (1955; 1959) opens up questions about what social workers know and show in their relationships with others in self-neglect work.

Chapter Seven brings this thesis to a conclusion. It identifies this study's key contributions and limitations and summarises my research journey. Suggestions for future research are put forward alongside my final concluding thoughts.

Chapter Two. The legal and policy framework of self-neglect work

2.1 Introduction

My experience as a local authority social worker has shown me that practitioners are not isolated individuals but dynamic actors interacting and working within organisational systems informed by law, policies and procedures. To understand social workers' experiences, I needed to explore this dimension of practice. A discussion I had with a safeguarding lead whose local authority agreed to become involved in this study has stayed with me. They described working with self-neglect as 'the elephant in the room,' adding that 'even with all this legislation, at times we still do not know what to do.' This comment resonated with my own experience, and I wanted to explore how social workers experience working with the legal and policy framework that informs self-neglect work following the implementation of the Care Act (hereafter CA) 2014 and Supporting Guidance (DHSC, 2022). To set the context for this exploration, the following provides an overview of the legal and policy context that informs self-neglect work in England, elements of which are returned to later in this thesis. It introduces the CA and explains its relevance for self-neglect and adult safeguarding.

2.2 The Care Act, safeguarding and self-neglect

The introduction of the CA and supporting Statutory Guidance (DHSC, 2022) was the most significant legislative change to adult social care since the National Assistance Act 1948 (Spencer-Lane, 2020). The Law Commission (2008; 2010; 2011) identified that the patchwork of legislation previously provided under the umbrella of the National Health Service and Community Care Act (NHSCCA) 1990 was outdated and required a significant overhaul. Within this review, the Law Commission (2011) also recognised that provisions for self-neglect needed to be included in any forthcoming legislation. The CA repealed a range of legislation and embedded what is described as the personalisation agenda, an overarching term for a range of policy reforms intended to transform adult social care (Department of Health (DH), 2005; 2006; 2008; H.M. Government, 2007). Through personal budgets and direct payments (DH,1996), personalisation promised increased flexibility and control to those receiving

services. However, a climate of austerity, sustained cuts and a lack of investment and planning in developing the adult social care workforce have presented significant barriers to local authorities actualising the policy objectives of the personalisation agenda (National Audit Office, 2018).

The CA introduced significant reforms which included a national eligibility for services following assessment (s.9) and placed carers' rights on the same legal footing as the person they care for (s.10). Most significantly for self-neglect, the CA put safeguarding adults on a legal footing for the first time (s.42-47), and on its implementation in 2015, self-neglect became included as a category of abuse and neglect within the CA Statutory Guidance, where it was defined as a 'wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding' (DHSC, 2022, para 14.17). Prior to the CA, local authorities' responses to safeguarding adults were guided by 'No Secrets' (DH, 2000), a multi-agency policy document issued under s.7 of the Social Services Act 1970. No Secrets identified abuse as 'A violation of an adult's human and civil rights by any other persons,' and self-neglect was not recognised within the No Secrets guidance as a safeguarding concern as it did not involve a third party. Now, under Section 42(1), the CA places a duty on local authorities to explore safeguarding concerns. If a person has care and support needs, is at risk of abuse or neglect and because of their needs is unable to protect themselves, the local authority is required to 'make enquires' (s.42(2)). A caveat on self-neglect states that 'A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour' (DHSC, 2022, para 14.17). This ambiguous guidance requires a judgment by the local authority, usually a social worker, to take the often difficult decision to decide on whether self-neglect is a lifestyle choice and if the person can control their own behaviour.

The CA also places a legal duty on local authorities to establish Safeguarding Adults Boards (SABs) (s.43). A key responsibility of SABs is to arrange a Safeguarding Adult Review (SAR) when an adult

in its area dies due to abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked together more effectively to protect the adult. Before the introduction of the CA SARs were called Serious Case Reviews (SCRs), and these terms are used interchangeably in the literature depending on if they are pre- or post-CA. The intention of a SAR is not to apportion blame but to explore what could have been done differently to have prevented harm or death 'so that lessons can be learned from the case and those lessons applied to future cases to prevent similar harm occurring again' (DHSC, 2022, para 14.168).

2.3 Making safeguarding personal and strengths-based approaches

In England, the government's emphasis on personalised approaches continued with the policy initiative 'Making Safeguarding Personal' (MSP) (2014), embedded in the CA through its supporting guidance. MSP aims to provide a practice framework that moves from a paternalistic approach to safeguarding adults to focusing on the person's involvement and places the person's wishes and desired outcomes as central guiding principles throughout an assessment. Although not cited in the CA itself, the Statutory Guidance states:

> Making safeguarding personal means it should be person-led and outcome focused. It engages the person in a conversation about how best to respond to their safeguarding situation in a way that enhances their involvement, choice and control as well as improving quality of life, well-being and safety (DHSC, 2022, para. 14.15).

MSP is informed by a strengths-based approach (Saleebey, 2009) and advocates that practice shifts from what is perceived as a deficit, risk paradigm that dominates statutory social work to engaging reflexively with risk, working in collaboration with the person, exploring their strengths and desired outcomes (Stanley, 2016). Championed by the Chief Social Worker for Adults (Preston-Shoot, Cooper and Romeo, 2015), with further practice guidance issued by the DHSC (2019), a strengths-based practice framework has been embedded in local authorities as the way forward for adult social work.

2.4 Choice and control

The underpinning philosophy of personalisation, the CA, MSP and strengths-based approaches hold the central principle that the person receiving services is the expert in directing their care, working on an underlying premise that people are willing to engage with social workers to facilitate this process. The philosophy of the CA and MSP can present practice and ethical challenges for social workers as, on the one hand, they advocate empowerment, but this can prove problematic when self-neglecting behaviours may require social workers to intervene as part of their professional duty to protect. These challenges are exacerbated if the person does not want to engage with services (explored later in 3.3). Pivotal in the decision-making process of whether a local authority has the legal authority to intervene in a person's life if they are self-neglecting and refusing support is whether a person has the mental capacity to make decisions about their self-care and the Mental Capacity Act (hereafter MCA) 2005 provides the legal framework that informs this process.

The central ethos of the MCA is that a person must be assumed to have capacity unless it is established (through application of the legal process set out in the Act) that they do not. Furthermore, section 1(4) states, 'A person is not to be treated as unable to make a decision merely because he makes an unwise decision'. The House of Lords Post Scrutiny Report (2014) identified that local authorities and partner agencies struggle to apply the MCA appropriately, and it is an 'add-on' instead of being central to practice. Further concerns identify a punitive rather than an empowering application of the MCA and that 'There are prevailing cultures of paternalism (in health) and risk-aversion (in social care) (author's brackets) preventing the Act from becoming widely known or embedded. The empowering ethos has not been delivered' (Summary, House of Lords, 2014).

Furthermore, rights under the European Convention on Human Rights (ECHR), enshrined in UK law under the Human Rights Act (HRA) 1998, particularly the right to private and family life (Article 8), the right to liberty (Article 5) and the right to freedom from torture and inhuman or degrading treatment (Article 3), are critical in the assessment of self-neglect. People who self-neglect may be living in inhuman conditions that put their lives at risk, but their rights to make these choices are protected and the legal provisions for local authorities to intervene are limited.

One option for intervention when working with self-neglect was repealed with the introduction of the CA. The National Assistance Act (hereafter NAA) 1948 s.47 provided a legal provision for the removal of a person if they were 'Suffering from grave chronic diseases or, being aged, infirm or physically incapacitated are living in unsanitary conditions are unable to devote to themselves, and are not receiving from other persons, proper care or attention'. Drawing on my own practice experience, using s.47 of the NAA as a legal intervention was rare due to an uncomfortable feeling that there would be a breach of human rights if the person in question had the mental capacity to make their own decisions. The CA does not appear to offer a commensurate legal provision to replace NAA s.47. Social workers have to consider a range of more expansive legal provisions, which include the Environmental Protection Act 1990; Housing Act 1985, 1996; Animal Welfare Act 2006; Public Health Act 1936, 1961 and 1984 that may need to be considered as part of an assessment depending on the level of self-neglect and how it is impacting the person, their property and the wider community.

Furthermore, the MCA 2005 (s.16 (2)), Mental Health Act 1983 (s.135), and the Police and Criminal Evidence Act 1984 (s.17) can provide legal authority to gain access to adults at risk where there are safeguarding concerns. In Scotland, the Adult Support and Protection (Scotland) Act 2007 and in Wales, the Social Services and Well-being Act 2014 provide access to records and power of entry in certain circumstances if there are concerns that an adult is at risk of abuse or neglect. These powers are valued by social workers in Scotland, where it is suggested that legal provisions in safeguarding

work can be helpful, when used proportionately, alongside existing social work skills (Mackay and Notman, 2017).

This chapter has provided an introductory overview of the law and policy framework that informs self-neglect work, elements of which will be returned to. It sets the context for the study and highlights the complex and often competing legal imperatives social workers must navigate when working with self-neglect, particularly in balancing a person's autonomy with a duty to protect. It is perhaps not surprising that social workers can struggle to navigate what can feel like a contradictory legal and policy landscape. At the time of writing, it has been seven years since the CA's implementation, and safeguarding adults, including working with self-neglect, continues to be an essential role for local authority adult social workers where their expert assessment and intervention skills are critical when working with complex family dynamics and supporting adults at risk (DHSC, 2022). The following chapter presents a literature review that explores what we know about working with self-neglect and provides an explanatory framework for the study.

Chapter Three. Social work and self-neglect, a literature review

3.1 Introduction

This thesis explores my research question, 'How do social workers experience and make sense of self-neglect work?' This chapter presents a literature review that examines what we know about this topic and identifies gaps in knowledge that I developed my research question to address. Reviewing the literature also enabled me to appraise methodological approaches that others have taken and draw on this to consider the most suitable for achieving the aims of my study. The chapter begins by explaining the methodological approach for the literature review.

3.2 Literature approach and methods

As illustrated by my own experience in Chapter One, working with self-neglect can present a range of contradictory perspectives, and my literature search mirrored this to some degree as my reading led me down various but interconnected paths. I realised I needed to adopt a reflexive approach to this literature review that allows for 'Synthesising ideas, theories and concepts from a broad range of literature' (Kitely and Stogden, 2014, p. 13). Also, that offers space for alternative perspectives on investigating the literature so that 'Conceptual and theoretical doors are left open wide enough to permit new ideas and serendipitous findings to emerge' (Padgett, 2017, p. 60).

Hart (2018) maintains that a literature review is a critical part of the research process and not something to be 'gotten over' (p. 18) and that undertaking a review of academic worth requires several elements and explains: 'Quality means appropriate breadth and depth, rigour and consistency, clarity and brevity, and effective analysis and synthesis' (p. 2). Hart (2018, p. 93, author's brackets) proposes there are, 'Two general types of review, the scholastic (traditional) review and interventionist (systematic) review' and suggests that the traditional review has been a long-standing approach adopted in dissertations. Each approach has characteristics that

can provide a more effective framework to answer the research questions depending on the purpose and target audience of the study. First, Hart describes a scholastic approach as a more traditional style as it identifies material that supports the aim of the review and is methodologically focused and often associated with evaluating theoretical positions, analysis and comparisons of specific approaches, and can include 'Primary research, existing theories, models and arguments (including interpretations)' (author's brackets) (2018, p. 95). Second, an interventionist (systematic) approach is more aligned with synthesising empirical evidence for use in medical interventions or policy changes. One approach is not superior to the other or separate as they have shared primary goals to identify critical sources of relevant material for their relative subjects and 'If done with a transparent methodology, can have an equal status in current research' (2018, p. 93).

Given that my research intends to explore how social workers experience and make sense of self-neglect, I decided that a scholastic rather than an interventionist (systematic) review provided a more suitable framework for this study. Hart (2018, p. 15) explains: 'Good scholarship is integration which is about making connections between ideas, theories and experience', and adopting a scholastic approach allows flexibility to adapt my thinking as my reading progresses. On exploring the literature on self-neglect Lauder (1999a) cautions that the discourse generated around self-neglect is uncritically accepted and can create a self-perpetuating academic bubble, and suggests that:

> There are nearly as many reviews of the literature as original research studies. The self-sustaining quality of the literature can be seen in the fact that many reviews cite the same literature, and having cited this literature, find themselves cited in further articles. This is problematic as ideas become established as fact rather than as tentative and provisional as most must be regarded in the light of the lack of empirical data. (p. 59).

In adopting a scholastic approach, I wanted to remain curious and open to different sources of information to develop my understanding whilst retaining a focus on empirical research to answer my research questions and to avoid the academic recycling Lauder cautions against.

Once relevant material was identified I undertook a process of analysis that required me to explore the literature, see how it was constructed and identify how the components related to each other in relation to self-neglect. I then undertook a synthesis of the literature. Hart (2018, p. 197) explains synthesis is 'the act of making connections between the parts identified in the analysis'. There are various approaches to synthesising data across a range of theoretical perspectives (Barnett Page and Thomas, 2009). Dixon-Woods et al., (2005, p. 45) draw on the work of Nobilt and Hare who outline two approaches, integrative and interpretive. They suggest that integrative synthesis focuses on the amalgamation of data and can be more associated with quantitative studies. In contrast, interpretive reviews achieve synthesis through incorporating the concepts identified in the studies. Given that the focus of this is study a qualitative exploration of social workers' experiences I decided that an interpretive approach to synthesising the literature was more appropriate. An illustration of my synthesis of the literature is provided later in this chapter in figure 2. Furthermore, I found that Critical Interpretive Synthesis (CIS) (Dixon-Woods et al., 2006) provided a helpful framework to support this approach (see Appendix 1 for detailed criteria). CIS recognises that social sciences research benefits from a more flexible approach than adopting rigidly defined perimeters. Using CIS allowed me to draw on a range of literature to 'maximise relevance and theoretical contribution' (Dixon-Woods et al., 2006, p. 10). The following explains the steps I took to identify research that addressed my research questions.

3.3 Explanation of search parameters

Although this is not a systematic review, I searched systematically for relevant material to answer my research question. My research strategy was informed by the following inclusion and exclusion criteria.

Inclusion Criteria

- Empirical qualitative studies
- Primary research undertaken with social workers/ front-line practitioners working with self-

neglect/hoarding

- Undertaken between 1999 and 2022 (My rationale for this timeline is that the DoH published 'No Secrets' in 2000 and I was interested in exploring if any references to self-neglect were cited around its implementation)
- International if available in English
- Interprofessional studies exploring multi-interagency working with self-neglect/hoarding where health and social care workers were directly involved.

Exclusion Criteria

- Quantitative studies
- Theoretical papers
- Literature reviews
- Non-English language studies

My initial intention was to identify empirical research that explored social workers' experiences of working with self-neglect. However, I realised early on that there were few empirical studies with this focus; some rare examples are Day, McCarthy and Leahy-Warren (2012), Doron, Band-Winterstein and Naim (2013) and Braye, Orr and Preston-Shoot (2011; 2014). Although there are differences in roles and responsibilities, there is arguably a shared experience across professions of working with self-neglect; therefore I broadened my search terms to include 'front-line practitioners, frontline workers, professionals, staff, healthcare staff, nurses' working with 'self-neglect or self neglect.' In England, the definition of self-neglect under the CA supporting guidance includes hoarding (DHSC, 2022) and hoarding and self-neglect can be conflated and used interchangeably in the literature and professional practice. In light of this, I included the following search terms in combination with the above, 'hoarding or compulsive hoarding or hoarding disorder' or 'safeguarding adults or safeguarding adults at risk or abuse and neglect.' Expanding my search criteria allowed for a broader range of material, thus developing a richer repository of knowledge that, as a researcher, allowed me to 'cross disciplinary boundaries, encounter new ideas and styles, and enhance the quality of their work' (Hart 2018, p. 18). Going forward, I will use the term 'practitioners' as an overarching term to include social workers and other front-line workers engaging in self-neglect work.

I searched the following databases: CINAHL Plus, APA PsycInfo, APA PsycArticles, Education Research Complete, Humanities Full Text, MEDLINE and Social Sciences Full Text, which resulted in a return of 1201 articles. I also undertook a further search on the Scopus database to ensure I had not missed any key material. This search resulted in 844 returns, many of which were duplicates, but there were some articles I had not previously identified in my previous search. Further searches on the Social Care Online database helped identify relevant reports that did not appear in my earlier searches. I browsed specific journals that I knew were relevant to my topic - the Journal of Adult Protection and the British Journal of Social Work - alongside citation tracking where I identified two relevant dissertations, a report and one article that did not show in my original search. The final number of empirical studies identified for this review was 41 which are marked with an asterisk in the references (see Appendix 2 for full details of the search process).

A challenge I found in searching for literature on self-neglect is that it is often subsumed into the broader definition of abuse and not explicitly identified in the abstracts. Therefore, I read all abstracts and full articles if they appeared relevant to my research question, although some did not have self-neglect in the abstract. Using CIS as a guiding framework was helpful as it advises that, 'Ongoing selection of potentially relevant literature should be informed by the emerging theoretical framework. Literatures not directly or obviously relevant to the question under review may be accessed as part of this process' (Dixon- Woods et al., 2006, p. 10). This process was valuable as it identified articles that appeared to fall outside my search parameters at first glance. For example, self-neglect was not explicitly identified in the abstracts, but I have included Band-Winterstein, Goldblatt and Alon's (2014, 2021) studies that explore how social workers experience working with elder abuse and neglect. My rationale is that these studies explore the impact of this work and the human distress this can cause, areas relevant to self-neglect and my research question. In terms of limitations, this subjective approach to the selection of literature may impact the ability of others to fully replicate this search, but as explained, this is not a systematic review.

While searching for empirical literature, I identified a range of literature that did not relate specifically to my research question. However, I thought it valuable as it offers an informative contextual, theoretical overview of self-neglect and thus provides an explanatory framework for the present study. Furthermore, although this study focuses on practitioners' experiences, I identified literature that provides the critical perspective of people affected by self-neglect. I thought this was important to include as it develops a better understanding of the topic and the range of perspectives social workers need to understand when working with self-neglect. The following section presents this contextual literature as a preceding section before I appraise the empirical literature that explicitly addresses my research question, which explores how practitioners experience self-neglect work. This chapter then concludes by explaining how I developed my research questions to address the knowledge gaps identified from undertaking this review.

3.4 Global perspectives of self-neglect

Globally, self-neglect is an increasing public health and social care issue. In the US, self-neglect has the highest referral rate within Adult Protection Services (Dong, 2017; Rowan et al., 2020), and a growing body of international research seeks to understand this complex phenomenon (Touza and Prado, 2019; Yu et al., 2019; Xu et al., 2022;). In Australia, McDermott (2008; 2010; 2011) and McDermott, Linahan and Squires (2009) explore the complexity of self-neglect and the ethical challenges it can present. Band-Winterstein (2012; 2018); Band-Winterstein, Goldblatt and Alon (2014; 2021) and Doron, Band-Winterstein and Naim (2013) provide an Israeli perspective of working with people and their families affected by abuse and self-neglect. Day and colleagues explore working with self-neglect in Ireland and bring together one of the first comprehensive resources for health and social care practitioners to capture global self-neglect perspectives (Day, McCarthy and Fitzpatrick, 2018). From an English perspective, researchers Braye, Orr and Preston-Shoot have been at the

forefront in developing an extensive body of work that explores the complexity of self-neglect and what works or hinders practice (Braye, Orr and Preston-Shoot, 2011; 2013; 2014; 2015; 2017; Orr, Preston-Shoot and Braye, 2019), and that explores organisational responses to self-neglect and Safeguarding Adults Reviews (SARs) (Preston-Shoot, 2017; 2018; 2019; 2021; Preston Shoot et al., 2020). Similarly, the team at Kings College London provide a body of work that explores the complex dimensions of self-neglect and hoarding, see Martineau et al. (2021); Harris (2022); Owen et al. (2022); Steils et al. (2022), and explores social work responses to self-neglect during the Covid-19 pandemic (Manthorpe et al., 2022). Some studies are returned to later in this chapter.

There are debates regarding how best to respond to self-neglect, but commentators agree that it is an under-researched, complex, multi-dimensional phenomenon (Lauder et al.,2009; Braye, Orr and Preston-Shoot, 2014; Mason and Evans, 2020; Owen et al., 2022) that does not discriminate and affects all echelons of society (Dong, Simon and Evans, 2012). Hoarding is subsumed into the definition of self-neglect in England within the CA Statutory Guidance. However, Hoarding Disorder (HD) is now recognised as a separate mental disorder within the Diagnostic and Statistical Manual of Mental Disorders (DSM5) (APA, 2013), where it is defined as 'Persistent difficulty discarding or parting with possessions, regardless of their actual value. This difficulty is due to a perceived need to save the items and the distress associated with discarding them.' Hoarding is also now included in the International Classification of Diseases (ICD) (WHO, 2021). Hoarding behaviours may not be formally diagnosed as HD but can be a common feature in self-neglect. People with hoarding behaviours can remain unseen until they come to the attention of the authorities due to complaints from the community where their hoarding may pose a fire or environmental health risk (Frost, Steketee and Williams, 2000) or when the person reaches a crisis point (Owen, 2022), highlighting the need for early identification and engagement from health and social care services. Attempts to define self-neglect have elicited conflicting discourses that debate the definition, prevalence, risk factors and understanding of self-neglect (Dong, 2017), therefore, agreeing on one collective definition is a challenge (Gunstone, 2003).

A suggested definition put forward by Gibbons, Lauder and Ludwick (2006, p. 16) describes self-

neglect as:

> The inability (intentional or non-intentional) to maintain socially and culturally accepted standards of self-care with the potential for serious consequences to the health and wellbeing of the self-neglecters and perhaps even to their community.

Although self-neglect lacks an agreed global definition, there is a range of behaviours commonly associated with this phenomenon, which can include hoarding objects and animals, domestic neglect, sometimes described as squalor (McDermott, 2008), the neglect of self-care and a refusal to accept medical attention (Koenig, Chapin and Spano, 2010; Braye, Orr and Preston-Shoot, 2014; DHSC, 2022). There are varying degrees in which these behaviours manifest themselves. Some people may meet accepted societal levels of personal hygiene but neglect their domestic environment, whilst others may display hoarding behaviours, but their homes are in a reasonable domestic state (Snowdon, Halliday and Banerjee, 2012). Others may present with physical and medical neglect and financial or global neglect (described as the inclusion of all types) (Burnett et al., 2014). Self-neglect is often associated with older people but can also affect younger people (Snowdon, Halliday and Banerjee, 2012).

Public interest in self-neglect and particularly hoarding has increased through programmes such as ‘Hoarder SOS’ (Channel 4, 2016) and ‘Compulsive Cleaners’ (Channel 4, 2019). The voyeuristic nature of these programmes has increased public attention but the ‘quick fix’ intense cleaning and decluttering approaches they portray are not supported by research which indicates that these approaches can cause more trauma than benefit to the people affected (Chapin et al. 2010). Furthermore, it is suggested that viewing such programmes can increase the stigma and sense of social distance towards those with hoarding behaviours and there is a lack of societal understanding of the phenomenon (Bates et al. 2020). However, although there is increased media attention this group is not as visible within health and social care services and can be difficult to identify as ‘It is a classic example of a human problem which falls into that grey area between health, social work,

housing services and environmental spheres of influence' (Lauder, Anderson and Barclay, 2005a, p. 318). The above literature illustrates that there is no definitive presentation of self-neglect; it is multi-factorial and can manifest in diverse ways.

Hurley et al. (2000) describe people who self-neglect as 'service refusers' and highlight that a lack of engagement is a key challenge when working with people who self-neglect as risks can escalate due to a refusal to accept health and community services. This refusal can have severe implications by putting the person at risk of early mortality due to untreated medical conditions, increased hospital admissions and multiple co-morbidities (Dong and Simon, 2014). These risks are exacerbated by living in unsanitary conditions and increased isolation (Day, Leahy-Warren and McCarthy, 2013) which can increase the risk of elder abuse (Dong, Simon and Evans, 2013) and homelessness (Snowdon, Halliday and Banerjee, 2012; Braye, Orr and Preston-Shoot, 2014), with more recent studies recognising the need to understand the connections between self-neglect, homelessness and safeguarding (Martineau et al., 2019; Martineau and Manthorpe, 2020; Preston-Shoot, 2020; Harris, 2022). Self-neglect can place tensions on community relationships if the person's behaviours negatively impact the wider community (Sengstock, Thibault and Zaranek, 1999; Frost, Steketee and Williams, 2000; May-Chahal and Antrobus, 2012). The challenge of defining self-neglect is debated within different theoretical perspectives that attempt to locate it within their conceptual realm (Burnett et al., 2006; Lauder et al., 2009); some examples are outlined below.

3.4.1 Biomedical

The recognition of self-neglect as a phenomenon is suggested to have originated in the U.K. (Martineau, 2020). Shaw's (1957) early study explored reports from health visitors of people over 60 (n139) who failed to meet expected societal levels of hygiene and domestic care, which they describe as 'social breakdown of the elderly'. Macmillan and Shaw's (1966) later study adopted a biomedical

lens to study people who did not conform to societal expectations for hygiene and cleanliness. They identify common traits of difficult personalities, poor self-care and nutrition, describing this constellation of behaviours as a medical 'senile breakdown syndrome' and offer the following description:

> The usual picture is that of an old woman living alone, though men and married couples suffering the condition are also found. She, her garments, her possessions and her house are filthy. She may be verminous and there may be faeces and pools of urine on the floor (Macmillan and Shaw, 1966, p. 1032).

Macmillan and Shaw add that this condition was not a passive deterioration and these patients had 'a hostile attitude to and a rejection of the outside community' (p. 1036). Gruenberg (1967) describes self-neglect as a range of behaviours described as 'social breakdown syndrome' associated with mental ill-health, withdrawal and social isolation. 'Diogenes Syndrome' is a term commonly associated with self-neglect and was coined by Clark, Mankikar and Gray (1975) who applied this term to 30 geriatric patients admitted to hospital living in gross domestic squalor, extreme self-neglect and isolation. The authors describe this group as having a 'filthy appearance about which they showed no shame' (p. 336) and noted their propensity to collect what the researchers described as rubbish and also introduced the term 'syllogomania' to describe what we now understand as hoarding. Patients presented with multiple health problems, but over half showed no clear evidence of psychiatric problems and were viewed as having above-average intelligence. Further studies suggest that self-neglect is a 'geriatric syndrome' (Pavlou and Lachs, 2006) due to the prevalence of common risk factors and functional decline associated with other geriatric conditions. Ernst and Smith (2011) support this view as they identified that physical health issues such as arthritis, incontinence and a lack of nutrition are common features in people who self-neglect. Dyer et al. (2007) suggests that over 50% of people who self-neglect have some level of cognitive decline, with Abrams et al. (2002) suggesting that depression and cognitive impairment may be precursors of self-neglect in older people. Furthermore, Finney and Mendez (2017) suggest that cognitive frontal lobe deficits may be a contributing factor to self-neglect behaviours and argue that further research on this issue may improve diagnosis and treatment.

3.4.2 Social constructionist

Lauder (1999a) argues that there is a paucity of robust empirical evidence to support a biomedical diagnosis of self-neglect and that a social constructionist perspective provides a more appropriate lens to understand this phenomenon. Lauder rejects the medicalisation of self-neglect and argues that it overshadows the critical issue that self-neglect is socially constructed and influenced by societal, economic and cultural factors. Furthermore, Lauder argues that the medical discourse blinkers our view to other ways of understanding self-neglect. He suggests that it is not an objective phenomenon that can be statistically measured through a positivist lens but is 'A constructed phenomenon which is the product of social and individual normative judgements, which are themselves rooted in the dominant discourse of cleanliness, hygiene and self-care' (ii; 1999a). Lauder et al.'s (2009) study explores theoretical frameworks of self-neglect and suggests that: 'A more functional and pragmatic approach to defining self-neglect suggests that we conceptualise this as a constellation of practical problems which health and social care workers encounter' (p. 448). Furthermore, the authors argue that the diagnosis of self-neglect is within a blurred set of criteria created by professionals who lack the critical perspective of people who self-neglect.

Bates (2022) argues that we need to broaden our gaze and recognise the historical, religious and political construction of self-neglect where the significance of cleanliness, washing and grooming are embedded in religious ceremonies in life and death. Bates draws attention to the political dimension of self-neglect and the 'dirty protest' in Northern Ireland where from 1976 to 1981 prisoners held at the Maze prison protested for the right to be viewed as political prisoners, not criminals, and made their protest by refusing to wash or slop out and smeared their faeces on cell walls. Bates suggests that contemporary society is obsessed with cleanliness, reinforced by market forces and that:

> If we look good we will feel good and so in times of economic boom people respond to this message with a noticeable increase in the demand for cosmetic and health products. Economic recessions accelerate government efforts to renegotiate the social contract between individuals and the state, re-emphasising the duty on each citizen to make the most of themselves via diet, exercise, appearance and preventative healthcare and thus rely less upon public funds (p. 25).

Additional studies synthesise elements of the above approaches to develop more integrated practice models, some of which are outlined below:

3.4.3 A hybrid approach

Further studies take a practical hybrid approach and move from a polarised position of either bio-medical or social constructionist to one that integrates elements of both. Dyer et al.'s (2007) large-scale US study of older adults (n500) defines self-neglect as a 'Failure to perform activities of daily living, which manifests as a combination of poor hygiene, squalor in and outside their dwellings, a lack of utilities, an excess number of pets and inadequate food stores' (p. 1674). The findings suggest that the precipitating factors of self-neglect do not sit solely in a bio-medical or social constructionist sphere. They result from a complex interrelation of medical and social care needs, manifest in physical and mental health issues such as depression, cognitive impairment, executive dysfunction and a decline in physical abilities. These presentations are often coupled with a refusal to accept health and social care support, increasing risk and social isolation. Burnett et al. (2006) argue that we need to consider the importance of social networks as they are underplayed when assessing self-neglect. The authors suggest that depression can contribute to self-neglect, but a lack of social networks can also negatively impact a person's physical and mental health. A conceptual framework put forward by Iris, Ridings and Conrad (2010) provides a holistic approach to assessing self-neglect by considering multiple factors, including social, environmental, financial, mental, physical health and personal choice dimensions. Zawisza et al. (2021) build on Iris, Ridings and Conrad's (2010) model to develop the Self-Reported Self-Neglect Scale (SRSNS), which assesses the impact of self-neglect on the person's

physical health and appearance and also assesses their living conditions, which the authors suggest provides a useful holistic assessment tool for health care and social care professionals. Furthermore, Liu et al. (2020) highlight the need for workers assessing self-neglect to use a standardised assessment tool to support professional judgement and decision making and to 'Promote common definitions so that caseworkers, supervisors, clients, researchers, and other stakeholders are speaking the same language in terms of types and severity of abuse' (p. 270). Within all of the above assessment processes ethical dimensions need to be considered when working with self-neglect, particularly in balancing a right to autonomy and a duty of care which can present challenges for practitioners (Koenig, Chapin and Spano, 2010; Mauk, 2011; McDermott 2010; 2011; Braye, Orr and Preston-Shoot, 2017; Day and McCarthy, 2018; Thelin, 2021). This topic is returned to later in this thesis.

The above discussions provide an insight into the wide-reaching global, historical and political debates surrounding self-neglect and highlight the range of conflicting perspectives practitioners need to navigate to try to make sense of this work. It is suggested that these debates often exclude the views of people affected by self-neglect (Lauder et al., 2009; Braye, Orr and Preston-Shoot, 2011). Although this study focuses on exploring practitioners' experiences, I thought it important to include literature that explores the perspective of those affected by self-neglect to develop a better understanding and shed light on the different perspectives' practitioners need to consider in practice.

3.5 The perspectives of people who self-neglect

Band-Winterstein, Doron and Naim's (2012) Israeli qualitative study explored the views of people who self-neglect (n16) and identified that participants' life stories were punctured with significant losses, traumatic events, violence and violence fractured family dynamics. Band-Winterstein, Doron and

Naim (2012) draw on the work of Bozinovski's (2000), 'continuity theory' and suggest that self-neglect is more than a set of behaviours and can be adopted as a protective measure to maintain control, continuity and sense of self. What professionals perceive as disorder and chaos are, in effect, the person asserting their sense of control and 'Their primary concerns become preserving and protecting identity and maintaining the style and type of control with which they are comfortable' (p. 52). Participants in this study had a profound distrust of people due to betrayal and abandonment within their life histories. Feelings of abandonment were revisited when workers developed relationships with clients but then closed their cases and moved on.

Day, Leahy-Warren and McCarthy's (2013) Irish study interviewed people (n8) who were self-neglecting. All participants felt disconnected from their families and communities and often had a history of poverty and frugality, and six people identified alcohol misuse as a problem in their lives. Behaviours identified were domestic squalor, hoarding and poor self-care alongside a range of physical and mental health issues; however, all participants were considered to have mental capacity. Vulnerability issues were also a concern as some participants were targeted and exploited in their community. Halliday et al.'s. (2000) study of people (n76) living in what is described as squalor in an inner London borough identified high rates of cognitive impairment and mental disorders that affected both younger and older people. Of those interviewed, only 41 felt they had someone they could confide in, with the remainder having regular interaction only with those involved in their care. This finding supports the studies by McDermott (2011) and Day, Leahy-Warren and McCarthy (2013) that identify a need for practitioners to have time to build trusting relationships to support the person and a need for community support to reduce isolation and improve self-esteem (Burnett et al., 2006). However, Halliday et al. (2000) highlight that it is sometimes difficult to understand if a person is isolated from their families because of their self-neglect or if self-neglect occurred due to a person being isolated from their families.

Kutame's (2007) US doctoral research explored the experiences of older people (n12) viewed as self-neglecting. Participants explained that their physical health had a significant impact as they feared falling and felt weak, which affected their confidence and ability to self-care. Participants explained that they gained strength from their belief in God and talked about 'unfulfilled dreams' where they had not achieved their childhood aspirations, such as career hopes, having a family or not being where they thought they would be at this stage of their lives. Furthermore, participants identified a strong attachment and a 'place identity' to their home, which instilled a sense of pride and resilience. They did not see themselves as self-neglecting and were distrustful of professionals whom they viewed as an intrusion. Lien et al.'s (2016) US study of people who self-neglect (n 69) identified traumatic personal experiences of loss, abuse and abandonment, problems with substance misuse and managing finances, chronic mental health problems and an overall distrust of people and medical support services. Lien et al.'s findings are consistent with those of Bozinovski's (2000), Kutame's (2007), Band-Winterstein, Doron and Naim's (2012), and Day, Leahy-Warren and McCarthy's (2013) studies. Lauder et al.'s (2009) study identified similar themes drawn from their interviews with people who self-neglect (n10). Although they note that the younger people in their study did not fit a stereotypical profile often portrayed in the literature, highlighting that they 'Maintained social contacts and were in close contact with health, social or voluntary services. These related cases suggest that lifestyles and behaviours which we classify as self-neglect are wider and less clear-cut than previously suggested' (p.453).

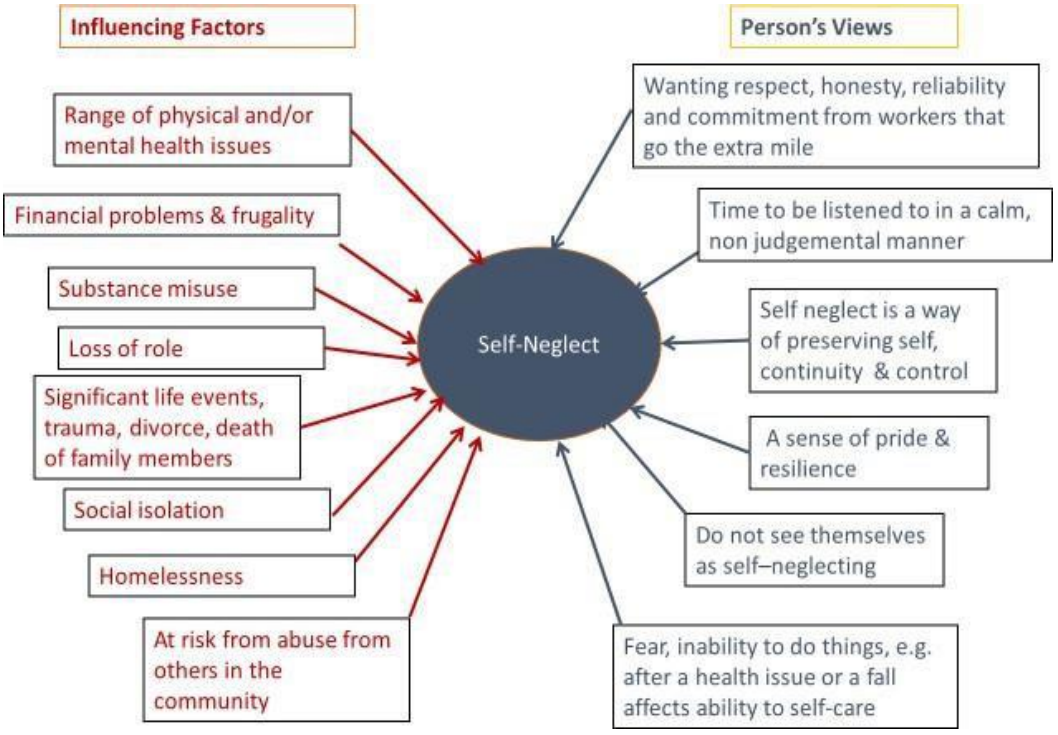
Braye, Orr and Preston-Shoot (2014) undertook one of the most comprehensive studies within England on self-neglect. Their study explores *inter-alia* the experiences of people who self-neglect (n29). Homelessness was a feature in 10 participants' lives where self-neglect was a reason and consequence of homelessness. Participants identified motivation, sometimes due to substance misuse and isolation, and physical and mental health problems were further obstacles to self-care. Some participants put the needs of others ahead of their own, whilst others were unsure how they

had reached a stage of self-neglect. The findings identified that there is not one typology of self-neglect and that each person's story is unique and needs to be listened to without preconception or judgement. When asked what they valued when practitioners engaged with them, participants stated they appreciated a person-centred approach that was honest, open and direct but without practitioners taking control. Participants valued reliable workers who would go the extra mile, not give up, and could offer solutions and reassurance in a calm and non-judgmental manner, making them feel more comfortable about their situation. In talking about his support worker, one participant explained what was important to him: 'He has been human, that's the word I can use. He has been human' (p.115). The above studies highlight that people affected by self-neglect want to be respected and have time to develop meaningful relationships with practitioners who can work in a person-centred manner and listen to their life stories in a non-judgmental way.

3.5.1 Integrating perspectives

The above discussions illuminate the diverse global perspectives that inform research debates about self-neglect's theoretical underpinnings, causation and possible interventions. They also include critical insights into what is important to those affected by self-neglect and identify factors that may have influenced their situation. The discussions highlight the importance of the relational and human aspects of self-neglect work and the significance of practitioners showing care and humanity to those they work with. I created the following illustration which integrates these perspectives, capturing the key themes from the wider debates on the causation and effects of self-neglect and the views of people who are affected.

Figure1. Integrating perspectives



The above viewpoints illustrate the broad range of differing perspectives practitioners must consider in self-neglect work. Given this complexity, I needed to understand how practitioners experienced these diverse views, not only as individuals, but how self-neglect practice is experienced within its organisational and policy context and what the literature says about this. Therefore, having explored the legal and policy framework and presented literature that provides a theoretical and contextual background for this study, the following section explores the empirical research (n41) that directly responds to my research question and explores practitioners' experiences under the following key themes,

- How organisations respond to self-neglect work,
- How practitioners experience multi/interagency working, and
- How practitioners experience working with people who self-neglect.

3.6 How organisations respond to self-neglect work

Satyamurti (1981, p. 8) suggests that to understand social workers' experiences, 'Their strategies for survival begins by looking at their organisational context'. One of the first comprehensive explorations into how organisations respond to self-neglect in England was Braye, Orr and Preston-Shoot's (2011) study which explored the interface between safeguarding and self-neglect. Three parallel workshops (n44), including Directors of Social Services, Safeguarding Board Members, professional leads from the NHS and the police, identified the complex challenges in identifying and intervening in self-neglect cases. The authors identified how literature highlights the importance of assessing both executive and decisional mental capacity, observing that, 'The complexity of assessing capacity can be illustrated by the challenge of accounting for the cumulative impact of a series of small decisions, each taken with capacity but together amounting to a situation that is not chosen' (2011, p. 35). Participants identified the need to build positive relationships and ensure that assessments were in-depth and reviewed regularly. Mental capacity should not be an excuse to discharge professional responsibilities when there is evidence that a person may be at risk. Intervention requires 'good old-fashioned social work' (p. 56). People with lived experiences of self-neglect are not included. This is a gap in this otherwise comprehensive study, although this is addressed in Braye, Orr and Preston-Shoot's (2014) later study.

A further scoping study by Braye, Orr and Preston-Shoot (2013) explored workforce development needs concerning self-neglect by interviewing staff involved in adult social care (n48) from five different authorities. The findings identified a need for clear guidance for staff concerning multi-agency working, improved support and training in mental capacity and risk assessments, and robust, supportive supervision. Assessing mental capacity was again a key theme, with practitioners questioning whether to intervene when people have mental capacity and recognising the risks for the person and their organisation where their choices 'challenged notions of human dignity' (p. 44).

Practitioners called for an organisational culture shift that allows them time to work flexibly and build trust, highlighting that self-neglect did not fit with a workflow system that closed cases if the person had mental capacity and refused services. Interestingly, some managers and practitioners in this study were confident to work outside of expected workflow systems to work differently with self-neglect (p. 51). Due to the challenging nature of self-neglect work, 'Practitioners were particularly mindful that they may be called upon to defend, against external criticism (from quarters such as the coroner), (author's brackets) the decision not to intervene, nor to impose solutions that would be resisted by the client' (p. 44). Braye, Orr and Preston-Shoot's (2014) later study was undertaken pre-CA implementation. In-depth interviews took place with managers (n20), practitioners (n42) and people who use services (n29) across ten local authorities. From an organisational perspective, the findings identified that local authorities were still in the infancy stage of developing policy and procedural responses to self-neglect with variations in implementation levels. Due to regional variations in how self-neglect cases were recorded, an accurate national picture was lacking. The findings call for clear strategic and operational structures for multi-agency governance of self-neglect work, supported by coherent protocols and policy guidance to inform practice. Further elements of this study, exploring multi-agency working and practitioners' experiences, are discussed later in this chapter.

Anka et al.'s (2017) mixed methods, two-stage evaluation study commissioned by a local authority set out to evaluate how an intense, time-specific intervention model could improve outcomes for people who self-neglect, specifically people who hoard, and therefore avoid escalation to a safeguarding concern. Semi-structured interviews were conducted with social workers (n3), social work managers (n3), external agencies (n6) and people who hoard (n13), alongside a satisfaction feedback questionnaire sent to those receiving the service (n20). The team focused on providing a preventative, intense 12 week intervention. Some cases received 20 weeks if more complex, with a small number receiving 24 weeks due to a need for ongoing input. Social workers valued time to work intensely on their cases and develop positive relationships with other professionals. Having self-

neglect recognised under the CA statutory guidance was considered beneficial, as this social worker explains: ‘Now people that self-neglect and hoard come through under safeguarding it is absolutely fantastic as far as I am concerned because now we have a process to follow’ (p. 73). Those receiving this service valued the time and consistent support of workers, and there were indications of an improvement in people’s well-being and home environments. This intense time-limited intervention approach yielded positive results, yet 10% of service users identified within the study required continuous input beyond 24 weeks. This point raises questions about how a time-limited approach may impact social work practice and workloads across a broader population when working with people with complex needs requiring longer-term support. The findings are difficult to generalise to a larger population as it is a small sample from one local authority. Nevertheless, with limited research into how organisations respond to self-neglect in England, this study provides valuable insights into how reconfiguring services to provide specialist input may improve multi-agency responses and outcomes for people who hoard.

Brown and Pain (2014) outline a progressive approach within their local authority where social workers are given time and resources to develop trusting relationships. Social work skills are identified as critical in successfully supporting people who hoard, and ‘An innovative social work perspective can achieve greater results than a typical care management approach’ (Brown and Pain, 2014, p. 3). They highlight that the level of intensive and practical support expected of social workers in their model is more than their usual role of signposting and referring to services; a more hands-on approach is required. Furthermore, social work skills are important in advocating and mediating with others, i.e., landlords, to prevent eviction, although their role must be embedded within a multi-agency, collaborative response. Brown and Pain (2014) provide valuable examples of positive practice in an area of limited research, although questions of objectivity and bias could be raised as they evaluate their own service.

3.7 How practitioners experience multi/interagency working and inter-organisational services in self-neglect

The literature uses various terms interchangeably to describe the shared experience of working together in a professional context, which can be confusing. These terms include partnership, integrated, interagency, interdisciplinary, multi-agency and interprofessional working (Quinney, 2006; Crawford, 2012). Hereafter, I will use the term multi/interagency working to describe working with other disciplines and agencies in self-neglect work. The following studies explore how practitioners experience multi/interagency working and consider inter-organisational features of how joint services supporting self-neglect and hoarding are structured and organised.

Lauder, Anderson and Barclay's (2005a) qualitative study explored how practitioners experience self-neglect work in a multi-agency setting. In-depth, semi-structured interviews were undertaken with housing officers (n12), environmental health officers (n3), social workers (n13), health care workers (n3) and people using services (n6). Findings identified a lack of a coordinated intervention where organisational constraints and priorities often challenged workers' responses. A need for early intervention is identified as key to allow agencies to work together to support people before self-neglect progresses into a chronic problem. A further paper by the same authors (2005b) explores a framework for good practice in interagency working. The findings identified a medical diagnosis in self-neglect proved to be a catalyst for services to be implemented, including practical assistance and involvement from psychiatrists, CPNs, nurses and allied professionals. Where a medical diagnosis was not in place, behaviours were viewed as a lifestyle choice and interventions from professionals were defined by the determination of capacity. The findings identified an emotional cost for workers involved in complex self-neglect cases. However, it is highlighted that positive partnership working might relieve some of these pressures. The above studies provide valuable insights into the differing perspectives of how practitioners perceive self-neglect, how they work with others, and the impact of this work, which is explored in more depth later in this chapter.

Gunstone's (2003) UK study undertook semi-structured interviews with practitioners (n7) in a community mental health team to explore their experiences described as the 'grey areas' of self-neglect practice. A thematic analysis of the data identified that workers with more experience working with self-neglect developed a higher tolerance to self-neglect situations, which may have affected their decision-making. Gunstone (2003, p. 293) suggests that: 'Reduced or increased tolerance because of personal or professional experience may lead to workers taking more or fewer risks, which will inevitably have an effect on the clients' care from aspects of both safety and autonomy'. There was a consensus that a clear definition of self-neglect and practice guidance was lacking, which was more evident when working with high-risk cases of severe self-neglect as workers required increased advice and support. There was a lack of knowledge about what policy and legislation practitioners could draw on to inform self-neglect work, which supports the findings from Lauder, Anderson and Barclay (2005a; 2005b) and Braye, Orr and Preston-Shoot (2011; 2013; 2014). However, a Care Programme Approach was valued as it provided a peer supervisory platform and a balance and checking mechanism to ensure that decision-making was person-centred and not influenced by dominant team members, the media or community sources. Workers also identified the danger of acting as social control agents in judging an acceptable level of self-care within society. Given the complex team dynamics, there was scope to explore further how professional roles may have affected the decision-making process in this context.

In England, the CA sets out duties for coordination and information sharing between partner agencies concerning safeguarding adults (s.43(3), s.45(1)), and it is recognised that multi-agency working is an essential element of safeguarding adults and self-neglect work (Cooper and Bruin, 2017; Barnett, 2018). Although responsive multi-agency approaches in self-neglect work are still lacking (Preston-Shoot et al., 2020), limited research post-CA has explored this, although Mason and Evan's (2020) study is one of the few, at the time of writing, that does.

Mason and Evans' (2020) qualitative study undertook semi-structured interviews with adult social workers (n11) to explore their experiences of cooperation when working with other disciplines in self-neglect work. The authors argue: 'Despite the ambiguities of self-neglect, we know very little about how cooperative practice is seen on the ground… particularly from the perspective of social workers who are key professionals in this area' (p. 2). A thematic analysis identified that social workers were fluid in interpreting their statutory role. Social workers valued input from other professionals, i.e., assessments from GPs and occupational therapists. However, in some contexts, some saw themselves as the linchpin of coordination, taking overall responsibility for the case management of self-neglect work. Fellow professionals' lack of knowledge contributed to the social workers' sense of ownership. As one respondent states: 'It's a bit of a grey area. I don't think that a lot of professionals know their level of responsibility with self-neglect, so it is up to us to figure it out' (p. 672). This finding was observed in Day and McCarthy's (2015) study, which identified that social workers had a higher level of knowledge than their community nurse colleagues. Mason and Evans's (2020) findings identified mixed opinions across agencies on how and when to intervene in self-neglect cases, with some disciplines expressing a more risk-averse, paternalistic approach that could present barriers to practice. Social workers expressed a loss of professional territory when cases were handed over to other workers to complete ongoing tasks due to time and resource constraints, whilst hospital social workers saw themselves 'as partners in an interdisciplinary team but emphasised that each discipline had a unique contribution' (p. 673). A lack of clear procedures, knowledge and training across agencies could impact collaborative working due to varying levels of understanding. It raises questions about whether the physical environment of working together fosters better working relationships in self-neglect work, as in a hospital setting.

Britain Thinks (2017), a report commissioned by Age UK, explored the views of older people experiencing self-neglect, their family and carers, and health and social care practitioners through

interviews and focus groups. In exploring challenges to effective multi-agency working, practitioners identified that a lack of coordinated responses could negatively impact the older person, with one participant stating: 'You can't work in silos… there needs to be a team around each person' (p. 40), highlighting how a lack of communication between services poses significant risks. The findings identified that health care workers became involved when self-neglect was more advanced. In contrast, housing support workers knew the person better having worked with them over time and could identify a gradual progression of self-neglect. As one housing worker stated: 'You can't just assume that someone with a dirty home is self-neglecting… you've got to know that person… my residents who have been homeless will tend to be a bit dirtier' (p. 39). These views support Lauder (1999a), who argues that self-neglect is a social construct informed by social and individual normative judgements of societal expectations of cleanliness and hygiene. The housing worker's statement highlights the danger of practitioners assessing levels of self-neglect at face value without knowing the person and their history.

Aspinwall-Roberts (2020) unpublished thesis explored how multi-agency working in self-neglect cases can be improved. This large-scale study interviewed a range of professionals (n245) from 17 different professional backgrounds involved in supporting people who self-neglect. Key findings identified a lack of understanding of each other's role which could result in conflict with some participants feeling their input was undervalued. Further findings identified a need for a designated lead and a coordinated approach; with multiple agencies involved in self-neglect cases there was a danger of professional overload. Additional themes identified were opportunities for professionals to meet early on to look at preventative approaches, access to multi/interagency training, and more time to work with people who self-neglect. Challenges with working with the MCA was a further theme discussed in the author's later study explored below.

Aspinwall-Roberts et al.'s (2022) study explores how agencies put the MCA into practice when working with self-neglect in multi and interagency forums and draws on the same sample outlined in the above 2020 study. A thematic analysis identified three key themes. First, participants and agencies did not fully understand how to apply MCA, which hindered the ability to deliver effective care. As one community mental health nurse explained: 'Actually, we have got a patient here that's not eating and drinking, or not washing, going out, and it gets missed because we are banging on about capacity!' (p. 4). Second, some professional groups were reluctant to undertake MCA assessments due to a lack of confidence and vulnerability about the outcome of the assessment if they got it wrong. However, the authors noted that these agencies 'were nonetheless highly critical of those who did, leading to considerable conflict between agencies' (p. 7). The final theme identified a perception that some workers manipulate the MCA to fit their agency agendas which can be driven by financial and resource pressures. An assumption of capacity is suggested to be used as an absolution of responsibilities by some agencies. The assessment of capacity is critical in self-neglect work, and the findings from this study are worrying as they echo the concerns identified in the House of Lords Post Scrutiny Report (2014), that there is a lack of understanding of the MCA and agencies can adopt a punitive approach in its implementation.

The concept of multi-agency, multi-disciplinary hoarding teams is new in the UK but more established in the US, where self-neglect has historically been located under safeguarding procedures and requires mandatory reporting in many states (Dyer et al., 2007). Chapin et al.'s (2010) US study was tasked with providing a clear picture to Multi-agency Hoarding Teams (MAHT) (defined as a group of diverse professionals providing coordinated responses to hoarding) of the characteristics of hoarding cases, how they came to the attention of the public sector, referral pathways and how to improve organisational responses. Through reviewing files and telephone interviews with MAHT members (n7) in seven counties and drawing on an ecological systems theory approach to inform their analysis, they identified that cases came to the attention of MAHT teams through complaints from the public, concerns from health and social care professionals, police and animal welfare. They identified two

approaches to hoarding interventions: a clinical approach using Cognitive Behavioural Therapy, which is successful but expensive and therefore limited, and MAHTs, which are the usual response. The findings identified that hoarding cases were brought to the attention of public services due to individual and environmental concerns, which progressed the case from a private matter to a public concern. The findings identified that forced cleaning of premises was expensive and did not address the hoarding problem. To break the negative cycle of cases going through repeated systems, a coordinated response, facilitated through joint coalitions, is suggested where social work skills are valued in sharing their expertise to improve responses.

Koenig et al.'s (2013) US qualitative study explored the views of a specialist hoarding team (n15) to explore their perspectives on their role within the team. The findings identified that the team prioritised cases based on a person's need for mental health, nursing, community support or housing issues, which were then allocated to appropriate workers. As one nurse states: 'Each of us know what we can and can't do, then, we decide who else we need to call in' (p. 63), although team members were encouraged to be creative and undertake training to develop new skills needed within their team. There is a commitment to a collective responsibility, regardless of which team member or discipline takes the lead. Team members recognised the complexity of hoarding and how mental health problems can be a core contributing factor and having a team member with expertise in mental health was identified as vital. Components of successful teamwork included respecting each other's skills and knowledge, adhering to policy guidance, assessing capacity, understanding the remit of their roles and continued funding to sustain posts. An equal sense of ownership of casework was driven by a commitment to provide a 'unified' approach, although role conflict due to a lack of clarity in understanding each other's responsibilities could upset this equilibrium.

Koenig et al. (2013) describe an equalitarian stance that appears in contrast to Mason and Evans's (2020) study, where although social workers adopted a range of approaches depending on the

context, they also felt that they had the primary knowledge and overall responsibility for self-neglect cases. The cultural contrast between the US and England may explain these differences. Koenig et al.'s (2013) US study involved a dedicated hoarding team. The recognition of self-neglect is more advanced in the US as many states have had a long-standing, mandatory requirement to report self-neglect and it is the highest referral rate to Adult Protection Services (APS) (Dyer et al., 2007). In contrast, Mason and Evans's (2020) study was undertaken in England, where roles and responsibilities concerning self-neglect are arguably still ambiguous due to its relatively recent introduction into safeguarding via the CA Statutory Guidance (DHSC, 2022).

Bratiotis's (2009) US unpublished thesis and subsequent study (2013), examined five hoarding task force teams comprised of human service providers, i.e., fire service, mental health, nursing, legal, public health and housing, to consider what drove their formation and to explore their practice and policies concerning hoarding. The 2013 study identified that three of the five task forces were formed to respond to a high-profile case that had gained significant public attention. The frustration of workers was also a key driver in creating such teams as they felt their solitary input was wasted in complex cases and needed a coordinated response to share resources, knowledge and skills. One task force began after a failure of interagency coordination, with one member stating: ' Each agency's problems (with the clutter) had been resolved by the homeowner but created another problem for another agency' (p. 248, author's brackets). A consistent mission statement across the five teams included improving outcomes for hoarding, education, and policy change, and collaboration was vital. The above studies identify the need for a shared collective and coordinated organisational response to supporting people who self-neglect, with clear protocols and guidance that allow space for person-centred practice. Bratiotis, Woody and Lauster's (2019) later study explored four community-based sites hoarding interventions through the lens of what they describe as a case management approach and draw on the definition put forward by Mas-Expósito et al. (2014) 'In that it is characterised as having three interrelated types of activities: identification of clients, service coordination, and service

utilization' (p.95). Findings echo similar themes from Bratiotis's earlier studies as they identify a need for coordination and collaboration of community services that utilise a broad range of skills, fire prevention, and health and social care services. Developing a supportive worker-client relationship was vital to success, with some workers developing further skills in intervention planning, decision making and direct practice skills to enable the people they worked with to sort and discard excessive items, with the authors highlighting that 'although resource-intensive, these activities appear critical to recovery' (p. 102).

In summary, the above studies provide examples of how organisations and teams orchestrate their responses to self-neglect. There is a consistent and long-standing call for clear policy guidance to improve organisational responses and multi-agency working (Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Brown and Pain, 2014; Britain Thinks, 2017; Mason and Evans, 2020) and to improve MCA assessments in self-neglect work (Aspinwall-Roberts et al., 2022). Good practice models can inform joint decision-making in working with self-neglect (Gunstone, 2003). The US MAHT models identify the benefits of a localised coordinated approach (Bratiotis, 2009; 2013; Bratiotis, Woody and Lauster, 2019; Koenig et al., 2013) and raise questions about how space and place may influence a sense of belonging in multi/interagency working. There appears to be limited attention given to how social workers in England are experiencing multi/interagency working with self-neglect following the introduction of the CA. Having explored their experiences in this context, the following section looks more closely at literature that explores how practitioners perceive, make judgements and are affected by working with self-neglect.

3.8 How practitioners understand and experience self-neglect

As explained in section 3.3, although my research questions focus on social workers, as empirical research was limited I included other front-line practitioners who work with self-neglect, such as

housing support workers and nurses, described in the following discussion as practitioners. My rationale was that their experiences provide a valuable perspective on working with self-neglect and can offer insights into the realities of direct practice. This aspect of the literature is presented as three interconnected themes. First, it explores how practitioners perceive and make judgments about self-neglect; second, how professional, ethical standpoints may influence practice; and third, the emotional and sensory impact of self-neglect work.

3.8.1 Practitioners' perceptions of self-neglect.

Lauder (1999b) undertook a multiple case study (n5) to explore how professionals, patients and family members perceived self-neglect. Findings from this early study highlight a discrepancy in how the patient and professional construct self-neglect and highlights that: 'It is not surprising then that many such 'patients' refuse treatment as they do not see any need for treatment in the first place' (p. 52). Furthermore, in all cases, Lauder identifies in workers a 'clear sense of therapeutic pessimism. Professional carers were not hopeful that any treatment would work, if in fact treatment was available' (p. 54). A further study by Lauder, Scott and Whyte (2001) explored the judgements of three groups of student nurses (n64), psychiatric (n67) and general nurses (n59) concerning self-neglect by undertaking a factorial postal survey using a range of vignettes that described a series of self-neglect cases. All groups gave a high response that patients have a lifestyle choice concerning self-neglect which was supported by a low response stating that they have no choice. The findings suggest that all three groups of nurses shared similar views, with the person's ability to self-care being a prominent factor in their decision-making rationale. Lauder et al.'s (2006) study continued this theme by exploring what factors may influence nurses' (n40) judgement when working with self-neglect in assessing a person's capacity and if they require intervention under mental health legislation. The findings identified that nurses placed patients in one of three broad categories: no mental illness, minor mental illness or severe mental illness. The findings raise questions about how nurses draw on their heuristic knowledge to make decisions when working with self-neglect and the authors caution against focusing

on a person's mental health status and ability to undertake functional tasks as indicators of capacity. As already identified in Lauder, Anderson and Barclay's (2005b), where a medical diagnosis was not in place, self-neglecting behaviours were viewed as a lifestyle choice and intervention from professionals was only triggered if there were concerns about a person's capacity. This contrasts with Lauder et al.'s (2001) study, where the ability to self-care was a prominent factor in the nurses' decision-making process on whether to intervene, illustrating that practitioners can perceive and respond to self-neglect in diverse ways.

Dyer et al.'s (2005) US study interviewed adult protection specialist workers (APS) (n24) to explore how they define self-neglect, using the findings to develop an operational definition. The authors adopted a mixed-methods approach and found that 36% of APS workers identified a 'derangement in the client's environment' (p. 5) as the primary defining factor of self-neglect, including smell, dirt, neglected pets and clutter. 18.4% identified poor personal hygiene, 12.8% identified health-related issues, 12% inadequate food stores and 6% cognition. In defining self-neglect, a consensus from the findings was that it was 'An inability or unwillingness to provide for care for oneself' (p. 5). The APS workers considered the differences between caregiver neglect and self-neglect, and they noted the difficulty in ascertaining this in some situations and drew on observations, experience and 'gut feelings' (p.6) to reach a conclusion. Workers also shared their frustrations with a lack of medical intervention where they felt there was a clear need for support, but because the person had the mental capacity to refuse medical services the medical team would not engage. This study identifies the disparity in how APS workers and physicians assess self-neglect and highlights the need for an assessment tool encompassing cognition, physical, social and environmental factors. Empirical research with APS workers appears limited, and this study may have been strengthened by exploring if there was a correlation between the indicators of neglect and the sense of duty or motivation for the APS workers to intervene.

McDermott's (2008) Australian study sought to understand how professionals (n24) understand and describe self-neglect. Although the workers described cases of personal and domestic neglect, only six of the 18 used the term self-neglect to describe cases that could be viewed as self-neglect. Participants used the term squalor to distinguish between a house being untidy and then squalor, where there is a presence of vermin, animals, waste and smells. Distinctions were also made between hoarding and collecting, with the terms sometimes used interchangeably between workers, but there was a tipping point where most participants felt collecting would then become squalor due to the points highlighted above. The findings highlight the differences in how professionals recognise, define and describe self-neglect. It is suggested that clarifying and defining levels of self-neglect may help in assessment and service delivery and enable professionals to 'Reflect on how their own values of cleanliness, age and ability can impact understandings of self-neglect, hoarding and squalor' (p. 248).

Johnson's (2018) US study explored home health nurses' (n16) perceptions of self-neglect amongst older people. Since self-neglect is the highest category reported to Adult Protection Services (APS), it was surprising that 75% stated that self-neglect was not taught in their education programmes, although all the nurses interviewed could identify the characteristics of self-neglect. They perceived self-neglect as 'a shield, to protect the self-neglecter' (p. 151) and that it was a sense of control for the person, which supports the findings from Bozinovski (2000), Kutume (2007) and Band-Winterstein, Doron and Naim (2012) discussed earlier, alongside feelings of frustration and a commitment to help. Nurses described strong emotional reactions to working with self-neglect where they were 'Shocked, saddened and even guilty about their inability to effectively intervene' (p. 153). Challenges included a lack of protocols to guide practice, effective multi/agency working and engaging medical social workers.

Mulcahy, Leahy-Warren and Day's (2018) Irish study adopted a qualitative approach to explore the perceptions of social workers (n12) and community and public health nurses (n75). The findings

identified that the complexity and range of diverse understandings of self-neglect could prove challenging, and it was used as a 'catch-all phrase' when there was 'A world of difference between *self-neglect cases* and *severe self-neglect'* (author's italics) (p. 167). Practitioners expressed a strong affinity to their clients alongside a duty of care and sense of responsibility, with one worker describing the need to 'cover yourself' (p. 168) due to the possibility of media or legal implications. There was a personal impact on workers as cases 'causes a lot of worry for staff' and can make the 'job… extremely difficult and stressful' (p. 168) as workers struggled to find a balance between consent and capacity and a person's right to autonomy with a duty of care. These complexities could be exacerbated by pressures from family and neighbours to intervene, although gaining their support was crucial. Recommendations highlighted the importance of relationship-building and person-centred practice in positive multi-agency working. The social work role was identified as valuable, although there was a lack of much-needed input from mental health services. McCann's (2018) Irish small qualitative pilot study explored one nurse and one caseworker's perspective on how they identified and responded to self-neglect and echoed similar themes. Key challenges identified were a lack of an agreed standardised assessment tool for self-neglect, engaging those to accept services, which can become more problematic due to mental health and addiction issues, and a need for a joined-up, multi-agency, multi-disciplinary approach.

Vailu'u's (2018) US doctoral research involved two focus groups with social workers (n11) who worked in adult protection services (APS) to explore what they thought were the barriers to working with older people who hoard. Key themes included a need for collaborative working, particularly in accessing mental health services for their clients, funding for community support to address hoarding, a need for a consistent protocol across agencies to respond to hoarding and a need for long-term support as opposed to a short-term case management approach. Respecting a person's autonomy whilst trying to find less intrusive ways to support raised ethical challenges. Furthermore, social workers identified a need for community education as there was a lack of understanding from the public about what social workers could legally do with hoarding cases, particularly since they did not have the powers

of children's social workers to go in and remove people from their home environments.

Wu et al.'s (2020) qualitative study interviewed female nurses (n21) working with older people in China to explore their perceptions of the influencing factors of elder self-neglect. Nurses identified that self-neglect could occur at any age, but it was most prevalent in older people who lacked an understanding of self-neglect and due to their physical decline and cognitive impairment did not recognise the health risks. Poor health awareness was a critical contributory factor, alongside isolation due to families working in cities away from the original family home. Nurses talked about how cultural expectations could impact self-neglect in Chinese culture and that a person must feel they can contribute to society and being unable to may result in low self-worth. Also, there is a 'family first' principle in Chinese culture where an 'overemphasis on one's own needs and well-being is considered to be selfish' (p. 142). The authors conclude that practitioners need to understand the complexity of self-neglect and work with family members to support and educate older people as soon as possible. This study identifies how culture can critically influence self-neglect and supports Bates' (2022) and Lauder's (1999a) arguments discussed earlier that we need to consider how social construction and societal expectations surrounding self-neglect can impact the person and practitioners working with them. Whilst it is recognised that females dominate the nursing profession globally, and this gender gap is more pronounced in China (Lu et al. 2021), it would have been interesting to have included male nurses given this study's focus on culture and family to see if their views differed.

Owen et al.'s (2022) qualitative study interviewed adult safeguarding leads from 31 local authorities across England to explore their understanding of the causes and impact of self-neglect/hoarding and how this may impact service provision. A thematic analysis identified that most participants thought self-neglect resulted from a range of interrelated contributory factors, including physical and social care issues of loss, isolation and bereavement. The majority of participants considered self-neglect

through a psycho-social lens, whilst a smaller number took a psycho-medical perspective and felt poor health could be the underlying cause. In terms of service provision, participants identified the need for early intervention to prevent situations from reaching a crisis point. A further finding was a need to understand what is 'normal' for a particular person's situation to develop a benchmark to assess how a person's situation may deteriorate. Furthermore, the authors suggest that:

> Better understanding the range of causes of self-neglect and/or hoarding by adult safeguarding managers (as well as frontline colleagues) (author's brackets) may assist effective assessment, engagement, risk management and intervention, and, while probably not 'fixing' the problem, aid in the achievement of better outcomes or prevention of severe consequences (p. 9).

The above studies offer insight into different professional perspectives on self-neglect, illustrating the diversity in how we perceive and understand this phenomenon. The following section develops this theme and considers studies that explore how ethical frameworks can inform practice within multi-agency contexts.

3.8.2. Negotiating ethics and values

Ethics is a fundamental component in the professionalisation of occupations (Banks, 2001; McDermott, 2011) and underpins social work education, practice and regulation (Professional Standards SWE, 2019; Code of Ethics, BASW, 2021). Beauchamp and Childress's (2001) ethical framework is widely adopted in health and has become more evident in social care professions. It is structured around the following four principles:

- Autonomy,
- Beneficence: to promote well-being,
- Non-maleficence: a duty to do no harm,
- Justice: ensuring equal access to resources.

When uncertainty and risk, often critical components of self-neglect work, cloud the pathway for practice, Evans and Hardy (2017, p. 952) suggest ethical frameworks can be drawn on as a 'higher order' to seek guidance and direction on how to act. However, the authors caution that ethics are not a set of rules but a process of critical negotiation. Adhering to these principles can present challenges in self-neglect practice with conflicting imperatives in balancing a person's right to autonomy with a duty of care to protect. Braye, Orr and Preston-Shoot (2017) highlight the dangers of taking a blinkered view that privileges self-determination above all else and suggest that the ethical dilemmas of balancing autonomy and protection in self-neglect work need to be sensitively explored. Differing ethical positions may pose challenges in multi-agency teams where different professional and ethical values may not align. The following studies explore how ethical frameworks are drawn on in practice.

Yeung et al.'s (2010) inter-disciplinary study used vignettes to explore how final-year social work and nursing students approached ethical decision-making when respecting clients' choices in situations where risk was a factor. The complexity of applying ethical principles in practice was illustrated within the findings as social work students held steadfast to the primary principle of self-determination and defended this stance even in situations of risk. In contrast, nursing students shifted from a position of autonomy to a duty of care when the client's physical health was at risk, whereas social work students' positions became more entrenched when their views were challenged. Yeung et al. draw on the work of Festinger (1957) to identify the impact of cognitive dissonance and noted that the social work students may have defended their ethical position to reduce their cognitive dilemma. The authors advise that: 'While their efforts to defend their ethical stances are commendable, they should be encouraged to avoid becoming defensive, hence depriving themselves of the possible benefits gained from the ethical reasoning of other professionals' (p. 1587). Although this study is not specific to self-neglect, I thought it was interesting as it illustrates how two disciplines, often closely aligned in self-neglect work, can determine different decisions when working with risk.

McDermott's (2011) study explores how front-line practitioners respond to situations of squalor through the lens of Beauchamp and Childress's (2001) ethical framework outlined above. This study adopted a qualitative approach involving a two-part method. The first was direct observation of workers in a community project supporting older people living in squalor, and the second was semi-structured interviews with front-line professionals (n18), 6 of whom were health professionals and 12 were housing-related workers. McDermott identified two approaches to autonomy associated with each group. Health workers adopted what is described as an objective fixed approach to autonomy and only intervened if it was legally identified that a person lacked capacity. They deemed it more important to respect the person's rights than to protect them from environmental risks. In contrast, housing-related workers would intervene to protect the person from harm even though they have mental capacity. This latter group also considered the broader impact on the community and identified the need for a relational model where a 'hands-on' approach, supporting the person with the cleaning tasks, could build trust and respect, focusing on the person's humanity. The findings suggest that staff in specialist housing and community roles, where time is recognised as a core element in the success of engaging those living in what is described as squalor, could be in a better position to support those in need than those in defined professional roles where their organisational context may constrain their time and where autonomy appeared to be the overarching principle.

Yip et al.'s (2022) Canadian study interviewed practitioners, social workers (n15) and nurses (n2) to explore how they experienced providing support to those who experience abuse, neglect and self-neglect within emergency situations. All participants identified the complexity of this work and highlighted the challenges of balancing ethical and legal aspects of autonomy and protection whilst noting the importance of seeing the person in context and understanding their lifestyle choices. Eight participants talked about the tension in adopting a strengths-based approach but having to traverse between the role of investigator and health care professional could violate trust with the people they work with. Participants also identified concerns of discrimination, describing how people were treated differently due to their race and socio-economic background, giving an example where a younger

person from an Indigenous background with substance misuse or mental health issues may not be treated as tolerantly as an older white person with dementia. Due to the complex nature of this work and lack of guidance, participants felt they were 'flying by the seat of their pants with no roadmap' (p. 130). The findings also identified the challenges for practitioners in managing large caseloads, limited resources, assessing capacity and lack of time, echoing similar themes from previous studies (Dyer et al., 2005; Mulcahy, Leahy-Warren and Day, 2018; Vailu'u 2018; Aspinwall-Roberts et al., 2022).

The above discussions illustrate how professional roles, responsibilities, resources and ethical viewpoints can influence how practitioners work with self-neglect. The following empirical studies look at the human and relational nature of working with people affected by self-neglect and the emotional and sensory responses it can elicit.

3.8.3 The emotional and sensory impact of self-neglect work.

The scoping study by Braye, Orr and Preston-Shoot (2013) (discussed earlier) identified that working with self-neglect could evoke a range of emotions. Practitioners in this study felt frustrated as they wanted to work in a person-centred manner but did not have the time or resources to do so. One participant explained: 'No time allowance is made for waiting for the door to be opened; a completely different culture is needed, one that isn't so time management focused' (p. 51). Practitioners talked about how challenging it can be to watch the deterioration of a person on a daily basis, whilst others highlighted the danger of becoming immune to the impact of working with self-neglect. As this quote from a practitioner working with self-neglect illustrates: 'It's insidious and cumulative; people can work for months and not realise how it's deteriorating' (p. 46). Others expressed fear and anxiety exacerbated by pressure from families, other services and communities, which could 'make practitioners quite jumpy' (p. 46). Braye, Orr and Preston-Shoot's (2014) later study identified similar themes: a lack of time in self-neglect work, challenges in multi-agency working, and a need for

organisational support and training. Practitioners felt pressured by workflow systems that did not allow for long-term work to build trusting relationships, which were thought essential in self-neglect work. The significant emotional impact of self-neglect work was also identified, as the authors explain:

> The personal, emotional impact on practitioners of working with self-neglect was also apparent; engaging with sadness and despair, and the poignancy of people's attempts to deal with such feelings, is deeply moving, and feeling helpless yet responsible is a very uncomfortable place to be (2014, p. 2).

Feelings of helplessness are echoed in Day, McCarthy and Leahy-Warren's (2012) Irish qualitative study (n7), which undertook a thematic analysis of semi-structured interviews with senior social workers working with people who self-neglect. The findings reiterate previous studies that self-neglect is a complex multi-dimensional issue, inadequately conceptualised and lacks a clear definition (Lauder, Anderson and Barclay, 2005a; Lauder et al., 2009; Braye, Orr and Preston-Shoot, 2011; Day, McCarthy and Fitzpatrick, 2018). Social workers in this study discussed the need for time to build a trusting relationship to understand the person's situation. Practice was hindered by a lack of knowledge, training, and valid assessment tools to assist in the early identification and support of self-neglect cases. Although a small sample, the findings offer a direct lens into the challenges of front-line practice, as this quote from a social worker illustrates: 'He is living in absolute squalor surrounded by rats, dogs, spiders, that I'd say would be as big as the dogs, it has not been cleaned or changed since about 1940 and he is living like that' (p. 732). These findings highlight that these situations can trigger strong feelings for social workers and raise ethical and practice considerations where people have mental capacity and self-neglect but refuse services.

Doron, Band-Winterstein and Naim's (2013) Israeli study sought to understand social workers' (n16) perspectives on self-neglect. In-depth, semi-structured interviews asked social workers the following question: 'What are the first three things that enter your head when talking about elder-self-neglect?' The findings identified three primary responses. The first was: 'How can you live like that?' Social

workers described self-neglect as an ‘unresolved riddle’ (p. 24), with one worker describing that a person was: ‘living in what I consider to be almost inhuman conditions’ and they were living ‘on another planet’ (p. 25). The second response captures the profound impact of self-neglect on day-to-day work and how powerful images and emotions remain with the social worker after the working day has ended, as illustrated in this quote: ‘I go outside and then immediately start thinking about myself. Even though I am young, how do you get to such a situation of neglect? What has gone wrong here with the whole system, everything comes home with me’ (p. 27). The third response is: ‘I keep trying,’ when social workers were determined to find creative ways to engage the person and how refusal can cause feelings of sadness and compassion. The study raises questions about whether safeguarding procedures are the most suitable framework to solve the riddle of self-neglect and whether there needs to be a better understanding of the causation and responses. Self-neglect can present complex dichotomies with workers trying to balance ‘Ethical, personal, and professional values and the tension between the actual desire to help and the recognition of the importance of respecting the clients' autonomy’ (p. 31). The authors conclude by identifying the need to develop an 'ideology' ‘That is rooted in a discourse of human rights, respect for autonomy and anti-ageism, which could assist the social workers to reconcile more easily with the decision to respect the self-neglecting elder’s choice’ (p. 31). The study provides a valuable contribution to the limited research on how social workers experience self-neglect work. However, given the strength of the social workers' accounts, it would have been interesting to ask how social workers process and make sense of these experiences, enabling them to work towards actualising the above proposed ideology.

Band-Winterstein, Goldblatt and Alon’s (2014) Israeli qualitative study explores how social workers (n17) experience working with elder abuse and neglect. Although the study does not explicitly identify self-neglect in the abstract, social workers' accounts describe cases that would amount to self-neglect; therefore I considered this study worthy of inclusion. The findings are drawn from in-depth, semi-structured interviews where social workers identified a sense of frustration for themselves and the client, as they often felt stuck and unable to progress cases and resolve abuse and neglect

concerns. Feeling stuck could cause feelings of anger, frustration and fear in taking responsibility for a case, resulting in anxiety and sleepless nights. All participants were female and talked about their maternal feelings being triggered as they connected with female family members in their caseload. These feelings caused them to reflect on their mortality and how their relationships may change within their family networks as they became older. Social workers explained how they could draw on these experiences and be enriched by witnessing the coping strategies of others. As the authors explain: 'The echo between the professional – personal – professional is deep and multi-dimensional, touching the social workers' lives in dimensions of self, couple relationships, parenthood and extended family' (p. 802). Social workers described a sense of mission to work in the face of adversity, to give a voice and advocate for those who are vulnerable and marginalised. The findings identified that this work could be enriching, creating mutual understanding and dialogue between social workers and the people they work with. As all the social workers in this study were female and maternal feelings are identified as a theme, it would have been interesting to see if a male social worker's perspective would have provided an alternative view.

Band-Winterstein, Doron and Naim's (2018) qualitative study extends their previous research by exploring social workers' (n16) experiences of working with self-neglect. Participants were asked to consider the following four domains: first, what are the first things that come to mind when talking about self-neglect amongst older adults? Second, could they describe their interaction with older adults who self-neglect? Third, they were asked about their encounters and emotional responses when working with self-neglect. Finally, they were asked what they think is the right way to treat self-neglect as a phenomenon (p. 196). Adding to the findings of the previous studies, the importance of multi-disciplinary cooperation is also identified here. A social worker expressed dissatisfaction with engaging health professionals and having to 'force them to make home visits' and described feelings of 'helplessness and frustration' (p. 205). Conversely, a participant shared a positive account of cooperation between care agencies, which illustrates the disparity in the experiences of multi /interagency working.

Band-Winterstein's (2018) qualitative study explores how nurses (n22) viewed self-neglect and how this impacts their professional and personal lives. Thematic analysis of interviews revealed three key findings. First, nurses thought the causation of self-neglect was primarily age-related and affected by physical and mental decline and could be associated with psychosocial factors such as social isolation, a loss of role, a lack of motivation, and a sense of abandonment. One nurse described the view of a person they had been working with: 'If others don't care then neither do I' (p. 974). The nurse explained that self-neglect is 'the first step towards suicide' (p. 975) as it was a vehicle to destroy their body. This finding supports Hafford-Letchfield et al.'s (2020) study of paid carers who felt the refusal by older people to accept care could indicate a sign of giving up on life. The second finding is described as the 'nurse's struggle for treatment,' which describes the overwhelming sensory, emotional and physical challenges for practitioners in supporting people who self-neglect and who live in unsanitary conditions. One nurse describes her experience: 'You smell the house even before you're inside. I can't tell if it's mold [sic], bad food or the person himself, I felt I was in another world, the house was a big mess, I just wanted to run away' (p. 976). The nurse could not undertake her duties and had to leave due to the sensory overload within the home environment. The findings from this study indicate a cognitive and emotional dissonance as nurses describe oscillating between repulsion, pity, empathy, anger and compassion. Lastly, the third theme identified was the question: 'What is our role here?' This theme was grounded in nurses' dilemmas when people needed support but refused. Some nurses took a rights-based approach, as one nurse states: 'Here the situation, and thus our role is more complex; they have autonomy over their body, and we have no right to interfere. The older adult is both the abuser and the abused, so what is our actual role here?' (p. 978). This study echoes the findings from Braye, Orr and Preston-Shoot's (2014) study, as it identifies the multi-dimensional complex experience practitioners can encounter on a home visit. The findings also identify the challenges for front-line practitioners in engaging a person who needs support but refuses and the ethical and moral difficulties this presents. This situation is complicated when working in unsanitary conditions, resulting in a sensory overload where one explained she had to leave as the

self-neglect was so extreme. In addition, nurses describe a complex set of emotions, from feelings of disgust to compassion, while simultaneously trying to undertake their professional duties and meet their organisation's expectations. The findings support Lauder, Anderson and Barclay (2005b) in that there is an emotional cost for workers involved in complex self-neglect cases.

Band-Winterstein, Goldblatt and Alon's (2021) qualitative study follows a similar theme to their 2014 study above as it explores how social workers (n17) experience and make meaning from working with elder abuse and neglect. Similarly, in this study, the authors do not identify types of abuse or neglect or specify self-neglect but given that self-neglect can fall within this remit, I thought it worthy of including. The authors highlight that working with people affected by abuse and neglect and witnessing their human distress can trigger negative responses in social workers. These responses can manifest in conditions such as compassion fatigue and secondary trauma (Figley, 1995; 2002) and can result in negative physical, emotional and psychological reactions. Findings identified themes where social workers could ‘sense the pain’ of those they worked with. This exposure and sense of responsibility for the person’s well-being and safety could cause them to then ‘take home the pain’, as the authors explain: ‘The concern and sense of urgency to relieve the clients’ distress spills over to the social workers’ personal life sphere, characterised by round-the-clock alertness (manifest in sleepless nights)’ (author’s brackets) (p. 579). The authors also identify, however, that social workers can reap benefits from these burdens and find personal growth that is ‘enriching and shaping’ as they learn and gain insights and wisdom from their clients' experiences.

Smith’s (2001) UK study provides insight into mental health social work with people who self-neglect. As a practitioner, Smith explores his experiences working with people who self-neglect and have enduring mental health problems. Smith recognises that part of working with self-neglect is the human response and explains: 'Part of the horror may be due to the fact that we may have recognised some of this process within ourselves’ (p. 37). Drawing on a psychoanalytic framework, Smith explores how

transference and countertransference may be experienced by the practitioner and describes how he would carry the anxiety about his clients:

> A feeling of being overwhelmed to the point of helplessness and powerlessness has clashed painfully with the desire to 'do something' to make this man's life more bearable, as I have perceived it to be one of unrelenting agony and torment for him…. However, concurrent with this line of thought is an equally overwhelming sense of everything possessing meaning, and if I were to remove it what would this man be left with? (Smith, 2001, p. 41).

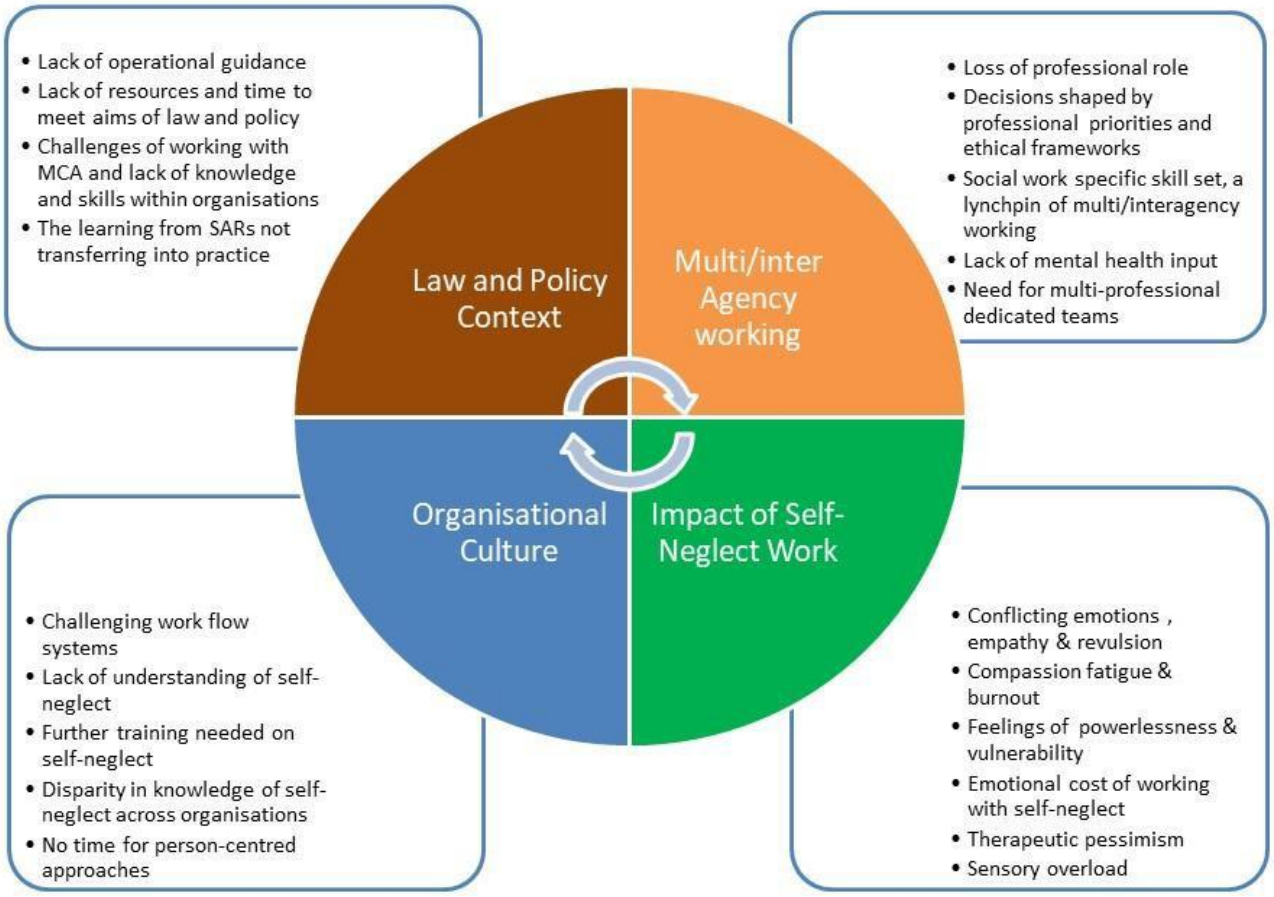
Whilst recognising that working with a person with poor mental health who hoards adds another dimension to self-neglect work, the emotional responses shared here chime with practitioners' accounts in the previous studies (Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Day, McCarthy and Leahy-Warren, 2012; Doron, Band-Winterstein and Naim, 2013; Band-Winterstein, 2018; Band-Winterstein, Goldblatt and Alon, 2014; 2021). Although these studies illuminate the emotional impact of self-neglect work, they do not explore in any depth how and where practitioners share and process these strong feelings and emotions. Although Braye, Orr and Preston-Shoot (2014) identify that supervision can be helpful for practitioners to gain support, I would suggest that this issue needs further exploration as there is a gap in understanding how practitioners articulate what they know and show concerning the impact of self-neglect work. Without this, there may be a danger of secondary trauma and compassion fatigue (CF) (Figley, 1995; 2002), a reduced capacity or interest in expressing empathy which can be a consequence of working with traumatised individuals (Band-Winterstein, Goldblatt and Alon, 2014; 2021). A study by Adams, Boscarino and Figley (2006) exploring specifically social workers' experiences of CF and psychological distress identifies that the likelihood of experiencing CF increases ‘If the professional was exposed to significant numbers of them [cases] and has a strong empathetic orientation’ (p. 103). They can vicariously experience the sense of trauma from the traumatised person they are working with. People who self-neglect can live in alarming levels of domestic and personal neglect (Bozinovski, 2000; Smith, 2001; Day, McCarthy and Leahy-Warren, 2012), and studies have already noted the emotional cost on practitioners working with self-neglect (Lauder, Anderson and Barclay, 2005a; Braye, Orr and Preston-Shoot, 2014). The

above studies suggest a need to look more closely at the sensory and emotional impact of self-neglect work on practitioners.

3.9 Conclusion.

Undertaking this literature review developed my understanding of what is known about practitioners' experiences of working with self-neglect and enabled me to draw on this new knowledge to develop my overarching research question. The literature identified that self-neglect is seen through divergent theoretical lenses and that practice is located within a complex, interconnected web of law, policy and organisational responses, professional expectations and personal relationships. The following diagram summarises the critical themes identified in this literature review.

Figure 2. Literature review: critical themes



The literature reviewed partly addresses my research question but also sheds light on areas worthy of further exploration. There is a call to develop a better understanding of how practitioners understand and experience working with self-neglect (Lauder, Anderson and Barclay, 2005a; 2005b; McDermott, 2008; Lauder et al., 2009; Day, Leahy-Warren and McCarthy, 2012; Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Britain Thinks, 2017; Band-Winterstein, 2018) and this is what my study intends to address. The literature reviewed provides valuable insights into the broader experience of self-neglect practice, although I want to take a narrower focus: I am specifically interested in how local authority social workers in England have experienced self-neglect work in their day-to-day practice

since the implementation of the CA. Therefore, with the insights I have taken from this literature review, I developed my research question to include sub-questions that consider how law, policy, organisational and interagency contexts impact social work practice alongside the relational and embodied impact of working with people who self-neglect. The following chapter presents these sub-questions and explains the theoretical and methodological framework I adopted that enabled me to explore them within this study.

Chapter Four. Methodology

4.1 Introduction

The literature reviewed in the previous chapter provides an important context for understanding the experience of working with self-neglect and identifies how front-line practitioners can struggle to find an appropriate response that respects the person's right to autonomy but also meets ethical and legislative obligations to protect adults at risk (Dong and Gorbien, 2005; McDermott, 2011; Braye, Orr and Preston-Shoot, 2014). There is a lack of empirical research that observes social workers' interaction with the people they work with during home visits (Bolger, 2014) and limited attention is given to the impact of working in unsanitary environments in self-neglect work (Braye, Orr and Preston-Shoot, 2011; 2014). Furthermore, recommendations from SARs suggest a need to examine the legal and policy context of self-neglect work to explore what enables or challenges social work practice (Preston-Shoot et al., 2020; Preston-Shoot, 2021). With the insights gained from undertaking the literature review, I developed my overarching research, 'How do social workers experience and make sense of self-neglect work?' to include the following four sub-questions:

- What impact does legislation, policy and local guidance have on self-neglect work? (This question explores how practitioners experience the formal statements of law and policy within their organisations)
- How does the organisational context influence self-neglect work?
  (This question explores the organisational culture in which the above policies are implemented and how practitioners experience this)
- How do practitioners experience multi/inter-agency work in self-neglect work? (This question explores how social workers see themselves and how they negotiate their role and others in self-neglect work within a local authority context)
- What impact does self-neglect work have on social workers? (This question explores the relational and embodied nature of self-neglect work).

I adopted a qualitative case study design to find the answers to the above questions as this provided an appropriate framework for exploring social workers' experiences within their organisational context. This approach allowed me the flexibility to draw on ethnography and symbolic interactionism as a theoretical lens to explore this case. The following chapter explains my rationale for adopting this research design and why this approach was selected as opposed to others. It then explains the application of the approach, data collection methods, how participants were recruited, and how ethical issues were addressed. This chapter then concludes with an explanation of how the data was analysed.

4.2 Research design

Selecting a research design to address the above research questions has been an iterative process. Exploring the range of theoretical and methodological approaches to find the best approach to progress my research questions was initially perplexing. As Crotty (1998) highlights, understanding the array of theoretical perspectives about creating knowledge can be confusing and is often exacerbated by using contradictory and inconsistent terminology. Given the conflicting perspectives of how self-neglect is constructed and understood by academics, practitioners and people who self-neglect (Lauder, Anderson and Barclay, 2005a; 2005b; Burnett et al., 2006), I decided that the most appropriate way of exploring my research questions was to draw on an ontological position, a way of understanding what constitutes reality, that acknowledges difference and provides space for the exploration of a range of subjective realities. As Gray (2014, p. 19, author's brackets in original) suggests: 'While ontology embodies understanding (what is), epistemology tries to understand (what it means to know)' and argues that having an epistemological framework for research methodologies allows for a 'philosophical background for deciding what kinds of knowledge are legitimate and adaquate'.

There are different perspectives on how social reality may be understood, with two primary research ontological positions: positivism and constructivism. For positivists, reality is independent of our knowledge - it exists 'out there' - whilst constructivists and others acknowledge that there may be multiple realities to be experienced (Gray, 2014). Whilst recognising there are limitations in these binary positions, constructivism is more compatible with the exploratory nature of my research study as it aims to discover social workers' individual subjective experiences of working with self-neglect. It also accepts that my experience of working with self-neglect may affect the collection and interpretation of the data as a researcher.

4.3 Symbolic Interactionism

This study aims to understand practitioners' experiences of self-neglect and how they engage, are affected by, and make sense of self-neglect work. In considering an appropriate theoretical framework for this study, I chose symbolic interactionism (hereafter SI) as a theoretical lens as it allowed me to explore how people understand their position, which is socially and culturally situated (Blumer, 1969). SI recognises that cultural and societal norms shape our understanding of reality, which the literature review identifies as influencing factors within self-neglect (Lauder et al., 2009; Wu et al., 2020). SI has an established pedigree and is located within a constructivist paradigm. It is a sociological perspective grounded in the philosophy of pragmatism developed by George Herbert Mead, an American philosopher, and then taken forward by his student Herbert Blumer (1969). The central belief is that people act toward things based on the meaning that those things have for them, and these meanings are developed from social interaction and modified through interpretation. This is achieved through the identification and re-negotiation of symbols and the interpretation of meanings attached to them. The literature review illustrated the range of competing imperatives that social workers have to interpret and make sense of, which include the legal, policy, organisational context, professional responsibilities and their personal responses to self-neglect. SI's emphasis on meaning offers a useful

perspective to explore how practitioners experience and make sense of the multi-factorial landscape of self-neglect work.

In explaining how meaning is understood, Blumer (1969) suggests that there are two conventional approaches. One is that meaning may be intrinsic to the thing itself and part of its natural makeup. There is no interpretive process required as the meaning is derived from the thing itself, i.e., a table is a table, which takes a positivist perspective discussed above, in that there is only one reality. The other is that meaning may be seen as a psychical process. The person's psyche may attach memories, ideas, attitudes and feelings associated with an object. However, Blumer suggests that SI presents an alternative view and argues that meaning is dynamic and interactive, created from the interaction between people:

> The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing. Their actions operate to define the thing for the person. Thus, symbolic interactionism sees meanings as social products, as creations that are formed in and through the defining activities of people as they interact (Blumer, 1969, p. 5).

SI identifies that as human beings, we must consider what the other person is doing or about to do, as this will inform our actions. Blumer describes this action as a 'line of activity'. This line of activity is vital when working with people who self-neglect as it reflects the complexity of practice where engagement can be a central challenge. A home visit to a person who is self-neglecting is a critical event where the practitioner can build trust and rapport within this line of activity. This exchange is often not straightforward in self-neglect work as the person may refuse to engage if they feel their choices are not being respected or may not see themselves as self-neglecting (as discussed in 3.3). Blumer (1969, p. 8) explains: ‘One may abandon an intention, or purpose, revise it, check or suspend it, intensify it or replace it… one has to fit one's own line of activity in some manner to the actions of others’. For me, this captures the dynamic and responsive nature of self-neglect work, which can be a constant, fluid negotiation of competing imperatives and where practice requires continuous mediation and adaptation. Each level of interaction, each line of activity, requires an interpretation, a

negotiation of rules, expectations and language, identified as symbols in the context of SI. Practitioners need to respond, interact with various symbols, and make meaning from a complex interplay of practice, policy and organisational expectations. These can include working with people at high risk due to self-neglect but refusing support and pressures from management and other agencies to find rapid solutions to address these concerns (Braye, Orr and Preston-Shoot, 2014).

4.4 Adopting a qualitative approach

The literature has identified that there is scarce empirical evidence of how social workers experience or make sense of working with self-neglect, with limited examples being Braye, Orr and Preston-Shoot, (2011; 2013; 2014), Day, McCarthy and Leahy-Warren (2012), Doran, Band-Winterstein and Naim (2013), or that observes social work practice in action (Morris, 2017). As Padgett (2017, p. 16) explains, a qualitative approach is appropriate when: 'You are exploring a topic which little is known about especially from an 'insider perspective'… and you wish to capture the 'lived experience' from the perspective of those who live it and create meaning from it'. This definition reflects the aims of this study; therefore I adopted a case study design that uses an ethnographic approach that includes participant observation, interviews and a reflective diary to capture my thoughts on the research process. Each component provides a different perspective and a broader lens that enabled me to explore social workers' experiences of self-neglect work. A qualitative approach also recognises that my own experience of self-neglect, my own bias, values and insights from practice, may influence the research outcomes. As Flick (2007, p. 7) explains:

> Qualitative researchers do not act as an invisible neutral in the field, but they take part when they observe (in participant observation) or make participants reflect their life and life history (in a biographical interview), (author's brackets), which may lead the interviewees to new insights about their situations and the world around them.

In contrast, a quantitative approach has its roots embedded within the natural science paradigm and a positivist approach. Quantitative studies strive to eliminate researcher bias and assert that another

researcher studying the same phenomena with accurate tools would achieve the same results. The underlying philosophy is an objective reality, one truth to be discovered (Denzin and Lincoln, 2013). This conflicts with my study's underlying philosophy, which starts with the premise that there may be a range of conflicting but valid viewpoints within self-neglect work, with the perspectives of social workers working with self-neglect within a local authority being the focus of this study. The following explains how a case study design offered me an appropriate and flexible framework to facilitate this exploration.

4.4.1 A case study design

I adopted a case study design for my research strategy as it allowed me to undertake an 'an empirical investigation of a particular contemporary phenomenon within its real-life context using multiple sources of evidence' (Yin, 2009, p.76). The sources of evidence I drew on in this case study included interviews and observations of local authority social workers working with people who self-neglect, and exploring what support, policies and guidance were in place within their organisations to support self-neglect practice. I also included comments from one local authority safeguarding lead who was not a participant in the study but someone I liaised with as part of the recruitment process. They shared their thoughts on the complexities of working with the legal framework surrounding self-neglect which I thought relevant to include.

'Case study' is an ambiguous term that can mean different things in different contexts and it can be hard to define what makes it distinctive (Ritchie and Lewis 2003). Padgett (2017, p. 35) suggests that the term case study is confusing as it refers 'to both method and product'. Yin (2004) suggests that a case study design's essential element is defining the 'case' and its boundaries In this application, the 'case' is local authority social workers (hereafter practitioners) working with adults with mental capacity and who self-neglect. The value of a case study design is that it provides me access to social work practice in context. As a researcher, it allows me to explore the multi-factorial nature of self-neglect work within a local authority setting to understand better how practitioners experience and make sense

of self-neglect work. A case study fits with a constructivist paradigm as it allows an:

> … exploration of a phenomenon within its context using a variety of data sources. This ensures that the issue is not explored through one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood (Baxter and Jack, 2008, p. 544).

A case study works well with exploratory research focusing on the 'how' and 'why' questions (Yin, 2014). Yin (2014, p. 9) proposes that the selection of a particular research method should not be related to a hierarchy but influenced by the following three conditions: (a) the type of research question posed, (b) the extent of control a researcher has over actual behavioural events, and (c) the degree of focus on contemporary as opposed to entirely historical events. These three conditions are applied to this study.

First, the type of research question posed. This is an exploratory study into the experiences of social workers working with self-neglect; therefore, the questions are guided by the findings from the literature review but are also open-ended and exploratory.

Second, the extent of control a researcher has over actual behavioural events. This study explores practitioners' experiences of working with self-neglect within their respective organisations and people's homes. As a researcher, these are complex and dynamic environments, and I do not have control over behavioural events.

Third, the degree of focus on contemporary as opposed to entirely historical events. This study focuses very much on the present in capturing the social worker's views of their recent experiences of working with self-neglect. Although there may be some historical element to the relationship between practitioners and the people we visit, the interviews and observations are not historical but located in the now.

In summary, a case study design allows me to go deeper to gain a 'thick description' (Geertz, 1988) of the case. A thick description requires me as the researcher to: 'Provide sufficient detail of all the

original observations or commentaries and the environments in which they occurred to allow the reader to gauge and assess the meanings attached to them' (Ritchie and Lewis, 2003, p. 268). A case study design allows me to apply the research questions in context and the flexibility to draw on a range of tools for data collection to observe how social workers navigate these constructs within a local authority setting. Furthermore, Gray (2014, p. 24) suggests that researchers have to: 'Study a subject's actions, objects and society from the perspective of the subject themselves' and that to realise this, as a researcher, I need to be alongside the participant in order to observe first-hand what is happening. The following section explains how I achieved this.

4.4.2 Ethnography

The focus of this study is to explore how practitioners experience working with people who self-neglect within a local authority context. My initial thoughts were to ask practitioners working with self-neglect to undertake a reflective diary to capture their thoughts when working with people who self-neglect. Janesick (1999) suggests that a reflective journal can enable participants to refine ideas and consider their responses to the research process. However, on further reading and reflection, I realised that to maximise my opportunity to get close to practice, I needed to be physically alongside practitioners as they worked. What propelled me to this decision was my belief that for practitioners to feel safe and share their experiences of self-neglect, I needed to be alongside them and occupy their place and space to observe first-hand how they negotiate their line of activity with people who self-neglect. Therefore, I decided to use an ethnographic approach as this gave me the access I needed to be alongside practitioners during home visits. A reflective diary was used solely to capture my observations and reflections on the research process.

Historically grounded in anthropology, ethnography is a field-based approach that aims to understand a culture or social group by participation and observation to explore their day-to-day lives (Krysik and Finn, 2013). Angrosino (2007, p. 14) suggests that ethnography: 'Is the art and science of describing a human group - its institutions, its interpersonal behaviors [sic], material productions and beliefs'. This approach allows me to be alongside practitioners to see first-hand their immediate experiences of self-neglect work and be 'a *subjective* participant in the lives of those under study, as well as an *objective* observer of those lives' (p. 15, italics in original). Ethnography provides a range of data strategies that enables the triangulation of evidence, including observation, interviewing, and documentary and archival material analysis. Floersch, Longhofer and Suskewicz (2014) suggest that ethnography and its focus on anthropology provide an approach that enables practitioners to 'theorize the particular-in-context' by providing 'empirically rich case studies of complex social problems' (p. 4), which aligns with my case study design. Furthermore, the authors suggest that although social work theories can enable practitioners to consider the broader impact of structural dimensions, such as how socioeconomics, culture and gender may affect the person, they do not address the immediacy of the present. It is suggested that we need to acknowledge the limitations and uncertainty of applying theory and suggest that 'social work is the act of using practitioner perceptual capacities to gather - seeing, hearing, thinking, and feeling - the contextual data relevant to a client's situation' (p. 4).

This focus on the senses outlined above by Floersch, Longhofer and Suskewicz (2014) resonates with my own experiences working with self-neglect. The sensory impact of working with self-neglect can be overwhelming (Band-Winterstein, 2018), and it is recognised that limited research explores how sensory experiences may impact social work; rare examples include Ferguson (2005; 2010; 2016) and Morriss and Morriss (2020). Exploring different sensory modalities to understand participants' experiences has been described as the 'sensory turn' (Howes, 2003; Morriss, 2017). Pink (2015, p. 26) suggests that sensory ethnography is grounded in the anthropology of the senses as it 'Deconstructs the notion of the mind/body divide to understand the body not simply as a source of experience and activity that would be rationalised and/or controlled by the mind, but itself as a source

of knowledge and subsequently of agency'. Furthermore, Pink suggests that sensory ethnography can bring new perspectives to understanding the relationship between sensory, embodied, and affective experiences within urban environments. Ethnographic experiences are 'embodied' in that the researcher learns and knows through her or his whole body. Furthermore, Pink proposes 'emplacement' goes further as it recognises that experiences are shaped by our minds, bodies and the material and sensory nature of the environment, and asks ethnographers who engage with the senses:

> To be more explicit about ways of experiencing and knowing that becomes central to their ethnographies, to share with others the senses of place they felt as they sought to occupy similar places to that of their research participants, and to acknowledge the processes through which their sensory knowing has become part of their scholarship or practice (Pink, xii., 2015).

Incorporating sensory ethnography allowed me to be alongside practitioners on home visits to experience what Pink describes as their emplacement. It allowed me to inhabit their space to experience the sights, smells, hearing, taste, touch and atmospheres whilst simultaneously recognising my own emplacement in this shared sensorial experience.

4.5 Reflexivity

As explained above, I chose to be alongside practitioners as they work to gain insights and share their experiences of self-neglect work, although as a qualitative researcher I recognised that my own experiences as a practitioner would filter the lens of what I observe and how I interpret the information I gather in my study. However, my experiences as a social worker were valuable because they provided a shared narrative to connect and build trust with the practitioners involved in this study and provided insights and a deeper understanding that I could bring to the research process. Although, I needed to acknowledge that these experiences may have influenced the choice of my methodological approach, my relationships with participants and my interpretation of the data. Using a reflective diary as a critically reflective tool allowed me to reflect on the research process and recognise and engage with incongruence, challenge and potential bias. However, Geertz (1988, p. 89) describes the 'diary

disease', a proliferation of written reflective accounts in practice, and suggests that researchers undertaking ethnographic research on a topic they are familiar with, such as myself, need to go beyond reflection to reflexivity. I needed to defamiliarise myself with this subject and undertake a much deeper scrutiny and analysis of my understanding. As a reflexive practitioner, I have had to deconstruct my 'taken for grantedness' of self-neglect, but this was not easy as I have 15 years of direct practice experience that has shaped who I am as a social worker and as a human being. These experiences stay with me and have, consciously or unconsciously, permeated the research process. I needed to be clear on who I am and how I present myself transitioning from practitioner to researcher. One of the challenges of practitioner-based research is that 'you may be tempted to "know" what you are going to find' (Dodd and Epstein, 2012, p. 159), and I needed to retain the opportunity to be surprised by the responses from the practitioners in this study.

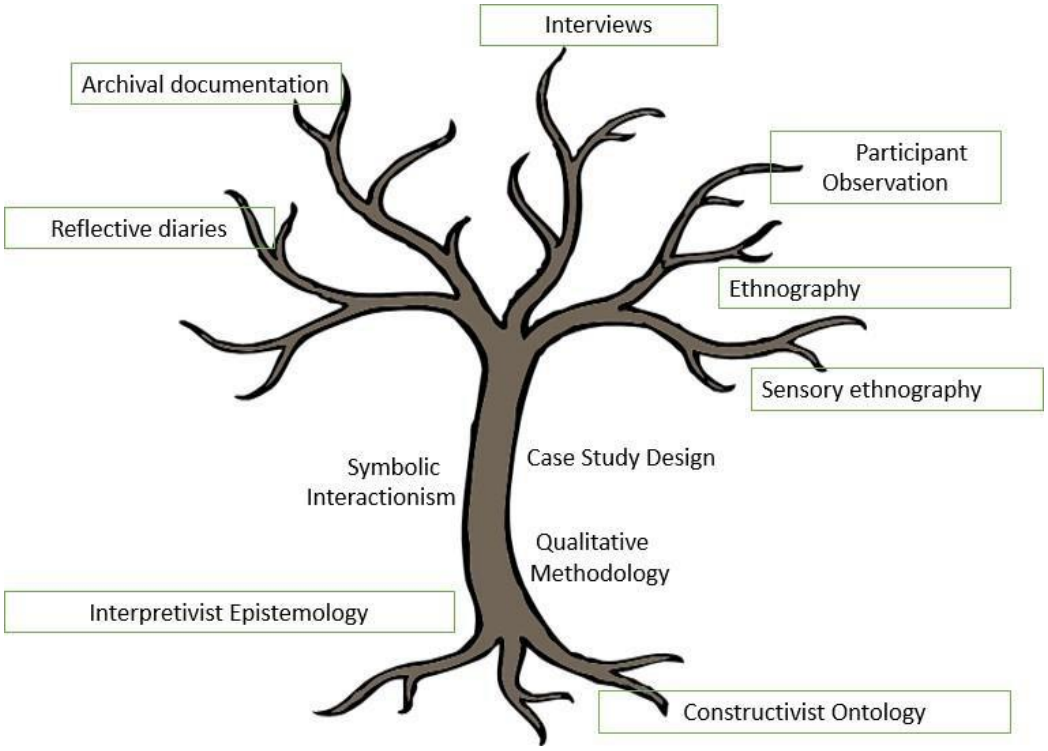
4.6 Reflections on my research design

As explained in 4.2, I initially struggled to understand and decide on the most appropriate methodological approach to undertake this study. I found Blaxter, Hughes and Tight's (2010, p. 64) explanation of understanding the array of different research methodologies and methods helpful by constructing them as two broad research families, qualitative and quantitative. This explanation provided a knowledge framework that enabled me to see the connected relationships between ideas of knowledge, research design and data collection methods within particular research approaches, enabling me to select the most appropriate research strategy/family to answer my research questions. I found Wolcott's (2009, p. 84, Figure 4.1) description of conceptualising research as a tree particularly useful. In his description, Wolcott visualises that the tree's trunk is firmly rooted in qualitative research, and the branches represent different strands of qualitative approaches, including participant observation, interviewing and archival sources. Wolcott suggests that as researchers, we can climb the tree to get the best vantage point and draw on the branches of qualitative research to provide us with the best means to address our research questions and explains:

> Each researcher makes a conscious choice as to where to get the best view for the information desired, and everyone realises that it is impossible to be everywhere in the tree at once, although there are positions from which the view is said to be more holistic and complete (Wolcott, 2009, p. 82).

Integrating Blaxter, Hughes and Tight's (2010) analogy of a research family and Wolcott's (2009) visual research tree enabled me to construct and visualise my own research tree. As in all family trees, I understood that characters in pivotal positions might dominate and influence others. I learnt that different research approaches produce different kinds of knowledge and that selecting research tools is more than just considering whether to adopt particular data collection methods, e.g., interviews or surveys. They hold much more significance as they pose 'Philosophical questions about how we understand social reality, and what are the most appropriate ways of studying this' *(*Blaxter, Hughes and Tight, 2010, p. 59). Adopting a qualitative approach offered me a range of vantage points where I could see possible connections in how practitioners as actors engage in a range of legal, policy, organisational, professional and personal contexts. The below configuration, Figure 3, illustrates how I adapted Wolcott's (2009, p. 84) research tree to conceptualise and summarise my research design for this study.

Figure 3. Conceptualising my methodology as a research tree.



4.7 Recruitment and data collection

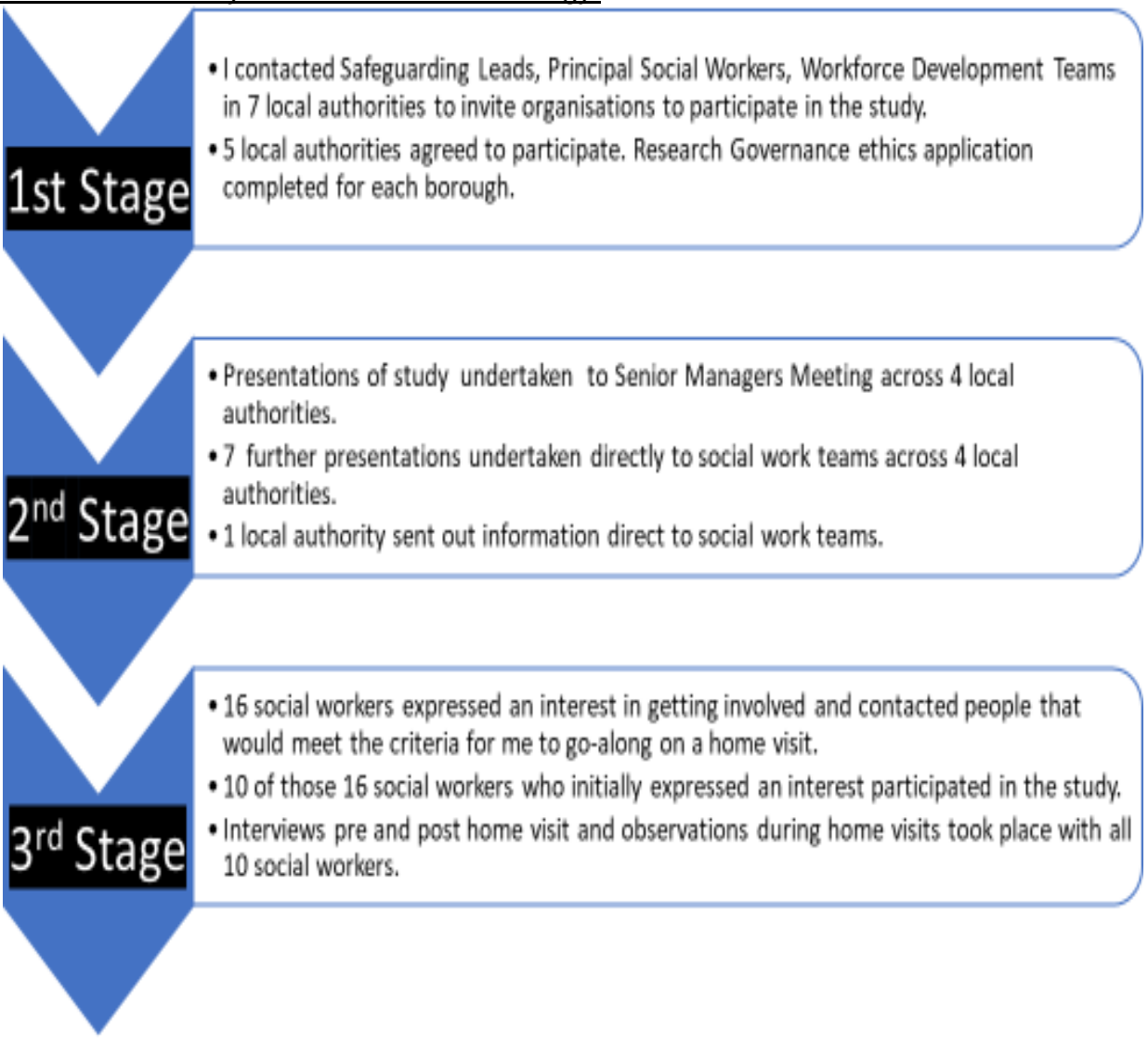
The above section explains the rationale for the methodology and why a case study was an appropriate research design for my study. The following explains how I recruited the practitioners for this case study, the process, challenges and data collection methods. As explained, the participants are practitioners working within local authorities' adult community teams with adults who have mental capacity and are self-neglecting their personal or domestic environment. As discussed above, a case study design enabled me to put a boundary around the 'case' and explore practitioners' experiences of self-neglect work within their own local authority organisational context. I adopted a purposive sampling approach as participants were recruited 'on the basis of known characteristics… such as

experience, roles etc., relevant to the research topic' (Richie and Lewis, 2003, p. 108). The following explains the practical steps I took to accomplish this.

With my experience working in different London boroughs, I used my range of contacts, primarily safeguarding adult leads and principal social workers, to invite their respective boroughs to participate in the study. I approached seven local authorities, and five expressed an interest in getting involved. I attended Senior/Team Managers' meetings in four different boroughs, gave presentations explaining my research, and secured their agreement to visit or email their respective teams to invite practitioners to participate. One borough sent information about the study to their social work teams via their workforce development team. I undertook seven further presentations directly to practitioners within their teams across four of the boroughs. The above process resulted in sixteen practitioners across five boroughs expressing an interest in participating, although the final number was ten participants (for reasons explained below).

Gaining access to LAs to recruit participants was challenging. I underestimated how complicated this process would be and assumed that doors would readily open with my contacts. This was not the case, and it took me over two years to collect my data. The recruitment process involved a significant amount of communication across all the boroughs involved, numerous phone calls and emails to the nominated point of contact, usually the safeguarding or workforce development lead, to set up my attendance at the team meetings. I had to be tenacious and continually follow up with those who had shown an interest. Due to the pressure of work commitments or a change in their circumstances, six potential practitioners could not participate, resulting in a final number of 10 participants. The following illustration summarises my recruitment strategy.

Figure 4. A summary of the recruitment strategy.



Gunstone (2003) identifies that those with more experience working with self-neglect can develop a higher threshold to risk. Therefore, I wanted to recruit practitioners with a range of experience to explore this. I also wondered if participants' gender affected how they experienced self-neglect work. However, a gender dimension was not evident in the findings, and as I had only a small number of males, I used non-gender-specific terms when describing the findings to protect their confidentiality. I also wanted to approach different boroughs to explore if demographics and social and economic factors affected self-neglect work. Although, as explained, recruitment was challenging, and the findings showed that all the local authorities had similar issues, working with austerity pressures and challenges with staffing and workloads, there were some differences, with some having more policies

and procedures than others. However, they all worked within the same context and shared more commonalities than differences. For example, all agencies used the London Multi-Agency Adult Safeguarding Policy and Procedures (Association of Directors of Adult Social Services (ADASS), 2019), where cases met the safeguarding criteria. The following table provides a summary of the participants:

Table 1. Research participants.

Participant number of Social Worker (SW)	Number of years Social Work Qualified	Local Authority
SW1	Over 10 years	Agency 1
SW2	5 -10 years	Agency 1
SW3	Over 10 years	Agency 1
SW4	Over 10 years	Agency 2
SW5	3-5 years	Agency 3
SW6	3-5 years	Agency 4
SW7	1-2 years	Agency 4
SW8	1-2 years	Agency 4
SW9	Over 10 years	Agency 5
SW10	Over 10 years	Agency 5

4.8 Ethical research

I took measures to ensure that the above participants, and the people we visited, were not adversely affected by being involved in this study. I drew on the ethical framework of Beauchamp and Childress (2001) to inform my approach, and whilst recognising there are overlapping features, I have used four key principles as a guiding structure which are addressed in turn.

- Respect for autonomy (which addresses self-determination, informed consent and confidentiality)

I met eight of the 10 participants by presenting at their team meetings, and I had phone calls with the other two who contacted me directly. In both instances, I supplied an information sheet (see Appendix 3) and consent sheets (see Appendix 4) that set out the aims and expectations of participating in the study. I explained that the information they shared and the details of the person we would visit would remain confidential and that their identities would remain anonymous. The interviews undertaken with practitioners were audio recorded on a device that only I had access to and were held on a private, password-protected computer with any identifying information removed. Once the data was gathered, all names were changed, and a coding process was applied to remove any distinguishing factors. The link between the participant's name and the code was known only to me as the researcher. All names used in the reporting of the study are pseudonyms. Participants' organisations are described generically, omitting any characteristics that may give rise to that organisation's identity and identified only as agencies 1, 2, 3, 4 and 5. Sampling participants across five different boroughs provided a further layer of confidentiality. Participants in this study shared personal and professional experiences of working with self-neglect, some of which reflected negatively on their agency. I explained that the information shared would usually be treated as confidential. However, as a registered social worker, if I witnessed practice that constituted a safeguarding concern, I explained that I would discuss it with the participant and share this information with their manager, informing the participant what I intended to do and why.

- Beneficence (doing good and the well-being of participants)

I was aware of a possible power imbalance between myself and the participants. As an experienced social worker and academic, I was mindful that participants might feel vulnerable in my observing their practice. I reassured participants that I intended to walk alongside them to give voice to their experiences of working with self-neglect. I was not there to assess their practice and would not feed information back to their managers unless I observed a practice that would constitute a safeguarding concern. Participants were informed that they could withdraw at any time during the study without any negative consequences. A further information sheet and consent form was given for the social worker to share with the person we would be visiting to ensure they were clear on the purpose of the study and expectations (see Appendix 4 and 5). This is explained more fully below.

Drawing on ethnography as a research approach gave me valuable opportunities to get close to practice to observe and interview practitioners working with self-neglect, although I needed to pay attention to non-maleficence (not doing harm) and beneficence (doing good and the well-being of participants). Haight, Kayama and Korang-Okrah (2014) highlight that adopting an ethnographic approach in social work research presents unique risks as research often involves working with marginalised and at-risk groups and caution that: 'Obtaining an in-depth understanding of such experiences requires sensitivity to the potential harm to participants caused by discussions of these topics' (p. 136). I was aware from my own experiences that self-neglect work can evoke strong emotions, but I felt confident that as an experienced social worker, I had the skills to support practitioners if they became upset during the research process.

- Non-Maleficence (not doing harm)

A range of measures was implemented to ensure this principle was addressed. The first was gaining ethical approval for this study, which Royal Holloway University Ethics Committee granted in 2016 (see Appendix 6). In addition, each of the five local authorities involved in this study required me to complete a further in-house research ethics application. As explained above, I was attentive to the needs of all participants and having the study scrutinised by both RHUL and the LA ethical committees, I felt reassured that all the necessary steps had been taken, although visiting people who self-neglect in their homes required vigilant attention to possible unplanned situations that could arise.

Visiting people who self-neglect in their homes required a further layer of ethical scrutiny as in adhering to the principle of non-maleficence (not doing harm), I wanted to ensure I did not cause any harm to the people we visited. A criterion for those we visited was that they had the mental capacity to consent to my coming along and were able to read and sign the information sheets and consent forms. I was aware that the person may still be vulnerable due to their living conditions and possibly poor health related to self-neglect. Therefore, I was guided by practitioners as they had a relationship with the person and could make an informed judgement on whether it was appropriate to invite them to be involved and for me to come along with the practitioner on a home visit. The practitioner took the role of explaining the research and sharing the information and consent forms. It was made explicit that the study focused on practitioners' experiences, and they would not be asked any questions and no personal data would be recorded. The person was encouraged to contact me directly to ask any questions on the purpose of the research and what it would entail, although none of them did. When we arrived at the home visit, I checked at the door that they were still in agreement and explained that I would leave at any time if they felt uncomfortable and that there would be no adverse consequences. Once inside, I explained I was there as an observer, checked that they had seen the information sheet, signed the consent form, and asked if they had any further questions.

- Justice (are the purposes of this research just, and what are the benefits and burdens for the research participants)

Although self-neglect is a growing feature in adult social work and in SARs (Preston-Shoot et al., 2020) and has a changed status under the CA, there is little research that explores practitioners' experiences (Mason and Evans, 2020). Providing a safe space for practitioners to reflect on their practice in the interviews offered insights into how they may gain support and guidance in self-neglect work.

4.9 Interviews

Two interviews were undertaken with each participant. The first was at their office, following which we travelled together to the home visit, or we would meet near the address of the home visit and undertake the first interview in my car. I reiterated that the interviews would be recorded and transcribed and that their contributions would be made anonymous and remain confidential.

Although I had previously spoken to the participants, I was aware that some might be anxious about being interviewed and observed. Roulston (2010, p. 204) outlines the challenges of qualitative interviews and suggests that understanding the assumptions about knowledge production will assist interviewers '... to consider the kinds of strategies that are implied for ensuring that they have addressed issues of "quality" in both interviewing practice and the research study as a whole'. Ralston sets out the helpful framework below and draws on Silverman's (2001) 'constructionist' model, which aligns itself with my theoretical framework and recognises that:

- the interview data is co-constructed by both interviewee and interviewer,
- audio recordings are undertaken for analysis to consider how the narrative and subsequent data was constructed,

- it explores how both parties orient to 'categories' which explore our joint understanding of the topic (in this instance self-neglect), and
- naturally occurring data is considered to be valuable to help understand how participants make sense of the topic (Roulston, 2010, p. 208).

During this first interview, I asked participants why they chose this particular case and asked for a brief summary exploring what other agencies were involved and what they hoped to achieve during the visit. I also asked how their organisations supported them with self-neglect work and the influence (or not) on their practice of legal and policy frameworks relating to self-neglect. These questions comprised a guided conversation rather than a prescriptive list (see Appendix 7). The second interview was undertaken immediately after the visit in either my or the participant's car. We discussed what the practitioner was thinking and feeling immediately after the visit, what emotions they had, what they thought had gone well, and what concerns they had. By this point, I had spent considerable time with participants, some up to 4 hours travelling together, which fostered a more open, natural discussion about their experiences and observations of the visit.

My initial intention was to take written field notes of my observations during the home visits. In planning for this, I was informed by the work of Reeves et al. (2013, p. 1370), who draw on the work of Spradley (1979) to suggest that the field notes should pay attention to feelings, the space, people's actions, sequencing of events, feelings and the physical things that are present. Although the above areas were helpful as a guiding framework, the reality was that due to the extreme hoarding in many of the homes we visited, I was unable to capture these in written form. I was in such close proximity to both the practitioner and the person we were visiting, often knees touching; it felt inappropriate and intrusive to take out a pen and paper to record my observations. I was also mindful that I wanted to pay attention to the physical and sensory experiences of both me and the participant during the visit and therefore needed space to observe what was happening around us. I mentally took note of key areas and recorded my thoughts on an audio recorder as soon I was alone, which were then

transcribed and formed part of my reflective diary. I was aware that my presence may have affected the behaviours of the practitioner and the person we were visiting. However, on reflection, I believe that the practitioner was focused on the job at hand, and I support the view of Becker (1971, p. 46), who suggests: 'Whether or not the person being observed knows what the observer expects of him, he dare not respond to that expectation. What he is involved in at that moment of observation is as a rule much more important to him than the observer is'. Participants were offered the opportunity to discuss the observations of their practice and have copies of the transcripts of the interviews to ensure they felt that their views were being presented as they intended; however, none took up this offer, (see Appendix 8 for an example of an interview transcript).

4.10 Data analysis

The data generated from this study was analysed using a Thematic Analysis (TA) method. TA was first introduced in the 1970s by physicist Gerald Holton and developed further by Braun and Clarke (2006; 2013; 2021) who were frustrated by the absence of a named method that provides a 'Systematic approach for identifying, analysing and reporting patterns and themes-across a dataset which was not tied to a particular theory' (Braun and Clarke, 2013, p. 178).

TA is unique in that it is solely a method for data analysis. It is not attached to specific ontological or epistemological frameworks and does not align with any prescribed data collection methods, for example, as Grounded Theory does with theoretical sampling and line-by-line coding. This flexibility and simplicity provided a suitable vehicle for my data analysis which was guided by my research questions and needed to be open to new data. I did not want to follow a rigid coding frame but wanted to allow the responses from the research questions to evolve through the coding process (Braun and Clark, 2006, p. 87). As Braun and Clarke explain (2013, p. 178):

> Themes can be identified in a data-driven, 'bottom-up' way, on the basis of what is in the data; alternatively, they can be identified in a more 'top-down' fashion, where the researcher uses the data to explore particular theoretical ideas or brings those to bear on the analysis being conducted (bottom-up and top-down approaches are often combined in one analysis) (author's brackets).

Sound qualitative analysis stems from an 'analytic sensibility' that requires the researcher to examine and interpret data to find repeated patterns of meaning (Braun and Clark, 2013, p. 201). To provide a framework to facilitate this, Braun and Clarke (2006) built on the ideas of Holton (1970) to develop a six-stage framework that sets out a transparent set of processes for data analysis which I applied to the data generated from this study; this will be explained later in this section. However, a critique of TA is that researchers may be in danger of imposing their meaning on the data without the structure and perimeters of a theoretical framework. The counterargument is that TA is not prescriptive or restrictive in analysing data as it is not tied to a particular methodological paradigm and provides space and flexibility to recognise data that may fall outside the research's parameters. Braun and Clarke (2021) have described their approach as reflexive TA as it 'not only demarcates it as a particular TA approach, it emphasises the importance of the researcher's subjectivity as analytic resource, and their reflexive engagement with theory, data and interpretation (p. 330). This was evident in my approach to data analysis, which involved top-down and bottom-up approaches: top-down as my research questions guided my data selection, but also bottom-up in that I was open to data that initially did not appear to be connected to my research questions. For example, I was interested in participants' emotional and sensory experiences of self-neglect, but I was surprised by findings that revealed the impact on participants when working with people with sensory impairments. A further surprise was the strong sense of respect and attachment the participants had to the people they were working with; particularly given the pressures and challenging environments they identified in self-neglect work.

I drew on Braun and Clarke's six stages of analysis (2006, p. 87) as a framework to structure my data. The following section describes how these six staged processes were applied to the data and what

steps were taken at each stage. It is important to note here that this was not a linear process; as Braun and Clarke describe (2006, p. 86): 'It is a more recursive process, where you move back and forth as needed, throughout the phases'.

Step 1. Familiarising yourself with the data

All interviews were transcribed verbatim. Following each interview, I repeatedly listened to the recordings, read the transcripts and notes from my observations alongside my reflective diary to identify areas of interest, and noted what Braun and Clarke (2013, p. 204) describe as 'noticing' initial thoughts and observations. Miles and Huberman (1994, p. 56) suggest that this observation stage is selective and that as a researcher, I am 'constantly making choices about what to register and what to leave out'. What proved interesting was how different messages were revealed by my listening to the interviewees and reading the transcripts. Listening to the emotion, tone and emphasis of words expressed by participants provided a further layer of depth and richness to the data.

Step 2. Generalising initial codes

Within TA, the coding process can be approached in two ways, selective coding and complete coding. Braun and Clarke (2013) explain that selective coding is: 'Identifying a corpus of "instances" of the phenomena you are interested in and then selecting these out' (p. 206). In complete coding, instead of detecting specific instances: 'You aim to identify *anything* and *everything* of interest or relevance to answering your research question' (author's italics) (p. 206). I adopted the latter. As a novice researcher, I felt this holistic approach would limit my opportunities to miss meaningful data. I was mindful of building my knowledge of the whole data corpus at this stage as I started to look past the words to connect meaning between the interviews, observations and my reflections and how they related to the research questions.

Step 3. Searching for themes

Braun and Clarke (2013) suggest that a common pitfall is for researchers to use the main interview

questions as the named themes, and this can indicate that the data has been summarised and organised rather than analysed. Braun and Clarke (2006, p. 84) identify two types of themes: semantic and latent. Semantic themes are described as being '… within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said or what has been written'. In contrast, a latent level looks beyond what has been said and '… starts to identify or examine the underlying ideas, assumptions, and conceptualisations and ideologies that are theorised as shaping or informing the semantic content of the data' (p. 84). I adopted a latent approach in data analysis as it enabled me to look beyond the semantic surface meaning of what was said. For example, participants described the pressure to close cases and to 'get their name off it' due to a sense of an impending crisis. However, looking beyond this semantic content and analysing data from the pre- and post-interviews and my observations revealed a sense of interdependency and attachment between practitioners and the people they worked with. After one home visit, a participant explained: 'I am kind of sad because I know there will be a moment where I won't be working with her anymore… she'll either sink or swim and that is tough' (SW6). This process was more than simply summarising the data as it allowed me to get behind the presenting information to explore in more depth how participants make sense of self-neglect work.

Step 4. Reviewing themes

In TA, it is not necessarily the number of times a code or theme is noted in the data that is important as Braun and Clarke (2012, p. 230) explain: 'It's about determining whether this pattern tells us something meaningful and important for answering our research question'. For example, three of the 10 participants identified how they could see themselves developing self-neglect behaviours, with one explaining to me following a visit: '… it has made me clean out my own cupboard!... I think "No, get rid"' (SW10). Although only three of the ten participants expressed this view, I thought it relevant to include it as it gives a valuable insight into the impact of self-neglect work. As a lone ethnographer, I drew on what Saldaña (2016, p. 37) refers to as 'member checking', discussing my analysis with a fellow student working on a separate project that provided a valuable sounding board to define my

themes. For example, I identified the theme of emotions by collating the codes of frustration, anger, worry, guilt, care and compassion (see Appendix 9 for an example of coding).

5. Defining themes

The following themes I identified related to how participants make sense and meaning from their relationships with the organisation, partner agencies, the person they are working with, and their sense of self. The themes are categorised for the analysis process but are held in one enveloping construct, the complex interconnected and multi-dimensional landscape participants have to navigate in self-neglect work. What was apparent in identifying these themes was their interactional relationship with each other, a cause and effect that connected each theme. This was reassuring because it confirmed that I had chosen an appropriate framework in Symbolic Interactionism (SI), in that SI recognises our realities are co-constructed, and meaning is made through interpretation and interaction with others, which came through strongly in my analysis of practitioners' experiences of self-neglect work.

Step 6. Production of the report

The report's construction (in this instance, the report is the findings) was shaped by the above themes illustrated by revelatory quotes that provided insights into how participants experience and make sense of self-neglect work. My observations of participants during home visits and personal reflections are also integrated into this report to provide an alternative perspective. I was acutely aware that although the data was selected to address my research questions, this process would have been influenced by my own experiences of self-neglect. Although TA provides a comprehensive framework to support data analysis, there needs to be recognition of possible bias and the need for reflexivity, which were discussed earlier in this chapter (4.5).

4.11 Conclusion

This chapter has explained my reasoning for adopting my methodological approach, which is grounded in a constructivist ontology and interpretivist epistemology. This approach supports my belief that there is no one truth, but social and historical contexts shape our realities and meaning is interpreted through our engagement with others, allowing for the exploration of the complex relationships and conflicting experiences of practitioners working with self-neglect. The recruitment strategy has been explained, and ethical considerations have been explored alongside confidentiality and data protection issues. The rationale for adopting a case study design and TA as a method of data analysis have been presented, illustrated with examples demonstrating how this method worked in practice. Key themes have been identified and will be presented in the following chapter.

Chapter Five. Findings

5.1 Introduction

This chapter presents the findings from my analysis of the data drawn from interviews and observations of practitioners working with self-neglect in local authorities. The findings are presented thematically, using themes informed by the thematical analysis of Braun and Clarke (2006; 2013; 2021). The analysis is illuminated by practitioners' anonymised and cross-referenced quotes as illustrated in the table, 'Research participants', Fig. 6 in Chapter Four, and includes my observations of being alongside them as they work. The findings are presented thematically using the structure provided by the sub-questions set out in my methodology chapter; thus, they explore the impact of legislation and policy, organisational contexts, multiagency working, and the relational and embodied nature of the work. These interrelated themes cast light on the overall research question of how social workers experience self-neglect work.

5.2 What impact does legislation, policy and local guidance have on self-neglect work?

As discussed in Chapter Two, the inclusion of self-neglect within safeguarding highlighted a need for local authorities (LAs) to develop policy guidance to support practice and organisational responses (Braye, Orr and Preston-Shoot, 2014). I was interested in whether the participants' organisations had policy and practice guidance on working with self-neglect and, if so, what impact this had.

Three of the five LAs involved in this study had self-neglect/hoarding policies and hoarding panels to support practitioners, whilst two did not. The three policies I looked at provided practice guidance on identifying and working positively with self-neglect. They signposted organisational resources, such as hoarding panels, where practitioners could seek support from senior managers for guidance on complex cases. One practitioner explained that in the absence of a specific forum, such as a hoarding

panel, self-neglect cases were discussed at a Multi-Agency Risk Assessment Conferences (MARAC), usually a forum to discuss high-risk domestic abuse cases, which they thought was not appropriate as the needs of people who self-neglect are very different. Practitioners who did not have policy guidance within their LA felt it was much needed, as one explained:

> I think having clear guidance is crucial. Speaking to other practitioners in different local authorities, there seems to be a lack of clear guidance from a managerial level. Just to give you an example, our protocol is still… I think it needs to be updated but it's not clear about what we could possibly do (SW9).

Interestingly, in contrast to the above, when I asked one practitioner whose LA did have policies in place if they drew on policies to inform their practice, they replied: 'No, I don't think I have the time' (SW8). Six of the ten practitioners said they did not have time to read policies on self-neglect and would only use them if cases were high risk or felt that a complaint was forthcoming. Instead of informing practice, guidance appeared to be used as a 'checklist' to ensure that all areas had been covered if anything went wrong; as this quote illustrates:'… It is good evidence because at least if, God forbid, this goes to a coroner's court or something awful happens, at least the officials can trace back that all the appropriate support has been provided' (SW2).

The majority of practitioners expressed frustration and helplessness concerning the legislation and guidance surrounding self-neglect at both a national and local level, although the Mental Capacity Act (MCA) 2005, which sets out the assessment process and proposed action if a person lacks capacity, was reassuring for practitioners, as one explained: 'the decisions are made for you' (SW8). Practitioners struggled to engage with the MCA, particularly where people had mental capacity but made decisions that put their health and safety at risk. One practitioner explained: 'It's very difficult working with someone who poses this high level of risk, but they've got capacity, and I feel like sometimes my hands are tied' (SW7).

The CA places a duty on local authorities to undertake a s. 9(1) assessment for anyone who appears to have care and support needs; this may include concerns around self-neglect. However, if it appears that a person is at risk of abuse and neglect and is unable to protect themselves due to self-neglect, they may be assessed as part of a s.42 safeguarding enquiry, as explained in Chapter Two. I asked practitioners about their experiences working with self-neglect under this safeguarding remit, which elicited a divergence of views. Four practitioners stated that having self-neglect under the remit of safeguarding was positive as it provided a structured focus: 'It's good that hoarding is out there… I'm informed by the law, like the Care Act… helping to reduce risk, prevention from harm and work within the law … without going over that boundary' (SW2). However, others felt that self-neglect's location within safeguarding procedures was not a good fit. They described that self-neglect had been 'shoehorned' into safeguarding just to locate it somewhere within organisational structures. As one practitioner explained: 'Safeguarding and self-neglect is a bit of a tricky one. It doesn't lie comfortably with me to be honest, I think they're trying to put it under a kind of umbrella, "so let's just stick it under safeguarding"' (SW3). When asked if it had made any difference having self-neglect under the remit of the CA, one practitioner replied: 'No, I think it's brought it more into the limelight but there's not the resources… we'll have the safeguarding meeting but actually the work's the same… it tends to be very slow' (SW5). However, one practitioner identified both strengths and challenges in this approach and explained:

> We are so concentrated on safety issues that sometimes you tend to forget the person. I think that safeguarding is a good way to discuss and to open the door to more, to the cooperation with other agencies but from a person-centred perspective, I don't know if it's the right route to take… I just find it a bit strange (SW9).

Of the 10 home visits I observed, nine cases met the safeguarding criteria due to self-neglect; the other case involved hoarding, but the practitioner did not think it met the criteria to initiate safeguarding procedures, but the person's needs were considered as part of a s.9 CA assessment. Of those nine cases, five had further adult safeguarding concerns not related to self-neglect and one case involved a child protection concern. Practitioners involved in these cases explained that having additional

safeguarding issues created significant work in already challenging cases. They explained they had to liaise with other agencies, such as the police or child protection services, which could disrupt their workflow, as this practitioner explained after we visited a woman who had previously disclosed a child protection concern:

> She started telling me about her son. Somebody had beaten him really badly because they thought he was abusing somebody else's 5-year-old son, then she went on to say, 'My son's got four children and they're under 10' and then she started saying, 'There was all these accusations years ago about him having child pornography' and oh for goodness sake, we're literally sitting there and there's flies jumping around and then all this stuff is coming out about her son! (SW7).

This practitioner explained that due to this disclosure they had to break confidentiality and involve their manager and child protection services, and the work they were doing around self-neglect stalled. The practitioner explained that their manager had given them additional time to work with this woman to build a trusting relationship. Therefore, due to this trust, they continued to work together after the child protection concern was resolved.

One practitioner identified further challenges for those who did not meet the financial criteria for support from the local authority, often described as self-funders. She explained that although the CA specifies that self-funders are entitled to support, there was a culture in her team in which others questioned why she was even involved with supporting a person who self-funds and self-neglects; they were perceived as not the team's responsibility.

The above findings illustrate a range of disparate experiences with conflicting views on whether self-neglect is best located under safeguarding procedures. Practitioners highlight the challenging interface of working with the MCA, managing further safeguarding concerns alongside self-neglect, and debates within teams on who should receive support. The following section develops this further

and explores how practitioners experience the organisational and management culture in which the above law and policy frameworks are implemented.

5.3 How does the organisational context influence self-neglect work?

All the practitioners interviewed identified a range of internal and external organisational pressures that included the pivotal role of managers, a lack of knowledge and understanding of self-neglect within their organisations, working in systems that did not allow for person-centred practice and additional external pressures from local councillors.

When asked if practitioners felt supported by their line managers, six of the 10 felt positive about their support, which they explained was essential to work constructively with self-neglect. This practitioner explained: 'I think the team, particularly my line manager, is very accommodating and recognises it is very much based on the relationship that you can build with that client' (SW7). And another stated:

> They want you to be creative and flexible, so in terms of working with somebody, I wouldn't have any issue with saying, 'It's been six months, it's still open to me and I'm still working on it', and I think that would probably be okay, they'd accept that. (SW6).

One practitioner highlighted that having managers with experience of self-neglect was particularly beneficial as they could provide practical suggestions: 'It's good the supervisor I have at the moment, she had a tricky case… she was able to give me some pointers. It really does help as she is still fresh with cases' (SW2). However, six of the practitioners, which included two who felt overall supported by their managers, expressed concerns about their managers' lack of knowledge and self-neglect experience. They were worried that this could be a barrier to accessing meaningful support; as one explained: 'When it comes to putting these concerns into practice and how to help social workers, I think it's difficult to find anyone from a managerial level, to say something more than, "We know that it's difficult"' (SW10). Another practitioner explained that this gap in their line

manager's knowledge, coupled with a lack of policy guidance, placed them in a vulnerable position, particularly with high-risk self-neglect cases. One practitioner explained: 'We have to take care of ourselves… I was feeling helpless… you got supervision, but your supervisor is on the same wavelength with you, they're not offering you any more than what you already know' (SW6). Four of the 10 practitioners did not feel fully supported by their managers, as supervision focused on practical tasks and pressure to meet prescriptive time frames to assess and close cases.

5.3.1 Self-neglect and a case management approach.

All 10 practitioners said that self-neglect work is not congruous with what they described as a 'case management' model implemented by local authorities. As one explained: 'Today we had the team meeting, and the expectation is that we close two cases every two weeks, and there are some cases that you cannot close' (SW6). All practitioners said that the complexity of self-neglect was not compatible with a fast throughput case management approach as it does not allow for time to build a relationship with the person, with one arguing: 'It doesn't really fit into the case management role, it's a bit of a square block against a round circle!' (SW8).

All 10 practitioners expressed frustration with organisational expectations and the lack of time allocated to self-neglect work. There were tensions between the time needed to build trust with the person and the demands of undertaking other complex work, as this practitioner explains:

> I'm not getting anywhere with this client and yet I'm putting in so many hours and yet, my caseload, I've got really urgent cases, clients that are in crisis, managing that, it takes a toll, it really takes a toll and it leads to frustration sometimes. So, I can get frustrated (SW6).

I observed some of this frustration on a home visit with a practitioner to an older man who had poor mobility. He had an extensive collection of books and magazines seen as a fire and falls risk by a physiotherapist who had recently visited. He found it difficult to respond to the practitioner's

questions and seemed vague and unsure. The man was unwilling, or perhaps unable, to give the practitioner the information they needed for the assessment, and I could sense the practitioner's frustration. During the post-visit interview, I asked them how they felt the visit went.

> Maybe I got a bit impatient with him, but I was just like conscious of the time and trying to get everything in one, and this is where the frustration is… with senior managers, they've just lost touch with frontline. I've seen this gentleman now, I will need to go back and see him several times before I accomplish anything. How am I supposed to work in that, accomplish what I am supposed to do in three months? It's just crazy. At the back of my head, I am thinking, 'Blimey, I've got to do this pretty quick because I need to get back to the office, do whatever I need to do and then start again tomorrow' and I'm thinking, 'that's awful'. I just want to make sure I've got all the information as much as possible but at the same time I am annoyed with myself because that's when I felt that I was trying to… rush in but I was getting a little bit like 'No, hang on, let me…' because he was going around the houses. So yeah, I'm a little bit annoyed with that, with me (SW3).

My observation and this quote illustrate how time pressures can manifest themselves in direct practice and impact practitioners' judgements and behaviours during home visits. A lack of time significantly impacted practice as all practitioners identified that time was essential to building trust. A practitioner shared a positive outcome of where they had the time to work in a person-centred way: 'He's told me he trusts me, he's more open… he's agreeing to do things that I'm suggesting which he wasn't doing before at all' (SW6).

5.3.2 Knowledge and understanding

The above themes identify the complex landscape of self-neglect work, but most practitioners expressed concern about their lack of knowledge and training to support people who self-neglect. They talked about feeling out of their depth and ill-equipped to respond to high-risk cases, for instance:

> I don't feel as practitioners we're well equipped at all to deal with such cases, definitely no training, I don't remember if I even had any training actually, so for me to start working with Mr X, I'm just thinking what can I do… but obviously the more you deal with, the more you get used to it, I was okay and I'm okay now but I feel the organisation definitely does not prepare us (SW6).

This view was echoed by nine of the 10 practitioners who identified a lack of training, guidance and support within their local authorities to support self-neglect work. Only one practitioner, who had over 30 years of experience and felt supported by their manager, was confident in their practice and said they did not need specific practice guidance, although those with less experience stated that they needed further support and advice. Some practitioners explained that a lack of knowledge and understanding of self-neglect work within local authorities resulted in unrealistic expectations being placed upon them to 'get something done', whilst at the same time they lacked the support and training to manage complex cases. This finding raises questions about how social work education prepares and supports social workers to work with self-neglect and if this topic is addressed in enough depth in qualifying and post qualifying social work programmes.

5.3.3 External pressures

Practitioners talked about pressures from external sources due to complaints from the community and other agencies, some of which they explained were motivated by the Grenfell fire tragedy (2019), Although the fire was caused by poor construction and the use of flammable materials, it highlighted the fire risks attached to hoarding as this practitioner explained: ‘A lot of it stems from Grenfell… a lot of housing are like “We need to make sure all the residents are safe”’ (SW1). Practitioners also talked about criticisms from local councillors and Members of Parliament (MPs), as this practitioner explains:

> … As soon as they know a practitioner or professional Social Services are involved it's like, ‘You're a practitioner, how can you let this person live like this?’ and you're thinking it's not me, you have the pressure and ‘Why haven't you done anything? This is disgraceful’…and then sometimes it can escalate, people going and getting their local MPs involved, then everyone's meeting, you have councillors, you have Environmental Health, you'll have senior managers, and you get bombarded with emails and you just think, ‘What do they want me to do?’ I've gone out and seen this person several times, particularly with clients who have got capacity, they understand the concerns, they understand what's been going on. And then you've got senior managers coming down saying, ‘So what are you doing about it? What's the worker done about it?’, do you know what I mean? I don't like stuff like that because you just forget about the person you're working with (SW3).

5.3.4 Summary

Overall, the above findings identify both internal and external organisational pressures experienced by practitioners working with self-neglect within a local authority context. Internal pressures included a lack of personal knowledge and experience working with self-neglect, compounded by a lack of understanding, support and training within the organisation and from managers. A lack of time to build trusting relationships was a central theme, raising questions about organisational responses and the appropriateness of using a case management approach or safeguarding procedures to respond to self-neglect. There was a divide with some practitioners saying that they did not feel supported by their line managers, whilst others felt their managers understood the complexities of self-neglect and allowed them some discretion and additional time to work in a person-centred way. External pressures on practitioners from outside sources included complaints from MPs and Councillors and increased management pressure to 'get something done'. These multi-factorial pressures brought frustration, compounded by not seeing a return on their hard work as some cases failed to progress.

5.4. How do practitioners experience multi/interagency working in self-neglect work?

Practitioners talked about expectations that had two connected strands: first, what they expected of other agencies and, second, what agencies expected of them. Most practitioners expressed frustration at what they saw as a lack of response and understanding from other agencies. For instance, one practitioner described feeling frustrated due to unrealistic expectations from partner agencies about what they could achieve in a limited time:

> It's often getting repeated referrals from other people which sort of say, ‘This is a problem’, ‘This is a problem’, it's like we know it's a problem, it's like ‘Why haven't you done this? Why haven't you done that?’ and it's like those are obviously the first things that we tried. It takes a multi-agency approach doesn't it really? I think some agencies feel that they make the online referral and they've done their bit, and then when you actually sort of say, ‘What do you expect from us? What are you hoping that we're going to do?’ they haven't thought that far, so it's like ‘This is your problem, off you go, deal with it’, it's like ‘What do you think we should be

> doing?' … How am I supposed to do everything in such a short amount of time? it's the old magic wand thing again isn't it? (SW3).

Five practitioners identified engaging mental health services in multi-agency work as a problem and expressed frustration that referrals to mental health services were downplayed or ignored. This practitioner explained: 'Well, we've referred to the mental health team because of the hoarding, but they have done very little' (SW5). This lack of response was compounded by a sense of isolation and frustration, as this practitioner describes:

> You just feel like you're banging your head against a brick wall… but you might go to health professionals and they'll say, 'That person doesn't have a mental health diagnosis so it's back to you', and it's really difficult sometimes trying to do some joint working together with other professionals, but sometimes the onus is on back to Social Services and they do feel like very much out there and it's always the practitioner at the frontline if anything gets up or there's a complaint, 'Who's the practitioner involved?' and then you see your name in all these emails to people and you just think, 'Oh God, my name up again' (SW3).

Practitioners talked about the expectation on them to enter homes to visit people where other agencies had refused, citing health and safety concerns. Two practitioners shared examples where the fire service refused to go upstairs to assess a property due to extreme hoarding as one explains:

> London Fire Brigade, they're not allowed to visit properties or rooms which are too cluttered, which put us in a position, to risk assess but I find it quite difficult… I think there should be more shared responsibility among professionals, the Housing department, Environmental Health department, London Fire Brigade. I think at the moment, we are still far away from a really coordinated approach (SW9).

Practitioners expressed disbelief that essential services such as the Fire Service and nursing would not go in due to unsanitary conditions and risks related to hoarding, but social workers felt they had no choice. As this practitioner explained: 'It's wrong that the fire brigade won't go upstairs but I go up there!' This practitioner also talked about their frustration with nurses: 'The nurses won't go in… he's got a colostomy bag and he's got diabetes, but they just said, 'No, we're not going in there' and I just think that's terrible!… the buck rests with us doesn't it!' (SW10). Frustrations were identified when working with housing departments where intervention felt invasive and disrespectful towards the

person. A practitioner described a situation with a housing officer: ‘They got somebody to go in and take pictures of her flat which would have been quite intrusive for her, but they'd never sat and talked to her’ (SW7), highlighting the danger that a lack of knowledge of self-neglect could result in oppressive practices.

Similar frustration was directed at private tradespeople who refused to enter properties to repair essential items due to unsanitary or crowded conditions, which left the person without vital services, as this practitioner explains:

> Before they were just going in and saying, ‘No, we're not doing work,’ how does that make her feel? They weren't mending her boiler, ‘No, we're not working in that environment’, so she didn't have heating or hot water for four months, they just wouldn't go in. Somebody came to fit a washing machine, a new one that she'd bought, ‘No, we're not going to take the old one out, we haven't got room to work’ and then you've got the washing piling up as well, so it was awful. Last chance saloon, if we don't go in, nobody's going to go in… talking about being angry you think every time you refer you think ‘This is all going to have to be done after the clean because nobody's going to go in’… but we have to! I was thinking about it, they say if an office is too hot or cold, there is this legal limit where you just can't operate at, we don't have that! Mind you, I have heard of practitioners being chased down the road by people with hammers, oh dear, we do it to ourselves don't we? (SW7).

5.4.1 Should I stay, or should I go now?

All practitioners acknowledged the need for workers and agencies with specific skills to support self-neglect work. However, five practitioners went beyond this to express a sense of attachment to working with people who self-neglect and a reluctance to close cases, as this meant that the case would go back to a duty or review team, and their involvement would cease. Furthermore, all practitioners described the significant amount of time it took to build a relationship and talked about breakthrough moments as this practitioner describes: ‘That was either a back me or sack me moment, either she was going to work with me or say, social services can all get stuffed’ (SW7). The majority of practitioners expressed concern that if they closed the cases and handed them over to others, i.e.,

support workers or housing officers, the good work they had achieved would be undone, and the person would revert back to self-neglecting behaviours. They had worked hard to develop a positive relationship and were reluctant to let this go, as this practitioner explains:

> This is a really strange feeling, you almost feel like you want the person all to yourself and just have that relationship between the two of you… I'm kind of sad because I know there will be a moment where I won't be working with her anymore and it's knowing where I've got to say, 'You've done really well and things are working and now, I'm pulling back a bit', she'll either sink or swim. So that's tough… I don't want her to feel the way she felt back in February, where she felt like nobody cared about her and she's worthless… it's like if all that invested time and effort was not… didn't bring us to some kind of way of her living where she was able to keep things going, it would be soul destroying. Frustrating beyond belief, if I saw a referral for her in two years' time and she needed another load of help from somebody else and the flat was in a pickle again, I'd feel like I'd failed! I know I haven't but that's how I'd feel (SW7).

5.4.2 Summary

In summary, practitioners identified that multi/interagency self-neglect work is complicated by both the input and the absence of other agencies. Self-neglect work appears to be poorly understood by other agencies, and practitioners can feel isolated by a lack of response and guidance from their line manager, the local authority and partner agencies. Practitioners felt like the 'last chance saloon' (SW7), where they were the only ones willing to enter hazardous environments to support people in high-risk situations. Despite these challenges, some practitioners expressed a strong emotional attachment to the people they were working with, presenting its own set of complications regarding boundaries and expectations. The following section explores practitioners' responses to the final research question, 'What impact does self-neglect work have on practitioners?'

5.5 What impact does self-neglect work have on practitioners?

Practitioners explained they experienced strong emotions and feelings witnessing a person's self-neglect, which are presented in the following themes: recognising feelings, sensory experiences and practitioners seeing themselves in self-neglect, which are explored in the following section.

5.5.1 Recognising feelings

When I asked practitioners if they thought there was an impact from self-neglect work and what feelings it brought about, most of them initially appeared perplexed by the question, as the following quote illustrates:

> Emotional… it's really weird you ask me that because I've never had to think... it's a bit like reflection isn't it? Because it's such an automatic... I've gone in there, practically looked at him, trying to meet with him, trying to deal with it emotionally, I have to be honest, I just feel a bit helpless (SW5).

Although I had been alongside practitioners as they worked and seen the complex cases they were working with, most of them said they had not felt able to think or talk about the feelings these cases evoked before I posed the question. Once they had time to reflect, they opened up and some described feeling overwhelmed with the complexities of self-neglect and expressed feelings of frustration, worry, guilt and isolation. Feelings of frustration are a consistent thread throughout these findings. Although practitioners talked about the need to work at a slow pace in self-neglect work, they also talked about how a lack of seeing any progress could result in compassion fatigue, as this practitioner explained:

> I'd just like to say hopefully I'm professional enough not to let this show, but it can be frustrating, you can get frustrated with the person and be like, 'Why aren't you helping yourself?'… So I can get frustrated, I think you can also get compassion fatigue a little bit about it and again, this is a balance that I struggle with as well because I have to think to myself, 'Is this compassion fatigue or is this me realigning my expectations?' and there is a difference (SW8).

Due to the slow progress of self-neglect work, seven of the practitioners explained they felt hopeless when they did not see any positive change, as this quote illustrates:

> So, I do come out thinking, 'I don't know when this is going to end'. A kind of a bit demoralising and… not that motivated although I want to support him and help him, but I know I'm doing it today and tomorrow is still not going to have achieved… it's a very long-term piece of work that I don't see an end to and it can be a bit demoralising, to be honest (SW6).

For these practitioners, a lack of progress appeared to affect motivation as one explained: 'I start off feeling really useful and because I'm a fixer I'm like 'We can do a lot with this' and then over time I think it grinds you down (SW7). Most practitioners expressed anxiety when a person has mental capacity but refuses health and community services, putting themselves at significant risk. They described how these cases, due to stress levels, could give practitioners sleepless nights, as this quote illustrates: 'Oh my God, are they going to be alright?… You're just sitting there with a sleepless night thinking I hope I don't come back tomorrow and they've gone back into hospital' (SW3).

I went with a practitioner on a home visit to see an older man whose home was extremely cluttered due to hoarding. The practitioner had organised support to clear some space as his wife was being discharged back home from the hospital. Although this man was not abusive during our visit, the practitioner told me that he had been verbally abusive to them in the past. This man's behaviour, his reluctance to engage with support services and the concerns around his wife's safety following discharge presented significant challenges for the practitioner. Following the visit, I asked the practitioner how they felt:

> It's horrible because you feel helpless, I think they're so vulnerable, one of them could be found dead in there and then I'd feel that it was my fault but yet it's not, there's nothing I can do… Oh, my goodness, I dream about him! [laughs] I do! It's awful, I really do… I used to just wake up thinking, *'Oh God, he's dead'…* I used to just wake up in terror, that something awful happened! And it's my fault because I haven't done it but what can you say, he'll just say 'no' to everything (SW10).

Seven practitioners talked about feelings of guilt and responsibility as the people they worked with were often lonely and socially isolated. The sense of personal responsibility and investment discussed earlier (5.4.2) is evident here also, alongside a commitment to the person that went beyond organisational expectations, but this raised issues of maintaining professional boundaries:

> I shouldn't really feel a massive responsibility, but I do because I feel like she's got no-one really and I'm it. So, I have to be careful that I'm not going over the line and being a practitioner and then being a friend, I'm friendly but I'm… yeah, it's a tricky one. The only thing I can say about working with this lady is that I feel kind of like… wrongly maybe, I'm feeling like I need to be protective of her but I'm not sure what from, but it's almost like I need her to be protected from herself and that's really terrible (SW7).

Two practitioners became tearful when discussing the people they were working with due to the person's situation and their sense of personal responsibility. I asked how they processed these strong feelings and if they discussed them in supervision. One responded:

> It is not something I had ever thought about before me and you starting talking, it's not something I have talked about in supervision with my supervisor and certainly not with my supervisees, because I supervise staff as well but I've never told anyone about how I feel… the feeling of not achieving, the feeling of it dragging on and I just want to move on… because I know something horrible will happen and it's got my name on it, and I can't sleep at night sometimes (SW6).

Most practitioners explained that their supervision focused on bureaucratic and practical tasks, such as making and chasing referrals to other agencies; they did not have space to recognise or reflect on their feelings and the emotional impact of self-neglect work. They would talk to their colleagues immediately after a home visit rather than wait for supervision with their manager. As this practitioner explains: 'I think often after you see someone, you want to talk about it more, almost straightaway while it's still fresh in your mind so you have a plan, so often it's like informal supervision, having a chat with a colleague' (SW7).

5.5.2 The sensory experience of self-neglect work.

All the practitioners explained how they were affected physically and emotionally working with self-neglect. For instance, four practitioners described how they had felt physically sick whilst conducting home visits. They shared experiences where there had been unpleasant smells due to self-neglect, hoarding and infestations of vermin or flies. It had been hard for them to mask their visceral reactions, but they did not want to appear disrespectful. A practitioner expressed guilt about their reaction:

> I sat down and the rubbish was literally over my head, it was that bad and there were flies going up my nose and it was pretty grim, I know that's not a very professional thing to say but it was 'Oh, there were flies', she said, 'They do get a little bit annoying' and they were landing on my paper and on my hands and I felt itchy for about two days afterwards, and I had a couple of showers when I got home and I thought, 'Is that an insult to her that I'm actually having a shower when I got home?' I almost felt like I was insulting her! I know that sounds silly (SW7).

All the practitioners talked about not wanting to appear judgemental when visiting people who self-neglect and how important it was not to show any outward reaction to unpleasant home environments. Three practitioners explained that they consciously did not dress differently or wear older clothes as a mark of respect, even though some properties they were entering were extremely dirty and had infestations of vermin. One practitioner explained that in their mind, this was a way of conveying to that person that they were not a lesser person because of their self- neglect and that they deserved the same respect as others they were working with.

However, many practitioners also recognised that the environments they worked in affected their practice. After a home visit I attended with a practitioner, they explained that they had to leave this person's home on a previous visit due to the smell. The practitioner explained they left without completing the assessment as they thought they would be sick and left on the pretence of an

emergency at home. They felt guilty they had failed the person somehow as they could not undertake their professional duties and explained:

> Today was not smelly because the door was open… the last time I left, I was feeling unwell, I really was feeling sick. That's the thing, respectful, I've come a long way to come and visit him and work with him so I want to stay the duration but I was really struggling, I was struggling, oh my goodness, by the time I left, I couldn't breathe, it was that bad but today it was not too bad, I think because the door was open (SW6).

Nine practitioners were working with people with high levels of self-neglect and expressed deep concern about how these people lived, although their level of experience appeared to influence their perspective. As one explained:

> I think when you have that continual exposure to similar kinds of environments, you're going into another parallel world, universe, but the values are inverted or upside down… whatever is normality becomes kind of twisted and acceptable and you kind of build up a relative perspective… you begin to think 'At least that wasn't as bad as the last one I went to, even though that was really bad'… I think you can lose a sense of what is right and wrong… It's like you are in your world, then you open up the back of the cupboard and you're in Narnia but it's not Narnia, this is a totally different world, one minute you're in your world, the next minute you're in a world where everything is upside down and a bit mad and a bit skew- whiff… what is that quote? A social worker is a broker of shades of grey, we work in the greys of human existence (SW4).

This quote illustrates how those with more experience appeared to have a less visceral reaction to self-neglect. Another practitioner talked about becoming '... Immune to it now… it's the smell of it but you get used to it… it doesn't bother me too much, but some people it probably does, especially new practitioners, to see someone for the first time is quite horrific' (SW5). Practitioners with less experience appeared to be more affected by the sights, smells, and overall sensorial experiences of self-neglect work. On one home visit with a recently qualified practitioner, we visited a younger man with a physical disability. When we arrived, he had just defecated down the hallway as he struggled with incontinence and did not reach the toilet in time. The smell of faeces was difficult for us both, but we managed the situation sensitively and made all efforts not to embarrass him. After

the visit, I asked the practitioner how they felt it went. They explained that they had made some progress since her first visit:

> I hadn't seen a home environment quite like that condition before, it was very dirty, smelled of urine as well and there was like fly pupae… there were flies in the room, flies had bitten him, he had marks on his face, so flies had been biting him, and I saw the marks on his skin, I felt bad, I felt a bit sorry for him if I'm going to be honest… (SW8).

The practitioner showed compassion for this man but explained that they felt overwhelmed. They explained their overriding emotion was guilt, feeling guilty that they may not have the experience and knowledge to do the best for this man and assess risk competently, explaining: 'It's probably my level of experience… I'm constantly asking myself 'How safe is safe?' you know, 'What is good enough?' (SW8).

I was interested in practitioners' emotional and sensory experiences of self-neglect, but I was surprised by findings that revealed the impact on practitioners when working with people with sensory impairments. One practitioner was working with an older woman who was deaf and who was hoarding, and they agreed for me to attend the home visit. When we arrived, we could barely walk through the corridor due to her collection of clothes and papers precariously stacked up to the ceiling. The practitioner was worried that she might be unable to raise the alarm if items fell on top of her due to being deaf. The following is an extract from my reflective diary that I recorded immediately following the visit and transcribed:

> The overwhelming feeling was of kindness and of empathy and just genuine connection between the social worker and xxxx and having to work with somebody who is deaf, trying to broach issues of hoarding, areas that you can normally drift into conversation and use language, how you're stripped away of the niceties of trying to softly introduce things because you just don't have the opportunity to do that. Just an overall sense of concern as such a high level of risk, when we were there, things fell over, she had to climb over a chair. I just felt really privileged to have accessed this world, this very different world and thinking about the sensorial experience of that. I feel quite emotional after it… she's a fantastic character but a sense of worry and isolation, recognising what might happen to this woman in the future.

The above accounts provide insight into the strength of feeling this visit evoked for the practitioner and me. The practitioner became upset in our post-visit interview as they described sleepless nights worrying about this person. Working with people who are deaf brought another layer of complexity to self-neglect work, an area I had not previously thought about.

Practitioners described visiting people who self-neglect in homes other agencies refused to enter due to health and safety risks. This raises questions about why these practitioners enter properties when others refuse and what is it about the organisational culture that influences these decisions. Practitioners' commitment to person-centred and non-judgmental practice was evident in my observations and in their accounts, whilst also opening up questions as to why they do not discuss this work's emotional and sensory impact with their managers in supervision. The following explores practitioners' explanations of how self-neglect impacts them and their relationships with others.

5.5.3 Recognising the impact on self

In interviews, four practitioners talked about how working with self-neglect caused them to reflect on their relationships and behaviours. On one visit, a practitioner who had been working with a woman intensively for several months explained how this had led them to reflect on their own relationships with family members:

> I came out of her flat and I thought, 'My God, I've been to visit this lady more times in the last two months than I've visited my own mother', so I thought, 'This is not a good thought', and I thought, 'Get a grip xxxx, you see your mother every week' but it does start to feel a bit that way when you've got to do intensive stuff with someone, you feel guilt then, 'Am I a good daughter?' all these thoughts are going through my head then (SW7).

On another visit, a practitioner explained that seeing the person's self-neglect made them feel that they did not want to hold on to any unnecessary domestic items because of a fear of developing hoarding behaviours and stated:

> I tell you what, it has made me clear out my cupboards! [laughs] It really has! I keep thinking, 'I can't, I mustn't keep things', it really has affected me like that, everything, I think 'no, throw it away', I had a big deep clean this last bank holiday, I thought 'I'm going to get rid of this' because you can see that in there, [referring to the home visit we had just attended] that's years of him and his memories and things and I think, 'No, get rid' (SW10).

Another practitioner explained that reflecting on their behaviour made them think about how they assess risk: 'I was thinking am I somehow in her league because I've got stuff in my place that's everywhere? Am I not seeing the risks because of that? Strange thoughts go through your head, definitely' (SW7). For some, working with self-neglect brought their vulnerabilities into focus. A traumatic life event, bereavement or loss could move us into a state of self-neglect as this practitioner explains:

> It is recognising my own vulnerability, that could happen to me, something could happen to my children. I don't know how I am going to respond to something like that. I think what separates you from that person is about the width of a cigarette paper and you don't know what is going to trip you over and you then you tip into that world and then you're on that other journey then (SW4).

5.5.4 Summary

In summary, all the practitioners shared experiences when they were affected by the sights, smells, and physical environment of the people's homes. Strong emotions included a sense of disbelief that people could live in conditions that were far removed from practitioners' own life experiences. Some practitioners could also see aspects of themselves in people who self-neglect, and their work brought their vulnerabilities and relationships into focus.

5.6 What helps in self-neglect work?

In the preceding section, practitioners talked about the impact of self-neglect work. The following describes the motivation and personal strategies practitioners drew on to help process and neutralise the impact of this work. Some explained that their compassion for the people they work with was their motivation. Others explained that returning to the normality of family life could recalibrate this work's sensory and emotional impact. Some suggested a need for structural change within local authorities and shared ideas about new ways of working with self-neglect.

5.6.1 Pride and compassion

Nine of the 10 practitioners worked with people for an extended period, between four weeks to 10 years (the tenth case was a new referral). They all shared positive stories in which they felt they genuinely connected with the person and could see a positive change, as these quotes illustrate: ‘Today, for the first time since I started work with Mr. X, I feel really positive, I feel encouraged, it's a good feeling, I feel he's finally working with me’ (SW6). Another practitioner describes her reaction to a positive outcome: ‘I never thought I'd have got him to clear that room so it's actually quite miraculous!’ (SW10). There was a tangible sense of care and respect in observing the interaction between the practitioners and the people they worked with. Despite the challenging home environments and the pressures identified that surround self-neglect work, all the practitioners showed unconditional positive regard for the people they worked with, as these quotes illustrate:

> I'm proud of her, I know that's a weird word, if that's not patronising but I'm proud of her. I'm happy for her, really happy for her as a person, that she's able to accept visitors that she doesn't know into her house! I was just proud of her, I thought, ‘Oh God, this is brilliant for you as a person’ (SW7).

> He's a guy that has got a lot to give, he's got so much to give, and I need to manage my expectations because in my mind, the world's his oyster but it's not about me, it's about him and what he wants to achieve, so there's that, I feel quite privileged (SW8).

Five of the practitioners talked about humour being a coping mechanism but also as a way of developing a positive relationship with the person; as this practitioner explains: 'I think there were issues about trust… but we got over that and we got quite a good rapport going on and I have a bit of banter, which is really important' (SW4). One practitioner talked about admiration:

> What I admired about her, she had literally the gall to stand up to people and you know, get away with things. She was just brilliant; do you know what I mean?! [laughs] And that's the only thing [laughs] that made me laugh, some of it was crazy but she made me laugh (SW3).

Building the relationship was vital, as this practitioner explained: 'I think to be honest the first thing I think is really important… particularly with this client group, is to try and dismantle the authority figure' (SW4). I observed this practitioner changing lightbulbs, fixing fuses, doing practical tasks, and saw how important this was in fostering a positive relationship, although undertaking these tasks was beyond the practitioner's usual remit. Their interaction was based on openness and negotiation. Another practitioner explained how their direct approach enabled them to move things on: 'Okay, kind of off the record kinda thing, but really be like "No, we need to do this," you have to be quite stern sometimes because sometimes you let them lead and we're not going anywhere' (SW3). The positive regard that practitioners described in their accounts were balanced with a sense of tough love, where they also talked about being persuasive and robust in their negotiations to encourage the person to accept support.

5.6.2 New ways of working

Practitioners shared frustrations with the current approach to self-neglect, with some suggesting new ways of working. From an organisational perspective, practitioners' suggestions included developing focused multi/inter-agency teams with resources and scope for long-term work. Most practitioners felt that more training, clearer guidance, and a better understanding of the complexities of self-neglect within local authorities, partner agencies and the wider community would improve collaborative working. One practitioner suggested that organisations have a 'Self-neglect or hoarding official

debrief, like a zone where you could share what you've learnt. Like she [the client] fed back about stuff that didn't work for her so how do I feed that back into how we work?... So we can make that better for her?' SW7).

Higher levels of experience seemed to help in negotiating self-neglect work. Practitioners discussed that having more experience gave them the confidence to challenge managers about decisions to close cases, as one explained: 'I think I've been fortunate. I've been working here for some time so the managers… when I've told them something they take what I've said and if I say, "Look it was really, really bad!" they will listen' (SW4). Another practitioner explained: 'I have had another one before [case] and my manager said, 'Close it,' and now, since I've had more experience, I've said, 'No, I'm not closing it, it's not right' (SW10). A small number of practitioners said it would be helpful if their managers would come out on visits with them so they could offer advice and provide support, acting as a consultant to offer advice. Others felt that some managers did not understand the realities of practice and needed to come out on home visits to experience the challenges, as this quote illustrates: 'I think because managers don't have to face it, do they, they don't see it. I've said to my manager many times, 'I think you should come out and see this', and she has offered to and then she never does!' (SW10).

Overall, participants' opinions about what helps in self-neglect work crosscut organisational, professional and personal boundaries. Practitioners put forward ideas to improve self-neglect work and to think differently about delivering services, suggesting the development of specialist multi-agency teams with more time and resources. Managers with self-neglect experience can help as they can support practitioners, impart their practice wisdom, and share an understanding of the complexities of this work. Furthermore, managers willing to go out with practitioners on home visits are valued as they can provide support, offer guidance on complex cases and remain connected to the realities of practice. Experienced practitioners respected in their organisations challenged

management demands by refusing to close cases and advocating for more time. They valued the support of their peers to help process their experiences and identified the normality of day-to-day family life as an essential counter to the stresses of self-neglect work.

5.6.3 Support strategies

Practitioners talked about personal strategies which helped lessen the impact of self-neglect work. One explained that they would walk in the park and sit and read a book chapter to bring themself back to a sense of normality following challenging home visits. Another explained that they would go home, take off their work clothes and have a long hot bath 'to leave the day behind' (SW7). Being with family and the normality of making dinner could help to counteract the emotional and sensory impact of self-neglect work. All the practitioners talked about how they gained support from colleagues and described how they would return from visits to discuss their experiences. This interaction helped them process and make sense of what they had seen and provided an informal, non-judgemental, safe space where they could be open and honest about their feelings. Practitioners also talked about how being part of this study had helped them reflect on their work and the importance of self-care, stating: 'But this, what you are doing is brilliant because I can see the importance, we have to take care of ourselves, we have to recognise what we are doing' (SW6).

5.7 Conclusion

This chapter has presented the critical themes identified in the findings, illustrating practitioners' complex and multi-dimensional experiences of self-neglect work. The findings suggest that local authority practitioners' experiences do not occur in a vacuum. They are influenced and embedded within a set of complex organisational, hierarchical and political structures shaped by legislation, policy, guidance and local context and are influenced by their relationships with their managers, partner agencies and colleagues. Central to these experiences are the complexities of direct practice

and the relationship between the practitioners and the person they are working with. These issues can raise ethical and practice challenges for practitioners in balancing conflicting demands with limited resources, particularly in respecting the person's right to make unwise decisions with a duty to protect. Practitioners shared a strong sense of professional commitment and personal investment in the relationships with the people they worked with, raising questions about boundaries and how this impacted their relationships with their own family and with self-neglect. Practitioners described a range of emotions when working with self-neglect, including attachment, responsibility, pride, compassion and compassion fatigue, protection, frustration and guilt. This chapter discusses these findings and the following chapter considers what may be behind these accounts.

Chapter 6. Discussion

6.1 Introduction

This chapter discusses how the findings presented in the previous chapter answer my research questions and how they support, differ from or extend the existing literature on how practitioners experience self-neglect work. As explained in Chapter Three, I drew on Symbolic Interactionism (SI) as a theoretical framework to inform this study, as its emphasis on meaning and symbols provided useful constructs to help me explore and understand how practitioners experience and make sense of self-neglect work. SI proved valuable as an exploratory lens as the findings revealed that practitioners' experiences are multi-dimensional and involve a complex interplay and negotiation between what would be described in SI as the symbols of law, policy, organisational context, professional identity and personal relationships. SI allowed me to step back from the immediacy of practice to holistically look at the complex interconnectedness of these themes to consider how practitioners navigate, re-negotiate, and adapt their practice and their 'line of activity' to meet a range of competing multiple demands. This chapter explores these themes and is structured as follows. First, the key findings are summarised to set the context. Second, the main body of the chapter considers the findings in relation to each research sub-question, using the literature to add depth to the analysis. I also discuss findings I had not anticipated and give reasons for the new reading I undertook to make sense of this new knowledge. This chapter concludes with suggestions on how the interpretation of this study's findings may contribute to knowledge in this field by providing ways of understanding how practitioners experience working with people who self-neglect.

6.2 Summary of key findings

Practitioners' responses identified that their experience of self-neglect work is multi-dimensional and involves a complex interplay between law, policy, organisational context, professional identify and personal relationships. Practitioners describe a contradictory legal, policy and organisational framework that advocates preventative, person-centred approaches to promote well-being, but these outcomes are often hard to achieve due to limited time, resources and managerial pressures within local authorities. Most practitioners described a performance-driven culture that focuses on meeting organisational deadlines and can deny the essential time needed to build relationships with people who self-neglect. Self-neglect work raises ethical tensions in balancing a person's right to autonomy and a duty of care, with practitioners feeling a strong sense of compassion towards the people they work with and a personal and professional responsibility to keep them safe.

The managers' role was pivotal in how practitioners experience self-neglect work, with six of the 10 practitioners feeling supported by managers who offered them some protection against bureaucratic organisational demands, such as giving them more time to work with their cases. Whilst four did not feel supported by managers whom they describe as not understanding the complexities of self-neglect work. They felt pressured to work in what they described as a case management system, which required them to assess and close cases within tight prescriptive time frames whilst holding heavy caseloads. All the practitioners described feeling challenged when working with partner agencies due to their unrealistic expectations of what practitioners could achieve. A lack of knowledge and understanding of self-neglect within their organisations and partner agencies contributed to this difficulty. Practitioners identified a complex emotional and sensory dimension to self-neglect work. Feelings of compassion, anxiety and frustration coincided with physical, visceral reactions towards self-neglect situations which caused practitioners to question their values, relationships and professional boundaries. However, the focus in supervision on bureaucratic tasks reduced space for practitioners to recognise or feel able to talk about the impact of self-neglect work with their managers. The following explores these themes in more depth.

6.3 What impact do legislation and policy have on self-neglect practice?

This research sub-question sought to explore how practitioners experience the formal statements of law and policy within their organisations. As discussed in Chapter Two, since 2014, the Statutory Guidance to the CA (DHSC, 2022) has identified self-neglect as a category of abuse and neglect. This change has resulted in LA's developing policies and procedures to inform self-neglect practice and highlight the valuable role practitioners undertake in self-neglect work (Braye, Orr and Preston-Shoot, 2014; Brown and Pain, 2014; Mason and Evans, 2020). There is little empirical research after the introduction of the CA that evaluates the implementation of these policies and how they impact self-neglect practice. Findings from studies that have been undertaken identify the need for clear policy and guidance to inform how organisations implement their responses to working with self-neglect (Lauder, Anderson and Barclay, 2005a; 2005b; Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Day, McCarthy and Leahy-Warren, 2012; Aspinwall-Roberts, 2020; Aspinwall-Roberts et al., 2022). Anka et al. (2017) found the inclusion of self-neglect within safeguarding to be welcomed as it provides a framework for multi-agency working. However, the literature suggests practitioners have mixed views on whether self-neglect should be located under safeguarding procedures due to the constraints of threshold criteria and questions about whether safeguarding is the best approach for self-neglect work (Braye, Orr and Preston-Shoot, 2013; Doron, Band-Winterstein and Naim, 2013).

Most practitioners in the present study welcomed the recognition of self-neglect within the CA statutory guidance (DHSC, 2022) and the emphasis on person-centred, strengths-based safeguarding practice, but felt they worked in a fragmented legal framework where the rhetoric did not match the reality of practice. The CA aimed to clarify the legal framework surrounding self-neglect, although Braye, Orr and Preston-Shoot (2011; 2013) suggest that legal rules may not be well understood and practitioners can rely on practice experience, although refer to legal rules where cases become more challenging. This view is consistent with responses from the more experienced practitioners in this study, where three practitioners explained they were more likely to refer to policy guidance if cases were high risk or

worried that a complaint or a coroner's enquiry might be forthcoming. Others with less experience felt reassured by adhering closely to a legal and policy framework to guide their practice, and where policies were not in place, they felt this was a significant gap. There seemed, therefore, to be a more nuanced, contradictory approach as to how practitioners engaged with law and policy in this study's findings, as although the majority of practitioners said they felt reassured when their organisation had policy and practice guidance, six of the 10 went on to say they did not have time to consult them.

The reluctance to use policies may suggest practitioners could experience policy fatigue when local authorities create an overabundance of policies to act as a bureaucratic comfort blanket around challenging topics such as self-neglect; as this quote illustrates: 'It's not the work itself burning practitioners out. It's more about the procedures, expectations, demands' (SW4). This sense of overload supports Preston-Shoot's (2019, p. 232) argument that: '… Providing further training and updating procedural guidance will only prove effective if practitioners and managers are enabled and supported in their workplace to implement what has been signposted'. Practitioners' reasons for not engaging in policies and procedures extend Braye, Orr and Preston-Shoot's (2015) analysis of SCRs as it sheds light on why practitioners did not follow procedures that were already in place.

A further theme identified in the literature review was the practice challenges for practitioners and ethical tensions in balancing a person's right to autonomy with a duty to protect when people have mental capacity but self-neglect (Gunstone, 2003; Lauder et al., 2009; McDermott, 2008; 2010; Day, Leahy-Warren and McCarthy, 2013; Doron, Band-Winterstein and Naim, 2013; Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Aspinwall-Roberts et al., 2022). The findings from the present study support the above, as practitioners identified feelings of helplessness and anxiety when they could not find a clear path through a conflicting legislative and policy framework to find the answers they needed. These cases provoked the most concern, and practitioners found it more straightforward and

less stressful if a person lacked capacity as they had the MCA to follow as a framework for intervention. These findings raise questions about the implications for practitioners trying to navigate what they describe as a contradictory legal landscape that advocates choice, control and individual responsibility but does not offer guidance when a person's choices may put them or their neighbours at risk. Practitioners described an overwhelming sense of personal and professional responsibility towards the people they work with, amplified by an often intense scrutiny from managers and external parties such as other agencies and MPs, adding further pressure on practitioners.

The literature also highlighted the difficulties when self-neglect transitions from a private matter to a public concern and negatively impacts community relations, possibly involving legal action if environmental health concerns are ignored (Frost, Steketee and Williams, 2000; Chapin et al., 2010; May-Chahal and Antrobus, 2012). Braye, Orr and Preston-Shoot (2014) and McDermot (2009) highlight that using forced entry and working in opposition to the person who self-neglects can lose trust, undermine person-centred practice and compromise finding a successful long-term solution in self-neglect work. The findings from the present study support the above views. Practitioners talked about the challenges of balancing the rights of the person with the needs of the broader community and how difficult this can be, which I experienced first-hand on a home visit with a practitioner where neighbours challenged us in the street to ask what social services were doing to address self-neglect concerns.

The literature also identified the critical importance of building trusting relationships with people who self-neglect as the central driver to effect positive change (Day, McCarthy and Leahy-Warren, 2012; Braye, Orr and Preston-Shoot, 2013; 2014; 2015; Brown and Pain, 2014; Britain Thinks, 2017; Aspinwall-Roberts, 2020). This view came through strongly in practitioners' accounts in the present study as they identified that relationships were the central instrument in their professional 'toolbox' of skills in working with self-neglect. They explained that they would exhaust every avenue to avoid

enforcing legal mandates to access a person's property due to environmental or public health concerns.

In summary, to the best of my knowledge and at the time of writing, this present study is the only empirical, ethnographic study that post-dates the implementation of the CA that explores how social workers experience working with self-neglect. The findings from this study suggest that even with the clarifications of law and policy introduced under the CA and its statutory guidance (DHSC, 2022), practitioners can experience a contradictory legal framework that can confuse rather than clarify and does not always offer them the answers they seek. How practitioners engage with the law and policy framework is nuanced, with less experienced practitioners more likely to rely on policy guidance and more experienced practitioners relying on their practice experience, illustrating that practitioners seek out and interpret law and policy in different ways. This finding supports Braye, Orr and Preston-Shoot's (2011, p. 64) view that knowing and applying the law is complex and nuanced and '…that research on adult safeguarding has found that the law is experienced as both difficult to understand and difficult to implement'. The findings from this study suggest that how practitioners interpret and apply this framework relies on an interplay of relational and situational factors, including their level of experience, knowledge and motivation to seek policy guidance and the complexities of the case itself.

6.4 How does the organisational context influence self-neglect work?

This sub-question explored the organisational contexts in which law and policy are implemented and how practitioners experience these contexts. A central theme in the literature identifies that person-centred approaches are a critical component in self-neglect work, where time is essential to build trusting relationships (McDermott, 2009; 2010; Yeung et al., 2010; Day, McCarthy and Leahy-Warren, 2012; Doron, Band-Winterstein and Naim, 2013; Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Band-Winterstein, 2012; 2018; Vailu'u', 2018). The literature also highlights the need for organisational systems that allow time for longer term work that can foster trust and enable person-

centred practice (Anka et al., 2017; Britain Thinks, 2017; Brown and Pain, 2014; Braye, Orr and Preston-Shoot, 2014, Aspinwall-Roberts, 2020; Aspinwall-Roberts et al., 2022).

The findings from the present study support these arguments. Practitioners talked about the frustration of working with a 'case management model', which they described as having organisational prescriptive time frames to assess, review and close cases and a fast-paced throughput approach that did not fit with self-neglect work. The findings raise questions about how adopting alternative, holistic assessment models, as suggested by Zawisza et al. (2021) and Liu et al. (2020), may provide practitioners with more effective assessment tools. Practitioners described being torn between two competing imperatives: management demands to comply with assessment time frames versus their commitment to their social work values, where they needed more time to work in a person-centred way. Practitioners' accounts support the argument that an increasing performance management approach jars with the slower pace needed to progress self-neglect work and that, without the resources, the rhetoric of the CA, MSP and strengths-based approaches falls short.

Practitioners' accounts resonate with what Banks (2016) describes as 'ethics work' - social workers seeing the situations they are in, trying to be good practitioners, working out the right course of action and justifying who they are and what they have done. Banks builds on Hochschild's (1983) notion of 'emotional labour', which refers to the management and suppression of emotions in work environments. Hochschild uses an example of airline staff suppressing their own negative emotions to maintain a caring, smiling, persona when managing rude responses from irate passengers. Banks develops this concept and applies the term 'emotion work' more broadly by exploring how social workers experience emotions towards the people they work with in a professional context. Banks suggests that: 'Emotion work has ethical significance, as emotions are about relationships with others or ourselves and our characters' (p.41) and adds that for social workers these emotions are intrinsically linked to ethics as they 'focus particularly on emotions linked to respecting, not harming,

caring for and about others and being ethically good people - for example, the emotions of compassion, guilt or shame' (p.42).

Emotion work also acknowledges a moral dimension where workers may experience a moral struggle to be good practitioners when working with conflicting priorities and agency constraints. Practitioners' accounts in my study also resonate with the concept of 'moral distress,' 'When one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action' (Jameton, 1984, p. 6). Mänttäri-van der Kuip (2020, p. 742) suggests that for social workers a contributory factor for moral distress can be that the 'inability to implement the ethical principles that are expected to guide their practice can be highly stressful', and this can negatively impact on social workers' moral emotions. Furthermore, Mänttäri-van der Kuip argue that although moral distress is a useful perspective to explore the 'experiences of moral suffering on the front line' (p.754), it is at risk of losing validity if not furthered conceptualised and tested out in empirical research.

Moral distress can provide a lens into the troubled space some practitioners describe in their organisations where rational technical approaches (Parton, 2000) are prioritised over person-centred practice. My observation of one practitioner illustrated this point as they reflected that they had rushed the person we visited as they felt under increasing pressure from their manager to gain all the information in one visit. During the visit, little time was left to get to know the person and build rapport, illustrating how a performance-driven culture could manifest in practice. The practitioner reflected on this afterwards and was frustrated and annoyed as they knew what they needed to do but did not have the resources to achieve it, experiencing what is described as moral distress. Practitioners' accounts highlight simultaneous challenges involving both ethical dilemmas and moral distress. There are ethical dilemmas in making the right choice between two or more competing ethical principles, for example, respecting a person's autonomy and the duty to protect. Although Weinberg (2009) cautions against conflating ethical dilemmas and moral distress and provides this distinction:

> Ethical dilemmas concern two or more courses of action that are in conflict (and will potentially have both positive and negative consequences), each of which can be defended as viable and appropriate. In contrast, moral distress arises if one

> action is preferred and seen as morally superior, but the actor feels blocked from pursuing it by factors outside the self (p. 144).

These challenges also resonate with what Weinberg (2018) describes as ‘ethical trespass’, where practitioners try to meet their professional role's ethical standards whilst navigating an: ‘intersection of multiple paradoxes’ (p. 5). Weinberg and Banks (2019) suggest that increasing managerial, neoliberal approaches that prioritise cost-effectiveness, efficiency and rationing of services are: ‘At odds with the value base of the profession, which gives high priority to principles such as respecting and promoting human dignity and worth, equality and social justice’ (p. 363). However, the findings also suggest that the situation is more nuanced and does not necessarily fall within the binaries of managerialism or professional practice. Managers have a central role in shaping practitioners' experiences of working with self-neglect, which the following section explores.

6.5 The Impact of the manager in self-neglect work

The literature reviewed identified how supportive organisational structures can facilitate person-centred practice (Brown and Pain, 2014; Anka et al., 2017) and that practitioners value managers’ support (Braye, Orr and Preston-Shoot, 2014). The findings from the present study are consistent with this view as they illustrate how managers play a pivotal role in how practitioners experience self-neglect work. Six of the 10 practitioners talked about being supported by managers who understood the complexities of practice and offered workers discretion to work flexibly and protection against organisational demands. In contrast, four felt unsupported, describing their managers as being disconnected from practice and not understanding the challenges of self-neglect. They operated at more of a managerial rather than practice level. As discussed above, I observed how the pressure from managers on practitioners to undertake assessments within restricted time frames directly impacted their practice and ability to work in a person-centred way. Although it was just one observation, it offers a direct insight into the realities of practice and provides a possible explanation

behind SAR findings (Preston Shoot et al., 2020) that practitioners in cases with tragic outcomes have often not engaged in person-centred practice. This finding is significant as it illustrates the critical role of the manager and supports Owen et al.'s (2022) argument that a better understanding of the complexity of this phenomenon would enable managers to be more effective in managing responses to self-neglect.

How practitioners describe their manager's approach reflects domination and discursive perspectives on management (Evans, 2009). The domination perspective is where managers and practitioners are two separate occupational groups. The manager's role is to monitor and regulate practitioners' practice through coercion and control of policies, budgets and performance targets. Managers are removed from their professional roots and are engaged in executing organisational goals. Four practitioners in this study described their managers as disconnected from practice and more focused on performance and budgetary demands than supporting them with direct practice challenges. In contrast to a domination perspective, there is a discursive strand. Rather than being a dominant detached force on the submissive practitioners they manage, managers show negotiation, sharing professional territory and an understanding of practice. There is no binary position, as the discursive strand runs alongside the domination perspective, and managers may be influenced by managerialism but consider professional issues and values in practice. This discursive strand fits the description of managers by practitioners who said they felt supported; managers were connected to practice, offering support and giving them the discretion to have more time on their cases. Managers in this group appeared to traverse both discursive and domination perspectives, meeting their professional and managerial responsibilities and understanding the challenges of front-line social work. This finding supports the idea of a middle ground between the binaries of managerialism and professionalism (Evans, 2011), as some managers could navigate between these positions, support practitioners and retain their connection to direct practice. The conflicting accounts of practitioners, some feeling supported by their managers and others not, chime with Harris (1998) and Evans (2011), who suggest that management structures within social services are fragmented and that front-line managers can align themselves more closely with the professional opinions of practitioners rather

than with the demands of senior management.

In summary, practitioners in this study expressed an urgent need to work differently and move away from what they describe as a 'case management' model to an approach that provides them with organisational and management support, knowledge and resources to support people who self-neglect. The findings suggest that local authorities as organisational structures can struggle with providing the support and time for practitioners to fulfil the pledges of the CA, MSP and person-centred practice. They also suggest that managers are important mediators in managing the interface between organisational demands and professional practice. Managers' recognition of professional objectives in self-neglect and their ability and willingness to enable practitioners to pursue them are thus crucial influences on how social workers experience self-neglect work.

6.6 How do practitioners experience multi/interagency self-neglect work?

The adult social care legal framework requires local agencies to work in partnership to support adults with care and support needs (CA, 2014, s.3, s.6, s.7) and those about whom there are safeguarding concerns (CA, 2014, s.42). Previous studies identify that a core component of effective self-neglect practice is collaborative, multi/interagency working which requires a shared ownership and commitment (Gunstone, 2003; Lauder, Anderson and Barclay, 2005a; 2005b; Lauder et al., 2009; Day, Mulcahy and Leahy-Warren, 2013; Braye, Orr and Preston-Shoot, 2013; 2014; Britain Thinks, 2017, Aspinwall-Roberts 2020), and where practitioners' expert knowledge provides a valuable contribution to multi/interagency work (Bratiotis, 2009; 2013; Brown and Pain, 2014; Day and McCarthy, 2015). Within the literature, however, there are also challenges identified in multi/interagency work due to role conflict and a lack of understanding of each other's roles and responsibilities (Gunstone, 2003; Koenig, 2013; Mason and Evans, 2020; Aspinwall-Roberts et al., 2022) and a lack of education and training in some disciplines involved in self-neglect work (Johnson, 2018).

The findings from the present study show that practitioners recognised multi/interagency working as an essential component of self-neglect work. However, the findings raise questions about how different professional orientations may impact the efficacy of multi/inter-agency working as practitioners often hold different views from partner agencies regarding thresholds of risk and their approaches to interventions, which could get in the way of effective collaborative working. This finding is consistent with Lauder, Anderson and Barclay's (2005a; 2005b) and Aspinwall-Roberts et al.'s (2022) studies in which workers' professional backgrounds could shape their priorities, and McDermott's (2010) study where organisational contexts can influence approaches to risk due to a managerialist drive for efficiency. The findings are also consistent with Yeung et al. (2010), who state that ethical positions could become entrenched in professional practice resulting in defensive positions in multi-agency work, and further support Braye, Orr and Preston-Shoot's (2017) argument for an ethical space where different perspectives can be sensitively explored and debated.

Practitioners in the present study talked about a mismatch in expectations, with other disciplines expecting more from them than they could give due to limited time and resources, resulting in feelings of frustration and anger. This finding supports Mason and Evans's (2020) view that joint work can be marked by conflict and that coordination in self-neglect work is dynamic, contingent on the actors taking on and allocating roles within a given context. Mason and Evans also identify that practitioners could experience a loss of a professional role in handing over work to others. This point was echoed in the present study as practitioners talked about a sense of loss and being apprehensive about handing over cases to other workers because they feared that the good work they had achieved would come undone. Although practitioners in this study expressed frustration about partner agencies' expectations, there was a fluidity in how they constructed their own professional identities during home visits with the people they worked with. Some dismantled the professional social work role to be more of a support worker by undertaking practical tasks outside of their usual remit. This finding aligns with previous studies, where workers were flexible, undertaking more practical tasks to build rapport and

promote engagement (Braye, Orr and Preston-Shoot, 2014; Brown and Pain, 2014; Britain Thinks, 2017).

A central theme in the findings was the need for more mental health expertise in multi/interagency work. Although hoarding is now identified as a mental disorder (APA, 2013; WHO, 2021), practitioners expressed frustration that referrals to mental health services were often refused as the person did not meet the threshold criteria for access to services. These difficulties are commonly found in SARs (Preston-Shoot et al., 2020), showing that, at the time of writing, the call for mental health expertise in self-neglect multi-agency work remains unanswered 17 years after it was made (Lauder, Anderson and Barclay 2005b). This finding is consistent with Koeing et al.'s (2013) US study, where already established multi-agency teams state that mental health expertise is vital in providing a coordinated response when working with hoarding.

In summary, the findings from this study are consistent with Brown and Pain (2014) and Anka et al. (2017), who suggest that in England, a different approach is needed in organising our multi/interagency responses to self-neglect, moving to one that provides dedicated, specialist, longer-term support. Studies by Bratotis (2009; 2013) and Koenig et al.'s (2013) US model of multi-agency hoarding teams may offer a way forward as they encompass a collective ethical framework and professional commitment that recognises each member's skills and contributions. In considering this literature, it is noteworthy to recognise that the inclusion of self-neglect within safeguarding in England has been relatively recent. It was 2015 when the CA was implemented, whereas in the US, self-neglect as a category of abuse has been established for much longer in many States (Dyer et al., 2007). Compared to the US, the UK is arguably in the infancy stage of establishing the best way to coordinate our organisational responses to self-neglect; therefore, the abovementioned example by Koenig et al. (2013) may provide a valuable model for future multi/inter-agency working.

6.7 What impact does self-neglect work have on practitioners?

This question explores the relational and embodied nature of self-neglect work. The literature review identified that self-neglect work could profoundly affect practitioners. Visiting people in their homes and seeing the unsanitary conditions they live in could distress practitioners (Day, Mulcahy and Leahy-Warren, 2012), and they expressed anger, frustration and worry resulting in sleepless nights due to witnessing the conditions that people were living in (Band-Winterstein, 2018). Practitioners struggled to solve the riddle of self-neglect (Doron, Band-Winterstein and Naim, 2013) and could become overwhelmed by this work's sensory and emotional impact (Smith, 2001; Braye, Orr and Preston-Shoot, 2014). These experiences could result in a 'therapeutic pessimism' (Lauder, 1999b) if practitioners do not see any progress with their cases, resulting in a loss of motivation and an emotional cost (Lauder, Anderson and Barclay, 2005b). The findings from the present study are consistent with this, as practitioners expressed an array of emotions and feelings that ranged from isolation, loneliness, and anxiety in managing the demands of self-neglect work to feelings of pride, compassion and responsibility towards the people they worked with. Moreover, the findings from this study add further insights as they illustrate the significance of managers in mitigating the impact of this work on practitioners.

6.7.1 Traversing the different identities in self-neglect work

A theme identified in the findings was that most practitioners in my study felt under increasing pressure from their organisation, partner agencies and external sources, i.e., councillors and MPs, to 'wave a magic wand' (SW3) and get something done. Practitioners described feelings of guilt and frustration as they knew what was needed in self-neglect work but did not have the time or resources to achieve it. The findings identified that a lack of practitioner experience could exacerbate these feelings and support Blomberg et al.'s (2015, p. 2102) view that: 'Practitioners with limited work experience, as well as those working within the public sector, suffer the most from extensive workloads and role

conflicts.' Practitioners in my study described a 'hamster wheel' syndrome working with self-neglect in which, despite all their efforts, they did not see any progress and could lose motivation, reflecting Lauder's notion of therapeutic pessimism identified above. They shared traumatic accounts of how witnessing people's suffering evoked strong emotions. Using Adams, Boscarino and Figley's (2006) concept of compassion fatigue may help to understand this; there is a psychological impact on practitioners trying to provide emotional support to people to help them change their behaviours. The author's caution: 'High emotional involvement without adequate support of feelings of personal work accomplishments and job satisfaction may leave the caring professional vulnerable to burnout' (p. 104). The strength of feeling and depth of emotion shared by practitioners in my study are echoed in Braye, Orr and Preston-Shoot's (2014) study, where practitioners describe working with self-neglect as producing an intolerable sense of responsibility leading to feelings of helplessness and anxiety (p. 137).

There are also interesting links in my study to Lavee (2021), who suggests that human services workers feel they have to go beyond their job description to give their clients additional time and emotional and psychological support. They show a strong devotion, a professional mission, to the people they work with even when this means self-sacrifice, and they 'strive to improve their welfare, above and beyond the scarce formal resources available' (p. 14). This view is supported by Band-Winterstein, Goldblatt and Alon (2014; 2021) who identified that practitioners were on a professional mission to support the people they worked with. Band-Winterstein (2018) and Doron, Band-Winterstein and Naim (2013) also identify a tenacity of practitioners not to give up on the person even when they refuse support, a feature that is important to people receiving services, who value practitioners who 'go the extra mile'.

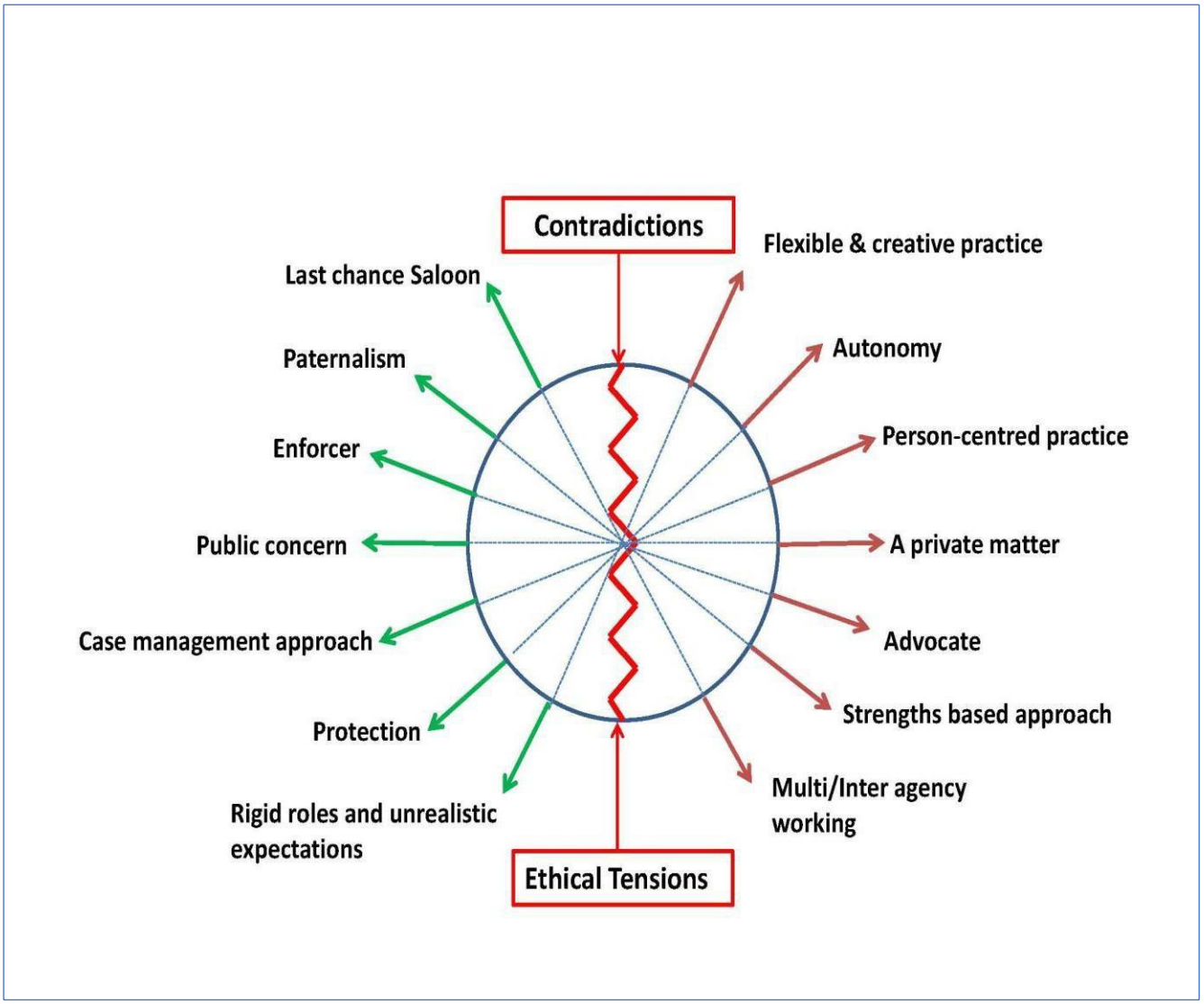
Practitioners in my study talked about going above and beyond their job roles, undertaking practical tasks and going into environments that pose significant risks. This finding also resonates with what

Lavee (2021) describes in organisational theory as the 'subjective norm' where workers are under social and professional pressure to perform. This combination of professional and organisational pressure may explain why practitioners in my study would go into houses to see people where other workers refused, as they felt professionally and personally responsible for that person's well-being. This sense of professional responsibility and personal investment was a central theme in this study. Practitioners grappled with competing demands of working in a person-centred way, finding the person, and listening to their story against a backdrop of organisational demands, diminishing resources and increasing caseloads.

However, there is a need to provide a balanced argument as there were also positive feelings and emotions that practitioners attached to self-neglect work; it was not all negative. Practitioners described feelings of care and commitment to supporting people to make positive changes. There was a sense of respect and pride among practitioners as they recognised the resilience of the people they worked with and how they coped in challenging situations, which is echoed in the studies of Day, Mulcahy and Leahy-Warren (2013), Band-Winterstein (2018) and Band-Winterstein, Goldblatt and Alon (2014; 2021). Practitioners in this study were also determined to continue trying to effect some positive change, which supports the findings of Doron, Band-Winterstein and Naim (2013). Practitioners also talked about the importance of understanding the person, listening to and valuing their individual life story, and how family dynamics and cultural values can impact self-neglect work, supporting the findings from Wu et al. (2020) and Britain First (2017). I observed care, compassion, and a tangible sense of achievement on visits where practitioners could see that the person they were working with had made positive steps in improving their personal care and living conditions. This change for the person was often significant as it meant that they could reconnect with family and have visitors in their homes, activities that most take for granted but they could not do previously due to self-neglect.

The evidence from this study illustrates that local authority social workers' experiences of working with self-neglect do not occur in a vacuum. They are influenced and embedded within a set of complex organisational, hierarchical and political structures shaped by legislation, policy and local guidance. This complexity is exacerbated by the diverse cultural and societal responses to self-neglect and its symbolic values (Lauder, 1999a; Wu et al., 2020; Bates, 2022). Using SI as a theoretical framework to consider the findings of this study shines a light on the many guises that practitioners inhabit in self-neglect work as they make and attach meaning to their interactions whilst they act as a conduit between the person, their profession and the organisational and legal context. The findings illuminate the complex process of working out 'the right thing to do' in any individual self-neglect situation whilst balancing often conflicting and contradictory expectations. Undertaking home visits in self-neglect work requires social workers to perform a simultaneous multi-faceted role as an 'assessor,' 'enabler,' 'advocate,' 'protector,' 'enquiry officer' and 'enforcer' and how in traversing these identities, and the boundaries between them, can become blurred and difficult to hold. Practitioners interpreted and made meaning from a range of responses from the people they work with, and where necessary changed or suspended their 'line of activity' (Blumer, 1969, p. 8) and their subsequent role. This shift was evident in the practitioner's account (SW7, 5.2), in which, due to a disclosure of possible child abuse, they had to interpret and make meaning from the disclosure and change their line of activity from enabler and advocate to enquiry officer. This finding is supported by Yip et al.'s (2022) study in which workers struggled to switch roles from health professionals to investigators due to safeguarding concerns. These changes can present ethical dilemmas as social workers traverse multiple roles and expectations. In the following Figure 5, I have adapted an illustration from Brent (2016) to capture the complex lines of activity social workers need to negotiate in self-neglect work and identify some of the contradictions and ethical tensions these can present.

Figure 5. Traversing multiple roles and responsibilities in self-neglect practice: ethical tensions and contradictions.



The findings identify ethical dimensions, or as one social worker described it, 'the rub,' between a range of competing roles and imperatives, legal, organisational, social work values and professional and personal investment, all condensed within the microcosm of one home visit. This account resonates with Muzicant and Peled's (2018) findings, where practitioners described what happens on home visits as being like an 'octopus' (p. 837) in trying to make sense of and undertake multiple tasks and roles.

6.7.2 Recognising feelings

A significant and surprising finding was that practitioners in this study struggled to recognise or discuss the emotional impact of self-neglect work. Their engagement in self-neglect work caused them to consider their vulnerabilities as human beings and reflect on their personal relationships. All the practitioners, bar one, said that they did not talk in any depth to their managers about the visceral and deep-felt feelings triggered by the work, as supervision did not allow space to explore this issue. I wondered why these emotions were not explored in supervision. The benefit of using a qualitative approach was that I had the flexibility to go where the participants were leading me. Using the lens of SI, I questioned what is being seen and heard in this line of activity between practitioner and manager and read new literature that I had not previously considered directly relevant, which the following explains.

Morrison (2007, p. 245) highlights the importance of emotional intelligence (EI), where practitioners are reflective and recognise and manage their own emotions while being aware of others and argues that this is a central component of person-centred, relationship-based practice and professional competence. An increasing body of knowledge explores the role and impact of emotions in child protection social work (Ferguson, 2005; 2010; 2016; Winter et al., 2019; O'Connor, 2020). Attention is also given to the emotional context of working with mental health (Smith, 2001; Gregor, 2010). However, as identified in the literature review, although self-neglect work can raise complex emotions, there is limited research on how practitioners explore these feelings and emotions. Ingram (2015) identifies the danger of suppressing practitioners' emotions in procedurally driven, bureaucratic organisations where technical-rational approaches dominate, denying them space to express emotions. Ingram draws on the work of Hochschild (1983) to highlight:

> What emerged from the results was a clear sense that organizational and professional culture provided practitioners with messages about the relevancy and 'safety' of exploring emotions. This led some respondents to present a technical-rational articulation of their practice in order to respond to perceived norms. (Ingram, 2015, p. 909).

This view may explain why some practitioners in this study had not thought about or felt able to talk about their emotions in supervision, which they said often had a procedural bureaucratic focus. Furthermore, Ingram (2015) highlights the vital importance of supervisors who can provide practitioners with a safe space to share and explore emotions and not allow the management function of supervision to squeeze out this critical element. The strength of emotion from practitioners in this study was often palpable, with two crying in the car following the home visits as they expressed a profound sense of compassion, pride and worry about the people they had visited. When I asked one if self-neglect had an emotional impact, they replied, 'I think the trouble is with social workers… you analyse what you've got to do, but you don't analyse how something made you feel' (SW7).

Ferguson writes extensively on how emotions and challenging environments can impact child protection social workers' practices when undertaking home visits (2005; 2010; 2016). Although he focuses on child protection, and unlike the present study takes a psycho-dynamic perspective, the findings from his work nonetheless resonate with practitioners' experiences in my study; there are shared themes across both types of work. Although working in child protection has unique characteristics, shared themes with self-neglect include working with involuntary clients in challenging home environments and sharing the pressures of local authority bureaucratic and managerial demands. Ferguson (2005) suggests that practitioners' failure to engage with involuntary clients may be influenced by a fear of unsanitary environments and contamination due to dirt and disease, resulting in premature withdrawal and closure of cases. Social work values that rightly advocate for anti-discriminatory and anti-oppressive practices may make it difficult for social workers to talk about feelings of fear and disgust as they do not want to appear disrespectful. Ferguson suggests that discussing such feelings 'has become virtually a taboo' (p. 790) within proceduralist approaches,

suppressing the exploration of the emotional impact of practice. Furthermore, Ferguson highlights the importance of relationships and suggests that: 'Encounters between workers and users of services are mediated through the emotions, senses and the ways which give rise to complex feelings and forms of reciprocity and resistance' (p. 783).

The national analysis of SARs (Preston-Shoot et al., 2020) identified that one failure in self-neglect cases was practitioners' lack of person-centred practice and premature closure of cases. There may be scope to consider what can be learned from practitioners' shared experiences across other practice areas regarding how they respond and make sense of undertaking home visits under challenging conditions to people who are resistant to support. The intense emotions practitioners shared in my study also raise questions about how they may impact workers' ability to sustain effective engagement when working in these circumstances.

6.7.3 The sensory impact of self-neglect work

The literature reviewed identifies the challenges of working in unsanitary environments and the impact this sensory overload can have on practitioners undertaking home visits to people who self-neglect. (Smith, 2001; Braye, Preston-Shoot, and Orr, 2011; 2013; 20; Band-Winterstein, 2012; 2018; Day, McCarthy and Leahy-Warren, 2012). The findings from the present study support this view as practitioners talked about home visits having an ethereal dimension, almost another world reality. They described trying to make sense of what they had seen, smelt, heard and felt, which was often far removed from societal norms and appeared to disturb their sense of reality, as this quote illustrates: 'You're going into another parallel world… you go to the back of the cupboard and you're in Narnia but it's not Narnia, this is a totally different world' (SW4). These findings echo Band-Winterstein (2018, p. 12), where a practitioner explained: 'I felt I was in another world…'. The findings suggest a transition where self-neglect work not only moves from a private matter to a public concern, as previously discussed (Chaplin et al., 2010; May-Chahal and Antrobus, 2012) but also moves across boundaries

from a professional role to a profound personal experience when practitioners talk about other worlds which some enter and inhabit, often putting themselves at risk during home visits. The literature review identifies limited attention given to home visits' environments and atmospheres and how practitioners' sensory and emotional responses may impact practice (Ferguson, 2005; 2010; 2016; Morris, 2017). Muzicant and Peled (2018) suggest that home visits elicit powerful bodily responses where practitioners encounter 'uncontrollable smells, sights, voices and touch' (p. 832).

Gunstone's (2003) study identified that experienced practitioners could become desensitised and develop higher levels of tolerance to the effects of working with self-neglect. The findings in the present study are consistent with this, as those with more experience indicated a higher tolerance to sights and smells of self-neglect work in contrast to those with less experience, who appeared to be more adversely affected. This finding raises questions about how levels of experience may act as a desensitiser to the visceral physical reactions to self-neglect. Using SI as an analytical lens, this may illustrate an example in which practitioners re-negotiate their line of activity and re-interpret the environments they are exposed to, becoming more disensitised as a protective measure to enable them to continue to undertake home visits in challenging circumstances.

Undertaking an ethnographic study allowed me to be alongside practitioners to share these experiences during home visits. Pink (2015) explains that ethnographic experiences are 'embodied' as the researcher learns and knows through the whole body's physicality. Pink suggests that an 'emplaced' ethnography is needed as this recognises how experiences are shaped by the relationship between our minds, bodies and the material and sensory environment we are in. This sense of emplacement materialised during a home visit I undertook with a social worker to an older man who was self-neglecting his personal care and domestic environment. The house was cluttered and in disrepair, with a strong unpleasant smell. The house was infested with mice which I could hear moving around under the sofa we were sitting on. We were there for an hour and a half, and I felt exhausted

and physically unwell afterwards. During the post-visit interview with the participant, there was a deeper understanding and honesty in our discussions as the practitioner opened up about how difficult it can be to work in such conditions. The following is an extract from my reflective diary which I completed in the car once I was alone directly after this visit:

> I went in, the smell, I could feel the stench getting stuck in the back of my throat, there's a huge amount of clutter stacked up, there was an old lampshade with a huge spider just hanging off the side, just by my arm as I went in, and it made me want to go 'oh!'. Very oppressive environment. The lights were on even though it was daylight. My overwhelming feeling is a sense of sadness but intensity. My head is absolutely splitting, I feel I want to go home and have a shower and wash my clothes because the smell was quite strong, so I feel I need to be clean but also kind of mentally, feeling very drained.

Our shared experience, our emplacement, as Pink (2012) would describe it, changed my position from an objective observer to a co-contributor. In this reflexive process, I recognised that, as a researcher, I was contributing to the research process by being engaged in the process of co-production by being present and part of a shared sensorial experience. This supports Morris's view (2017, p. 16) that: 'The emphasis on reflexivity and co-production is one of the ways in which sensory ethnography chimes with social work practice.' The intimacy of sensory ethnography allowed me to share a privileged space with practitioners as they worked. I believe this fostered trust, which enabled them to open up about how these home visits and self-neglect work could make them feel, although, as discussed above, most practitioners did not talk about this with their managers in supervision. The following section considers possible barriers that may get in the way of practitioners having this conversation.

6.8 Making the unseen seen and the unsaid spoken

In analysing the findings, another theme that I had not anticipated, and which did not seem to be addressed fully in the self-neglect literature, was that most practitioners struggled to recognise and

articulate the emotional impact of self-neglect work, which was surprising as this came through so strongly in their interviews and my observations. It was only through spending time with practitioners and building trust and rapport that they opened up about their feelings. With this strength of feeling, I was puzzled that most practitioners did not talk about these feelings and emotions with their managers in supervision. The reasons for this are unclear, but I think it is a significant finding in several ways. My earlier discussions outline the complex multi-dimensional terrain practitioners navigate in self-neglect work and the powerful feelings this work can evoke. Although the need for practitioners to have a reflective space to explore the challenging dilemmas and emotions of self-neglect work has already been identified (Braye, Orr and Preston-Shoot, 2014; 2017), my findings suggest that this may not be happening.

If practitioners do not have space to think or talk about these feelings and emotions, they may manifest in other ways and contribute to possible problems such as stress, burnout and physical and mental health issues (Figley, 1995; 2002; Adams, Boscarino and Figley, 2006). These adverse outcomes may also impact practitioners' ability to practice and get in the way of building trusting, positive relationships with people who self-neglect. Building a positive and trusting relationship is a crucial element of successful self-neglect work (Day, McCarthy and Leahy-Warren, 2012; Day, Leahy-Warren and McCarthy, 2013; Braye, Orr and Preston-Shoot, 2011; 2013; 2014); therefore, I suggest anything that may hinder this process is worthy of further attention. Using SI as a theoretical lens, I wanted to understand what affected practitioners' ability to recognise and talk about the emotions generated from self-neglect work. In this pursuit, I expanded my reading to include further literature to try to make sense of this, which the following section discusses.

I wanted to make sense of what practitioners were telling me about their experiences in supervision and read the work of Pithouse (1998) who proposes that social work is an inherently 'invisible' trade, that often takes place in the privacy of people's homes, therefore is not witnessable and made real

by others and suggests that ‘Good work can only be seen through a good account’ (p. 178). The practitioners in the present study focused on the practical tasks in supervision, perhaps enabling them to give ‘a good account,’ but they did not discuss the emotional and sensory impact of self-neglect work. In attempting to understand and make sense of why practitioners did not discuss this element of their work in supervision and why they opened up to me and not their managers, I explored the work of Goffman, Presentation of Self and Facework (1955; 1959) to try to make sense of this finding and think about why this might be. This approach aligns with my theoretical framework of SI as it explores how we present ourselves in different situations, what we share, and what factors may influence our behaviours in specific contexts. Goffman (1959, preface) describes interactions as performances that are reliant on a range of connective factors and explains: ‘The individual in work situations presents himself and his activity to others, the ways in which he guides and controls the impressions they form of him, and the kinds of things he may and may not do whilst sustaining his performance before them’.

Goffman draws on the concept of ‘Facework’ to explain that we present a particular identity, a ‘face,’ a self-image we want to present to others in any given situation. The face is not fixed, and the individual, whom Goffman describes as an actor in the performance, takes action to ensure that the face they present is consistent with what they want to present depending on the given context. Goffman (1969) explains that the actor presents a definition of the situation within an interaction influenced by what they anticipate the other actor in this interaction expects. Using Goffman’s lens, I thought about this in the context of what participants had described in supervision, and that supervision is an interaction between two actors finding a line of activity, interpreting and making meaning from their interaction. Goffman suggests that how we project ourselves at the beginning of our interaction sets the tone for the ongoing relationship between parties. There is a drive for an equilibrium, a ‘working consensus;’ therefore, the actor is expected to: ‘Suppress his immediate heartfelt feelings, conveying a view of the situation what he feels the other will be able to find at least temporarily acceptable’ (p. 20). I wondered if this might be why practitioners do not talk about their emotions in supervision, it could be that the practitioner does not want to disrupt the line of activity,

the working consensus they have established with their manager at the onset of their relationship. It could be suggested that as casework develops and the emotional experiences connected to self-neglect work accumulate and intensify, practitioners may not feel able to change 'face' and disrupt the working consensus outlined above to include these new elements as they were not part of the initial projection. As Pithouse (1998) identifies, social work is an invisible trade, and if work is not quantifiable in a climate of managerialism and procedural bureaucracy, it is harder to evidence, and this work remains unseen. There appears to be an organisational environment where practitioners feel pressurised to 'show and tell' their work in supervision as the throughput of cases is seen to validate their role in a performance-driven culture, rather than use supervision to 'explore and reflect' on their self-neglect work. Practitioners talked about management pressures to get the job done and how a case management approach undermined their social work skills by limiting time and resources. These experiences support Challis and Davies's (1986) view that care management is more about allocating resources than specialist skills. The findings suggest that a case management ideology may not only permeate local authority organisations but also influence how adult community practitioners see themselves. As Goffman describes it, this particular 'front' is already established and may affect what practitioners think they should be focusing on and therefore sets the tone of what is thought permissible to discuss in supervision. Practitioners may have suppressed their feelings about self-neglect work as they see their value to their organisation is measured by their attendance to bureaucratic tasks. As discussed in Chapter Four (4.4.3), this emphasis on showing results is increased by organisational demands and external pressures, such as complaints from local councillors and MPs, who do not appear to understand the complexity of self-neglect work and who expect rapid remedies to long term problems.

Furthermore, Goffman (1959) suggests that in our performance, we try to portray infallibility and hide the mistakes, and we will 'tend to show them only the end product, and they will be led into judging him based on something that has been finished, polished and packaged' (p. 52). This view may explain why practitioners do not want to or do not feel able to talk about the messy elements of

practice, the intense contradictory feelings and sensory overload in supervision, as they may feel pressure to present a more polished account of their casework. Goffman also suggests that the actor may conceal and underplay aspects of their behaviour that do not fit their role's 'idealised' view. This perspective may explain why practitioners did not talk about the feelings of helplessness, guilt and compassion fatigue identified in the findings, as these emotions may not conform with their idealised view or the 'face' they want to present in supervision to their managers, organisation or to the social work profession itself.

The literature (Smith, 2001; Day, McCarthy and Leahy-Warren, 2012; Braye, Orr and Preston-Shoot, 2014; Doron, Band-Winterstein and Naim, 2013; Band-Winterstein, 2018) and the findings from this study identify the range of feelings self-neglect work can evoke: disgust, sadness, despair and helplessness. Sharing negative feelings about the people they work with may not conform to an idealised face practitioners want to present in supervision. Practitioners also talked affectionately about the same people they had expressed negative feelings about, sharing positive feelings of compassion, pride and respect. Facework also entails saving the face of others. As Goffman (1955, p. 227) explains: 'In trying to save the face of others, the person must choose a tack that will not lead to loss of his own; in trying to save his own face, he must consider the loss of face that his action may entail for others'. Practitioners may not want to share the disgust they felt in people's homes in supervision to save the face of the people they worked with.

The loss of face of others that Goffman describes may be connected to how practitioners present themselves on home visits. Three practitioners described how they would always ensure that they looked smart and wear the same clothing worn to the office so the person would not think that they thought any less of them, even though some of the homes we visited were extremely dirty and in a state of disrepair. This may suggest that practitioners were not just saving the face of others by wearing their office clothes as a mark of respect, but they were also holding themselves accountable

regarding how they presented to the person. There are still unanswered questions about why practitioners spoke to me about the emotional and sensory impact of self-neglect work but did not share these powerful emotions in supervision, although Goffman's concept of Facework provides some suggestions to make sense of this.

Practitioners did talk to colleagues in their teams to gain support and to process what they had experienced after difficult visits. There was an immediate need to talk this through with others who could understand their shared experience. Perhaps having the shared experience of working with self-neglect, practitioners felt they could discuss these experiences with me. Alternatively, using Goffman's lens of Facework, did practitioners open up because I was in the role of researcher and they were the researched; therefore, they had to perform to this role? Alternatively, perhaps they could show me this particular face and offload as they would not see me again. I also questioned if the ability to discuss self-neglect work's emotional and sensory impact was more about where these conversations were located and with whom. Was this influenced by a professional or a managerial discourse? Given the focus on performance and bureaucratic tasks practitioners described within a managerial discourse, a professional discourse may offer more scope for understanding, acceptance and safety to explore these profound emotions with fellow practitioners who can relate to these experiences and have the expertise and knowledge that some managers appeared to be lacking. Peer or clinical supervision, as offered in other areas of social work, i.e., mental health, away from a line management focus, may offer a safe space for practitioners to recognise and make sense of the profound emotional and sensory experiences of self-neglect work that they describe.

6.9 Conclusion

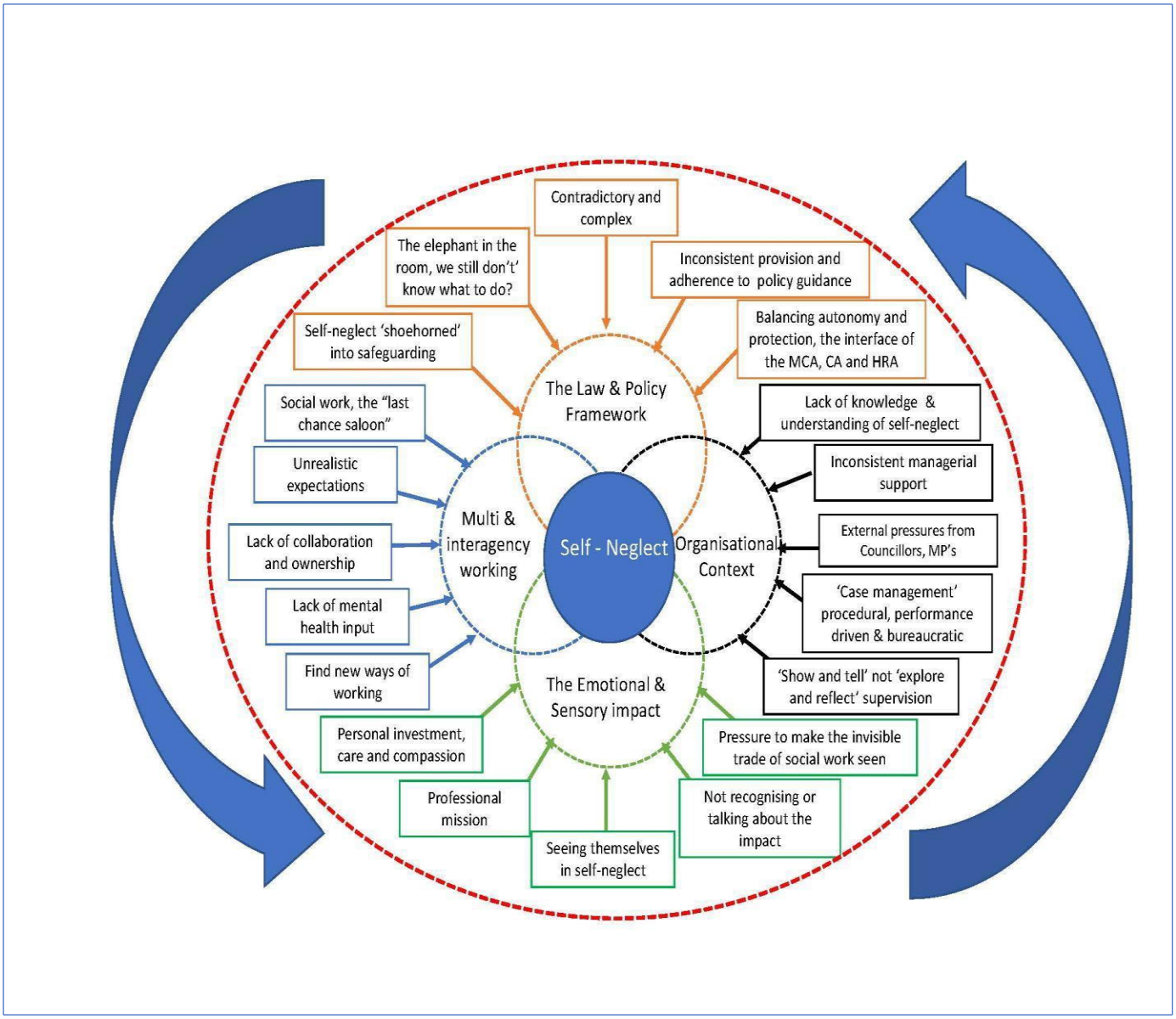
This chapter has discussed how this study's findings answer my research questions and connect to the literature reviewed in Chapter Three. The findings identify ethical dimensions, described by a

practitioner as ‘the rub,’ between a range of competing roles and imperatives, legal, organisational, professional role and personal investment. The discussion sheds light on the complex, multi-dimensional landscape of self-neglect work and illustrates how practitioners can be challenged by navigating a range of competing expectations in a climate of reduced resources and limited support. Practitioners experience the organisational context of self-neglect work in diverse ways. A central theme is that local authorities’ managerial, time-pressured and bureaucratic processes can act as barriers to good practice in self-neglect work. Although national and local policy surrounding self-neglect recommends taking time to build trust and person-centred approaches, in day-to-day practice achieving this was challenging. Seeing first-hand how some practitioners struggled to find time to build trusting relationships with the people they worked with due to management pressures offers a cautionary warning. Their experiences do not reflect recommendations from SAR findings (Preston-Shoot et al., 2020) and research evidence that advises taking time to build trust and adopt person-centred approaches (Braye, Orr and Preston-Shoot, 2011; 2013; 2014; Brown and Pain, 2014). Practitioners' accounts in this study indicate that organisational expectations to meet the aims of the CA and Making Safeguarding Personal (MSP) 2014 are unrealistic in terms of what practitioners can achieve with limited time support and resources.

Practitioners in the present study were profoundly affected by the emotional and sensory experiences of this work, supporting the findings of previous studies (Smith, 2001; Day, McCarthy and Leahy-Warren, 2012; Doron, Band-Winterstein and Naim, 2013; Braye, Orr and Preston-Shoot, 2014; Band-Winterstein, 2018), although surprisingly they did not always recognise or feel able to discuss these feelings in supervision. Drawing on the work of Goffman (1955; 1959), suggestions have been put forward as to why this may be. Without a safe space to explore and reflect on these emotions, they may become internalised, concealed, and unable to be processed and may manifest themselves as stress and possible burnout for practitioners. This may offer insights into why some practitioners in SARs are identified as not engaging with the person they are working with, closing cases too early and lacking person-centred practice (Preston-Shoot et al., 2020, Preston-Shoot, 2021).

In drawing this analysis to a close, the diagram below provides a summative illustration of what this study tells us about the complex, interconnected and multi-dimensional landscape social workers have to navigate to find a way through a range of competing roles and imperatives in self-neglect work. These include legal, organisational, and professional expectations and personal relationships, alongside the often profound sensory and emotional impact of this work.

Figure 6. Social workers' experiences: Navigating the multi-dimensional landscape of self-neglect practice



The evidence from this study suggests that to understand social workers' experiences, there is a need to take a holistic view and recognise that the above domains are indispensable, interconnected dimensions of practice that need to be seen as a whole yet will be pieced together differently by each individual social worker in each individual case. My analysis suggests a need to acknowledge these multiple paradoxes and profound experiences of practitioners working with self-neglect and find ways to encourage safe exploration of this work's emotional and sensory impact. The following chapter will provide an overall conclusion to this thesis, identifying key themes and areas for further research.

Chapter 7. Conclusion

7.1 Introduction

This chapter concludes this thesis and reflects on the research process and the study's key messages. It begins by discussing the limitations and benefits of my methodological approach alongside reflections on my research journey. I consider how the findings support and extend what is known from the literature, how they answer my research questions and make an original contribution to the emerging body of knowledge on self-neglect work. Finally, I will consider the implications for policy and practice, with some ideas for future research.

My overarching research question was, 'How do practitioners experience working with self-neglect?' As explained in Chapter One, the motivation was drawn from my experience of working with adults who self-neglect, as this work had a profound impact on me, and I wanted to draw on my own experiences and explore how other practitioners experienced this work. Undertaking the literature review was a critical process in developing my approach. I learned that practitioners' experiences of self-neglect reached far beyond my own experience and are multi-dimensional, located within a complex interplay of law, policy, organisational context, professional identity and personal relationships. Therefore, my initial research question was developed to include the following sub-questions to capture this complexity:

- What impact does legislation, policy and local guidance have on self-neglect work?
- How does the organisational context influence self-neglect work?
- How do practitioners experience multi/inter-agency working in self-neglect work?
- What impact does self-neglect work have on practitioners?

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I located the study within a social constructivist theoretical paradigm influenced by Symbolic Interactionism (Blumer, 1969). SI's emphasis on how actors make sense of their interactions provided a suitable framework to explore how practitioners experience and make sense of self-neglect work. My first thoughts about collecting the data were to ask practitioners to capture their experiences of working with self-neglect using a reflective diary (Janesick, 1999). However, I had a disconcerting feeling that something was missing in this approach. A reflective diary would not allow me to access social workers' immediate experiences and see, hear and feel their experiences of self-neglect work, which was the crux of what I wanted to explore. I was also concerned that asking busy practitioners to complete a reflective diary may feel burdensome as it was another administrative task. I wanted to know how social workers in local authorities understand self-neglect work and how they make sense of their experiences and navigate what Blumer (1969) explains as a line of activity, which describes how we connect and make meaning from our interactions with others. I decided that the best way to achieve this would be to accompany practitioners as they undertook their day-to-day work and therefore changed my approach to an ethnographic case study.

This study involved observing and interviewing 10 social workers from five different authorities working with people who were self-neglectful and had mental capacity. I observed each social worker undertaking a home visit and interviewed her/him just before and after the visit. The interviews were audio-recorded and transcribed alongside my observations of the visit. I undertook a thematic analysis of the data using Braun and Clarke's (2006; 2013; 2021) framework for analysis. After setting out the findings in Chapter Four, I then, in Chapter Five, took the discussion to a deeper level, interrogating the findings by reference to the literature and exploring how they supported, differed from, or offered alternative perspectives; I will return to this later in this chapter. The following explores the strengths and limitations of the research design I employed to answer my research questions and shares my reflections on my methodological journey.

7.2 Strengths and limitations

As previously discussed, I developed my research sub-questions to address the themes I identified from undertaking the literature review, although, on reflection, each question could be a stand-alone piece of research. Within the constraints of a 50,000-word thesis, providing the necessary depth and breadth to explore each question was challenging. I was concerned that this limited my ability to present the data in as much detail as I would have liked, and I considered focusing on one area, such as the emotional and sensory aspect of self-neglect work, which I found myself drawn to due to my own experiences. However, undertaking the literature review was a pivotal part of my learning. It enabled me to stand back and see the multi-connectivity of self-neglect work and how the law and policy context, the organisational culture, multi-agency working, the professional role and personal responses are indispensable connected dimensions of practice. Omitting one of the research questions would have lost an essential locus of practitioners' experiences and limited this study's ability to take a holistic exploration of self-neglect work, and, on balance, I think it was the right decision to include all the questions. The following reflects on my approach to answering these research questions.

7.3 Reflections on my research design

I located this research study within a social constructivist theoretical paradigm influenced by Symbolic Interactionism (SI) (Blumer, 1969). SI offered me a way to observe and think about how practitioners interpret and make meaning from their interactions with others in self-neglect work. Furthermore, I drew on Goffman's (1955; 1959) concept of Facework as an exploratory lens that aligned with the theoretical underpinnings of SI and enabled me to try to make sense of a significant finding: why practitioners were able to discuss the emotional and sensory impact with me but not with their managers (this point is returned to later in this chapter). Methodologically, I believe the richness of the findings from this study is due to its ethnographic approach, which allowed me to be alongside

practitioners, share their space and observe how they experience and make sense of self-neglect work. It enabled me to be alongside them on home visits to see, smell, touch and share their encounters and gave me access to their experiential and sensory experiences that undertaking interviews alone would not provide.

7.3.1 Generalisability

My rationale for adopting a case study design was that it enabled me to put a boundary around the 'case,' which for this study was to explore practitioners' experiences of working with self-neglect within their own local authority organisational context. This small study (n10) provides valuable insights into practitioners' experiences, but the findings are not generalisable to a broader population due to the limited numbers. It could be suggested that there is a tentative analogous generalisation as the findings offer insights into how practitioners experience working with self-neglect across five local authorities. Furthermore, perhaps this study offers depth rather than breadth as it does not look at practitioners' experiences in isolation but also brings in their broader context.

7.3.2 Being an Insider researcher

I have a range of experience working with self-neglect, and the profound effect this work had on me motivated me to undertake this study. My experience was valuable because it enabled me to build a rapport with participants as we had a shared experience, but I was also aware of the danger that I could overidentify. I found it difficult to shift my identity from practitioner to researcher at the start of this study. Listening back to my early interviews and reading the transcripts was helpful as I could see where I needed to step back and reset my boundaries. I was not a fellow social worker going on a joint visit; my role here was a researcher observing practice. I also questioned if I was processing my own historical distress of working with self-neglect and using this study as a form of research therapy. Using my reflective diary and supervision helped me talk through my feelings and enabled me to move

beyond reflection to reflexivity to understand my difficult transition from practitioner to researcher. An ethnographic approach allowed me to be part of a shared experience with practitioners and pay attention to my physical responses and sensory experiences during home visits, although this also presented challenges, as explored below.

7.4 Ethics in motion

Undertaking participant observations in people's homes presented unexpected situations. Although my role as a researcher was primarily an observer, my role adapted to the needs of the situation and the participants during some home visits. As Bachman and Shut (2007) explain, a participant observer encompasses a continuum of roles from being a complete observer to being a covert participant; they highlight that 'many field researchers develop a role between these extremes, publicly acknowledging being a researcher but nonetheless participating in group activities' (p.263). An example of my role on this continuum is where I helped a practitioner struggling to move rubbish to access a person's home, and I supported another practitioner when the person we visited appeared unconscious; thankfully, the person was just in a deep sleep. I was there as a researcher, not a social worker, but as a registered social worker and a human being, I needed to support others when these situations arose. Retaining the distinction between roles was difficult, and my boundaries may have become blurred on these occasions. However, on reflection, I stand by those decisions to intervene as I believe it would have been unethical not to. This reflects Bachman and Schut's view that participant observation is on a continuum and may need to adapt depending on the situation.

These events reinforced the value of adopting SI as a theoretical framework and illustrated that SI is not an abstract concept but a living, tangible feature in my research. I was aware I was a dynamic actor in this research process. I had to find what Blumer would describe as my 'line of activity' by negotiating my role and interpreting meaning from my interactions with others within the research process, and also what 'face' (Goffman, 1955) I was presenting in different situations.

7.5 Sensory ethnography

Due to hoarding, an ethnographic approach brought my physical presence into cluttered environments with very little space to move. Some homes I visited had suspected faeces on the chairs where we were invited to sit, and I had to decide: do I refuse or sit? I drew on my practice experience and surreptitiously slipped my plastic handbag over the seat before I sat down to avoid offending the person. I was affected by some of the home environments as described earlier. I felt uncomfortable about recognising these feelings as if, in some way, I was making a negative judgement on the person we had visited by having to go home immediately, shower and change my clothes, a feeling shared by a practitioner in this study (SW7). As Pink (2013, p. 263) identifies: 'Ethnographic experiences are “embodied” in that the researcher learns and knows through her or his experiencing whole body'. I recognised that my own embodied experience enabled me to have a shared experience with the practitioner during our home visits. This reflexivity moved me beyond just my own ideas about the research process to include recognising my own physical experiences and sensations, although some may argue that this embodiment, this shared experience, may have affected my objectivity and shaped my interpretations of the findings. Adopting an ethnographic approach enabled me to access an unfiltered perspective of day-to-day practice, but it was not without consequence, as it presented challenges in retaining my objectivity due to the emotional and sensory charged nature of some home visits. Again, I found that utilising my reflective diary and discussing these experiences with my supervisor helped make sense of my responses. The following section summarises the key findings from this study and what I consider the important messages.

7.6 Contributions

To the best of my knowledge, at the time of writing, there have been no other ethnographic studies undertaken in England after the introduction of the CA that observe practitioners on home visits to people who self-neglect. This study contributes further evidence to the body of empirical research in this emerging area. Using SI as a theoretical lens allowed exploration to consider how social workers negotiate and make meaning from working with self-neglect in an often-contradictory practice landscape. Due to its ethnographic approach and getting up close to practice, this study offers insights into the realities of practitioners' day-to-day experiences. The following provides a summary of the key messages drawn from the research questions presented in this study.

7.7 A summary of key messages

In response to the sub-questions set out in 7.1, practitioners described a complex and sometimes contradictory legal and organisational framework in which they were often unable to navigate and find the answers they needed, particularly when navigating the interface between the MCA and self-neglect and balancing competing imperatives of respecting a person's autonomy with a duty of care. Participants noted that the inclusion of self-neglect under the remit of safeguarding within the CA guidance is a positive catalyst for a call to action, bringing together relevant agencies. However, some questioned whether placing self-neglect under the safeguarding umbrella was the most appropriate response as self-neglect work jars with the often fast-paced approach set out in safeguarding procedures. More emphasis on early assessment and prevention facilitated by a s.9 assessment under the CA may offer a more appropriate response, allowing practitioners time to develop trusting relationships and work with people who self-neglect before situations reach a crisis point, thus averting the need for s.42 safeguarding response.

A key theme in the literature reviewed (3.6, 3.7) was the call for organisations to develop policy and practice guidance and training to support practitioners working with self-neglect. Practitioners in this study echoed this call, explaining that they can feel out of their depth with complex cases due to a lack of organisational support and guidance. However, this finding proved contradictory as practitioners also explained they did not refer to policies even when they were in place but drew on their professional skills and experience to guide their practice in self-neglect work. The findings suggest that an overabundance of policy documents can result in a 'white noise', a policy fatigue where practitioners struggle to hear or see the relevance of using them. There appears to be a paradox that developing policies to guide practice can sometimes confuse rather than clarify. Accessible, succinct policy documents, giving examples of how the law and policy guidance can be brought to life and be applied to day-to-day practice, may go some way to bridge this gap. The evidence from this study suggests that how social workers engage with law, policy and guidance is nuanced and influenced by practitioners' level of experience, risk and the complexity of the case they are working with. Furthermore, practitioners' accounts suggest a need to review the efficacy of the current legal framework for working with self-neglect and point toward exploring other human-based relationships and person-centred approaches to improve organisational and practice responses.

Although the literature reviewed in 3.7 identifies that multi-agency working is a central component of successful self-neglect work, the evidence from this study suggests that there is still significant work to be done to achieve this. Practitioners described multi/interagency working as problematic in self-neglect work, and a common theme was the feeling of isolation and frustration due to a lack of response and understanding from partner agencies. The literature explored in 3.7 proposes alternative models for working with self-neglect which may provide solutions to the sense of isolation and pressure practitioners describe. The evidence from this study suggests that specialist, self-neglect community teams with dedicated mental health, health and social care community practitioners who work together in a shared, egalitarian capacity, providing a consistent and skilled response, may offer a more effective working model.

The evidence from this study also revealed a complex emotional and sensory dimension of self-neglect work. Practitioners' feelings of compassion, anxiety and frustration coincided with visceral physical reactions towards self-neglect, causing them to question their values, relationships and professional boundaries. The literature reviewed in 3.8 supports this view but the findings in this study extend this point as practitioners went further in relating this to how the law, policy and organisational context influenced their experiences and, importantly, how the relationship with their managers was pivotal in how they experienced working with self-neglect. Practitioners described how supervision often focused on technical, bureaucratic tasks to meet organisational demands and did not allow space for them to talk about the emotional and sensory impact of self-neglect work. The findings from this study suggest that the personal and professional investment practitioners give to the people they work with can overwhelm and raise conflicting emotions. Their compelling accounts present a sound argument for more attention to be given to the emotional and sensory impact of self-neglect work

The results of this study are timely in that, at the point of writing, the first detailed analysis of Safeguarding Adults Reviews (SARs) has been published (Preston-Shoot et al., 2020). This report identifies that self-neglect was a significant theme in over 45% of 231 SARs analysed. Areas of poor practice identified in the report suggest a lack of person-centred practice, poor communication and a lack of engagement. The findings from the present study suggest we need to look more closely behind this data to understand the complexities of direct practice and how the current austerity measures in adult social care, and the lack of resources, staffing and time, can impact self-neglect work. As Braye, Orr and Preston-Shoot (2015, p. 86) suggest, SCRs involving self-neglect need to go further and provide a more in-depth critical analysis, giving more attention to ‘How values and beliefs, for example, about responsibility, choice, autonomy and care, impact on individuals and multi-agency systems’. Furthermore, the evidence from this study suggests practitioners need a safe space to recognise and reflect on the experiences of working with self-neglect, so the challenges of working in this pressurised environment do not negatively impact or manifest in behaviours that may get in the way of person-

centred practice.

A significant finding, and something I was perplexed by, was that practitioners could talk to me about the profound emotions of self-neglect work but did not feel able to talk about this in supervision to their managers. I explain in 6.8 how I drew on Goffman's (1955; 1959) concept of Facework to try to make sense of this. I suggest that practitioners may not want to reveal a particular 'face' in supervision as their intense positive and negative feelings towards the people they work with may be incongruent with their organisation's professional practice expectations. There may be a fear (as some practitioners described) of not performing as their supervision focused on reporting back to managers on procedural completed tasks; their supervision agenda was more focused on 'show and tell' rather than 'explore and reflect'.

Finally, this study identifies how self-neglect work raises ethical tensions in balancing a person's right to autonomy with a duty of care. Practitioners felt a strong sense of compassion towards the people they work with, combined with a personal and professional responsibility to keep them safe, resulting in practitioners going into unsafe environments where other agencies refused to go. I have drawn on the work of Lavee (2021) (6.7.1) to try to make sense of why practitioners visit and revisit unsafe and unsanitary homes and suggest that a complex milieu of professional and social pressure, alongside an organisational culture of neoliberalism and austerity, may also place an ethical and moral responsibility on practitioners to go beyond the remit of their role. This study also raises questions as to why local authorities allow this to happen and identify the following as good practice, as this quote from a SAR illustrates: 'There were many examples of agency workers being tenacious and compassionate, often putting themselves in risky environments to try and provide support' (Preston-Shoot et al., 2020, p. 85). This study shows that navigating these complex demands can put practitioners at increased physical and emotional risk, and where they can see what the right thing to do is but lack the organisational resources, which can result in moral distress (Weinberg, 2009).

7.7.1 Answering my research question

The research sub-questions set out in 7.1 provided the framework to answer my overarching research question, 'How do social workers experience working with self-neglect?' Each sub-question explored a different element of practice. The overall sum was greater than its parts as it illuminates how practitioners' experiences are embedded within interactional multi-dimensional constructs of legal, policy, organisational, professional and personal domains (illustrated in Figure 6). The evidence from this study suggests that looking at one element of practitioners' experiences in isolation blinkers our view, limiting our ability to see how the different dimensions of self-neglect practice influence and impact each other. There is a cause and effect that ripples through these connected practice dimensions. By taking a holistic view a clearer picture of practitioners' experiences emerges and identifies that working with self-neglect is intellectually, ethically, physically and emotionally challenging, yet also provides opportunities for practitioners to have positive relationships with people who self-neglect that are underpinned by a profound commitment to care, compassion and anti-discriminatory practice.

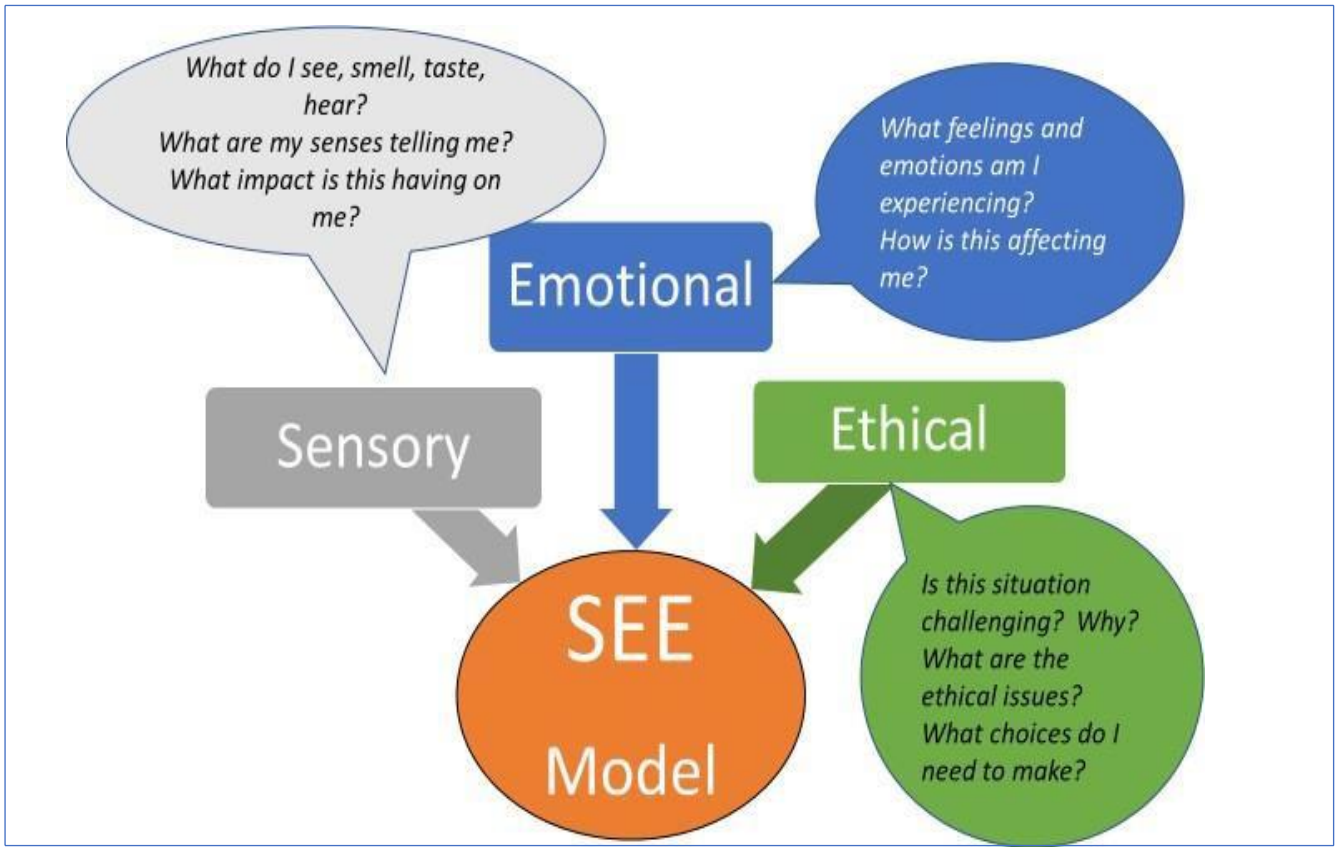
7.8 Implications for policy and practice and the need to be seen

A significant theme from this research was that practitioners struggled to talk about the often profound emotional and sensory impact of self-neglect work with their managers in supervision. Supervision appeared to be an opportunity to make their 'invisible trade' (Pithouse, 1998) seen by the attention to bureaucratic tasks. There was pressure on practitioners to be seen to meet legal, policy, organisational and professional expectations in a range of contexts. For example, there was a need to be seen by MPs and local councillors to be 'getting something done', to be seen by other agencies to provide solutions to often unsurmountable problems, to be seen by managers to address case management tasks and to be seen by the people they work with as having time, care and compassion to understand their situation. Furthermore, an analysis of Serious Case Reviews where self-neglect

was a feature noted a lack of person-centred approaches where practitioners failed to ‘see the person’ (Braye, Orr and Preston-Shoot, 2015, p. 77). In contrast, the significant impact of self-neglect work on most practitioners was not being seen by themselves or others.

In terms of implications for practice, I have reflected on how these conversations could be encouraged and provide practitioners with a safe space to explore the sensory, emotional, and ethical elements of practice within supervision. Given the growth of self-neglect work, I believe the evidence from this study justifies the inclusion of a prompt on supervision agendas. Such a prompt may go some way to act as a catalyst to start this conversation and open up space for practitioners to 'SEE' (Sensory, Emotional, Ethical) themselves in self-neglect work and not just see the expectations of others. Figure 7 below sets out my suggested approach that may offer managers a tool in supervision to encourage practitioners to think and talk about their experiences of working with self-neglect, which participants in this study were reluctant to do.

Figure 7. SEE – A suggested agenda item for supervision in self-neglect work



Adopting a SEE model as a standard item in self-neglect supervision may encourage discussion about what practitioners see, smell and feel during home visits and give them legitimacy and permission to talk about this work's emotional and sensory impact. Exploring and talking through the ethical challenges practitioners identified in this study may minimise the impact of moral distress and compassion fatigue discussed in Chapter Six. Furthermore, peer or clinical supervision offered in other areas of social work, i.e., mental health, may also offer a safe space for social workers to recognise and make sense of the experiences of self-neglect work. The suggestion raised by a practitioner (SW7) of having a 'self-neglect or hoarding official debrief, like a zone where you could share what you've learnt' may go some way to embed a culture of support and collaboration for practitioners and continue to develop expert knowledge within organisations.

The evidence from this study suggests that strategic and collective mechanisms need to be in place throughout the organisation, from supervision, supportive line managers, clear, succinct policies and procedures that can engage practitioners, and professional and peer support forums to gain support and guidance with complex cases. Organisations need to find new ways of working with dedicated teams with the resources, expertise and time to work with people in a meaningful way that may help respond to the concerns identified by practitioners in this study.

7.9 Areas for future research

The findings illustrate that the emotional and sensory impact of self-neglect work and relationships was a significant theme. The proposal above for a 'SEE' model to draw on in supervision with self-neglect cases would warrant a pilot study to test how effective it could be in enabling practitioners' experiences to be allowed to surface and made more explicit. More broadly, I would be interested in developing this further and exploring how other disciplines involved in self-neglect work in England since the changes brought in under the Care Act are affected by this work and, if so, are there commonalities or differences with the findings from this study. A key finding from this study is for adult community services to think differently about the existing approaches to responding to self-neglect. Multi-agency specialist teams operating in the US offer ways to think differently about a collective response to self-neglect (Bratiotis, 2009; 2013; Koenig et al., 2013). Developing a better understanding of the shared experience of self-neglect work, its impact on workers, and what support needs to be in place may provide a solid foundation to develop successful alternative approaches to multi/interagency working. The evidence from this study suggests that how we approach working with self-neglect needs to change. The increasing number of self-neglect cases and the complexity of this work identified in SARs (Preston-Shoot et al., 2020) provides further evidence to support this view. Further research may help build the foundations to support new ways of working. As outlined in the above models, approaches that move away from professional silos and towards specialist, dedicated teams with the resources, knowledge and skills to work collaboratively may offer a way forward.

7.10 Final reflections

This research process has extended my understanding beyond my own experience of self-neglect and shown how the connected and multi-layered dimensions of this work can ask us difficult questions by examining our values, personal and professional relationships, and behaviours. The following quote encapsulates my learning journey:

> The researcher is also a narrator and an active producer of 'knowledge' in research… the researcher is also involved in writing his or her life, reflecting on experiences both within and outside the research context – both are also related. Here, there is the 'intellectual biography' of the researcher who not only 'translates' the experience of others but also writes and interprets their own life (Roberts, 2002, p. 86-6, cited in Blaxter et al., 2010, p. 264).

Undertaking this thesis has reinforced my passion and respect for social work. Seeing how practitioners navigate the complex, multi-dimensional demands of self-neglect work whilst retaining their commitment to care for the people they work with has been inspiring. As the analysis of the SARs (Preston-Shoot et al., 2020) identifies, social work does not always get this right, but this study suggests we need to look behind this data and give more scrutiny and credence to the significant task placed on practitioners working with self-neglect within a climate of austerity and reducing resources. The weight of responsibility, organisational demands, and the emotional and sensory impact of this work needs space to be seen and explored in a safe and supportive manner by organisations and managers who understand the complex demands of this work. This is the fundamental concluding message of this thesis, and I would argue that it is an essential starting point in developing a better understanding of practitioners' experiences of working with people who self-neglect.

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Appendices

Appendix 1. Key Processes in Critical Interpretive Synthesis (Dixon-Woods et al., 2006).

- A review question should be formulated at the outset but should remain open to modification. Precise definitions of many constructs may be deferred until late in the review and may be a product of the review itself.
- Searching, sampling, critique and analysis proceed hand in hand, and should be seen as dynamic and mutually informative processes.
- Searching initially should use a broadly defined strategy, including purposive selection of material likely or known to be relevant.
- The analysis should be aimed towards the development of a synthesising argument: a critically informed integration of evidence from across the studies in the review.
- The synthesising argument takes the form of a coherent theoretical framework comprising a network of constructs and the relationships between them. The synthesising argument links synthetic constructs (new constructs generated through synthesis) and existing constructs in the literature.
- There is a need for constant reflexivity to inform the emerging theoretical notions, as these guide the other processes.
- Ongoing selection of potentially relevant literature should be informed by the emerging theoretical framework. Literatures not directly or obviously relevant to the question under review may be accessed as part of this process.
- CIS encourages an ongoing critical orientation to the material to be included in the review. Some limited formal appraisal of methodological quality of individual papers is likely to be appropriate. Generally the aim will be to maximise relevance and theoretical contribution of the included papers.
- Formal data extraction procedures may be helpful, particularly at the outset of the review, but are unlikely to be an essential feature of the approach.
- CIS does not offer aim to offer a series of pre-specified procedures for the conduct of review. It explicitly acknowledges the "authorial voice"; that some aspects of its production of the account of the evidence will not be visible or auditable; and that its account may not be strictly reproducible. Its aim is to offer a theoretically sound and useful account that is demonstrably grounded in the evidence.
- CIS demands constant reflexivity on the part of authors of reviews. Authors are charged with making conscientious and thorough searches, with making fair and appropriate selections of materials, with seeking disconfirming evidence and other challenges to the emergent theory, and with ensuring that the theory they generate is, while critically informed, plausible given the available evidence.

Appendix 2. Search Strategy for Literature Review

Date of search 23rd July 2022

Data Bases Searched: Host EBSCO - CINAHL Plus; APA PsycInfo; APA PsycArticles;Education Research Complete; Humanities Full Text; MEDLINE; Social Sciences Full Text , Scopus, Socialcareonline, Emerald.

Name of category of search terms applied	Search strategy used, including any limits	Total number of results found	Comments	Number of articles included
S1	social work	354,802	S1, S2, S3 provided the overall search terms that were then combined and modified for the first search as presented below.	
S2	(self-neglect or self neglect) OR (hoarding or compulsive hoarding or hoarding disorder) OR safeguarding adults OR "safeguarding adults at risk OR (abuse and neglect)	61, 314	As above	
S3	social work or social workers or social work practice or social services) OR frontline practitioners OR frontline workers OR (frontline staff or healthcare staff or healthcare professionals or healthcare workers) OR healthcare professionals OR (professionals or	3,217.54	As above	

	practitioners or staff)			
S1 + S2	Narrow by - hoarding behaviour Narrow by - social workers Narrow by - social work Narrow by: - protective services Narrow by - elder abuse	964	This resulted in a number of articles included children, so the search terms were narrowed further .	
S1+S3	NOT , child children or adolescents or youth or child or teenager	899	All abstracts were reviewed of which 57 articles were read in more detail	25 empirical articles selected for review
S2 + S3	NOT , child children or adolescents or youth or child or teenager	2,946	Search refined and narrowed further due high number of returns	
S2 +S3	**Narrow by** - best practices Obsessive; compulsive disorder - health care delivery - dementia patient-professional relations professional practice professional ethics animal welfare - social workers - self-neglect - hoarding disorder elder abuse - compulsive hoarding social services - abuse of older people	302	All titles and abstracts were reviewed. Although they were primarily duplications from the previous search. 15 articles were read in more depth.	5 empirical articles and one dissertation were selected for review.

Database - Scopus	Self-neglect or Self neglect	844	All titles & abstracts were reviewed which were not duplicates of the above search, of which 51 were read in more detail.	3 empirical articles were selected for review
Social Care online	Self-Neglect, Then narrowed by limiter of NOT children	933 141	All titles and abstracts were read, 23 were read in more detail	This search identified 3 articles that other searches did not. The other materials were duplications of the above searches.
Web of Science	"self-neglect" or hoarding, or compulsive hoarding, or safeguarding adults, or abuse or neglect	401	All titles abstracts reviewed. 36 Articles identified as relevant.	None selected as all duplications of previous searches.
Emerald Insight, (host to Journal of Adult Protection)	Self-neglect	243	All titles reviewed	All relevant articles were duplications
Citation tracking				1 empirical article, one report, two dissertations identified
Total				41 items selected for the literature review

Appendix 3. Information Sheet for Participants – Social Workers

Self-Neglect Study, Information Sheet

Invitation

As an experienced social worker, I have developed an interest in working with self-neglect, and I am undertaking this research study as part of my doctoral thesis. This information sheet explains the aim of the study and what it involves, and I very much hope you would like to participate. If you are interested or want to find out more, please contact me for an informal discussion and I will answer any questions you may have without obligation.

Researcher - Maria Brent, email - m.brent@sgul.kingston.ac.uk Telephone 07903 628867

What is the purpose of Study?

This study aims to explore social workers' experiences of working with adults who have capacity but who neglect their personal care and/or domestic environment. It is recognised that working in this area can be challenging for social workers. This study will explore these experiences to generate new knowledge and contribute to a better understanding of social workers' experiences and support needs within this area of practice.

Why have you been asked to participate?

As a social worker working in adult services, you may be working with a service user who is self-neglecting and may feel that you would like to get involved.

What will happen if you take part?

I plan to meet with you first to explain the project in more detail and answer any questions you may have. I would then like to come along with you to observe a home visit. I would not ask any questions or become involved in any discussions, unless the service user asks me a direct question. Before the home visit, if possible, I would meet you at your office so we could travel to the service user's home together. During this time I would like to explore your thoughts about the forthcoming visit to consider what you are hoping to achieve and if there are any areas of concern you may have. If it was not possible to travel together I would like to come to your office just before the planned visit to have this discussion. If at any time the service user felt uncomfortable with my presence during the visit or it was felt I was having a negative effect by being there I would leave immediately. After the visit I would

travel back to the office with you and use this time to explore how you felt the visit went, what you thought went well and any other areas you would like to discuss. If it was not possible to travel back together I would like to meet you after the visit at your office so we can have this discussion then. With your permission our conversations will be audio recorded. I will provide you with a transcript of our interview and offer you a further opportunity to meet up to discuss the content. Your participation is completely voluntary and you can withdraw from the study at any time without having to give a reason and without any negative consequences.

How will service users be invited to take part in this study?

Services users invited to participate in this study will be identified by the social work teams themselves as they will know which service users may be willing and able to participate. Service users will need to have capacity and the social worker will be provided with a consent form and information sheet to give to the service user which explains the aims of this study and how the information will be used. The service user will also have the opportunity to contact me directly to ask questions to ensure they were completely satisfied and in agreement to my observing the home visit before it occurred.

What are the benefits of getting involved?

The findings from this study aim to develop new knowledge and insights that can be shared to promote good practice and also identify support needs for social workers going forward. On a personal level, getting involved will provide you with an opportunity to reflect on your own practice and have a chance to talk through your own experiences of working with people who self-neglect.

Are there any disadvantages?

I do not believe there are any disadvantages to you getting involved in this study other than the time to allow me to talk through any questions you may have and meeting you before and after the visits.

If you take part will your identity and information be confidential?

Your participation in this study will be anonymous and confidential and your details and the information you provide will only be seen by myself as the researcher. All information and recordings related to the study will be stored in a locked desk which only I will have access to. Once the information is collected yours and the service user's name will be changed and given a code which will be applied to remove any distinguishing factors and to ensure confidentiality. Information shared will be treated as confidential. However, if practice is observed that constitutes a safeguarding concern I have a professional duty as a registered social worker to discuss this with you and also share any concerns with your manager. You will be asked to sign a consent form that indicates you understand your participation in this study. Your signed consent form will be stored separately from the responses you provide to ensure they remain anonymous and confidential.

Who has approved this study?

This study has undergone ethical review at Royal Holloway University and within your organisation.

Many thanks for reading this information and please do not hesitate to contact me for an informal discussion, without obligation, to find out more.

Appendix 4. Consent form to participate in study

Title of Project: An exploration of Social Workers' experiences of working with self-neglect.

Name of Researcher: Maria Brent

1. I confirm that I have read and understand the information sheet for the above study (YES/NO)

2. I have had the opportunity to ask questions. (YES/NO)

3. I have received satisfactory answers to any questions (YES/NO)

4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. (YES/NO)

5. I agree to participate in this study. (YES/NO)

.

_____

Name of Participant *Date* *Signature*

_____ _____ _____

Appendix 5. Information sheet for people affected by self-neglect

Invitation to participate in a research study

Information Sheet for Service Users

Invitation

Hello, my name is Maria Brent and I am a researcher undertaking a doctorate at Royal Holloway University. You have received this invitation as you are working with a social worker that I would like to observe working with you. If you are interested in taking part your social worker will go through the information sheet with you and answer any questions. If you have any queries please do not hesitate to contact me for an informal discussion and I will answer any questions you may have. Thank you.

Researcher - Maria Brent, Doctoral Researcher email - m.brent@sgul.kingston.ac.uk
Telephone 07903 628867

What is the purpose of Study? At different times in our lives a person may find that they are affected by poor health and this can affect their ability to look after themselves. This can be difficult to recognise or accept. In these situations it is sometimes hard for social workers to find a way to help the person. I want to explore social workers' experiences of practising in difficult circumstances and would like to observe the social worker who works with you.

What will happen if you take part? I would like to accompany your social worker on a home visit. My role is to just observe the social worker. I would not ask any questions or become involved in your discussions unless you asked me a question directly. However, if at any time you asked me to leave I would do so immediately. Your participation is completely voluntary and you can withdraw at any time without having to give a reason and without any negative consequences. With your permission I will take some notes during the visit that will focus on the social worker's responses.

If you take part will your identity and information be confidential?

Your participation in this study will be confidential and your details and the information provided will only be seen by myself as the researcher. The findings of this study will be included in my doctoral thesis and may also be shared in other reports for educational purposes. Details of all participants will be completely anonymous. I will make sure that your personal details cannot be identified in any of the final documents of this study. All information related to the study will be stored in a locked desk which only I will have access to. Notes of visits will be destroyed once the research is completed. I would only need to share your details if I thought that you or another person was at significant risk. If that happens I would tell someone who can help, but only after I have talked with you about it first.

You will be asked to sign a consent form that indicates that you understand your participation in this study. Your signed consent form will be stored separately from any notes I have made to ensure your identify and your social worker's identity remain anonymous and confidential.

What are the possible benefits of taking part? The findings from this study will help social workers think about how they work with people in difficult circumstances and how they can improve their practice with service users.

Are there any disadvantages? I do not believe there are any disadvantages to you getting involved in this study. I will be coming along with the social worker on a scheduled visit so I will not take up any more of your time.

Who has approved this study? This study has undergone ethical review from Royal Holloway University and the Adult Community Services within your local Council.

Many thanks for reading this information and please do not hesitate to contact me for an informal discussion, without obligation, to find out more.

Best wishes

Maria Brent

Appendix 6. Ethical Approval for the study from Royal Holloway University Ethics Committee

Result of your application to the Research Ethics Committee (application ID 26)

Ethics Application System <ethics@rhul.ac.uk>

Thu 12/15/2016 3:53 PM

To: Brent, Maria (2012) <Maria.Brent.2012@live.rhul.ac.uk>;Evans, Tony <Tony.Evans@rhul.ac.uk>;ethics@rhul.ac.uk <ethics@rhul.ac.uk>

PI: Professor Tony Evans

Project title: Exploring Social Workers Experience of Working with People who Self Neglect

REC ProjectID: 26

Your application has been approved by the Research Ethics Committee.

Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee ethics@rhul.ac.uk

Appendix 7. Interview Questions

- Can you tell me why you have chosen this case?
- What are you hoping to achieve?
- Are there any challenges with this case?
- Does the law, policy, and local guidance help you in your practice? If so, in what way?
- Do you know of policies in your organisation regarding working with self-neglect? Do you use them?
- How does working with self-neglect fit with the organisational expectations of you as a social worker?
- How do you experience working with other agencies in self-neglect work?
- Do you think you could work differently than what you do now?
- What do you think may be better?
- What can the organisation do you to support you?
- Do you think there is an emotional response to working with self-neglect? How does this make you feel?
- How do you manage to balance the person's right to make unwise decisions and a duty of care to protect the person?
- Do you think the amount of experience you have working with self-neglect impacts how you work?
- In what way? Do you think you look at risk differently? Why?
- How do you respond to working with self-neglect, are you affected by the smells, sights, and images? What is it that stays with you from this visit? Why do you think that is?
- Do you gain support from the organisation and have supervision? Do you talk about the impact of this work?
- How do you process this?
- Would you do anything differently?
- Anything that you would like to add?

Appendix 8. Interview Transcript

Prepared For:	**Maria Brent**
Recording Details:	**160701008**
Date of Transcription:	**13 April 2019**
Transcriber:	**xxxxxx**
Recording Length:	**50m**

Int[1]: Thank you for being willing to get involved in the project, I'm wondering before we go out and see this lady, just to talk through, you've chosen this case, what was it about this case that you thought would meet the criteria? What's the background?

R[2]: The background to this case is that we had the referral from Housing because the lady had a lot of let's just say personal items in her flat, which were putting her tenancy at risk, it was so full up of stuff.

Int: Was it hoarding?

R: Hoarding, yeah.

Int: Was it personal …?

R: She's got a compulsion to shop through catalogues, she's not got the internet but she does telephone ordering. When I saw her, she had about 40 or 50 jigsaw puzzles, four or five carpet cleaners, floor cleaners but none of them had been opened, they were just all there and even though the people from Housing hadn't actually visited her, through hearsay from neighbours they'd heard about this.

I can't remember who it was that went round and took pictures of her flat and sent it through to us, it looked bad and then contact was made with her on duty and she agreed to have a blitz clean at that point because it was paid for by Housing, so that might have made her think, "Actually, if I'm going to have help and if it's going to be paid for …", but they said they'll only pay for one, if it gets like that again then it's over to us or over to her.

I went out to see her and sat down somewhere, I sat down and the rubbish was literally over my head, it was that bad and there were flies going up my nose and it was pretty grim, I know that's not a very professional thing to say but it was-

Int: But that's what I'm kind of looking for, for you to be really honest … I want to draw out your experiences, so you're not unprofessional, the purpose of this is I want you to feel comfortable to actually just talk through, that's one of the questions for me, what was the environment like? What was your experience?

R: It felt pretty sad really because she's not actually that old a lady, she's in her late 70s but she's had quite a sad life, she was telling me she'd had a divorce and her husband had beaten her, wasn't a very nice man, beaten her when she was pregnant, her son had been taken into care but we never really got into why he was taken into care for a year when he was a teenager, lots of

[1] Interviewer
[2] Respondent

different things, her sister had died and she'd got, she just feels, she told me on that first visit, she said, "I feel really worthless in the situation I'm living in and everything's out of control" and it was really … just the first visit, it wasn't about thinking about the grand solution for her life, I'm going to wave my magic wand and make her feel better but it was just about getting to know her, and then I said I'd come back with my boss and we'd have a bit more of a chat about what we could do to help her.

So the second time we went to visit her, we said to her, "We'll take you out to a local café, just have a cup of tea and we'll look at buying a few bits for the kitchen," like some wipes and a bin and little things.

Between getting to know her in late February and now, I think I must have visited her about seven or eight times but not all of it to do with social, well I suppose you could call it social work stuff, she's not very good at answering her phone because she says that people ring her and try and sell her stuff, so when you ring her, if you don't get an answer, my boss will say, "you know what you've got to do .." and I think "oh goodness me", so I literally pop my head in when I'm going to pick my daughter up from school, I'll knock on her door and say, "Are you alive in there because you're not answering your phone?" and she'll go "ooh", I said "maybe we ought to come to a plan where you ring me once a week and let me know you're alive because this isn't working", it's not working in terms of using up, I don't tell her however many cases I've got but it's not a good use of my time making her feel like she's under surveillance, that's not good, that's not what you want.

But she's had her clean of her flat which she's giving me feedback for my xxx portfolio in terms of how that whole process made her feel and there is learning around, well because it wasn't booked by me, I felt slightly out of control of it as well and she says that whole two days was a bit overwhelming for her. So I think maybe we need to help social workers to help people by having some kind of information about what a person can expect from those days when people go in. I wasn't able to give her any information, I was making it up, I was ringing cleaners saying, "How long are you going to be there? Can she stay there? What kind of chemicals are you going to use? Can she help you?" and depending on who you're working with, which cleaner you're working with, sometimes people will say no, the person has to go out the flat because we're using chemicals, "We'll let you know when we get there" and it's all a little bit kind of not very satisfactory is it?

So that day, I went in and said "Oh, I think it's going to get a bit fraught in here and you might want to put your shoes on and we can go out for a couple of hours", which we did and we pottered around Tesco, the lady wanted to buy herself some nappies, it's a long story, she doesn't buy incontinence pads because she thinks they're too expensive and I said to her, "You need to get them through the NHS", so we've managed to sort that out but at the time, she was buying nappies and we thought there might be a child in the flat, it was "oh for goodness sake."

So she said she felt the whole process was overwhelming but now she's come out the end of it, she's feeling a lot more positive about her flat, she's

got a table there that she can use, there was no furniture that she could use, you couldn't put anything down on the floor, you had to wade through the floor. She can put her jigsaw out now and people can come to her flat to do work, before they were just going in and saying, “No, we’re not doing work,” how does that make her feel? They weren’t mending her boiler, “No, we’re not working in that environment”, so she didn’t have heating or hot water for four months, they just wouldn't go in. Somebody came to fit a washing machine, a new one that she’d bought, “No, we’re not going to take the old one out, we haven't got room to work” and then you’ve got the washing piling up as well, so it was awful.

But I don't think, we’re getting there but I don't think she ever quite saw the link between how her flat was and people’s reaction to it, I don't think she ever made the link between the two.

Int: Would she meet the criteria, thinking about since the Care Act’s come in, do you think that’s made any difference to working with people like that? Do you think about the criteria? Would she meet the criteria?

R: Definitely in terms of the impact it was having on her, just in terms of managing her home hygiene and even preparing food, there wasn’t any space for doing that, so she was going out, buying ready-made stuff but it’s not healthy for her as she’s diabetic.

Int: So she had other health issues as well.

R: She’s got other health issues as well and she says she’s got depression, a lot of it is to do with past stuff that went on but she said that the state of the flat was really making her feel like she was not really worth bothering about, it was that bad.

Int: And she mentioned as well about her feeling worthless and it sounds as if she’s had quite a traumatic past with what’s happened to her as well.

When you first went in, I'm wondering what your feelings were about the environment was like, smell, sights …

R: My boss said to me, the second time I went out to her, my boss said, “Has she got a problem with personal care? Is there a smell?” and I literally looked at my boss and I said, “We’ll get to the front door of the block and you’ll know where we need to go,” it was that bad, the smell from the flat was emanating out of the main door of the block.

I went to see her and I just thought, “We’re in the 21st Century” and I know part of it is her not wanting to give up stuff and put stuff in the rubbish and I know there’s lots of reasons for that but I thought, “My god, somebody is living like this, it’s really dire, we’re worrying about who’s telling us what to do in Europe and why’s and wherefores of that, wasting all that time and there’s people like that, who are living basically in a, her house was like a wastepaper bin, that’s what it’s like, she couldn't move.

I went in there and I said, “oh I found a pair of glasses on the floor, are you using these?”, “I wondered where they were” and it almost made me want to laugh, it was so dire [laughs] I said to her, “How can you find things that are really important to you?”, she said, “Well, I’ve got a system” which she has, she had a system for keeping her wool and then said, “I knit stuff for the neonatal unit at xxxxxx Hospital”, I told my boss when I got back and she said, “It’s very well-meaning but could you imagine if they knew the kind of environment that those things were being knitted in?”, I didn’t want to burst her bubble so I said, “That’s really caring, that’s really kind of you” and I just thought, “oh my goodness”.

Int: You mentioned flies …

R: Oh there were flies, she said, “They do get a little bit annoying” and they were landing on my paper and on my hands and I felt itchy for about two days afterwards, and I had a couple of showers when I got home and I thought, “Is that an insult to her that I'm actually having a shower when I got home?”, I almost felt like I was insulting her! I know that sounds silly.

Int: No, not at all.

R: I felt like, “Am I being judgemental, wanting to have a shower?”, I know some people when they go out to visit somebody who’s got problems with hoarding, they won’t wear normal clothes and I thought, “I'm not wearing jeans out to the flat, that’s not very respectful, I’ll wear my normal work gear” … but yes, some people wouldn't, they’d literally wear a slightly amended version of what they normally wear but I thought, “No, that’s not my style, you're going into somebody’s house, if it’s sanitary or not is another thing”.

Int: It’s interesting how that made you feel, just the kind of emotion, do you think there was like an emotional impact to that type of work? Have you thought about it like that?

R: I don't know about emotional on me …

Int: You talked about coming home and struggling with your own, are you being judgemental or not or just having two showers, you mentioned that….

R: No. The only thing I can say about working with this lady is that I feel kind of like … wrongly maybe, I'm feeling like I need to be protective of her but I'm not sure what from, but it’s almost like I need her to be protected from herself and that’s really terrible, I don't know, it’s not kind of what I'm, she’s even got this little list of things that we agreed we’d do and she’s doing some things and I'm doing some things, and she says it helps her but the emotional impact, the only thing I can think is that I’ve been with people at university who are really, really spotlessly clean, that’s all I can say and if they went into my house, they’d see that my husband’s like a collector of stuff so I was wondering whether I was not quite as affected by it as other people might be, because I'm used to living in like, my husband orders stuff and there it is and it hasn’t been opened yet, so I was thinking am I somehow more numb to it?

Whereas other people, if they don't mop their kitchen floor like every night, they'd have a panic attack if they weren't squirting Jif everywhere, I was thinking am I somehow in her league because I've got stuff in my place that's everywhere and because I've been studying, it's not been cleared up? And I'm thinking does this not register? And then I started thinking , "Am I not seeing the risks because of that?," I thought, strange thoughts go through your head, definitely.

Int: Do you think your level of experience, because even though you're a newly qualified social worker, you've worked for a long time under Adult Community Care, do you think that level of experience impacts on your view of risk or how you respond?

R: I think there definitely is a risk but … the housing people even emailed me and said, "Are there mice in there?" and I said, "If there are, I couldn't hear them", these are the kind of conversations I was having and I thought, "I was actually listening out for scurrying noises in there" and if somebody actually said to you over dinner in the evening, "How did your day go?" and you actually said the real stuff you'd been doing, they'd be like [laughs], yeah you can't tell everybody everything because it just gets too strange. I was so busy chatting to her that at one point I thought I'm not listening for the noise of mice and I thought, "What would I be looking for?" and I said "As far as I could tell, there was no mouse droppings" and I thought I don't even know what mouse droppings look like. Goodness me.

When I first went there, I was trying to develop a relationship with her but I was trying to do it this way and then I was trying to look around me thinking, "How bad is it?", so I was torn between … you could say my dual role, trying to get to know her but assess what was going on. But yeah, it did help that I'd been working for older people's team before and most people, I don't know, some people might think because she's let the place get into such a state, has she got capacity at all because she's obviously not able to make a decision about throwing things out.

I remember one time there was a, it made me think about that lady, she came to xxxxx and she was talking about mental capacity and she said she believed that if you're not able to make a decision at the time it needs to be made, you lack capacity and I thought that just about covers all of our, because she's obviously, at the time it needed to be made, she was not able to get rid of things for whatever reason but with a lot of encouragement, she agreed to it so at that time, but yeah it's … yeah.

Int: Just trying to balance up the right autonomy and people have the right to make their own decisions, if they look like they've got capacity but then you've got that duty of care, do you ever feel management pressure about these cases from the organisation?

R: Yes.

Int: About moving them forward or timeframes?

R: I think if she'd been living in her own house with her own mortgage or owning her own place and she'd have been declining help, and she had capacity, you'd be really hard pressed to do anything because xxxx, my boss, was talking to me about cases before where she's had people like, in her situation but who have got their own house and won't engage and the court has gone with them and said, "It's not affecting anyone else, they're in their own place, it's not like they're semi-detached and the infestation is going over to … everyone's got to live and let live".

We've had to talk to people through letter boxes, that's a toughie but with this lady, it was a little bit more, she was willing to go with having a clean, big thing, she agreed to it and she's got a tenancy and she was worried, she said, "Is there a possibility they might throw me out?" and I said, "We haven't got to that stage yet but the fact that you've mentioned it means you know it's a possibility".

Int: So being honest with her about what the implications were.

R: Yeah.

Int: I'm wondering with your other work, if you've worked with self-neglect, have similar issues come up for you? Are there particular cases that have stuck with you?

R: I remember one guy I visited, this is years ago and he was in a flat and he was a hoarder, he must have had about 100 used razors in his bathroom but they were all kept very well, and he used to collect his urine in butter dishes around the edge of his bed and he said, "I don't need a urine bottle, these are easier to use", and the weird thing I could actually see the logic of what he was saying, I thought in terms of shape … I said "but once you use them, empty them out," it was almost like a Howard Hughes moment, it was that kind of moment and he had a shopping trolley in his flat and he had 50 tins of rice pudding in there. It was a very strange, but he was able to get out to Tesco, he was pottering around … and when I met him on the front door, he didn't have anything on at all, no clothes, so I said "If you want me or a home carer to come into chat to you, you're going to have put something on, I'm not coming in there like that", so he put something on and I said, "by the way, there's a flat over there, there's children in there because I can see toys, come on ..". That was the oddest visit I've ever done. They kept saying the flat was filthy, it wasn't clean to most people's standards but it wasn't filthy, didn't have lots of stuff everywhere but it was very strange collecting behaviour, he was quite a lonely guy, he wasn't from this country, he was from the old Yugoslavia and he didn't have any family and …

Int: So there's something about that loneliness. Just wondering about the organisation, with this lady you've been to see her X amount of times, how do you feel the organisation supports you with these cases in your supervision around them?

R: My supervisor's really good, she's come with me once or twice to see this lady and she was helping me go through the boxes, we said, "If you're not able to

go through the boxes, do you want us to open them up and have a look at what's in there?" and she said yes, so my boss was, she wasn't just telling me what to do, she actually went with me and went with me to Tesco and so …

Int: How did that feel for you?

R: It felt a bit weird because we were walking around Tesco, you realise the struggles you have to do to get a wheelchair that's got a shopping trolley on the front and all the hassle, it's like you're asking for the earth, it's like "We need one with a shopping trolley on the front", "it's there", "yes, how are we going to get to ..?", people who are wheelchair users, I admire their resolve.

Int: How did you feel having your manager alongside you?

R: It was a bit weird because I always feel like , this is a really strange feeling, you almost feel like you want the person all to yourself and just have that relationship between the two of you, but you know it helps to have someone come in and go, "No, we need to focus on this today, forget that" and you think "okay", sometimes it feels nice when it's just the two of you, you kind of feel possessive about the person if that's not sounding a bit odd.

Int: It's interesting and do you feel they give you the time that you need to work with these cases?

R: Definitely, she came out with me the last time and she did an observation and the lady gave feedback about me as well, and she's never said to me, "Don't go out and see her" because if I don't get a reply from her phone, she'll say "Just pop in, doesn't have to be long, just five minutes, just make sure she's all right", she's got diabetes, even though she's a lady who's on a mobile and can ring her own doctor, xxxxx never nags me about going out to her …

Int: Do you think the changes around the Care Act, I'm not sure of xxxxx policies around hoarding and self-neglect, do you draw on that at all? When you're in the moment, do you think about those policies or do you just get on with the job?

R: I think about them and I did read, because I remember xxxx telling me, we've got hoarding information on our, what do we call it, this xxxxsystem where it's like everything, we've got xxxx resources and we've got xxxxx resources, it's all on this one website where all our information is together and I did read some before I went to see her but I did go on Hoarding UK and Help For Hoarders and all these other websites before I saw her.

Int: Have you found that helpful? Do they have a hoarding panel here? When you get high risk cases, how do you manage that?

R: I can't remember, sorry.

Int: But that's useful in a way because from what you've described, do you think you rely on just your personable social work relationship skills rather than thinking about policies and procedures?

R: I have done but maybe if it was a case where she wasn't … if we weren't making progress, probably I would be, yeah.

Int: So from my understanding, is there a sense that the more risks there are, maybe you might be following procedures more?

R: Hmmm.

Int: Why would that be, do you think?

R: Yeah, that is the tricky question. It's a bit like, it's a separate case but a lady recently who I went to visit and her partner was not really engaging with us and she was at risk. Now normally, I'd just work with family and you look at supporting somebody if they have family or partners but because this lady was at risk, I went down the road of doing a mental capacity assessment and we had a best interest meeting and it all went that way.

This has gone off the point slightly but even though this lady, it's been about a relationship and been about her sticking to what she said she's going to do and me sticking to what I'm going to do, it is within a framework, even though probably I'm not aware of it.

Int: It's interesting to unpack why you feel, you mentioned risk, do you think if the risks are higher, you feel more secure following policies and procedures?

R: No, you're right.

Int: You mentioned risk with that last case …

R: I think you rely on what you know is a path you've got to follow, if the risks are still there and you've gone out and visited and the risks are still there, there's been no … I think you do rely on procedures more but whether, I mean the lady here, the risks of her becoming, with the flat becoming like this again are there, if she doesn't have ongoing support so I'm ultimately working with her and doing everything at her pace but I think if there was a moment where I thought, if I suddenly said to her, "By the way, you're going to have to pay £20 a week to Homecare" and I she said, "I'm not having it", I might have to say to myself, well, is this lady making a proper decision based on, yeah I'd have to think about where I went from there because it's like we chat all the time about her and my boss is always saying, "It's really good what we've done so far but it won't amount to anything less she's able to keep it going, we're going to be back where we are now in two years' time".

Int: And how will that make you feel?

R: Dire because it's been really hard work and I know she's worked really hard as well, where she said she's at now, she said she feels like a load has been lifted off her shoulders so I don't want he to feel the way she felt back in February, where she felt like nobody cared about her and she's worthless.

Int: So you feeling dire, just unpacking that, I'm wondering how you as well, what kind of feelings that's rose up?

R: I'm probably not very good at analysing my feelings but I think when you put a lot of work into something and work with somebody a lot and see them a lot, and develop a relationship, you don't want things to go wrong for them and it's weird, I know the Care Act is all about prevention and not being overbearing with people and just letting them manage their lives as much as possible, but sometimes you do have to be a bit more kind of like "This is the way we need to go" and because it's been that kind of, it's not been the kind of relationship I've been used to where she's obviously thinking, "How have you got on with that because you said you were going to do that?" and it's like "How have you gone on with that because you said you were going to do that?" and it's like if all that invested time and effort was not, didn't bring us to some kind of way of her living where she was able to keep things going, it would be soul destroying.

Int: In supervision, do you think you're able to explore those, it sounds like you've got a supportive …

R: We don't really go into the emotional side of it.

Int: What you've said is quite powerful emotions you've invested, you've described how you might feel …

R: Frustrating beyond belief, if I saw a referral for her in two years' time and she needed another load of help from somebody else and the flat was in a pickle again, I feel like I'd failed! I know I haven't but that's how I'd feel.

Int: In supervision, do you feel the sensory impact that you've described, the flies, the smell, the senses you say of possible frustration when things don't go as well, do you think you have space for that in supervision? Do you talk it through?

R: Yeah, up to a point, you've got more space for it in your reflective supervision which we have in the xxx year but of course after this year, you won't have reflective supervision.

We've just had a restructure where instead of having two big teams, we've got six new teams, our team manager said we'll have a team meeting every month but in between we're going to have a group supervision and pick out one case where everyone can offload and talk about a case and why it's been difficult and how they're feeling.

It's difficult in supervision, you have an hour and a half and you might have to go through, I don't know, 13 cases so … tricky!

Int: What could supervision, organisation wise, policy wise, is there anything you feel would help you in self-neglect work? Any gaps? Anything you'd need to keep going and just keep your stamina up in

terms of your practice? What do you think is missing? What would help?

R: My manager is really good so I can talk to her when I come back from meeting this lady so there's no … but something formal in place?

Int: What might help you more? We're unpacking some of your feelings, would you be comfortable doing that in a big group or is there space for that in your one to one supervision, have you thought about the emotional and sensory impact of self-neglect work and some of the frustrations?

R: Some of the frustrations I feel are that the Housing department launched the referral, which I understand they had to do because of the tenancy issues but they'd never met her, that's what bugs me, they'd kicked off the referral and got somebody to go in and take pictures of her flat which would have been quite intrusive for her, but they'd never sat and talked to her and I know that's my role, and then I actually spoke to Housing about her they said, "oh my God, you stayed there that long?", and you think "Yes, because I have to get to know her and see how she's managing her health and food, it's not all about …".

It would be good, it's a bit like when I was talking about the frustration before of not being able to engage with somebody, the good thing about this lady is she has engaged so there's been reduced stress that way but then it's been a commitment time wise.

I remember somebody who was doing a social work course, did a presentation to our team meeting two or three years ago and they were talking about therapy for people and how that needs to be for a long term, lots of sessions, so the person can unpack the reasons why they're doing what they're doing but yeah, it's almost like you need a little talking shop to come back and say, "oh my goodness, I've just been to this", we do it but we do it informally, you come back and you won't mention the name and you'll say, "You've just been on this visit and it was like this, this and this", or you'll have a coffee but it's not formal.

I remember once, this is unconnected with this case, once I was at coroners court for a gentleman, a man I'd worked with and I was offered a debrief then because there was lots of stuff going on and it went on for months. We know it's there but yeah, you do have to have proactive supervisors or managers who offer it to you because they have to recognise that you might be, but we have to show leadership and say, "I'm struggling with this because XYZ" or "it really got to me today".

Int: Do you feel there's a different way of working, you talked about different models, do you think that that might be an option because you touched on it there about longer term, like the therapy, do you feel that we need to think about different ways of working and what that might look like?

R: I think this particular lady could be, because my boss and me have sat down and this lady really does , well not enjoy but she likes having time to talk about herself and her own needs and she's grateful when I ring and she says, "Hello, love" and I'm almost worried that she's seeing me as something I'm not now, so that's the rub, because I've been supportive.

Int: When you say seeing you as something that you're not, what do you mean?

R: Her son is not involved, he's not seen her for a year, he said he's not going to visit her, partly because he's got four young children and I don't think he was going to bring them to the flat ever, she knows that I'm a social worker but I know a lot of people in my department, when they do their visit they say, "This is my role, this is how long I'm going to be involved and my involvement will be ending as of ..", I'm not very good at that! To my cost! I'm in the position of having to say to her, "I know I visited X number of times but long term, it might be better for you to have support from ..", like we have these, from Age UK, personal independent coordinators and they chat about befriending and different things and if there's any risks or any problems, they'll refer back to us.

Int: Is there a sense about you letting go of her and her letting go of you because you mentioned you'd be really heartbroken if you see her referral in the future?

R: Maybe, maybe because this is my first, because this was part of my development as a social worker this year and xxxx (manager) said, "it would be good for you to work with somebody who's got problems with hoarding and this is part of your development, how you engage with them", so I've almost invested more time in this lady's case than I normally would because I just don't want anyone to say, you didn't try your utmost but I don't know if it's made it worse for her. It's a toughie.

Int: I'm mindful of the time, what time did we ..?

R: She's only about 6/7 minutes up the road in the car.

Int: Is there anything that you feel with your work, that you'd be doing anything differently? We've touched on a few areas there, you mentioned boundaries or maybe even after the visit we could look at that, is there anything else that you feel about this case that's triggered for you in these discussions?

R: I think I'll mention something to you after the visit because there was something she mentioned to me about her son from way back, it led to me having to make a safeguarding referral to xxxx and that was tricky because her son obviously rang her and had a go at her about it, and said he wouldn't be visiting because of it and I had to tell her that it was me. Tricky. And that was on the day she was giving the feedback about me as well, I said to xxxx, "I bet that feedback was interesting" and she said she didn't mention it, "she said you've been really supportive", that was either a back me or sack me

moment, either she was going to work with me or say, Social Services can all get stuffed.

Int: That's really interesting because it's about your role as a social worker , building up the relationship and then a safeguarding issue coming in and you having to change your role because … did she share that with you when you weren't expecting it?

R: I think it was first or second time we met, she started telling me about her son, somebody had beaten him really badly because they thought he was abusing somebody else's 5 year old son, then she went onto say, "my son's got four children and they're under 10" and then she started saying, "there was all these accusations years ago about him having child pornography" and oh for goodness sake, we're literally sitting there and there's flies jumping around and then all this stuff is coming out about her son and I'm thinking, first of all we'll worry about children being in the flat because of the nappies, well there aren't any, thank goodness, no children and "now she's telling me all this other stuff about children that aren't even living in xxxx".

XXXXX (managers name) said next time we go out, we're going to sit down, have a coffee and as soon as she gives us the children's names, you get on ..", because I did ring xxxx and they said, "You need to find out more, find out their names, find out their ages", I thought "oh my goodness."

Int: How did that feel for you, having to change roles?

R: Not very comfortable at all, I knew I had to do it but it wasn't great but I knew I had to, I know children's needs are paramount, that's it, the Care Act is clear about that but it didn't feel great and ultimately, I felt if nothing's in it, nothing's in it, they can make an enquiry and say "it's something that we thought was a risk but it's not". Everyone says, "oh yeah it's going to be a hoarding case" and you think, "Yes, well there's a few more things going on …"!

Int: That's brilliant, we can have a chat after the visit as well, how did that feel for you?

R: That's fine!

Int: Did it kind of make you think about anything differently, even starting to have the conversation?

R: I think the trouble is with social workers, we just get on with things, we don't ever analyse how something made you feel, you analyse what you've got to do but you don't analyse how something made you feel. It's not an easy one is it?

Int: Do you think that's important for you, to do that?

R: [Pause] The thing is with me, I just think about people, where they're at and I get angry about things and think, "why is this person living like that?" and then I say "who can I blame? Is she to blame?."

Int: You mentioned anger …

R: Yes, it does make you angry, living like that, they're unseen as well because if the referral hadn't come in from Housing, nothing would have changed. It's weird that neighbours, apart from one neighbour who rings her, the only reason the neighbours were interested is because it was affecting them.

Int: Is that where your anger comes from?

R: Yes, it's annoying, I think it says something about where we're at. I won't mention society, we're just individuals and families but it's a bit like that.

Int: From what you've talked about, it's interesting because I'm exploring as well the emotional impact of that and you've mentioned anger and frustration, in the interests of the person as well, how do you process all that?

R: I suppose I think now we've got the referral, let's do something positive, at least make contact with her, it wasn't me that made contact with her initially but when I rang her, she said, "Yes, I'm quite happy for you to come round and visit, take me as you find me" and I said, "Don't worry about that" and she said, "and I want you to know that I've made a genuine effort to try and tidy up …", but when I first visited her she said, "somebody from your department called me a lazy bitch", I said "Who said that?" and she gave me a name, I need to look into it, I said, "Who would say that and why would they say that ?", and she said, "I suppose they think I'm not making an effort to tidy up".

I'm thinking is that something she's heard from us or someone else? I don't believe she's a lazy person, I just think she's not been well, emotionally well and things have just got overwhelming but …!

Int: Was it somebody from the council?

R: So she said. Who knows?! You can't imagine it but …

Int: But she seems quite reasonable, otherwise she's not going to be telling you something different.

R: No.

Int: I'm looking forward to meeting her.

R: She's a nice lady. She's got cellulitis, she's got a problem with her legs.

Int: Is that why, I suppose I should have asked, obviously you've got the hoarding but why she's meeting the criteria under the Care Act, is it clear and support and got physical care needs?

R: Yeah, she struggles with walking, she's got cellulitis, she's got diabetes, she told me she had MS suspected but not been confirmed, she's got heart problems as well, she's got a problem breathing and the occupational therapy people have been in and they said they're going to, she's on the waiting list

for a wet room for the bathroom but they said that will be about a year, so in between now and then, she needs to have a home help come in and help her get washed really.

Int: And the services, will they go in there?

R: They will now, they wouldn't have done before, no.

Int: Do you feel sometimes, sometimes social workers are the last ones …

R: Last chance saloon, if we don't go in, nobody's going to go in, imagine a man wouldn't even go in and have a look at her boiler and that was actually one of the clearer places in the flat, he just would not … talking about being angry, the weird thing is because I've worked with her, I'm almost angry with them for not making more effort and then I'm thinking, "XXXX, get a grip, really? Come on, it's a reasonable response, the place was full up".

Int: Do you think that's your social work values coming through?

R: Yes, I think "you need to make a bit more of an effort," like we have to!

Int: So looking at people that they should …

R: Yes, should be a bit more like us but then you think no, they've got work to do, they've got machines to fit and you know, they're just not going to go that extra bit and she actually has said to me that she won't have the GP visit her at home, she said "I go to him".

Int: What do you think that's about?

R: She said, "I've known him for 20 years", she even buys him birthday presents, she said, "We've got on very well", I think … possibly she has got a nugget of insight into … not wanting him to judge her.

Int: I'm wondering, she has that relationship with you but she won't let the GP, how does that make you feel?

R: I'm glad she did, I'm really glad she did, I was expecting her to come to the front door of the block and say, "Thanks but no thanks" but …

Int: What do you think is …?

R: She said "take you as you find me" and literally, yeah …

Int: What do you think it's about your relationship? Looking at your relationship with this woman, what do you think it is about her that she's been able to let you in, obviously she's not letting the GP in, there's something obviously about her relationship with you that you've developed, what do you think are the strengths of that? What do you think has made the difference?

R: I think she knows that when I say I'm going to do something, I'm going to do it, I mean it might not be that week but I will do things and she'll say, "oh, this person came round to visit, you did that didn't you?", and I'll say "Yeah, I made the referral, so yes" and obviously she's computing and thinking well, "when this lady says she's going to do something, she will actually do it", everyone else, it's like "I've come to fix your boiler, I'm not doing it now …", "I've come to fit your washing machine, now I'm not because …", so everyone is backing off so obviously she thinks my word is my bond kind of thing.

I don't know about the, maybe the social side of it, I'm not a person who talks in riddles or jargon, like some people go out and say, "this is a social care assessment" and you think "what does that mean?", just say you've got one out there to chat to her about how she's managing, don't put it all in that … I don't write any notes when I go out and see her either, I know pretty much what I said to her and usually she's got her list and I tick off what I've done and I write a little date on it, so that's how we work.

I think she trusts me, that's the basis of it, and I think she probably thinks I remember things, like I say "I'll remember when you said that, we said we were going to do this" or she'll say "How come you know about that?".

Int: So you listen, you really listen to her …

R: Yeah, I really listen, I try and listen and I'll always say to her, "How are we getting along with that?", so don't be surprised today if she asks me to put her microwave on the worktop because I said to her today, "clear your worktop …."!

Int: Do you think that kind of practical, hands on, just getting in there ..?

R: Yeah, I'm afraid so, I know all the lecturers at university say "You must be person-centred and empowering", yes, we know, sometimes people will, you're empowering them to do their bit and then you're meeting them in the middle somewhere. It seems to work with her anyway.

Int: That's great.

[CLOSE]

Appendix 9.

Example of identifying theme for organisational and management from coding and collating interview transcripts

SW8 - I think about them and I did read, because I remember xxx telling me, we've got hoarding information on our, what do we call it, this xxx system where it's like everything, we've got xxxxresources and we've got xxx resources, it's all on this one website where all our information is together and I did read some before I went to see her but I did go on Hoarding UK and Help For Hoarders and all these other websites before I saw her.

I have done but maybe if it was a case where she wasn't … if we weren't making progress, probably I would be, yeah.

I think definitely now obviously with the Care Act and how they've put safeguarding right at the, safeguarding and self-neglect as part of safeguarding, it's right at the front, it's statutory for us to tackle and to deal with, I don't feel as social workers we're well equipped at all to deal with such cases, definitely no training, I don't remember if I even had any training actually, so for me to start working with Mr XXXI'm just thinking what can I do?

Supervision F working with Mr X I'm just thinking what can I do?

F - When I started working with him, I was thinking, "Okay, so where do I see it? How do I behave?", things like that, nothing prepared me to say "You're going into his home" and I'm not [inaudible 00:09:01] but when you're in it initially, but obviously the more you deal with, the more you get used to it, I was okay and I'm okay now but I feel the organisation definitely does not prepare us for …, I do not have the time to be visiting xxxx every two weeks, I've got other serious urgent cases, stuff like that.

I've never really but this what you're doing is brilliant because I can see the importance, we have to take care of ourselves, we have to recognise that what we are doing, because like I said, before I've been coming, I was feeling really helpless and then still, you got supervision but your supervisor is more or less on the same wavelength with you, they're not offering you any more than what you already know, but knowing

That's the thing, the organisation, today we had the team meeting and the expectation is we close two weeks every week and there are some cases that you cannot close, that's what I said to you before, it's like sometimes it can be so frustrating and you think, "Where will this end?", "Where does it end?"

Commented [mB1]: Read policies but cant remember them, maybe would if case wasn't going in the right direction, so use policies as a check list, safeguard.

Commented [mB2R1]:

Commented [mB3]: Only using polices when things aren't going well.

Commented [mB4]: Lack of support/training , CA not helped

Commented [mB5]: Lack of support/training , CA not helped

Commented [mB6]: Need for emotional supervision, recognise feelings

Commented [mB7]: Helpless, emotions, lack of support from managers

Commented [mB8]: Where does this end, frustration with time frames and not seeing progress , organisational pressure

Int - And do you find in terms of the organisation support, supervision,the organisation, team managers, colleagues, where do you get your support? Where do you process and work these things through?

SW6 It's a mixture of things, I do like talking to people, to help me think about things, I can talk about it in supervision to my supervisor, I think often, after you see someone, you want to talk about it more, almost straightaway while it's still fresh in your mind so you have a plan, so often it's like informal supervision, having a chat with a colleague, having a chat with XXX, with my manager about this gentleman and what we thought might be, what his issues are and what sort of things might he be interested in?

Some of the things, you think about them on the bus or you might be at home and have a really good idea about what might appeal, I don't really know.

Int: Do you think there's any, in terms of supervision, do you think in terms of any learning development needs, training, anything wider in the organisation that they could be doing to support you to develop your knowledge and practice in this area of work?

R: They have got policies, they do have policies and we've got access to lots of research and things like that.

Int: Do you actually draw on that in the moment, do you think?

Commented [mB9]: Policies in place but no time to look at policies

R: No, I don't think I've got time.

Do you think that these particular cases fit into the organisational expectations of you as a social worker with a case because you discussed there might be an allocated set of time you're expected to move things forward, closed cases, how do you feel the organisation expectations fit with working with self-neglect?

SW10- Absolutely, I think a new approach has to be developed for self-neglect cases, especially for these severe hoarding cases. The challenges from my point of view is first of all the timeframe we have, lack of resources, we are not in a position to visit every single day, not even every single week, well we can potentially but given our workload and other cases, we just can't.

To build the relationship with the client is quite difficult and to find the right balance between respect for self-determination on the one side and also to protect the person.

I think also there seems to be, I think, having clear guidance is crucial, is really important but I think in xxxxx, speaking to other social workers in different local authorities, there seems to be a lack of clear guidance from a managerial level. Just to give you an example, our protocol is still, I think it needs to be updated but it's not clear about what we could possibly do.