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SELF-HARM IN PEOPLE WITH LEARNING DISABILITIES.

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Summary

Section A

A systematic literature review on the experiences of people with learning disabilities who self-harm. Quality assessment of 12 qualitative papers was guided by the CASP. Through thematic synthesis of these paper three central themes were developed: (1) Negative experiences, (2) The act of self-harm, and (3) A different response. Self-harm took place in a negative context which affected an individual's self-view and created overwhelming emotions. Responses to self-harm could be experienced as punitive or uncaring which furthered the individual's negative experiences. Responses which reduced self-harming behaviour were identified. The implications for clinical practice and research were discussed.

Section B

Presented here, is a study exploring how professionals in the care sector work with people with learning disabilities who self-harm. Interviews were conducted with 11 participants and data analysis, informed by critical realist grounded theory methodology, produced four main concepts: a caring vocation, a distressing experience, navigating distress, and powerlessness. A preliminary model of how professionals navigate distress when working with people with learning disabilities who self-harmed was developed. It considered both personal and systemic contexts which influence and are influenced by this process. Implications for clinical practice and research were discussed.

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Section A:

The experiences of people with learning disabilities who self-harm: A meta-synthesis

Word Count: 7469

Abstract

Background: Self-harm is prevalent in people with learning disabilities however, it is often subsumed under the umbrella term ‘challenging behaviour’. Few studies have sought to understand self-harm, as a unique entity, from the perspectives of people with learning disabilities. The current review sought to redress this by synthesising the related qualitative literature.

Methods: Databases were searched to identify relevant qualitative literature. Twelve eligible studies were included and the CASP appraisal tool was applied to assess quality. Thematic synthesis was used to summarise and generate new interpretations from the literature.

Findings: Three themes were identified: negative experiences, the act of self-harm, and a different response. Self-harm took place in a negative context which affected an individual’s view of themselves and created overwhelming emotions. Responses to self-harm could be experienced as punitive or uncaring which furthered negative experiences. Building connections and developing autonomy were a more helpful response.

Conclusions: People with learning disabilities suggest the reasons for their self-harm are similar to those in the general population. Responses to self-harm are often negative but people with learning disabilities can offer insights into responses deemed more helpful. Future research may wish to explore the experiences of staff who work with this client group

Keywords: People with learning disabilities, self-harm

Introduction

Self-harm has been conceptualised as “a wide range of things that people do to themselves in a deliberate and usually hidden way, which are damaging” (Camelot Foundation/Mental Health Foundation, 2006). It was estimated that, in England, the proportion of people who reported self-harm has increased from 2.4% in 2000 to 6.4% in 2014 (McManus et al., 2014). The prevalence of self-harm in people with learning disabilities (PwLD) is perhaps even higher with recent estimates suggesting between 7.5% and 24% of this population self-harm (Bowring et al., 2017; Deb et al., 2001).

Defining self-harm

There has been considerable debate about how the action of people hurting themselves is conceptualised; interchangeable terms denote nuances in the way this act is understood across research, policy, and practice (Heslop & Lovell, 2013). In North America the term non-suicidal self-injury (NSSI) attempts to distinguish self-harm from attempts to take one’s own life (American Psychiatric Association, 2013), while in the UK self-harm has been defined as “any act of self-poisoning or self-injury carried out by an individual *irrespective* of motivation” (NICE, 2011).

Within a mental health context, ‘self-harm’ has been used when referring to people in emotional distress (Hawton et al., 2012). It is often understood as a meaningful behaviour which serves a variety of nuanced functions for the individual (Nock, 2009). These may include relief from emotional pain (Babiker & Arnold, 1997), a way to regulate emotions (Klonsky, 2007) or a way to seek care from others (Scoliers et al., 2009). Klonsky (2007) conducted a review of empirical research in this area including qualitative reports from people who self-harm. They suggested that self-harm predominately served as an affect regulation strategy. Support for self-harm as self-punishment, an escape from disassociation or feeling numb, and as a means of interpersonal communication, was also found.

Nock (2009) presented an integrated theoretical model of ‘non-suicidal self-injury’ (NSSI) which proposed that NSSI is a means of regulating aversive affective experiences. The model considered how an individual’s life history can lead to intrapersonal and interpersonal vulnerabilities which influenced their stress response in everyday life. Much research has explored the risk factors associated with self-injury in the general population, specifically adverse life events including abuse (Hawton et al., 2002), violence (Hawton & James, 2005), relationship difficulties (Haw & Hawton, 2008) and socio-economic deprivation (Hawton et al., 2001).

Self-harm in people with learning disabilities

Throughout theory, policy and practice multiple labels are, or have been, used to homogenise a group of people with diverse needs and abilities based on the socially constructed concept of ‘intelligence’ (Webb & Whitaker, 2012). The term ‘intellectual disability’ has become increasingly used both internationally and in the UK professional discourse (British Institute of Learning Disabilities, 2017), and is generally used to describe those assessed to have an IQ under 70 who experience impairment in cognitive and functional domains (Schalock, et al., 2010). In the UK the term ‘learning disability’ is most commonly used in UK social care policy (Department of Health, 2001) and is recognised and enshrined into UK cultural and legal contexts (British Psychological Society, 2010)[1]. However, this term too is socially constructed, time-bound and determined by social meanings (Albrecht & Levy, 1981).

The particular social constructions of the term ‘learning disabilities’ has consequences for the care and treatment of PWLD over time (Rapley, 2004). Notably, there is often a difference in

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[1] Given this the term learning disability or people with learning disabilities (PwLD) will be used throughout this paper

how the act of hurting oneself is understood in individuals with and without learning disabilities and this has been reflected in the labels applied (Heslop & Lovell, 2013). The term ‘self-harm’ is used in mental health services when referring to people in emotional distress (Lovell, 2008), however, for PwLD the term ‘self-injurious behaviour’ is most frequently used (Jones et al., 2004). Lovell (2008) argued the term ‘self-injurious behaviour’ is characterised by environmental reinforcement and stimulation, lack of wilful intent, absence of symbolic meaning and increased likelihood of biological origin.

As such, approaches to understanding self-harm in PwLD have primarily explored biological and behavioural underpinnings; some consider this as contentious as these models are rarely considered in relation to people without learning disabilities (Heslop & Lovell, 2013). Early hypotheses suggested that self-harm functioned to regulate levels of arousal in PwLD (Lourie, 1949) either through blocking out aversive over-stimulation or acting as an extreme form of self-stimulation (Heslop & Lovell, 2013). More recently research has focused on exploring ‘behavioural phenotypes’, suggesting that mutations in different genes may influence the manifestation of self-harm behaviours in PwLD (Huisman et al., 2018). Although some research has found people with particular genetic syndromes are more likely to self-harm (Arron et al., 2011), others have found that once risk factors had been controlled self-harm was no more prevalent in these populations (Oliver et al., 2009). Behaviourist approaches, based on the belief that the environment determines behaviour, are also commonly used to understand behaviour that challenges, including self-harm, in PwLD. Applied behavioural analysis seeks to provide a detailed assessment of behaviour, including antecedents and the consequences that maintain it, to offer behaviour-based intervention strategies (Heslop & Lovell, 2013). This functional assessment forms a core part of the Positive Behaviour Support approach (LaVigna & Willis, 2012).

Based on these theoretical underpinnings, the response to self-harm in PwLD may include controversial restrictive practices such as antipsychotics and physical restraint or behaviour modification (Heslop & Macaulay, 2009). For example, despite a general shift from punishment-based strategies to reinforcement-based responses, punishment-responses to PwLD who self-harm continue to be used (e.g. Vascelli et al., 2021). The programme – ‘stopping the over-medication of people with an intellectual disability, Autism or Both’ (STOMP), highlights the overuse of psychotropic medication for PwLD (Branford et al., 2018). Understanding self-injury from an environmentally dependent or organically driven position oversimplifies the complexities of self-harm and is likely to ignore the social risk factors or emotional needs of PwLD (Jones et al., 2004).

Moreover, self-harm by people with learning disabilities is often more broadly subsumed under the umbrella term ‘challenging behaviour’ or ‘behaviour that challenges’. ‘Challenging behaviour’ has been defined by Emerson (1995, p. 4) as: “culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to limit seriously use of, or result in the person being denied access to, ordinary community facilities”. The label describes a range of behaviours including self-harm, aggression, destructiveness and stereotypical behaviours which can have a significant negative impact on the individual or those around them (Griffith et al., 2013). This framework positions the challenging behaviour as something which needs to be ‘fixed’, and PwLD in need of ‘intervention’ (Nunkoosing & Haydon-Laurelut, 2011). Drinkwater (2005) remarked on how professionals sought to assimilate PwLD into ‘normal’ life and suggested resistance to this goal was discoursed as ‘challenging behaviour’. Including self-harm under this umbrella term further pathologises the behaviour and reduces the behaviour to be a ‘symptom’ in a checklist of possible behaviours for a person that ‘challenges’ (Griffith et al., 2013).

The views and experiences of people with learning disabilities

Typically research with PwLD has been done to, rather than done with, however since the 1990's there has been a shift towards a consumer-orientated focus in the development and evaluation of health and social care services and, with it, a commitment to service user participation (Gilbert, 2004). Including the voice of PwLD, is vital to ensure they are involved in the mainstream research affecting their lives. Despite this relatively little attention has been given to the personal experiences of PwLD who self-harm and receive interventions and support for this.

To date, Griffith and colleagues (2013) have conducted the only thematic synthesis to explore the experiences of PwLD with behaviour that challenges, including self-harm. Individuals described how the cumulative stress of living in residential placements and interpersonal attitudes of staff contributed to their behaviours. Restrictive interventions were regarded as punitive, ineffective, and stressful, and could further increase behaviour that challenges, although positive relationships were acknowledged as helpful. The synthesis provided a rich insight into the experiences of PwLD and clear policy and practice implications. Importantly the synthesis highlighted a difference in how participants who self-harmed and those who displayed aggression talked about the reasons for their behaviours. Those who self-harmed described a range of short (e.g., coping with strong emotions) and long-term factors (e.g., being the victim of abuse) which led to the behaviour, compared to descriptions of more specific environmental triggers for those who displayed aggression towards others (Griffith et al., 2013). Given this distinction, further independent research to explore self-harm as a separate entity may be helpful.

Rationale and aims

The separate categorisation of self-harm and self-injurious behaviour confines PwLD to a discrete homogenous group and has determined the way that this behaviour is understood and thus supported. Furthermore, when this behaviour is subsumed under the category of behaviour that challenges the meaning and understanding of these actions for PwLD may be lost. This review will seek to explore self-harm, as defined by NICE (2011) “any act of self-poisoning or self-injury carried out by an individual irrespective of motivation”, in PwLD. To ensure that the personal experiences and viewpoints of PwLD are heard, qualitative methods are best placed. However, single qualitative studies often have small sample sizes and may be overlooked in the development of healthcare policy and practice and therefore assimilation of qualitative studies through systematic grouping and analysis can have greater impact. (Griffith et al., 2013). Drawing together qualitive research this report aims to (a) synthesise the experiences of PwLD who self-harm and (b) identify the type of intervention or support provided to PwLD and what is deemed most helpful.

Method

Study design

Meta-synthesis is a systematic approach to review and synthesise qualitative research with the dual purpose of summarising and generating new interpretations from qualitative publications (Finfgeld-Connett, 2010). Thematic synthesis (Thomas & Harden, 2008), a type of meta-synthesis, was chosen for this review. It relies on line-by-line coding which allows the researcher to remain as close as possible to the accounts of PwLD, while drawing on the researcher’s own interpretations to generate new insights. The procedure described by Thomas and Harden (2008) was adhered to in this review (see Table 1).

Table 1

Stages of Thematic Synthesis

Preparatory stage	
Searching the literature	Identifying all relevant studies
Quality assessment	Assessing quality of qualitative research to avoid drawing unreliable conclusions
Extracting data	Determining what will be included as ‘data’ Extracting relevant data from included studies
Thematic synthesis	
Coding text	Line-by-line coding
Developing descriptive themes	Translating concepts between studies Grouping codes by descriptive themes
Generating analytical themes	‘Going beyond’ the data to generate analytic themes which answer the research question

Literature search

An electronic literature search was conducted using PsychINFO, MEDLINE, CINAHL and ASSIA databases covering the period up to 18th November 2021. Search terms used are outlined in Table 2. reviewed, and a Google Scholar search conducted, to identify further relevant articles.

Table 2

Terms Used in Database Search

Search Terms
[Self-harm* OR Self-inj* OR self harm* OR self inj* OR challenging behav*]
AND
[intellectual* disab* OR learning disab* OR mental* retard* OR intellectual* impair* OR development* disab* OR mental* handicap*]
AND
[Qualitative OR Interview* OR View* OR experience* OR perspective*]

Additional search terms, including descriptions of self-harm behaviour such as "head banging", did not yield additional results and were therefore not included in the search. Reference lists were manually reviewed, and a Google Scholar search conducted, to identify further relevant articles.

Following the search, duplicates and articles clearly unrelated to the review aims, based on article title, were excluded. Relevant articles were then reviewed by abstract and full text to determine eligibility based on the inclusion and exclusion criteria in Table 3.

Table 3

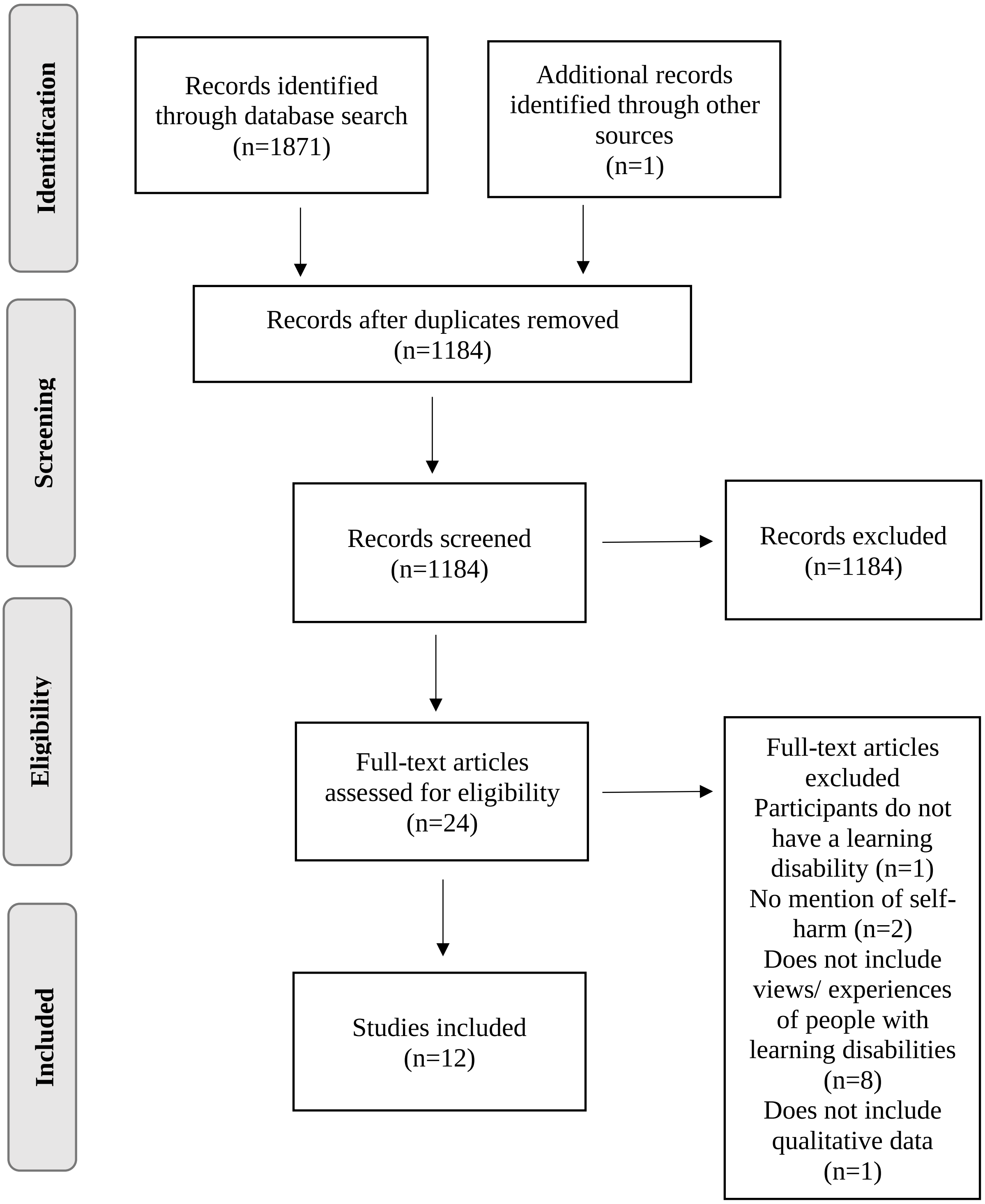
Inclusion and Exclusion Criteria

Inclusion
Published in English
Participants have a learning disability including co-morbid diagnosis
Participants aged 18+
Qualitative design or mixed design with clearly identifiable qualitative findings
Included the views or perspectives of PwLD about self-harm
Exclusion
Participants did not have a learning disability, for example a diagnosis of autism spectrum condition only
No exploration of the perspectives of PwLD
No explicit mention of self-harm or unable to identify which participants self-harmed

Following the removal of duplicates, 1183 papers were screened by abstract and title. Subsequently, 32 articles were read in full, of which 12 met the inclusion criteria. The screening process is illustrated by the PRISMA diagram (Moher et al., 2009) in Figure 1.

Figure 1

PRISMA Diagram



Quality assessment

The Critical Appraisal Skills Programme (CASP, 2018) appraisal framework for qualitative studies was used to evaluate the research (Appendix A). This framework was chosen as it has a strong methodological focus and covers issues of reflexivity and ethics (Leung, 2015), deemed important in qualitative research with a population of PwLD. All reviewing was conducted by the author; results can be found in Appendix B.

Thematic synthesis

Thomas and Harden (2008) suggest all data labelled as 'results' or 'findings' is extracted and analysed. However, in this review the decision was made to only extract direct quotes from PwLD who self-harmed. This enabled a wider range of studies to be included in the review, for example those where both PwLD and carer's views were assimilated in the conclusion or where the focus of discussion was not on self-harm yet reference to this was made in the quotations. It also ensured the voices of PwLD were central. In studies where more than one group of participants was involved (e.g., PwLD and their carers), only data originating from PwLD was extracted. Similarly, where studies included participants who self-harmed and/or displayed other behaviour that challenges, only the data from participants who self-harmed was reviewed; where it was impossible to identify those participants these studies were excluded.

The thematic synthesis followed three stages as outlined by Thomas and Harden (2008; Table 1). During the initial stages data was analysed inductively by the principal investigator using line-by-line coding to code themes according to meaning and content (Appendix C). NVivo software was used to enable the translation of concepts between studies to create a bank of codes. These codes were then grouped into a hierarchical structure (Appendix D). The third stage of the synthesis involved going beyond the initial codes to create analytic themes which moved beyond the findings of the primary studies.

Reflexivity/ quality

To promote rigour, a bracketing interview was undertaken to consider the researcher’s prior experiences, biases and assumptions and how these impacted on the thematic synthesis. An audit trail of the development of descriptive and analytic themes was kept, and this analysis was discussed in supervision.

Results

Presentation of studies

In total, 12 studies were analysed, all published within the last 20 years (Table 4). Most studies (nine) were published in the UK with further studies published in the Netherlands, Canada and Republic of Ireland. Studies employed a range of qualitative methodology to explore the views and experiences of PwLD. In five of the studies participants were recruited from secure forensic settings, while in other studies recruitment took place via NHS or community settings. Most participants were described as having a “mild” to “moderate” learning disability.

The 12 studies varied in their aims; some papers focused specifically on self-harm while others were broader in their approach focusing on behaviour that challenges, including self-harm, or specific therapeutic approaches such as music therapy or dialectic behavioural therapy (DBT).

Table 4

Main Characteristics of Included Studies

Author	Study location	Participant demographics	Research topic and aims	Data collection	Analysis
Brown & Beail (2009)	UK forensic setting	9 participants: 4 male, 5 female; mild LD	Aims to explore participants' experiences of their self-harm and their understanding of this behaviour, and participants' experiences and understanding of other people's responses to their self-harm, including interventions	Semi-structured interviews	Interpretative phenomenological analysis (IPA)
Browne et al., (2019)	UK NHS forensic setting	9 participants: four male, five female; 2 Asian, 7 White British; FSIQ between 59 and 72	To generate a theory, drawn from service user perspectives, of the process of engagement with DBT and how this relates to perceived change.	Semi-structured interviews	Grounded theory
Clarke et al., (2019)	UK (NHS Trust) and Ireland (private specialist learning disability service)	8 participants: 5 male, 3 female; mild to moderate LD	Explore how PwLD understand their own challenging behaviour and what shaped this understanding. Explore the relationship between how challenging behaviours are managed and wellbeing	Semi-structured interviews	IPA
Duperouzel & Fish (2008)	UK NHS forensic setting	9 PwLD: five female, four male; mild to moderate LD. 9 staff members: four nursing assistants and five qualified nurses	To synthesise two previous studies to detail the experiences of people with mild/moderate learning disabilities who self-harm, and those who work with them.	Unstructured interviews in the original study	Phenomenological approach

Author	Study location	Participant demographics	Research topic and aims	Data collection	Analysis
Duperouzel & Fish (2010)	UK NHS forensic setting	9 participants[2]: five female, four male; mild to moderate LD	Aims to capture the meaning participants attributed to their own self-harm and the perception that participants have of the care they received	Two unstructured interviews for each participant	Phenomenological approach
Gleeson et al., (2020)	Ireland; learning disability service for people with challenging behaviour	6 participants: 2 male, 4 female; mild to moderate learning disability	To explore the experiences of PwLD who live with others who engage in challenging behaviour	Semi-structured interviews	IPA
Harker-Longton & Fish (2002)	UK NHS forensic setting	1 participant: female, mild LD	To explore the understanding of self-harm from a personal perspective of the research participant	3x individual interviews	Phenomenological analysis
Heslop and Macauley (2009)	UK	25 PwLD (3 withdrew): 6 male, 19 female; 3 participants had limited verbal communication. 15 family members, 33 professionals	To explore the experiences of people with learning disabilities who self-injure, including the ways in which they have been supported	Semi-structured interviews	Grounded theory is reported methodology although no model developed
Lundsky & Gracey (2009)	Canada	4 female participants; 3 Caucasian, 1 Black Canadian	To explore the challenges faced by women with learning disabilities in the emergency department and get suggestions on how to	Focus group	Thematic analysis

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[2] It appears that the participants in Duperouzel & Fish (2008) and Duperouzel & Fish (2010) are the same. Both studies were included due to different methodology and inclusion of different participant quotations for analysis.

Author	Study location	Participant demographics	Research topic and aims	Data collection	Analysis
			improve crisis management from the perspective of service users		
McKensie et al., (2018)	UK	7 participants: 5 male, 2 female; all White British	To obtain the views of PwLD about what was important to them in relation to receiving Positive Behavioural Support	4 participants took part in a focus group and three had individual interviews	Thematic analysis
Ogilvie (2019)	UK	2 participants with mild to moderate LD (1 male, 1 female) and their staff team	Investigates the use of music therapy for PwLD who self-harm.	Semi-structured interviews administered to participants at the start of the study, and twice more at six-monthly intervals	IPA
Wolkorte et al., (2019)	The Netherlands	13 people with LD: 8 male, 7 female; 12 mild LD, 1 moderate LD. 7 proxy interviews with carers/ family members: 5 male, 2 female; 1 moderate LD, 6 severe LD	To provide an overview of the views and preferences of PwLD on various aspects of challenging behaviour including: factors that contribute to the development and/ or maintenance; the process of assessing the function of challenging behaviour and the context in which it occurs; interventions; health professionals approaches; the use of medication	Semi-structured interviews	Thematic analysis

Quality assessment

A summary of the quality appraisal using the CASP framework can be found in Appendix B.

Aims and design

Most studies clearly set out their research aims. In all cases qualitative methodology was deemed appropriate and justification provided. Several of the studies failed, or only partially justified the specific research design used; one study citied it used grounded theory however this did not appear to be the case (Heslop & Macauley, 2009). Interpretive phenomenological analysis (IPA) was the most used design, but studies also used thematic analysis. Interviews were conducted through a mixture of focus groups and one-to-one interviews with neither appearing to generate more rich data.

Sampling and data collection

Most papers provided an adequate description of how participants were selected, however less attention was given to why participants selected were most appropriate. Notably, Harker-Longton and Fish (2002), who interviewed one participant, provided little information about how and why ‘Catherine’ was recruited to the study. Many of the participants were not recruited directly but approached initially through carers or clinicians. While these ‘gatekeepers’ can have a useful role, they will also have their own view about the value of the research and who could contribute to it and thus there may be bias in participant selection (Nind, 2008).

Most of the studies were conducted within the UK with a significant proportion recruiting participants from secure settings. Recruiting from only these settings may limit the usefulness of the findings for those in the community. Similarly, most participants in the studies had “mild-to-moderate” learning disabilities. Given that self-harm is more common in people with a more severe learning disability (Deb et al., 2001), only two papers sought to include the voices of this population either directly (Heslop & Macauley, 2009) or via proxy interviews (Wolkorte et al., 2019).

Reflexivity

The extent to which author reflexivity was considered across papers was varied. Most papers acknowledged that the researcher's own ideas may have influenced the data analysis and how these biases were considered, for example the use of a reflexive journal (Gleeson et al., 2020). However, few authors made explicit what the author's views were, or considered how these affected the development of the research question and data collection process. This lack of reflexivity is particularly problematic in an often-polarised subject area, such as the use of restrictive interventions, and when power differences between researcher and participant exist.

Ethical issues

The need for informed consent is central to any ethics protocol but particularly important for PwLD who have, historically, been seen to lack capacity to make decisions, lived in situations where choice may be limited and experienced coercion (Nind, 2008). All authors commented about ethical issues; several provide exemplary detail about the process of gaining informed consent (e.g., Ogilvie, 2019; Browne et al., 2019). Relatively few studies described measures taken to debrief or support participants who participated in sensitive conversations focused on potentially distressing experiences.

Data analysis and findings

All papers provided an overview of the data analysis process but for many this was limited, and it was unclear how themes developed. As in Ogilive (2019), it would have been useful to have examples of how initial data was coded and how hierarchical themes developed. Some papers (e.g. Browne et al., 2019) made explicit the steps taken to ensure data validation and considered the researchers’ own role in the data interpretation. All papers reported the findings in response to the original research question. Overall, the value of research was good. As identified above, many papers reflected on the limitations of the participant group and how findings could be generalised to individuals with more ‘severe’ learning disabilities (e.g. Browne et al., 2019).

Evaluation

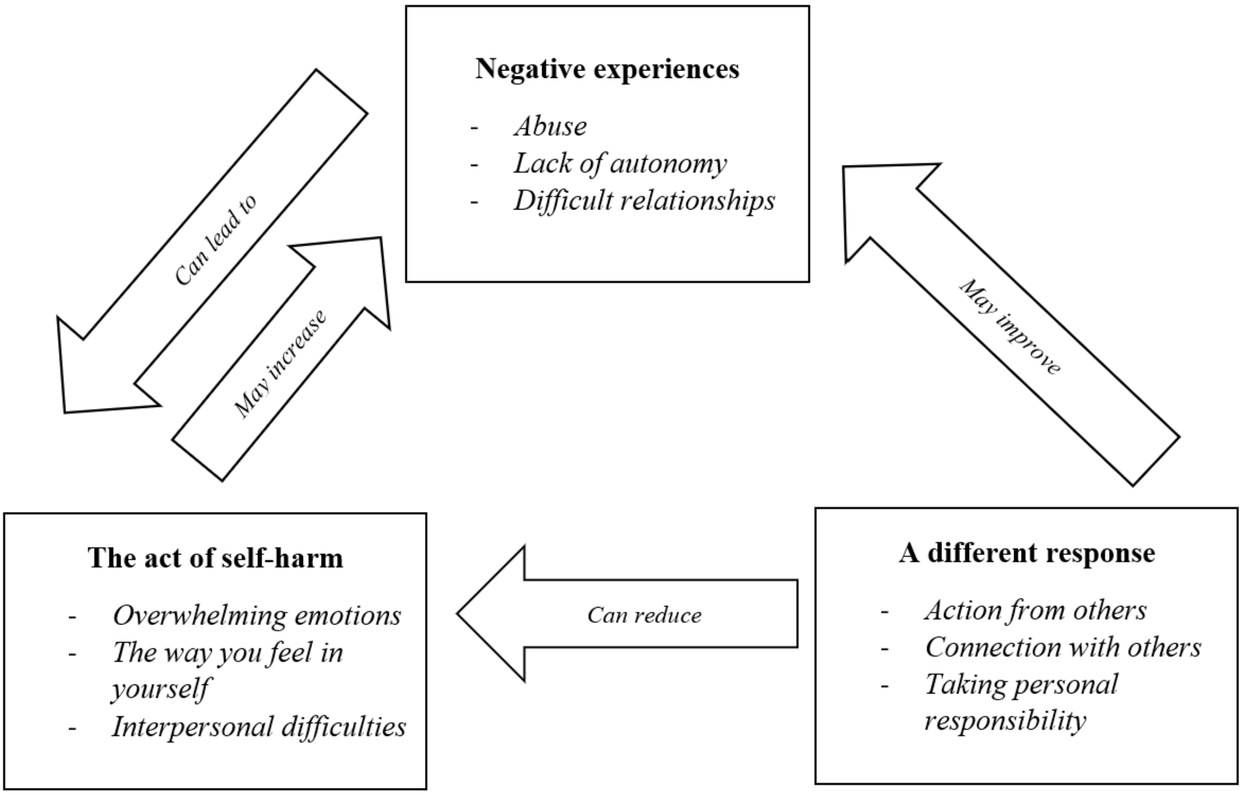
Overall, an evaluation of the studies with the CASP framework found adequate results and as such all papers were included.

Thematic synthesis

Through the analysis, three central themes relating to PwLD experiences of self-harm were inductively developed: (1) Negative experiences, (2) The act of self-harm, and (3) A different response. A thematic map is presented in Figure 2. Support for the themes and example quotes are presented in Appendix E.

Figure 2

A thematic map



Negative experiences

This theme encapsulated the range of negative experiences faced by participants who self-harmed. These experiences were reported across the participants' life-span and are important in understanding the context in which self-harm takes place. These experiences were also identified in response to participants' self-harm which may further maintain this negative context for the individual.

Abuse. Participants in six papers reported experiences of abuse, either historically, for example by parents (Heslop & Macauley, 2009) or in their current environment, for example by other residents (Gleeson et al., 2020). Some made explicit links between these experiences of abuse and their self-harming behaviour (Brown & Beail, 2009) while others were more tentative in suggesting self-harm scars reflected past “problems” (Harker-Longton & Fish, 2002). Participants also experienced abusive responses from professionals following their self-harm: “I was falling asleep, one [*ambulance driver*] smacked me hard across the face” (Lunsky & Gracey, 2009). Restrictive interventions, such as increased observation or personal searches were described in one paper as ‘degrading’ and participants felt they were ‘being violated’ (Duperouzel & Fish, 2010).

Lack of autonomy. Across seven papers, participants described a range of experiences which reflected a lack of autonomy, choice, or control in their own lives. This lack of autonomy influenced participants’ self-worth, they perceived others treating them as ‘kids’ (Heslop & Macauley, 2009) or ‘an animal’ (Harker-Longton & Fish, 2002). As a result of their self-harm participants described a further loss of autonomy, for example removing belongings (Heslop & Macauley, 2009), or restricting outings to the community (Browne et al., 2018). These restrictions did not prevent self-harm (Duperouzel & Fish, 2008) and could make individuals feel worse leading to further episodes of self-harm: “I don’t like it, it makes me mushed when I’m on level three or four it really cracks my head up more” (Duperouzel & Fish, 2010).

Difficult relationships. Difficult or poor relationships, particularly with professionals, were reported across 11 papers. Participants reported feeling ignored (Heslop & Macauley, 2009), rejected (Harker-Longton & Fish, 2002) or as if they were “a nobody” (Brown & Beail, 2009). Poor relationships meant that reaching out or talking to others was difficult for participants. Participants spoke about how a lack of trust (Browne et al., 2018), connection (Wolkorte et al., 2018) or understanding (Duperouzel & Fish, 2008) could prevent them from opening up. Some participants reported feeling ‘judged’ because their self-harm was misunderstood: “They’re nasty. They call me attention seeking. There is more to it than that” (Lunsky & Gracey, 2009).

In six papers, participants reported feeling ignored when they did talk to others about their self-harm. Participants described how staff would focus on physical injuries of self-harm but did not provide the space to talk: “they’d take me to hospital, get me stitched up and that, you know. Nobody would talk to me about it. No” (Duperouzel & Fish, 2008). However, even if space was given to talk, others’ responses felt uncaring if ‘wishy washy’ (Duperouzel & Fish, 2008) or lacking proper attention (Heslop & Macauley, 2009). Not being listened to had serious consequences; one participant described how abuse by professionals was ignored (Lunsky & Gracey, 2009) and another who’s request for help was ignored ended up self-harming (Duperouzel & Fish, 2010).

The act of self-harm

The second theme, ‘the act of self-harm’ describes the way participants understood and experienced their own self-harm immediately before, during and after the event. Participants in 11 papers referred to their own experience of self-harm describing aspects of emotional, personal, and interpersonal experiences.

Overwhelming emotions. Across nine papers, participants reported a range of emotional experiences and described how self-harm functioned as a way of coping with these emotions. Different emotions could precede self-harm; the most common was anger, referenced in seven papers: “Yeah…you know my picture frame?…Punched straight through the glass and that’s all running down with blood… I was very cross” (Ogilvie, 2019). Other emotional experiences included feeling sad or low (Gleeson et al., 2020), anxious or fearful (Harker-Longton & Fish, 2002) or stressed (Browne et al., 2018). Only one participant, who communicated non-verbally, reported that feeling ‘excited’ led her to ‘bite her hand’ (Heslop & Macauley, 2009).

In seven papers participants reported feeling overwhelmed by emotions. Four papers discussed how self-harm functioned as way of ‘getting your feelings out’ (Duperouzel & Fish, 2010). In several papers, the physical pain of the self-harm was masked by the intensity of emotional experience (Brown & Beail, 2009) and could provide pleasurable physical sensations: “I was getting what I realize now was a massive adrenalin rush, a massive amount of adrenalin rush” (Duperouzel & Fish, 2010).

After self-harming, participants in six papers reported more positive emotions including feeling “happy” (Duperouzel & Fish, 2008) and “calmer” (Lunsky & Gracey, 2009). However, in four papers participants described feeling worse (Ogilvie, 2019) or the previous negative emotions returning (Harker-Longton & Fish, 2002). Self-harming also increased the participants anxiety about the consequences of their actions: “I get upset ‘cause things are going through my mind sometimes of what’s going on….what’s gonna happen and … ‘cause I don’t want that to happen” (Heslop & Macauley, 2009).

The way you feel in yourself. Participants in eight studies described the way in which self-harm was associated with the way participants “feel in [themselves]” (Duperouzel & Fish, 2010). Participants portrayed a negative self-image and described themselves as “silly” (Browne et al., 2018) or “useless” (Ogilvie, 2019) and hating themselves and their body (Heslop & Macauley, 2009). Participants often described feeling unable to cope (Heslop & Macauley, 2009) and lacked confidence in their ability to use other skills: “I just stopped trying them skills and stayed in my room” (Browne et al., 2018).

For participants in five studies self-harm was part of a suicide attempt. Such behaviour was often linked to participants’ feelings of low self-worth: ‘I’m useless, it’d be better if I wasn’t here.’ (Ogilvie, 2019). For one participant self-harm was used as a ‘punishment’ for the way she felt about herself: “I used to feel like I had to punish myself, for being dirty. I was dirty so I had to punish myself.” (Harker-Longton & Fish, 2002). After self-harming participants in four studies reported feelings of shame and were critical about their own self-harming: “I had the thought in my head, the voice would be going, ‘You self-harm over nothing’”. (Heslop & Macauley, 2009).

Only one paper identified any association between physical wellbeing and self-injury; several participants indicated ‘tiredness’ may be a trigger, and another identified how they self-harmed in the lead up to a seizure: “Sometimes, when I start building up to a seizure I start bashing myself there, there, on my neck, on my body, on my arms, I get my teeth and bite myself” (Heslop & Macauley, 2009).

Interpersonal difficulties. Interpersonal difficulties were associated with participants self-harming in eight studies. Participants described how interpersonal conflicts could lead to self-harming: “I would argue with somebody and then I would get down and end up hurting myself” (Heslop & Macauley, 2009). In response to these interpersonal difficulties participants in four papers reported harming themselves rather than directing their behaviour at others: “Oh, I were right angry inside and, er, instead of attacking somebody, I used to self-harm you see” (Brown & Beail, 2009). Interpersonal difficulties associated with bullying by other residents (Heslop & Macauley, 2009) and staff (Duperouzel & Fish, 2010), feeling unsafe or threatened (Gleeson et al., 2020) and witnessing others’ distress (Brown & Beail, 2009) were also spoken about in the context of self-harm.

Seven papers discussed how self-harm affected those around the participant. Participants reflected on how their self-harm could make others feel “upset” (Brown & Beail, 2009), “scared” (Heslop & Macauley, 2009), or “worried” or frustrated (Ogilvie, 2019). Others’ responses left participants feeling worse or more ashamed of their behaviour: “I feel worse inside, feel daft. Every time I look at the scars then I feel bad, messing people’s lives, it’s horrible” (Harker-Longton & Fish, 2002).

A different response

The theme ‘a different response’ describes what participants have found helpful in either preventing, or responding to, their self-harm. All papers included participants views of this topic and three sub-themes were identified: action from others, connecting with others, taking personal responsibility.

Action from others. Participants in 10 papers identified how others taking assertive action could be helpful in either preventing, or responding to, self-harm. Heslop and Macauley (2009) reported participants wanted staff to recognise their change in mood and encourage them to talk rather than self-harming: “sometimes I hope, when I’m in the middle of doing it, I hope that somebody will come up and talk to me before I do it”. Policies or practice aimed at restricting or reducing self-harm were sometimes deemed helpful, for example keeping certain items locked away (McKenzie et al., 2018; Ogilvie, 2019) or offering rewards for changing behaviour (Browne et al., 2018). On the other hand, in three papers participants commented that accepting or allowing self-harm would be more helpful (e.g., Lunsy & Gracey, 2009).

Restrictive interventions, such as using restraint, medication, or seclusion were seen by some participants as helpful, particularly in hindsight. They appeared more helpful where participants were able to have some choice or control over these measures: “I’ve asked for everything to be away at first, until I’m better.” (Harker-Longton & Fish, 2002).

Connecting with others. Relationships and connections with others were important in preventing, or responding to, self-harm in 10 papers. Relationships were noted with peers (Browne et al., 2018), friends (Heslop & Macauley, 2009) or family (Duperouzel & Fish, 2010) but typically focussed on relationships with care-staff and other professionals (Duperouzel & Fish, 2008). For many, the relationships involved an active connection with others, but participants also identified that simply being around others (Heslop & Macauley,

2009) or thinking about connection with others could prevent them from self-harming: "I think twice before I jump into action, I think of the people who care about me, I've got loads of friends, they wouldn't be happy if I did something stupid" (Duperouzel & Fish, 2010). In two papers, participants shared how connecting with others who self-harm could make them feel less alone: "There's people all round the world does it. I'm not only one, it's just life" (Heslop & Macauley, 2009).

Building trust (Browne et al., 2018) and feeling understood (Heslop & Macauley, 2009) were important factors in building relationships. Having these relationships enabled participants to share their self-harm with others to seek help (Ogilvie, 2019), or comfort (Harker-Longton & Fish, 2002). Although participants found this difficult they reported feeling relieved afterwards: "I just spat it out… there was a big ton weight coming off my body to make me feel better that somebody knew….Aye, I was glad, I was very happy with myself that I told somebody" (Heslop & Macauley, 2009). Having space to talk about self-harm, and other difficult experiences, was noted in six studies. Participants shared how talking was helpful as a way of understanding and coping with difficult experiences or emotions.: "people would come up and sit me down and talk to me and calm me down" (Gleeson et al., 2020).

Taking personal responsibility. Across 10 papers participants reported taking personal responsibility towards accepting, managing, or reducing their own self-harm. There was an awareness of the possible risks associated with self-harm including injury (Brown & Beail, 2009), infection (Heslop & Macauley, 2009), and possible death (Harker-Longton & Fish, 2002). Five papers spoke about self-harming being a personal choice, and participants felt entitled to do, or stop, this behaviour: "People don't realize that I want to do it, why can't I? One day it'll all stop but not now, it keeps me going." (Harker-Longton & Fish, 2002). Alternative ways of coping were discussed in 10 papers: this included time alone (Gleeson et al., 2020), keeping busy (Heslop & Macauley, 2009), writing (Clarke et al., 2019) or using music (Ogilvie, 2019). In four papers participants shared ways they would try to talk themselves out of it: “You just keep saying to yourself no, don’t do it and you keep running over it in your head, what you’d lose and what would happen and….all that” (Brown & Beail, 2009). Participants also discussed alternative strategies they used to create similar physical sensations such using a punchbag (Heslop & Macauley, 2009) or biting lemons (Harker-Longton & Fish, 2002). For some, blocking out thoughts of self-harm by going to sleep (Ogilvie, 2019) or distracting themselves with TV (Heslop & Macauley, 2009) was also helpful.

In the longer-term participants reported therapy could enable them to understand their own experiences and emotions and thus problem solve when these difficult feelings arose: “Then I’ll write a list, and then I think, well I need to sort this, this, and this out, then I sort it out and that gets rid of it. So, it’s so simple” (Heslop & Macauley, 2009). In two papers participants discussed how their own understanding of their behaviour could then be used to support staff through the development of their own WRAP Plan (Wellbeing Recovery Action Plan; Heslop & Macauley, 2009) or staff training (Duperouzel & Fish, 2010).

Discussion

This review sought to appraise and synthesise the qualitative literature to better understand the experiences of PwLD who self-harm and identify the type of intervention or support provided that is deemed most helpful. A systematic literature search identified 12 papers which captured the views and experiences of PwLD who self-harmed. Studies varied in quality; lack of researcher reflexivity and poor description methods of data analysis were key weaknesses across the studies. Higher quality studies did not contribute more to themes and therefore themes with fewer studies should be treated with caution (Thomas and Harden, 2008). Three themes were identified across the papers through a process of thematic synthesis: negative experiences, the act of self-harm, and a different response. These are discussed in relation to the initial aims of the review to (a) synthesise the experiences of PwLD who self-harm and (b) identify intervention or support deemed helpful to PwLD.

The experiences of people with learning disabilities who self-harm

The theme ‘negative experiences’ reflected the negative experiences PwLD faced and suggested how these may create a context in which self-harm takes place. Key difficulties included experiences of abuse, lack of autonomy and difficult relationships. PwLD are more likely to be exposed to traumatic life events than the general population (Hatton & Emerson, 2004) as well as experiencing daily stressors as more impactful than their peers (Bramston et al., 1999). They are reported to have limited social networks, primarily staff or family members, (Forrester-Jones et al., 2006) and the use of restrictive practices such as antipsychotics and physical restraint or behaviour modification are well documented (Heslop and Macaulay, 2009). PwLD have often faced experiences of stigma (Paterson et al., 2012) and indeed the label’s ascribed to this group over the years have often been devaluing, dehumanising and focused on ‘deficit (Heslop, 2013). Recent scandals such as the closure of Eldertree Lodge in Staffordshire (Paduano, 2021) and impact of Covid-19 (Halliwell, 2021) suggest this negative context remains.

This review was the first to explore self-harm specifically, but findings were in line with similar previous research. A systematic review conducted by Hulbert-Williams and Hastings (2008) suggested an association between negative life experiences and psychological distress in PwLD, including self-harm. Griffith and colleagues (2013) explored the experiences of PwLD and challenging behaviour including self-harm. Individuals described how the accumulative stress of living in residential placements, poor interpersonal relationships, and long-term factors such as experiences of abuse contributed to their challenging behaviours. Similarly, research exploring the risk factors associated with self-injury in the general population have also found strong links between adverse life events including abuse

(O’Connor et al, 2009), and relationship difficulties (Haw and Hawton, 2008). Fliege and colleagues (2009) identified that self-harm may be associated with low self-esteem and lower belief in self-efficacy.

‘The act of self-harm’ captured PwLD’s experiences of their own self-harm and the meaning they made of this behaviour. Interpersonal difficulties, poor self-worth and overwhelming emotions lead PwLD to use self-harm as a coping strategy. Similarly, Klonsky (2007) suggested that the primary function of self-harm in people without learning disabilities appeared to be emotional regulation. This is in line with the experiential avoidance model of self-harm (Chapman et al., 2006) which suggests that self-harm is a method of avoiding uncomfortable and distressing internal events such as feelings, thoughts, and memories. They suggest avoidance provides some short-term relief which is supported by the experiences of participants in this review (e.g. Heslop & Macauley, 2009). However, this short-term relief may lead to increased discomfort in the long term as avoidance may create heightened distress and prevent emotional processing (Chapman et al., 2006). This review highlighted participants’ experiences of negative emotions returning and perhaps worsening when reflecting on their behaviour or considering its impact on others. Similar experiences have been noted recent review on self-harming in adolescents conducted by Lindgren and colleagues (2021).

Adopting a social approach, self-harm is understood in a context where social, political and economic factors can all lead to a context in which PwLD feel disempowered (Heslop, 2013). It appears ‘the act of self-harm’ functions as a coping strategy, as a way to regulate emotions (Klonsky, 2007). Nock’s (2009) integrated theoretical model of ‘non-suicidal self-injury’ (NSSI) proposes that NSSI is a means of regulating aversive affective experiences occurring because of negative life experiences. But self-harm is not solely due to the individual; it is the interaction between individuals and their social context which creates a context where self-harm is used and maintained (Heslop, 2013).

Intervention and support deemed helpful to people with learning disabilities

Ways of preventing or responding to self-harm that were deemed more helpful to PwLD were captured in the theme ‘a different response’. These included others taking helpful action, the importance of meaningful relationships, and the ways in which individuals could develop a deeper understanding of their own experiences and find alternative coping strategies. Previous research has also found that people find connection and talking to others about self-harm helpful; this included adolescents (McAndrew & Warne, 2014), prisoners (Marzano et al., 2012), and those who had received inpatient psychiatric care (Lindgren et al., 2004). Similarly in the Griffith and colleagues (2013) review, the theme ‘beneficial relationships with staff members’ reflected the positive impact staff relationships, particularly the opportunity to talk with others and feel respected, could have on the well-being of PwLD with behaviour that challenges.

Through connection with others this review found that participants learnt alternative strategies and developed their understanding of their own difficulties. Kool and colleagues (2009) conducted interviews with twelve women who had stopped self-harming. They identified six phases in stopping self-injury. Participants moved from having ‘limits’ set by others to improve a sense of safety to developing greater understanding of oneself and learning new strategies to cope with difficult emotions. Connection with others was identified as key to all phases of the process (Kool et al., 2009).

A lack of positive relationships and feeling as if there was nobody to talk to, captured in theme ‘negative experiences’, was reported across many papers in the review. Until the 1990’s few PwLD had access to psychological therapies (Sinason, 2002). Research also suggests that care staff lack confidence in broaching the subject of self-injury with PwLD

(Duperouzel & Fish, 2008). Working with people who self-harm can be emotionally challenging and a previous review found staff described avoiding self-harm and the associated distress that it brings (O'Connor & Glover, 2017). O'Conner and Glover (2017) propose this means that people are not given the opportunity to talk about their self-harm. When avoidance by staff is no longer possible, staff distress may be expressed intensely, often through uncaring or punitive approaches, towards patients.

The theme 'negative experiences' captured responses to self-harm deemed unhelpful to PwLD including interventions which were experienced as abusive, punitive, or uncaring. Punitive responses to self-harm, including judgemental comments and having treatment withheld, are reported by many who self-harm (Taylor et al., 2009) and negative attitudes towards people who self-harm remain (Saunders et al., 2012). Restrictive practices such as antipsychotics and physical restraint or behaviour modification are commonly used with PwLD (Heslop and Macaulay, 2009) despite campaigns and evidence from PwLD that these are unhelpful (Bradford et al., 2018). Indeed, the review by Griffith and colleagues (2013) found PwLD perceived restrictive practices as 'stressful', 'painful', 'ineffective' and in some cases 'abusive'. Moreover, this was conceived to further emotional discomfort and increased negative feelings towards the current context which in turn lead to further episodes of 'challenging behaviour' (Griffith et al., 2013). On the other hand, this review did find that some individuals found them useful for minimising harm. Similarly, Johnson and colleagues (2017) found young people in secure settings also reported restrictive actions to be both helpful and unhelpful; what appeared important was that these measures were carried out sensitively, respectfully and as part of a collaborative relationship.

This review identified that the type of intervention or support provided to PwLD deemed most helpful is that which provides a sense of connection and autonomy for the individual. These 'different responses' increase the individuals 'personal power' and increase experiences of ‘power with’ in which people work together (Neath and Schriner, 1998). ‘Negative experiences’, which can be experienced as punitive or uncaring, further the lack of power PwLD have maintaining the social context in which self-harm takes place (Heslop, 2013).

Strengths and limitations

The use of thematic synthesis allowed the assimilation of multiple qualitative studies to explore the perspectives of PwLD on their own self-harm; this integrative analysis can bring more informed and effective changes in clinical practice (Thomas & Harden, 2008). However, qualitative methods do not aim to provided generalisable findings and while there was consistency between papers, the individual perspectives of participants, for example in whether they find restrictive interventions helpful, did vary. In particular, the experiences of people living in the community, those with more ‘severe’ learning disabilities, and the voices of those unable to communicate verbally were lacking.

Overall, the number of participants was modest. The decision to only code direct quotes from PwLD who self-harmed enabled the inclusion of more papers where the aims of the study were not to explore self-harm directly, but this was discussed by participants. Further, it ensured the participants voice was central, which is important given that relatively little attention has been given to the personal experiences of PwLD. However, this data was still influenced by the original researchers’ data collection, analysis and reporting. Given there was a lack of researcher reflexivity in many of the studies, caution when generalising these findings should be taken.

Clinical implications

The review highlighted how self-harm takes place within a context of ‘negative experiences’ in people’s lives. Clinicians should be aware of discriminatory attitudes, social inequality and potential abuse and be prepared to challenge this when necessary (Heslop, 2013); this could include involvement in movements such as ‘STOMP’ (Bradford et al., 2018) or psychologists for social change (McGrath et al., 2016) Moreover, we should attempt to move away from authoritarian practices and be working together with PwLD (Neath & Schriner, 1998). Collaborative formulation (Johnstone, 2013) helps understand the experiences of the individual including their own unique self-harming behaviour and what they deem to be a helpful response. Positive Behaviour Support (PBS) plans are often used to understand and reduce behaviours including self-harm (Snell et al., 2005). Although inclusion of PwLD in the development and creation of these plans can pose a significant challenge (Kruger & Northway, 2019), it is vital clinicians continue to strive towards this to ensure autonomy and empowerment for PwLD.

The findings of this review highlight the importance of relationship and connection for PwLD who self-harm. Others did not need to provide ‘specialist’ support, just caring relationships and the opportunity for the individual to talk, however, many professionals report feeling unskilled and uncertain about how to respond to this behaviour (e.g. Duperouzel & Fish, 2008). Opportunities for staff training to increase awareness and understanding of self-harm behaviour may be helpful. Involving a person with learning disabilities in this training not only increases the individual’s ‘power with’ (Neath & Schriner, 1998) but has been shown to positively improve staff empathy and attitude towards behaviours that challenge (Hutchinson et al., 2014). Opportunities for reflection through peer and individual supervision may also support staff to understand and process their own responses to others’ self-harm.

Research implications

There is a need for further research to capture the views of a more diverse population of PwLD who self-harm, for example those from ethnic minority backgrounds or living in community settings. Heslop and Macauley (2009) demonstrated how the experiences of those with more severe learning disabilities or those unable to communicate verbally can be included in research and the inclusion of these groups should be a priority. Involving PwLD in this research will ensure that it is relevant and meaningful to people’s lives (Gilbert, 2004). Throughout the reviewed research connection to and response from others, particularly staff, was significant in the context of an individual’s self-harm. Previous research has highlighted how working with people without learning disabilities who self-harm can be particularly challenging (O’Connor & Glover, 2017). Further research to explore these issues, specifically with those who work with PwLD, may guide training for staff and thus the care they provide. Much of the present research focusses on the experience of staff within secure or inpatient settings, given that most PwLD live in the community (MENCAP, 2016) research in these settings is particularly needed.

Conclusion

Self-harm is more prevalent in PwLD than the general population. However, it is often subsumed under the umbrella term challenging behaviour and relatively few studies have sought to understand it from the perspectives of PwLD as a unique entity. The current review sought to redress this by reviewing and synthesising the related qualitative literature. A thematic synthesis identified three themes relating to peoples experience of self-harm: negative experiences, the act of self-harm, and a different response. The themes highlighted how self-harm took place in a negative context of abuse, lack of autonomy, and poor relationships which affected an individual’s view of themselves and created overwhelming emotions. Responses to self-harm could be experienced as punitive or uncaring which furthered the individual’s negative experiences. Building connections and developing autonomy were seen as more helpful responses which may reduce self-harming behaviour. Future research may wish to explore whether these themes are similar across a broader spectrum of PwLD and seek to further explore how staff understand and respond to this behaviour.

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Section B:

Navigating distress: How care professionals work with people with learning disabilities who self-harm

Word Count: 7986 (503)

Abstract

Background: Working with people with learning disabilities who self-harm is emotionally challenging. This research aimed to understand the way in which social care professionals work with people with learning disabilities who self-harm in residential or supported living settings.

Methods: Eleven participants were interviewed about their experiences working with people with learning disabilities who self-harm. Data was analysed using grounded theory.

Findings: The model illustrated how care professionals navigate distress when working with self-harm. Self-harm evoked feelings of powerlessness and uncertainty, which was experienced as a threat to professionals' caring identity. Professionals moved between attempting to reduce and control the distress, learning to tolerate or accept the strong emotions that self-harm evoked.

Conclusions: The findings build on previous research about the emotional impact of self-harm and the way in which this may shape professionals response. Further support for professionals working with people with learning disabilities who self-harm is needed.

Keywords: People with learning disabilities, self-harm, grounded theory, carer

Introduction

‘Self-harm’ has been defined as “any act of self-poisoning or self-injury carried out by an individual irrespective of motivation” (NICE, 2011). It has been understood as a meaningful behaviour which serves a variety of nuanced functions for the individual (Nock, 2009). Research has suggested self-harm is highly prevalent in people with learning disabilities (PwLD) with estimates suggesting between 7.5% and 24% of this population self-harm (Bowring et al., 2017; Deb et al., 2001). It is a concerning issue implying that the individual is distressed and needs support (Heslop & Macauley, 2009). However, in many studies, PwLD reported unhelpful responses from others to their self-harm including feeling judged (Lunsky & Gracey, 2009), ignored (Duperouzel & Fish, 2010) or punished (Brown & Beail, 2009). These experiences were associated with difficulties engaging in therapeutic interventions to find alternative ways of coping (Browne et al., 2019; Wolkorte et al., 2018) and led to further episodes of self-harm (Duperouzel & Fish, 2010).

Understanding and attitudes towards self-harm

The National Institute for Health and Care Excellence (NICE) Guidance on Self-Harm (2013) set an expected standard for professionals’ attitudes towards those who self-harm, as staff attitudes are often reported to contribute to poor experiences of care. Interviews with professionals suggested they held a range of beliefs about self-harm in PwLD: that it is part of the person’s nature; a means to feel in control; a coping strategy; and a way to rebel against the system (Fish, 2000). Professionals understanding and attitude towards self-harm is important as it can influence their response to clients (Saunders et al., 2012). Some professionals working with PwLD reported attitudes towards self-harm as being intrinsic to the individual, part of their learning disability (Samways, 2021). There is a concern that if the locus of responsibility for self-harm is intrinsic to the person it may lead to a sense of apathy or futility of care (Huband and Tantum, 2000).

Weiner's (1986) attribution model suggested attributions made about the cause of behaviours as internal, stable, and controllable would elicit more negative emotional responses, which in turn affect helping behaviour. This model has been extensively used to explore how attributions professionals made towards behaviour that challenges influenced their willingness to help. 'Challenging behaviour' is described as 'culturally abnormal behaviour of such an intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to limit the use of, or result in, the person being denied access to ordinary community facilities' (Emerson & Einfeld, 2011). It is an umbrella term describing a range of behaviour, this includes behaviour that is directed towards others, aggression, and behaviour directed towards the self, 'self-harm' (NICE, 2015). As 'challenging behaviour' is often used to locate the problem within the person, the term 'behaviour that challenges' has been used (NICE, 2015).

Despite much research the application of the attributional model to understand responses to behaviour that challenges has been inconsistent (Wilner & Smith, 2008). One explanation is that different attributions were made about self-harm compared to other types of behaviour that challenges in PwLD. Stanley and Standen (2000) presented staff with three different case studies describing different topography of behaviour that challenge in PwLDs. In case studies where clients were described as more independent and behaviour was more outwardly directed, aggressive towards others or destructive of property, professionals made more attributions of control and negative affect and demonstrated less propensity to help. On the other hand, if the behaviour was self-injurious, and the client described as more dependent, the greater the professionals attribution of stability, positive affect, and propensity to help. Similarly, Bailey and colleagues (2006) reported a more significant correlation between stable attributions and negative emotions for professionals when working with self-harm, which they suggested may be related to feelings of pity. This was compared to other behaviour which challenges, where internal attributions were correlated with negative emotions, suggesting professionals blamed service users for this behaviour. This distinction suggests that self-harm may be better understood outside of the wider literature about behaviour that challenges.

Samways (2021) conducted a review to compare the attitudes of professionals working with self-harm in the general population and PwLD. The review found only four papers relating to working with PwLD (Dick et al., 2011; Fish, 2000; James and Warner, 2005; Snow et al., 2007) highlighting the paucity of research in this area. Professionals in both groups reported self-harm was an emotionally meaningful behaviour used as a way to cope with distress. For PwLD this distress was perceived as connected to both current circumstances and past experiences such as powerlessness or abuse. Self-harm was also perceived as a form of communication. Professionals working with PwLD considered this an understandable reason for self-harm, considered meaningful within the context of relationships. However, for people without learning disabilities self-harm as a communication was viewed more negatively and was often labelled as ‘manipulative’ or a way to ‘get attention’.

Attitudes towards self-harm in the general population have been found to influence the response of professionals (Saunders et al., 2012). For example, research has found that when people who self-harmed were deemed ‘manipulative’, their behaviour evoked feelings of frustration in professionals and reduced professional’s anxiety about risk. This led to the self-harm being ignored or avoided (Wilstrand et al., 2007). On the other hand, understanding the ‘need’ for self-harm enabled community nurses to have more empathy and seek ways to engage with their clients (Thompson et al., 2008). Given the difference in attitudes noted above (Samways, 2021) it is unclear whether these findings can be generalised to the way in which professionals respond to self-harm in PwLD.

Working with self-harm

Working with people who self-harm can be emotionally challenging for the people who support them (O'Connor & Glover, 2017). Professionals working with PwLD reported strong emotional responses to self-harm including frustration, guilt, fear of blame, helplessness and loss of confidence in their own abilities (Fish & Morgan, 2018; Fish & Reid, 2011). Similarly, professionals reported feelings of failure (Leddie et al., 2021), anxiety (Thompson et al., 2008), helplessness (Hopkins, 2002), and frustration (Marzano et al., 2015), when working with people who self-harm in the general population.

Understanding the emotional experience of professionals is important as it may influence their response to self-harm (O'Conner & Glover, 2017). For example, anxiety arising from holding responsibility for the client's welfare may result in more coercive responses to risk such as psychotropic medication (Lundegaard Mattson & Binder, 2012). O'Conner and Glover (2017) synthesised qualitative literature to understand how inpatient professionals work with individuals who self-harm. They suggested that self-harm creates emotional distress for staff members which drives attempts to manage risk. When attempts to manage risk are deemed 'unsuccessful' professionals may experience a sense of defeat. This was associated with a decrease in empathy and avoidance as a way of coping. When avoidance was no longer sustainable professionals expressed their own distress through punitive approaches such as humiliation and minimizing the patients distress.

To date, no research has sought to explore how the emotional experience of professionals may influence their response to self-harm in PwLD. Although the emotional experience for professionals working with both groups appear similar, it is unclear whether the findings from the general population can be applied to PwLD due to potential differences between perceptions of these client groups. For example, O’Connor and Glover (2017) highlighted how distress arising from self-harm could be managed by collaboration and shared responsibility for risk between professionals and the service user. However, a review exploring the attitudes of professionals towards PwLD and mental health problems found professionals were less inclined to involve PwLD in decision making and saw little need to empower them to understand more about their conditions and treatment (Ee et al., 2021).

The context of care

O’Conner and Glover (2017) highlighted how organisational challenges within in-patient settings influenced how professionals worked with people who self-harm. People who self-harmed were regarded as draining on already limited resources which led professionals to prioritise organisational, rather than individual patient, needs (Hadfield et al., 2009). Moreover, professionals emotions such as fear were exacerbated in systems where they felt isolated and uncertain (O’Conner & Glover, 2017). Similarly, in community mental health settings, nurses reported feeling unsupported by NHS services and described fearing ‘blame’ if their clients were to self-harm. This was associated with their perceived role in monitoring risk (Thompson et al, 2008).

Research to explore the experiences of professionals has focused on forensic settings, however this represents only a small population of PwLD who self-harm. In 2018, over 50,000 PwLD lived in residential care or supported accommodation (Public Health England, 2020). A competent and stable social care work force is essential to provide consistent, high-quality community care to PwLD (NHS England, 2014). However, there has been a growing problem with recruitment and retention within the sector (Bottery, 2020) with low pay, low status and poor leadership identified as key barriers to employment and retention (Moriarty et al., 2018). The Covid-19 pandemic further increased stress for those in the sector and highlighted a lack of support within the system (McFadden et al., 2021).

Supporting individuals with learning disabilities can be extremely demanding (Leoni et al, 2020). Significant levels of stress and burnout among professional, between 25 and 32 percent, have been reported in the literature (Hastings et al., 2004; Hatton et al., 1999). Exposure to behaviour that challenges has been consistently identified as a notable source of stress, and associated burnout, for professionals working with PwLD (Ryan et al., 2021) although less is known about self-harm uniquely. Given the unique challenges of the social care sector it is worth further exploring how professionals support PwLD who self-harm in these settings.

Aims

Working with people who self-harm can be emotionally challenging for the people who support them (O'Connor & Glover, 2017). Although the prevalence of self-harm in PwLD is high (Bowring et al., 2017; Deb et al., 2001) relatively little research has been conducted to explore the experiences of professionals working with this client group. Further, research that has been conducted has been primarily based in secure forensic settings and the applicability to community social care settings, which support a significant number of PwLD, is limited. Professional experiences, beliefs, and systemic factors all appear important in understanding how others respond to self-harm, although there appears no framework for understanding this interaction. Therefore, through development of a grounded theory, the current study sought understand the way in which social care professionals work with PwLD who harm themselves.

Method

Design

The study utilised a qualitative design using modified grounded theory (Glaser & Strauss, 1967; Urquhart, 2013). It should be considered 'modified' as theoretical sampling was not consistently applied due to recruitment constraints (Corbin & Strauss, 2015). Grounded theory allowed for exploration of participants' subjective experiences and is deemed useful when exploring social processes with the aim of developing a new theory to explain the phenomena (Oliver, 2012; Urquhart, 2013). The fundamental components of grounded theory are outlined in Appendix F.

Epistemological position

Grounded Theory is associated with 'epistemological neutrality' and as such has been utilised by researchers from different epistemological positions (Urquhart & Fernández, 2013). This research was approached from a critical realist epistemological perspective. This stance presupposes an objective reality exists independently to our thoughts, but this reality is "mediated through the filters of language meaning-making and social context" (Oliver, 2012, pp. 374). As such, it was considered that the theory was generated from the data through an interaction between objective reality and researcher interpretation.

Participants

Sample size was not determined prospectively but between eight and sixteen participants were sought to reach theoretical sufficiency (Dey, 1999). Individuals working in any residential setting for PwLD were considered eligible for this study (Table 1).

Table 1

Study Inclusion Criteria

Inclusion
Currently working in a residential setting (supported living or residential care) for adults (18 or over) with learning disabilities (as defined by the residential setting)
Currently working alongside at least one individual who self-harms (defined as "any act of self-poisoning or self-injury carried out by an individual irrespective of motivation" (NICE, 2011))
Have "experienced" (defined by the participant) this individual self-harm (defined above) during the last 12 months

Recruitment

To ensure visibility, the study was advertised through a variety of methods which included advertisements on support worker networks via Facebook and approaching care organisations via contact details available in the public domain (see Appendix G for advertising material). An initial screening questionnaire hosted by Qualtrics (Appendix H) provided more information about the project. Demographic information provided supported the inclusion of a range of experiences. Participants were recruited through both purposive and snowball sampling. Theoretical sampling was used where possible however, due to difficulty recruiting participants all eligible participants were invited to take part.

Demographics

Eleven participants were recruited: Table 2 details participants demographic information.

Table 2

Participant Demographics[3]

Participant number	Gender	Age	Care organisation	Role	Time in care sector
1	Female	35-44	A	Manager	10-20 years
2	Male	18-24	A	Support worker	Less than 1 year
3	Female	25-34	B	Support worker	10-20 years
4	Female	25-34	C	Senior manager	10-20 years
5	Female	45-54	D	Senior manager	More than 20 years
6	Male	25-34	C	Manager	5-10 years
7	Female	25-34	C	Other	2-5 years
8	Female	25-34	D	Support worker	10-20 years
9	Female	25-34	C	Other	Less than 1 year
10	Male	25-34	C	Support worker	2-5 years
11	Male	25-34	D	Other	2-5 years

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[3] Other roles included behavioural analyst and behavioural specialist

Ethical consideration

Ethical approval was obtained by the Canterbury Christ Church University Ethics Committee (Appendix I). The research was developed and conducted in compliance with the British Psychological Society's (BPS) code of ethics and conduct (BPS, 2018).

Prior to arranging an interview, participants were provided an information sheet (Appendix J), given time to ask questions and consider their participation in the study. Written informed consent was gained (Appendix K) and consent checked verbally at the beginning of the interview. These documents were developed in collaboration with the Salomons Advisory Group of Experts by Experience (SAGE). Participants were reminded of their right to withdraw from the interview at any point and their choice to not answer any questions. After the interview participants were debriefed and invited to discuss any concerns; signposting was provided as appropriate.

Interviews were recorded and transferred to a password protected device. Audio files were transcribed and anonymised by the author to protect participants confidentiality. Participants had eight weeks following the interview to withdraw their data.

Procedure

Data collection

Semi-structured interviews, lasting between 36 and 80 minutes, were conducted via a secure video call platform (Zoom). An interview schedule, developed in consultation with SAGE, was used to guide questioning although questions were flexible and influenced by the participants' responses. While the core questions remained constant, the interview schedule was modified to further explore emerging concepts and gaps in the data (Appendix L-M).

Data analysis

Three interviews were initially conducted after which data collection and analysis were completed simultaneously. Data analysis occurred through an iterative process, moving between coding, conceptualisation, and theory building (Corbin & Strauss, 2015); Table 3 illustrates the data analysis process. Throughout the research process a range of analytic strategies, including questioning and making comparisons, were used (Corbin and Strauss, 2015).

Table 3

Stages of Data Analysis (An Iterative Process)

Stage of analysis	Description
Open coding	Following transcription initial interviews were coded line-by-line to encourage the researcher to stay close to the data (Urquhart, 2013). Line-by-line coding was completed for the first four interviews (Appendix O).
Focused codes	Open codes were then refined into focus codes (concepts) to synthesise and refine the large amount of data generated. Focused codes were constantly compared with previous data, across and between interviews.
Selective coding	Selective coding involved organising focused codes into higher level conceptual categories and subcategories
Theoretical coding	Theoretical coding developed theoretical ideas about the connections and nature of relationships between concepts. The process of making these connections and therefore developing a theory is core to the grounded theory approach (Corbin & Strauss, 2015).
Theoretical sampling	Where possible additional participants were recruited, and the interview schedule adapted, based on emerging concepts from earlier interviews.
Memos and diagrams	Throughout analysis memos and diagrams were used to capture researcher thoughts, observations, and reflections throughout the analytic process (Appendix P-Q). They enabled the researcher to keep a record of emerging concept relationships and the theory development over time (Corbin & Strauss, 2015)

Quality assurance

Guidelines were used to ensure the quality and credibility of the research (Yardley, 2000). The researcher's experiences and beliefs were considered to have an influence on the research process and analysis, in line with the critical realist epistemological position. To promote reflexivity, the researcher conducted a bracketing interview prior to beginning data collection (Appendix N). A research diary (Appendix R) was kept throughout the study and was used to consider how the researcher's own position influenced data collection and analysis.

During analysis sections of data were independently coded by the project supervisor and an independent peer. Coding differences and category labels were discussed to explore the author's analytic process. The use of memo's brought awareness to the researcher's cognitive processes during data analysis (Payne, 2016) and stages of the data analysis documented to support the integrity of the research (Appendix P).

The generated model was sent to participants (Appendix S) to ensure it represented their experiences and feedback was sought.

Results

This project sought to understand how care professionals work with PwLD who self-harm in community registered care or supported living settings. Interviews were conducted with 11 participants and data analysis produced four main concepts: a caring vocation, a distressing experience, navigating distress, and powerlessness. These are summarised in Table 4 (see Appendix T for focused codes and illustrating quotes).

Table 4

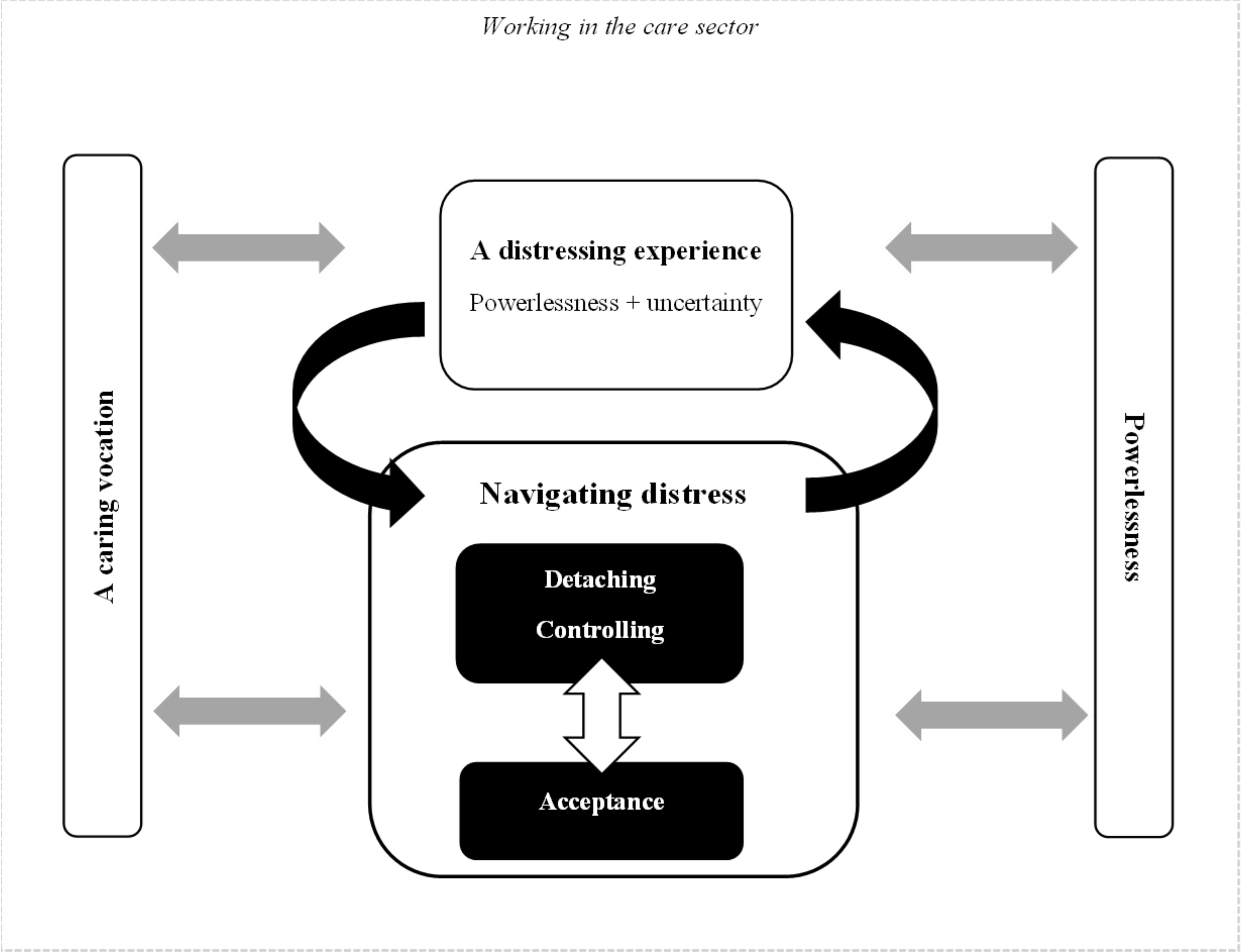
Concepts and Sub-categories

Concept	Sub-category
A caring vocation	Doing care
	Knowing the service user
A distressing experience	Strong emotions
	Physiological response
	A threat to identity
Navigating distress	Using professional power
	Seeking certainty
	Reducing the emotional temperature
	Towards acceptance
Powerlessness	Powerlessness in the care system
	Lack of power in the learning disabilities context
	Protecting against powerlessness

Figure 1 presents the findings in a preliminary model. The model depicts how professionals navigate distress when working with PwLD who self-harm within the context of the care system.

Figure 1

Navigating Distress when Working with PwLD who Self-harm



The model highlighted how professionals identified caring as their vocation. Professionals sought to 'know' the service user, by drawing on their experiences and relationship with the individual, to ensure certainty in the support they provided ('a caring vocation'). Witnessing self-harm was a distressing experience and challenged professionals caring identity. It evoked strong emotions, particularly anxiety, which drove people to find ways of coping with the distress created by feelings of powerlessness and uncertainty. Different strategies were utilised depending on a range of factors including individuals' values, experience, level of risk, personal characteristics, relationship with the service user etc. Through experience, professionals described a process of becoming 'desensitised', which reduced the distressing nature of this event, while simultaneously developing their understanding of self-harm and empathy with the service user ('navigating distress'). Participants moved towards greater acceptance of the uncertainty around self-harm; this reinforced their positive identity as a carer. Experiences of powerlessness in the context of the care system for PwLD, influenced professionals distress and the coping strategies they utilised ('powerlessness').

A caring vocation

The model suggested that working in social care was more than a job, it was caring vocation. Professionals drew on their personal values and experiences which shaped the care they provided. Ultimately, the job was about supporting the service user. To do this professionals invested in the relationship with their client, which enabled them to 'know' the service user and strive to provide person centred care. Seeing the difference that their support made motivated professionals to continue in the job.

Doing care

Participants spoke about the innate skills required in the role. This suggested that it was more than just a job but a vocation.

> *Quite often you say you can either do ‘care’ or you can’t, you know, there is no in between; you can’t just do it for a job - you’ve either got to be invested or, or you’re not, or you end up being a really bad support worker. (Participant 1)*

Participants had a wealth of experiences of caring, both personal and professional, which they drew on in the role. For one participant, her own Autism Spectrum Condition (ASC) diagnosis was particularly useful in understanding and adapting support for service users. Personal values were related to empowering PwLD including advocacy, improving quality of life, creating equality, connecting to the community, and building confidence. These values shaped professionals’ perception of their job role and the way in which they supported PwLD.

> *It’s not like professional members, [indicates gap with hands] people we support. So when you’re on activities join in, have fun, don’t stand at the side while someone’s doing something, you’re not a bodyguard…being equal is a big part of it. (Participant 4)*

For participants seeing the difference that their support is making was described as ‘rewarding’, ‘worthwhile’ and a ‘privilege’. Witnessing this change appeared to motivate professionals to stay in their caring vocation.

> *There has been a few issues with a young lady that we support, but from that we're now seeing positive changes and that's just like everything really. Makes it very worthwhile... (Participant 9)*

Knowing the service user

Supporting the service user was identified as the central aspect of their role. Participants sought to ‘know’ the service user and the type of support they needed.

> *Each person has different kind of ways of communicating, they have different kind of risks, they have different desires and wants and stuff like that. So it's very kind of like,*

> *have to be person centred. You can't do a one size fits all approach at all. (Participant 11)*

Participants drew on their skills and experiences, and built a relationship with the service user, to develop this knowledge. When this was not possible, participants appeared more uncertain about how they should support individuals.

> *It's frustrating sometimes to understand things from them because normal kind of behavioural methods and things like that, wouldn't really, aren't really appropriate (Participant 7)*

Participants attempted to reduce or prevent the service users self-harm through the support they provided. Again, the emphasis was on "knowing" the individual which enabled person-centred support.

> *He spends a lot of his time downstairs, you can, you can always, now that you know how he displays himself, you kind of know how he's feeling so you can interject early really, you can be proactive about it. (Participant 1)*

A distressing experience

Working with PwLD when they self-harmed was distressing. Participants described experiencing strong emotions and a physiological response in these situations. Self-harm evoked feelings of powerlessness which was experienced as a threat to professionals' values and caring identity. Uncertainty about the reason for the self-harm, and how they should respond, heighted participants distress.

Strong emotions

Participants described a strong emotional response to self-harm and for many it was upsetting to witness. This was in part due to the distress they saw the service user in and feeling helpless in knowing how to support them.

> *He was very distressed by that, very, and oh I felt awful, I mean just watching him sort of melt down. (Participant 2)*

Fear and anxiety were reported by participants, particularly related to the potential risks to the service user and themselves. The intensity of the behaviour and severity of injury was often shocking, particularly for less experienced staff members.

> *It's quite like she does really go for it, but when she's banging her head against wall and punching, she does really go for it like you are a little bit like, like that [shocked expression]. (Participant 8)*

Participants also described feeling angry or frustrated in response to the self-harm. This was directed towards themselves, if they had been unable to prevent the situation; towards others, for creating the context in which self-harm took place; and towards the service user, particularly if the self-harm, accompanied by other ‘challenging behaviour’, was felt to be a personal attack on the professional.

> *If there is an incident and you are, erm, subject to shall we say, I’ll use the correct terms, challenging behaviour, that can be very frustrating, especially if you are not able to quite figure out why it’s happened or if you feel it’s been targeted towards you, that can be very, very difficult. (Participant 3)*

Physiological response

A physiological response to self-harm, particularly when experienced first-hand, was also reported by participants. This appeared important in driving their response.

> *I remember my heart rate was really quite high at this point, but you kind of, you forget all that as soon as the adrenaline kicks in and you just think you know his safety is first at this point really. (Participant 10)*

A threat to identity

The distress caused by self-harm appeared related to the way in which it challenged professionals' values and caring identity. Many participants were self-critical about their own role and failure to prevent the behaviour.

> *It sort of knocks you for six, it really makes you question, it's quite sad to see and you know I mean she was doing so well, then, erm, that one thing ... you know I was questioning myself as a manager, "am I in the right job?" How could that have happened? (Participant 5)*

Participants' uncertainty about the reason for, and response to, self-harm increased their distress. This was heighted for inexperienced professional members, who were uncertain of their role, and for more experienced or senior members of staff who felt a responsibility to support others in the team.

> *Useless, useless, it's horrible, and especially when sometimes people might look for me for like the answers. I'm like "I don't have the answers!" (Participant 9)*

As well as increasing distress, these judgements about self-harm could perpetuate participants experiences of powerlessness. Feeling personally attacked increased participants' sense of threat, and attributions around personal helplessness could increase fear of blame and sense of ability to make change.

Navigating distress

Professionals sought different ways of responding to self-harm to manage the distress created by feelings of powerlessness and uncertainty. Participants tried to reduce distress, for themselves and the service user, through attempts to detach from, or control, the anxiety arising as a result of self-harm. Attempts were made to monitor risk and seek certainty in understanding and responding to self-harm. With increasing exposure to self-harm participants described a process of becoming 'desensitised', which reduced the distressing nature of this event. However, as participants developed their understanding of self-harm and relationship with the service user they were also able to resonate with the self-harm. Being able to hold these two positions without excessive polarisation was important and participants were able to move towards greater acceptance of the service users self-harm and enabled them to navigate this distressing experience.

Using professional power

Responding to risk was often described as the immediate priority by participants driven by anxiety about the risk of physical injury. Participants exerted their professional power and variety of strategies to manage risk, and reduce their own sense of threat, including use of restraint, protective equipment and ensuring a safe distance. The environment, past experiences and participants values influenced the strategies used.

> *So I've never, I've never really erm…I am a little bit against physical interventions and restrictive practise. I, I definitely understand that it's necessary and it's needed erm, like for safety reasons. So, say like he, he isn't allowed in the kitchen and that's, it's a little bit different… (Participant 9)*

Participants discussed long-term management of risk and increased vigilance. This included strategies to control the environment and involving other professionals. Alongside this, participants were able to hold the service user's experience in mind. They recognised the potential for ways of managing risk to become restrictive and the need to balance this with the service user's rights.

> *After that she had to have consistent visual, which was awful for her but equally, we just couldn't take that risk until it reduced. (Participant 1)*

In response to self-harm participants described exerting their power to get the service user the support they need, even when they felt quite powerless in the system.

> *I had to kind of go "with all due respect I am more qualified than just a support worker but also we have been asking you to do these assessments for god knows how long and you haven't delivered on them". (Participant 3)*

Seeking certainty

In response to feelings of helplessness, participants sought certainty about the reason for self-harm and the way in which they should respond. Certainty was sought through involving others, documentation, monitoring and assessment, rules and guidelines, and training.

> *We've had to do like a behaviour scale as well, to say about like giving them clear criteria of when like maybe you should intervene, when you should report, you know all that kind of stuff. (Participant 6)*

Participants also attempted to understand the self-harm and empathise with the service user. By drawing on their relationship with the individual ('knowing the service user') and their own life experiences they sought to mentalise the service user's experience.

> *It sort of, it was like watching, erm, a child have a meltdown in the supermarket when they have been unable to get what they want put in the trolley. (Participant 2)*

Through the process of the interview participants reported a variety of explanations for the service users self-harm falling broadly into three categories 'environmental', 'biological', or 'emotional'. However, there were often multiple levels to understanding the behaviour and participants would hold these simultaneously.

> *It can sometimes be about tangible things, so like "I want a diet coke"...if he was worried about something, you get the attention as well don't you? Not only in terms of like I'm saying he's doing it for attention, but the function of the behaviour is to gain social attention to help him problem solve. So, he's worried, he needs people to fix things, so they will come quick when I shout and slap. (Participant 4)*

Reducing the emotional temperature

Participants described how they sought to reduce the distress around self-harm for themselves, the service user, and other professional members. Participants used deactivation strategies and described ways of reducing their own distress by detaching physically, leaving the room, 'compartmentalising' or mentally detaching from the self-harm incident. Through repeated exposure to self-harm participants reported becoming desensitised to self-harm which ultimately reduced the distress they experienced.

> *It seemed more scary at that point, when you haven't kind of seen it across lots of people. But when you have, it's almost like a little bit, being like a little bit desensitised as well to how like shocking that can be. (Participant 7)*

Although this was generally perceived as a helpful way of coping participants were aware of the potential negative consequences of desensitisation and the potential impact this had on their caring role.

> *In fact, it's very stressful and it does play, it takes a toll, and so I think after a while people kind of become a bit callous to it in order to protect themselves to a certain extent...I think that was where that kind of boredom of it came out of. (Participant 6)*

Supporting other staff members was important following an incident of self-harm, particularly for more senior professionals. Despite their own distress and concern for the service user, participants were able to detach from the emotional experience to provide emotional containment for their team.

> *I care a lot about the people we support but in those moments you have to be really unemotional, and you have to be unemotional for other staff members as well, you have to kinda project that "this isn't anything to panic about", (Participant 4)*

After the incident participants were able to reflect and share with their teams their own uncertainty and feelings of powerlessness evoked by self-harm. This protected against the ‘blame culture’.

> *Well, I, I suppose just me talking about personal experience, talking about where I've been, I've been in their position. I understand how hard that is when you think someone getting hurt. (Participant 6)*

Participants also attempted to calm the service user, for example distracting the service user from their distress and encouraging them to ‘just move on’ (participant 2). Participants also supported the service user to find alternative coping strategies and reduce incidents of self-harm (and distress) long-term. These actions appeared aligned with the participants values to empower PwLD.

> *I would be doing some kind of really basic self-esteem things like what are you good at, that kind of thing…we also tried to get him involved in and this, this, this lasted for a little while in like college, and, and then, like he volunteered at a local, local food bank for a little while, and, and he felt important there. (Participant 11)*

Towards acceptance

At times participants needed to tolerate the distress from self-harm, either because they felt they had no other options, or because they thought it was best for the service user. Participants were able to ‘stick it out’ by holding in mind, and prioritising, the needs of the service user.

> *He also needed us because we had been with him, 'cause I was observing, it’s two other professionals that have been with him. So, we kind of just had to be there and stick it out really, it wouldn't have been right to been swapping. (Participant 9)*

With experience participants moved towards tolerance of distress and greater acceptance of uncertainty. This included uncertainty around the reason for self-harm, their own response to the behaviour and the inevitability of some mistakes.

> *There isn't always necessarily a full explanation to be given…I can give points of it, but ultimately there's some bits that are gonna happen and, and it's hard, we, we don't know that...(Participant 6)*

There was also greater acceptance of why individuals might self-harm, acceptance of one's own lack of power to control this behaviour, and thus tolerance of self-harm and the potential distress it may cause. Participants emphasised the relationship with the service user and the need to prioritise the service user needs.

> *Yet these years and years of torment in people, you know, and you're not going to make it, you're not going to make it go away. You're just going to make it bearable, you know, and you're gonna make it how they need it to be made? (Participant 5)*

Powerlessness

The model highlighted feelings of powerlessness within the care sector which influenced professionals' experience working with PwLD who self-harm.

Powerlessness in the care system

Participants described being undervalued as a profession. They lacked the authority to make meaningful change for the service user they supported which increased feelings of helplessness when self-harm did occur.

> *Erm, so when she said that to him and the self-harm happened, it was very…you're frustrated because your like, I'm going to swear sorry, just "for F***sake" basically (laughs). Erm, frustrated for him, frustrated for yourself, frustrated that we, we've made, raised these concerns so many times and nothing's been done. (Participant 3)*

Participants also reported feeling unsupported by their managers, or other professionals in the system. The ‘blame culture’ increased anxiety when self-harm occurred but participants also acknowledged how they perpetuated this cycle in their own response to self-harm.

> *An MDT meeting is held, you know. And unfortunately, in this, the world that we live in now, it's very much a blame` culture. Who is to blame? And everybody is looking at… and I was even doing the same (Participant 5)*

Working in care was described as a difficult job and professionals faced personal risks. One participant captured how these experiences may not be appreciated by people not working in the sector.

> *And then that's when she started smacking her head against the wall, but that was in public as well, because that day, my… at that moment my mum drove past the house. And that so that was a little bit like, I think my mum was like “Oh my God!” like yeah, “What are you having to work with?” (Participant 8)*

Professionals faced a variety of service-related challenges including a lack of staffing, poor communication in the network, and a lack of resources. Covid-19 placed additional demands on professionals’ time and required innovative ways to support service users.

Lack of power in the learning disabilities context

Participants acknowledged how PwLD are often an overlooked group in society and experience a lack of power in their own lives. There was a sense that this further increased the challenge for care professionals wanting to empower this group of people but finding themselves stuck working against disempowering systems and stigma in society.

> *And then working with support people who have known him for a long time to try and get out of entrenched like opinions about him and see, uh, more positive side and work towards the, the like growth of him. That was quite difficult (Participant 11)*

Protecting against powerlessness

More positively, participants talked about how they felt less powerless by having a supportive team. An open environment, with good information sharing, and shared responsibility protected against the ‘blame culture’.

> *Erm, it’s having that environment around you where people feel free to talk without having lots of scrutiny poured on them, and you know, people analysing their decisions, it wasn’t like that there, people there were very friendly, it was a very open environment, hats off to them really, great, great stuff (Participant 2)*

Participants identified how they could gain power through professional qualifications, which in turn enabled them to utilise different responses to self-harm.

Discussion

The current study sought to understand the way in which social care professionals work with PwLD who harm themselves. It specifically explored these experiences within residential or supported living settings given that previous research has focused on secure forensic settings and the applicability to community social care is limited. The resulting model captures how professionals navigate the distressing experience that is self-harm. It considered both personal and systemic contexts which influence and are influenced by this process.

Link to previous literature

Attitudes and attributions

Previous research has sought to understand how an individual’s understanding and attitude towards self-harm can influence their response (Saunders et al, 2012). Similarly, research has explored how attributions about the behaviour of PwLD may also affect the response from professionals (Jones & Hastings, 2003; Stanley & Standen, 2000). Typically, research has highlighted negative attitudes of professionals which can lead to unhelpful responses (Jones & Hastings, 2003; Saunders et al, 2012; Wilstrand et al., 2007).

In this study, negative attitudes were less frequently reported, and professionals appeared to hold multiple understandings about the meaning of the self-harm. Samways (2021) also found that professionals supporting people with intellectual disabilities displayed attitudes and attributions reflective of both biobehavioural and psychosocial theories of self-harm. They reported a greater emphasis on understanding self-harm in the context of the relationship, and an underlying assumption that professionals were in a relational setting, doing relational work (Samways, 2021). While professionals understanding of self-harm was not insignificant, in the present study it appeared the emotional impact of the work drove the response of professionals to PwLD who self-harmed.

Emotional distress

The study highlighted how working with PwLD who self-harmed was a distressing experience; professionals experienced a range of emotions and associated physiological responses. This was consistent with previous research which highlighted the emotional challenge for professionals when supporting people with, or without, a learning disability who self-harmed (e.g. Fish and Reid, 2011; O'Connor & Glover, 2017).

The distress caused by self-harm related to the way in which it challenged professionals' values and caring identity. 'Moral injury' may occur when exposed to events which involve taking, failing to prevent, or witnessing action that directly violates one's moral beliefs and values (Litz et al., 2009). The participants self-criticism reflected their perception of their own responsibility and failure to prevent the self-harm. Furthermore, working in care is a difficult job characterised by difficult working conditions, poor pay, persistent high turnover rates and lack of resources (Hussein et al., 2016, Hussein, 2017; Rubery et al., 2011). These challenges meant professionals were unable to provide the support they felt the service user needed, further exaggerating their own sense of powerlessness and failure in preventing self-harm. Uncertainty about the reason for, and response to, self-harm also increased participants distress through attributions of their own helplessness. Feelings of helplessness in response to self-harm are common (Akinola & Rayner, 2022). In this study uncertainty about the reason for, and response to, self-harm increased participants distress through attributions of their own helplessness. Mason (1993) identified this as a position of 'unsafe uncertainty' in which the ability to make decisions, or feel one can usefully influence others, is compromised because of low self-confidence and associated feeling of powerlessness.

Coping and attachment

The present model suggested that the emotional impact of self-harm was central in shaping the way in which professionals responded. Participants used a range of coping strategies, ongoing cognitive or behavioural efforts, to manage the distress (Lazarus & Folkman, 1984). The model identified several 'controlling' strategies used by participants. As noted in previous studies, professionals' initial response to self-harm was hypervigilance and an attempt to manage risk (O'Connor & Glover, 2017). Professionals also attempted to manage the anxiety arising because of self-harm through seeking certainty about the reason for the behaviour and how they should respond. This, Mason suggested is an attempt to seek 'safe certainty' (Mason, 2019). It mirrored the identified need for further training by participants in previous studies (e.g. Fish & Reid, 2011) and also involved turning to other professionals, or using legislation, as one may lack a sense of personal agency when in a position of 'unsafe uncertainty' (Mason, 2019).

In this study, participants also used strategies to emotionally detach, or distance themselves from the self-harm, as a way of reducing distress. Again, this is in line with previous research which has found professionals use emotional detachment or avoidance as ways of coping with their own distress (Leddie et al., 2021; O'Hara et al., 2021). Over time, through repeated exposure, participants described a process of desensitisation (Rachman, 1967) to self-harm. Overall, desensitisation appeared to be a beneficial process for the current participants, enabling them to tolerate the distress from self-harm and thus be more measured in their response, avoiding more restrictive interventions. Previous research has suggested that this coping style can be adaptive in the short term because it protects the individual from overwhelming feelings of anxiety (e.g. Olff et al., 1995).

Civilotti and colleagues (2021) suggest that the coping strategies adopted are affected by an individual’s attachment style. When experiencing a distressing or threatening situation a person’s attachment system is activated and hyperactivation or deactivation of the attachment system is then used to regulate distress (Mikulincer & Shaver, 2005). People who rely on hyperactivating strategies seek proximity and protection from others, are hypersensitive to possible threat and more likely to ruminate on personal failings. Those who employ deactivating strategies seek to supress or discount threats which may activate the attachment system while striving for self-reliance and distancing themselves from others (Mikulincer & Shaver, 2005). The present model suggested that professionals used both coping styles. Participants ‘controlling’ responses reflected hyperactivating strategies, while the distancing or desensitisation process appeared to mirror deactivating strategies. A study of police officers also found that they used both hyperactivating and deactivating strategies in response to traumatic incidents at work (Civilotti et al., 2021). The extent to which a person relies on deactivating strategies (avoidance) or hyperactivating strategies (anxiety) may reflect their attachment style (Brennan et al., 1998) and this has potential implication for how they respond to self-harm.

Towards acceptance

In this study participants alluded towards the dismissive or hopeless attitudes of colleagues towards PwLD, and the negative impact this had on the support they provided, leading to disengagement or restrictive interventions. Previous research has also suggested that reliance on hyperactivating or deactivating coping strategies is associated with negative outcomes including exhaustion, low mood and depersonalisation (Civilotti et al., 2021). O’Connor and Glover (2017) noted that controlling responses to manage risk often resulted in restrictive practices including close observation, isolation, medication, and restraint. Similarly, previous research has suggested that desensitisation may be linked with negative attitudes towards self-harm and potentially a sign of burnout (Kenning et al, 2010; Marzano et al., 2013). Despite these negative responses reported in colleagues, participants themselves were able to remain empathetic towards the service user and provide support, despite a level of detachment from the self-harm. A functional balance was being able to move between the two without excessive polarisation. According to Bowlby (1969) the caregiving behavioural system is complimentary to the attachment system and activates to provide support or safety to another person. Under conditions of threat the attachment system is primarily activated driving people to seek safety for themselves, as witnessed in the coping strategies initially described by participants above. However, when people feel reasonably secure themselves, they can direct attention to others needs and provide support, despite the context of thereat (Mikulincer & Shaver, 2005). This may explain why participants were able to hold in mind service user needs and responded in more compassionate ways.

Mikulincer and Shaver (2005) suggested that this attachment security, which drives caregiving behaviour, can be dispositional or environmentally induced. An individual’s own attachment experiences may shape the caregiving they provide, however this response can also be shaped by the system around an individual (Schuengel et al., 2010). Participants spoke about the importance of having support from colleagues, and from more senior staff members in the organisation, which may have acted as a ‘secure base’ and sense of security (Biggart et al., 2017; Bowlby, 1988).

Professionals in this study also moved towards accepting uncertainty about the risk, the reason for self-harm, and their own response. Mason (1993) proposed a process of moving towards a position of 'safe uncertainty'. Safe uncertainty involves a deeper curiosity, an ability to take a position of not knowing, an openness to experiment with difference, and a more collaborative way of working together (Mason, 2019). This shift appeared related to participants' experience, and again a supportive work environment. O'Connor and Glover (2017) also highlighted the importance of a supportive work environment particularly the role of active management, supervision, and debriefing. which enabled open communication, reflection, and shared experience.

Limitations

While theoretical sufficiency appeared to be met, due to a limited pool of potential participants theoretical sampling did not always guide the evolution of the model. Without this core element of grounded theory methodology it may be more appropriate to consider this study an 'abbreviated' version of grounded theory (Corbin & Strauss, 2015).
Attempts were made to recruit participants from a variety of professional backgrounds and with different levels of seniority within the management structure of the care sector. This inclusion allowed for different perspectives to emerge. While a greater number of female participants reflected the make-up of the social care workforce, the sample lacked ethnic diversity which does not reflect professionals in the care sector (Skills for Care, 2021).
Those that self-identified to take part in the project may have espoused a greater interest and thus understanding in self-harm or working with PwLD more generally. Given that one of the emerging concepts was 'caring as a vocation' it would have been useful to interview professional members who perhaps did not share these values. It is also worth noting the potential for self-censorship in the interviews, which is more likely to occur when interview

topics reflect respondents' identities (Yannos & Hopper, 2008). This may have prevented participants from sharing understanding of, or responses to, self-harm that did not align with their values.

Respondent validation received at the time of writing suggested that the model did seem to capture the experiences of professionals working with PwLD who self-harm. However, feedback was limited to only three respondents, and due to time constraints more detailed feedback could not be sought.

Clinical implications

This study highlighted the emotional challenge of working with people who self-harm in the already demanding context of social care. High levels of emotion may inhibit distress tolerance, empathy, and motivation which are essential in the delivery of compassionate care (Cole-King & Gilbert, 2011). Sharing the challenging nature of this work and the difficult emotions it can bring up was deemed helpful for participants as a way to manage the distress. Previous research has suggested supervision and reflective practice are useful to increase reflection, distress tolerance and sharing of experiences and subsequently improve care (Artis & Smith, 2013; Wilstrand et al., 2007). These should be routinely embedded into care organisations.

Participants in the current study sought further training as a way of seeking certainty; the model suggests that this may be helpful in managing some of the anxiety arising as a result of self-harm. Indeed, previous research has found that training is associated with more positive attitudes towards self-harm (Saunders et al., 2012) and can reduce the use of restrictive interventions by encouraging a more recovery orientated approach (Karman et al., 2015). However, it is important to hold in mind that this study suggested that moving towards an acceptance of uncertainty was also helpful for professionals when working with people who self-harm. Mindfulness has been described as a practice of safe uncertainty (Moss et al., 2008). Previous research has found mindfulness-based stress reduction programs have had positive outcomes in healthcare professionals including decreasing stress and burnout (Shapiro et al., 1998, 2005, 2007). These practices may also benefit professionals in the social care sector.

In line with previous research the study noted that individuals hold a multitude of reasons for an individual’s self-harm (Samways; 2021). Clinical psychologists might be particularly well placed to increase opportunities for professionals to develop shared client formulations which can then shape understanding and delivery of person-centred care. Previous research has suggested professionals find team formulations in learning disabilities services helpful, developed their understanding, and positively impacted on professionals’ work with the service user (Turner et al., 2018).

Participants emphasised the current powerlessness for professional, and service users, within the social care system. Psychologists may work with service users, professionals, and organisations to advocate for system-level changes including the empowerment of PwLD and greater recognition of the role of carers. Clinical psychologists working towards socio-political change may have further reaching impact than working individually (Browne et al., 2020; McGrath et al., 2016).

Future research

Further research may seek to test the fit of the current model with a broader range of professionals working in social care including people who are not white British. Additionally, including professionals who have recently left, or are considering leaving the care sector, may provide further insight into the challenges of working with this population. Research should understand how personal values influence the work, and explore the potential distress, or moral injury, experienced when these values are not upheld. Furthermore, exploration of individual attachment styles and the impact that this may have on coping responses should be considered. This may further develop our understanding as to why restrictive or punitive practices may be used.

Other research designs, including longitudinal studies that track professionals' experiences over time, might further investigate factors that influence the shift towards tolerance of distress, uncertainty, and acceptance of self-harm. Factors which facilitate this process, particularly the importance of the organisational context, could be explored in greater depth. Most importantly research could examine this move towards acceptance from the service users' perspective and the support they perceive to be most helpful in response to their self-harm.

Conclusion

Working in the care sector with PwLD is a demanding job (Leoni et al, 2020) and high levels of stress and burnout are reported, particularly when working with behaviour that challenges (Ryan et al., 2021). Self-harm is often subsumed under the umbrella term 'challenging behaviour' (Samways, 2021) however less was known about the experience of professionals working with self-harm uniquely, deemed important given the high prevalence of self-harm reported in PwLD (Bowring et al., 2017; Deb et al., 2001). Outside of the field of learning disabilities, research suggested professionals working with people who self-harm found it emotionally challenging (O'Connor & Glover, 2017). Emotional responses, and attitudes, influenced professionals response towards people who self-harmed (O'Connor & Glover, 2017; Saunders et al., 2012). Research also found that working with PwLD who self-harmed was emotionally challenging (Fish & Morgan, 2018; Fish & Reid, 2011) however how this affected professionals' response to self-harm was unknown.

This study aimed to better understand the way in which social care professionals worked with PwLD who harm themselves. Using grounded theory, a preliminary model of how professionals navigate distress when working with PwLD who self-harmed was developed.

Self-harm evoked feelings of powerlessness which was experienced as a threat to professionals’ values and caring identity. Uncertainty about the reason for the self-harm, and how they should respond, heighted participants distress. Professionals moved between attempting to reduce or control the distress self-harm created and towards learning to tolerate or accept the strong emotions that self-harm evoked. A functional balance was being able to move between the two without excessive polarisation. Individual attachment style and the wider organisational context were important in shaping this process. The findings build on previous research about the emotional impact of self-harm and the way in which professionals’ emotional response and understanding of the behaviour may shape the response.

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APPENDICES

Appendix A: CASP framework for qualitative research

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Appendix B: Summary of CASP evaluation

Paper	Aims	Methods	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research
Brown & Beail (2009)	Yes: Aims to explore participants' own experiences of their self-harm and understanding of other people's responses to their self-harm, including interventions	Yes: Qualitative method due to exploratory research seeking to explore participants experiences and understanding	Yes: IPA chosen as it aims to understand experiences from participants subjective individual perspective	Yes: Recruitment is appropriately described and discussed by the authors.	Yes: A description of data collection provided including how local procedures for working with this client group were followed and implications for the presence of additional staff members considered.	Yes: Acknowledgement about how the researcher own ideas may have influenced the research process and steps taken to make these explicit acknowledged.	Partially: Approval by local research ethics committee reported. Limited information about how the study was explained to participant and other ethical issues	Yes: Detailed description of the analytic procedure followed by the researcher. Sufficient quotes provided to illustrate themes. Contradictory findings could have been included	Yes: Four master themes identified in relation to initial research question. Credibility of research discussed.	Yes: The study adds to limited research on views and experience of PwLD and considered findings in context of previous research. Limitations for study and suggestions for further research discussed
Browne et al., (2019)	Yes: To develop a theory from service user perspective about process of engagement with DBT and how this relates to perceived change	Yes: Qualitative methodology used to develop model from service user perspective which is identified as a gap in the literature	Yes: Constructivist grounded theory was employed as it facilitates generation of explanatory theory from the data, rather than simply describing experiences. Focus on change process with DBT lends itself to process model developed through grounded theory	Partially: A description of sampling strategy is provided including inclusion and exclusion criteria. Participants were only recruited from secure settings although the aims do not explicitly define this scope.	Yes: An adequate description of the methods used for data collection provided including recording, transcription and details of the data collection and parallel analysis undertaken in grounded theory. Data collection was via semi-structured interviews and consideration of guidelines	Partially: A statement about reflexivity provided considering how researchers own experiences may influence data interpretation. The study considers acquiescence during interviews but interviewers relationship to participants not considered.	Yes: Ethical approval obtained. Consideration of ethical issues particularly consent process highlighted	Yes: Detailed account of process of grounded theory including constant comparison, simultaneous data collection and analysis and clear examples provided. Reflection on researchers own role and the use of memo's and supervision to reflect critically on this.	Yes: A explicit model provided which encapsulates findings produced in response to initial research question. The sample included individuals who had completed, dropped out or were currently undertaking DBT, thereby providing negative case comparisons,	Yes: presents the first theoretical understanding of the pro- cess of engagement with DBT and related change for PwLD. Explicit links made to existing understanding and clinical implications highlighted. Areas for further research suggested. Limitations in generalizing the data (e.g.,. to populations with more severe LD) discussed

Paper	Aims	Methods	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research
					for interviewing PwLD				follow up interviews were conducted with two participants to test categories and there was more than one analyst.	
Clarke et al., (2019)	Partially: Aims of the research differ slightly between abstract (explore relationship between how challenging behaviours are managed and wellbeing) and introduction (explore how PwLD understanding of own behaviour impacts on overall wellbeing).	Yes: Qualitative methodology chosen to explore the subjective experiences of individuals.	Yes: IPA chosen to conduct detailed examination of participants lived experiences and their interpretations of challenging behaviour.	Partially: A description of the sampling strategy is provided however limited detail about how participants were identified and recruited. Discussion of limitations of generalizing to individuals with more severe learning disability discussed.	Yes: An adequate description of the methods used for data collection provided including recording and transcription. Overview of topics discussed in interviews provided.	Partially: Explicit statement of reflexivity of the first author provided including epistemological stance and views on positive behavioural support framework. Other authors positions are not identified. How views may have influenced the development of the research question and data collection not explicit.	Partially: It is not clear from this study whether ethical approval was sought. The authors briefly discuss seeking informed consent and practices put in place to ensure participants felt comfortable during the interview.	Yes: Description of the analytic procedure followed by the researched provided. Analysis involved independent analysis by authors and comparison between transcripts.	Yes: Authors identify four master themes and consider how these themes may relate to each other.	Yes: The study makes steps in conceptualizing how PwLD come to understand their own behaviour and makes tentative recommendations for services. Transferability of findings to individuals with more profound LD discussed. Suggestions for further research suggested.
Duperouzel & Fish (2008)	Partially: This is a synthesis of two existing papers with	Yes: Qualitative methodology used in the initial	Partially: Phenomenological approach chosen as it is concerned with	Partially: A limited description of the sampling strategy, more	No: Very limted detail about data collection. More	Partially: Statement made about how researchers examined own	Partially: Brief statement stating ethical approval and	Partially: Brief overview of data analysis however more	Partially: Overview of findings provided and attempts	Yes: Discussion of the study findings in the context of existing

Paper	Aims	Methods	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research
	a slightly different focus and aims to synthesis them. The aim appears to be to determine common themes affecting staff and service users although this is not explicit.	studies which aimed to explore the experiences of staff and service users around self-harm	the study of an experience (self-injury) form the perspective of the individual. Limited detail	details may have been provided in the original papers but the paper with PwLD was no published. Participants recruited from one service only	information may have been provided in initial studies.	beliefs and "bracketed" these viewpoints however no reflection on how this may have influenced data collection. Researchers appear to work in the setting where the research took place.	informed consent sought.	details of "cylindrical process" could have been provided. Sufficient data is presented to support themes however contradictory data is not explored.	made to highlight similarities and differences between service users and staff views. Discussion of the credibility of findings is limited	literature, although in some areas these links could be made clearer. Recommendations for practice made although further recommendations for research could have been suggested.
Duperouzel & Fish (2010)	Yes: Aims to capture the meanings attributes to self-harm and the perception that people have of their care	Yes: Qualitative methodology chosen to explore the subjective experiences of individuals. Linked to NICE self-harm guidance (2004)	Partially: Phenomenological approach chosen as it is concerned with the study of an experience from the perspective of the individual. Limited detail	Yes: Detailed description of participant recruitment and sampling. Reasons for participant withdrawal could have been discussed as source of potential boas in sample.	Yes: An adequate description of the methods used for data collection provided including recording and transcription. As each participant took part in two or more interviews consideration was given to how this process influenced data collection	Yes: Consideration to how personal beliefs and biases may have influenced data collection and interpretation. Steps taken to increase awareness of this noted. Researchers appear to work in the setting where the research took place.	Yes: Consideration of ethical issues including individualised process of seeking formed consent and considering participants comfort during interview. Ethical approval from appropriate bodies sought. Follow up support for participants could have	Yes: Description of analytic procedure followed by researcher provided. Participants were consulted about emerging themes The authors state they attempt to suspend "personal meaning and interpretations" but could have included further critical analysis of	Yes: Four main themes identified relating to how self-harm is used as a coping strategy and response to self-harm; results are discussed in relation to original research question. Authors identify "some very individual accounts" of self-harm but discussion of these possible	Yes: The study adds to limited qualitative research on the view and experiences of PwLD. Practical recommendations for clinicians made although further research not discussed.

Paper	Aims	Methods	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research
							been discussed.	own role in data analysis.	contradictions were limited.	
Gleeson et al., (2020)	Yes: To explore the experiences of PwLD who live with others who engage in behaviours that challenge	Yes: Qualitative methodology chosen to explore the subjective experiences of individuals. Previous research largely quantitative.	Yes: IPA chosen to conduct detailed examination of participants lived experiences. Discussed possible concerns using IPA with PwLD and justification for its use	Partially: A limited description of the sampling strategy provided. No further discussion about recruitment (i.e. who chose not take part). Participants selected from one service only.	Yes: A clear description of interview procedure and detail regarding the interview schedule included. Use of a pilot study do develop the interview schedule.	Partially: States the use of a reflexive journal during the process of interpretation and acknowledges the researcher role in the analysis. Further consideration could have been given to how researchers influenced data collection and formulation of the research question	Partially: ethical approval sought. Brief mention of ethical guidelines including consent and confidentiality, but further detail could be given particularly working with PwLD	Yes: Description of analytic procedure in IPA followed by the researchers. Analysis was independently audited by the third author and themes discussed with initial participants to ensure these were reasonable representations of their experiences.	Yes: The authors provide a comprehensive set of findings as subordinate and sub-themes, illustrated by participant quotes, in relation to the original research question. Limitations discussed	Yes: Findings discussed in context of previous research. The study makes explicit clinical implications of the findings in the context of current practice guidelines. More specific areas for further research could have been highlighted
Harker-Longton & Fish (2002)	Yes: To explore understanding of self-harm from a personal perspective of the research participant (Catherine)	Yes: Qualitative methodology chosen to provide an account of the experience individual from a personal perspective	Partially: Justification of the phenomenological approach, though not particular method of analysis, as it seeks to describe lived experience	No: No explanation of how Catherine was selected as the participant for the study other than she was known to the researcher	Partially: A description of the data collection process is provided although more detail about the total number of interviews and information about how interviews were	No: Researchers comment on their own history of relationship with Catherine but do not consider how this shaped the development of this research project or the data collection	Yes: The authors provide great detail about the ethical considerations as well as possible limitations in their own project. No evidence of approval by an ethics committee	Partially: Description of how transcripts were analysed provided however no overview of "umbrella elements". The authors own role is not critically appraised	Partially: Catherine’s experiences are summarised however statement of findings is not particularly clear. Credibility of findings is limited, for example no mention of review by	Partially: The research only sought to describe a personal account of self-harm in the context of a residential service; suggestions are made for how Catherine may be further supported however the findings are not generalised.

Paper	Aims	Methods	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research
					conducted was not				another analyst	Suggested replication
Heslop & Macauley (2009)	Yes: Aims of the research outlines including detail about how the research proposal was developed	Yes: Qualitative methodology chosen to explore the subjective experiences of individuals.	No: Grounded theory cited as the approach to analysis however no generation of overall theory but analysis of results in thematic way.	Yes: Detailed description of recruitment of participants; there is discussion around ensuring diversity particularly including participants who may have limited verbal communication. Details of participants who withdrew from study included.	Yes: A clear description of interview procedure and detail regarding the interview schedule included; this included information about how the interview schedule was adapted based on participants communication abilities. Use of a pilot study do develop the interview schedule.	No: There is no statement of reflexivity provided by the researches however how the research project was initiated is outlined. Challenges of interviewing PwLD including the role of power imbalances were highlighted but no indication of how this may have influenced data collection.	Yes: Consideration of ethical issues including informed consent, ensuring participants wellbeing, and post-interview support. Ethical approval from appropriate bodies sought	Partially: Brief overview of data analysis however no thematic map of overarching "theory" outlined. Use of constant comparison between developing themes and further data collection described. Multiple quotes to illustrate themes. The authors own role is not critically appraised.	No: No succinct link between findings and initial research questions. Credibility of findings not discussed.	Partially: The study adds to limited qualitative research on the experiences of PwLD particularly those who do not use verbal communication. Findings are not discussed in relation to the current literature or critically appraised. It does propose recommendations however no explicit links to existing theories are made. No suggestions for further research
Lunsky & Gracey (2009)	Yes: to learn about the challenges faced by women in the emergency department (ED) and get suggestions on how to	Yes: Qualitative methodology chosen to explore the subjective experiences of individuals.	Partially: Although the design (thematic analysis) seems appropriate to answer the research question the rationale is not explicitly discussed in the paper	Yes: Description of how participants were recruited provided. Given that initial recruitment strategy appeared	Yes: Details of data collection process outlined including how interviews are conducted. Reasons for using focus groups with	No: There is no statement of reflexivity provided by the researchers	Yes: Ethical approval was sought. Sufficient detail about how research was explained to participants and consent sought outlined.	Partially: Description of how data was analysed provided. How categories/ themes were derived from the data is not clear however	Yes: Research findings are discussed in response to the original research question. Limitations of current	Yes: The study is the first to explore the experiences of women with LD in ED. The findings are discussed in relation to existing knowledge and

Paper	Aims	Methods	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research
	improve crisis management from the perspective of service users.			widespread it would be interesting to include some comment about why only four participants took part.	people with learning disabilities justified. Setting for data collection unknown.			quotes are provided to illustrate themes. Contradictory findings are not discussed	research discussed	understanding. Discussion of limitations in transferring knowledge to other populations and suggestions for further research provided.
McKensie et al. (2018)	Yes: To explore the perceptions of PwLD about positive behavioural support (PBS)	Yes: Qualitative methodology chosen to explore the subjective experiences of individuals.	Yes: "Inductive thematic analysis". Suitable for analysing both interview and focus group data, situates the themes strongly within the data	Yes: Overview of sampling strategy provided. As participants were recruited through advocacy organisations some participants receiving PBS may have been excluded. Awareness of possible bias due to sampling strategy	Partially: Appears to be some interviews and some focus groups but unclear the number of participants why these were chosen other than personal preference. Use of semi-structured interviews appropriate	No: There is no statement of reflexivity provided by the researchers	Yes: Ethical approval sought. Details about consent procedure. Participants had option to attend interview with support worker if they wished.	Partially: Description of how data was analysed provided. How categories/ themes were derived from the data is not clear however quotes are provided to illustrate themes. Contradictory findings are not discussed	Yes: Finding summarised explicitly and discussed in response to original research question. Credibility of results considered with data analysed by two researchers and response validation. Discussion of potential contradictions limited.	Yes: The study adds to limited research on the views and experiences of PwLD regarding PBS. Some consideration of contribution to existing policy and practice and how the findings may be utilized by future research.
Ogilvie (2019)	Yes: Principle and secondary research questions outlined.	Yes: Qualitative method due to exploratory research seeking to explore participants	Yes: IPA concerned with obtaining a detailed account of how somebody experiences a particular phenomenon and	Yes: Description of how participants were recruited provided including descriptions of reasons of	Yes: Clear description of interview including development of questions. Justification provided for using staff	Yes: Explicit statement about researchers epoche and consideration of how their role (as music therapist) may affect the interviews.	Yes: Detailed description of how research was explained to participants and consent sought. Ethical approval	Yes: In-dept description of analysis process including examples of data and coding and	Yes: Finding summarised explicitly and discussed in response to original research question; there were	Yes: Clearly outlines the contribution of the study to existing knowledge and discusses both clinical implications and

Paper	Aims	Methods	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research
		experiences and understanding	is about the person's own experience and perception of it.	participants who were not included in the study.	focus groups vs individual interviews for service user.		(including amendments) discussed	development of themes.	multiple aims and initial questions so results section is dense. Reflection on credibility of results.	areas for further research.
Wolkorte et al., (2019)	Yes: To provide an overview of the views and preferences of PwLD on challenging behaviour. Specific research questions provided.	Yes: States the importance of including the experiences of PwLD in research and practice. Qualitative methodology allows focus on views and experiences of PwLD	Partially: Although the design (thematic analysis) seems appropriate to answer the research question the rationale is not explicitly discussed in the paper	Partially: Overview of sampling strategy given. Details about how this group identified participants, and in what settings, not provided. Justification for using "proxy" interviews provided.	Yes: An adequate description of the methods used for data collection provided including recording and transcription. Overview development of interview schedule and included topics provided.	No: There is no statement of reflexivity provided by the researchers	Partially: Reviewed by appropriate ethical body. The authors discuss certain practices put in place to support the participants however process of informed consent not discussed. Debrief or follow up not discussed.	Partially: Adequate account of the analytic process, further quotes may have been useful in illustrating themes. Initial analysis to compare responses from PwLD and proxy interviews however further details not given.	Yes: Results summarised, and credibility of findings highlighted including analysis and comparison between different researchers. Findings discussed in relation to previous research including possible contradictions Limitations of the study, including the use of proxy interviews, discussed	Yes: Adds to the limited studies on the views and experiences of PwLD about challenging behaviour particularly as it is non-UK based. A number of recommendations for research and policy are made as well as recommendations for further research

Appendix C: Data extraction and initial coding example

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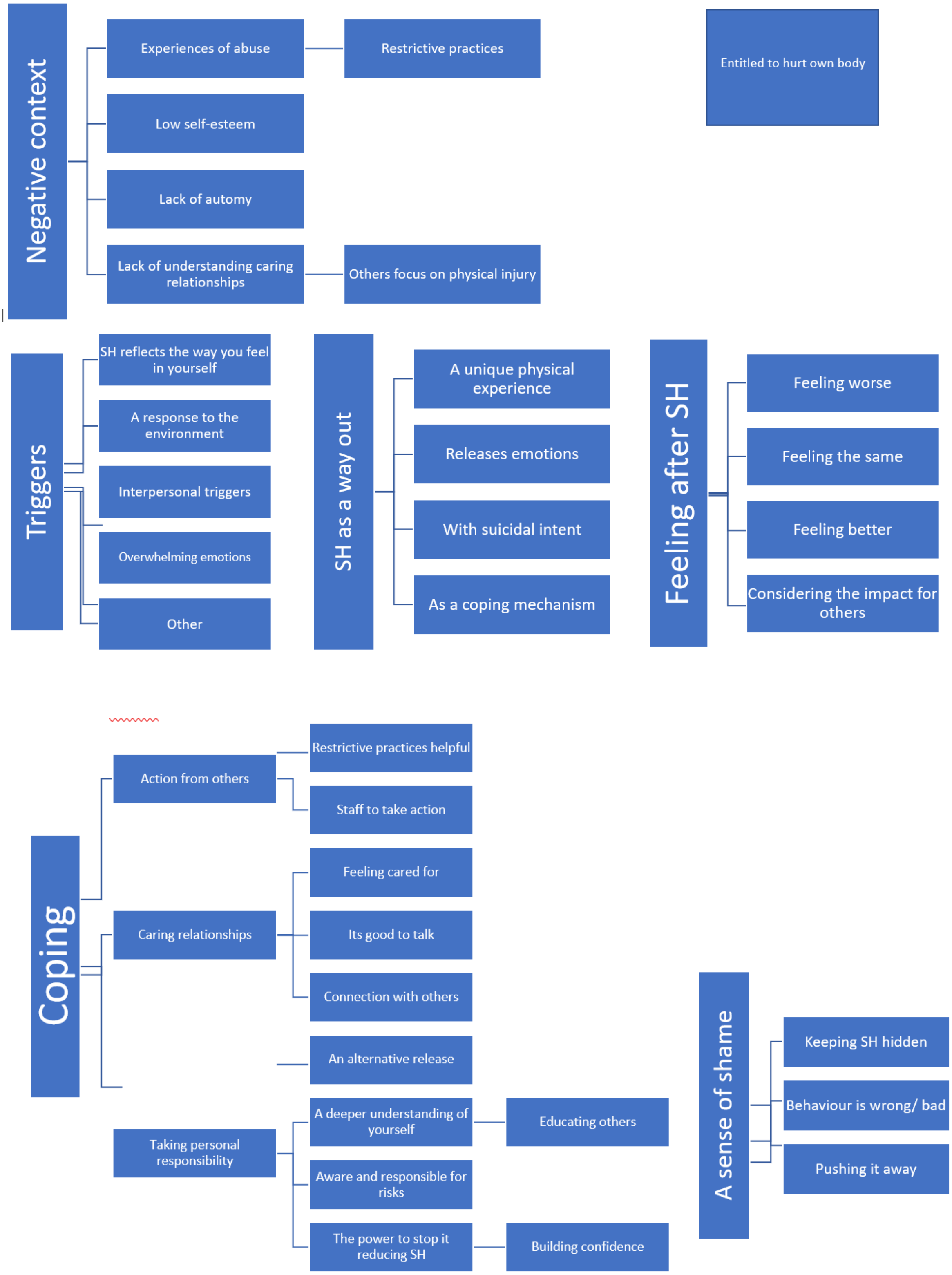
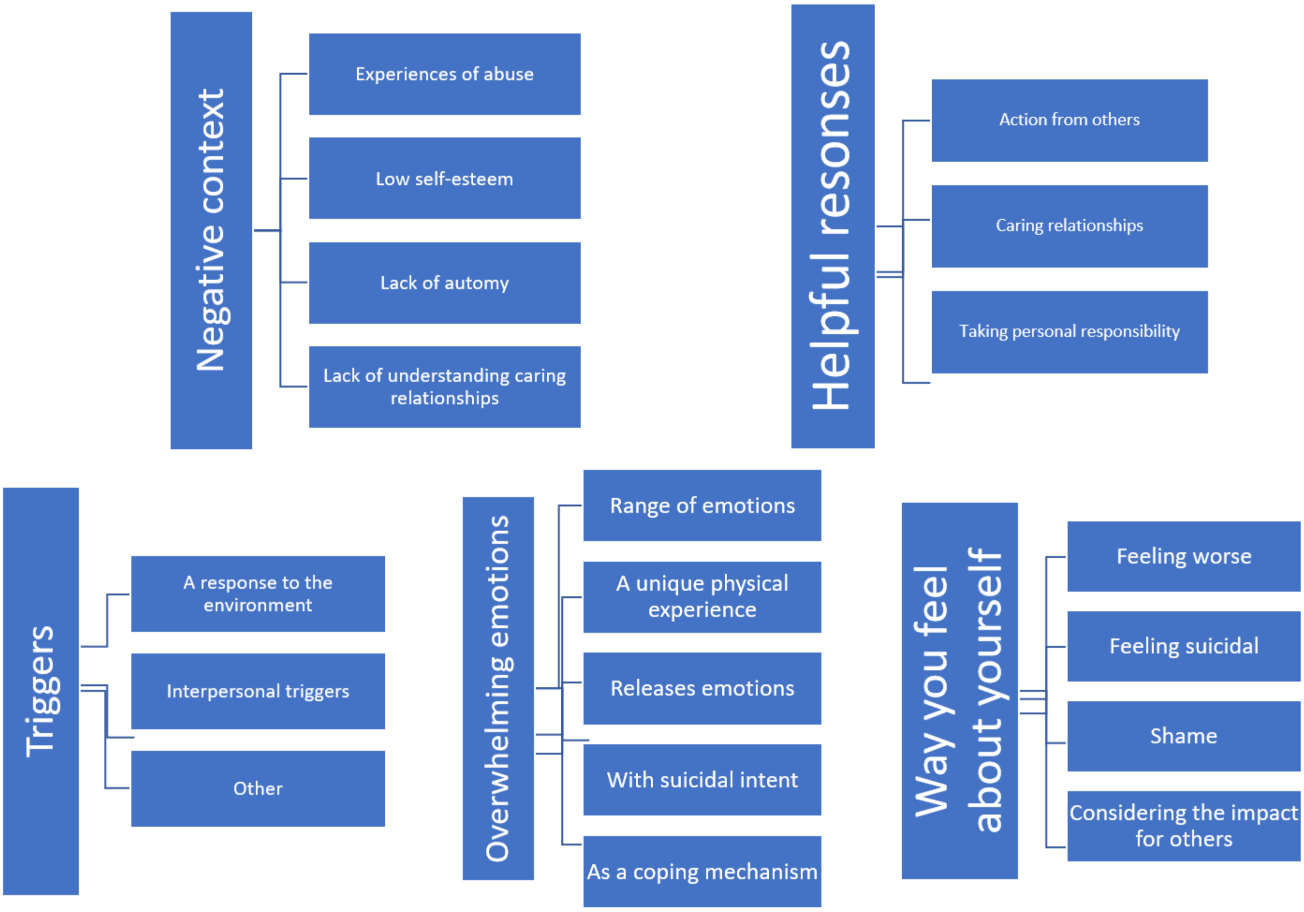
Appendix D: Development of hierarchical themes

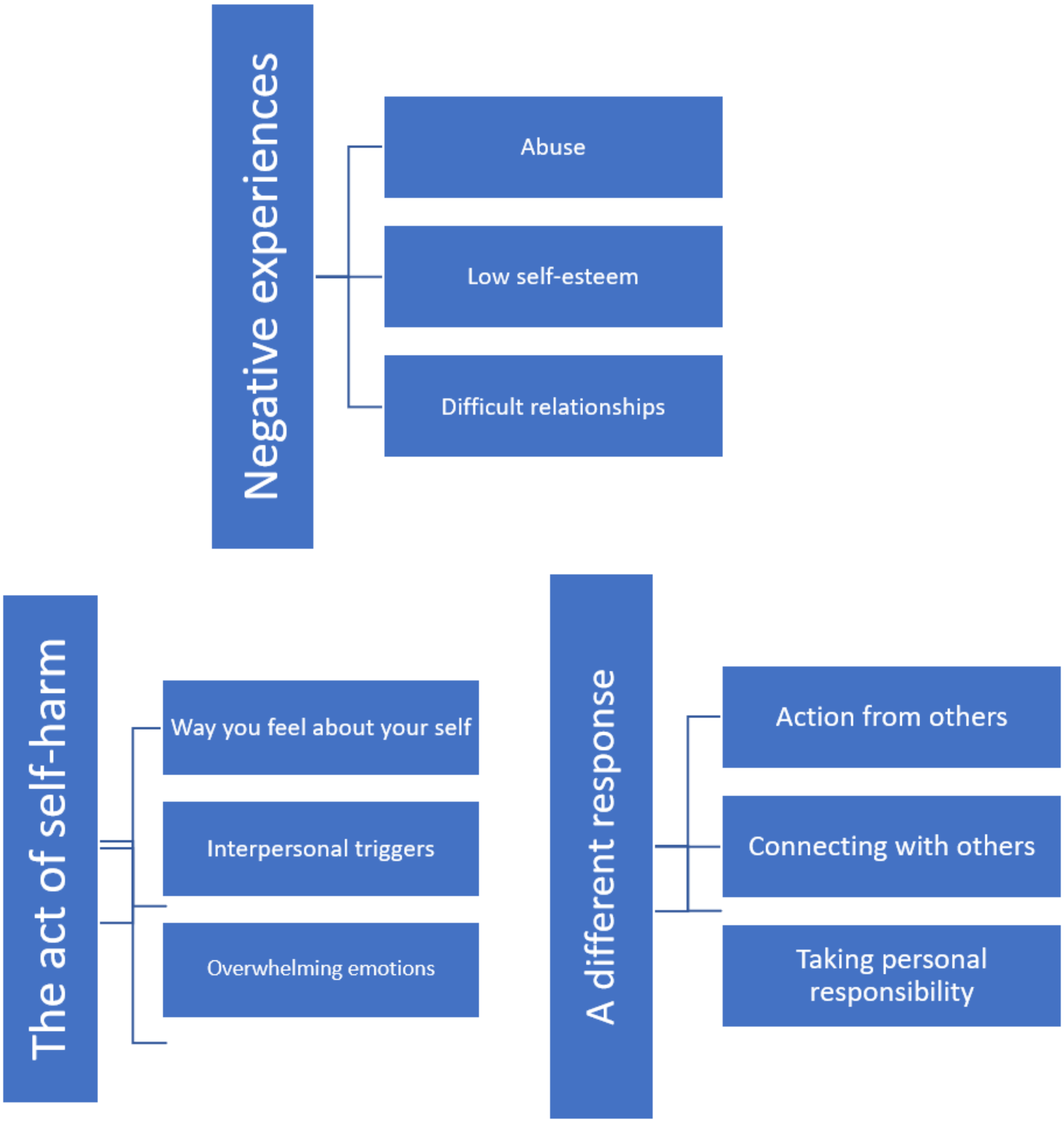
Stage 1



Stage 2


Negative context
Experiences of abuse
Low self-esteem
Lack of automy
Lack of understanding caring relationships
Helpful resonses
Action from others
Caring relationships
Taking personal responsibility
Triggers
A response to the environment
Interpersonal triggers
Other
Overwhelming emotions
Range of emotions
A unique physical experience
Releases emotions
With suicidal intent
As a coping mechanism
Way you feel about yourself
Feeling worse
Feeling suicidal
Shame
Considering the impact for others

Stage 3


Negative experiences
Abuse
Low self-esteem
Difficult relationships
The act of self-harm
Way you feel about your self
Interpersonal triggers
Overwhelming emotions
A different response
Action from others
Connecting with others
Taking personal responsibility

Appendix E: Themes, codes, and illustrative quotes

Theme	Sub-theme	Code	Number of papers	Illustrative quote
Negative experiences	Abuse	Historic abuse	2	My childhood was messed up. Can remember what started all this self-harm business because my mum used to beat me up really bad, that's why it all started 'cos my Mum was nasty to me…my Mum said I was a **up and, an accident. [Quietly] I'm not a **up. I'm not an accident… and that's how the absconding started
		Abuse in current environment	1	Pulls your hair and that and hits you and kicks you
		Implied abuse	3	Wendy: What do they mean to you those scars? What do they mean to you? Catherine: [long pause] Problems. [long pause] Past. Wendy: What do you think when you injure yourself? Catherine: It still hurts. Pain in there. [points to her heart]
		Abusive responses to self-harm	3	Went through complaints procedure at hospital, but it was ignored. If we assault them, we go to jail or court [and this happened to her]. But if they assault us, it is ignored. What gives them the right to assault us?
	Lack of autonomy	Lack of control over environment	5	Not really, no…I have to wait till the staff come in until I can get my breakfast cereal out. I think that's a stupid idea…
		Deprivation of liberties	3	I've been on my section for eleven years, so I cut up after my TCP's [treatment and care planning meetings] and my section renewals,
		Treated less like an adult	3	I'm not a kid or a baby. I'm not an animal either but I'm in this cage . . .
		Further restrictions as result of self-harm	5	Well when I've cut up in the past there's your punishment of putting you on a level three for a few months until things get better. That's what they've always done with me. They punish me by putting me on a higher supervision level, increase my supervision level to a level three..,
		Restrictions not helpful	4	They'll take everything off me, I think it's damn rude, they shouldn't do that. I should be trusted shouldn't I?
		Seeking greater autonomy	1	I'd like to get free time and see all my friends in the club, and then I wouldn't have to sit with staff in the club.

	Difficult relationships	Feeling ignored or not listened to	6	I was determined not to self-injure, I told staff as a matter of urgency, but they really wasn't paying much attention, and they weren't doing things quick enough to remedy the situation…
		Others don't care	4	He said, 'You can hit yourself as much as you like, I don't care.' That's what he said. Yes he did say that….I was upset when he said it.
		Rejected	2	Catherine: They leave me always. Everyone leaves me, they're leaving me, nasty aren't they? I feel rejected and lost, it always happens, they leave. [long pause] Everyone does.
		Lack of positive relationships	3	I don't know who to go to
		Judged	3	I also feel that people shouldn't judge us as they've never had to go through what we've had to go through.
		Feeling misunderstood	6	They don't really understand why I was at that, why I was hurting myself
		Talking is difficult	5	I couldn't tell them that I wasn't alright. Otherwise they'll say to go chat in the calming room and all this, cos talking to them doesn't really help that much
		Others expect too much	2	You are a smooth talker and so.. so people think you can handle everything, but that is not the case at all.
The act of SH	Overwhelming emotions	Sad or low	5	Like being in a thick fog…like being in a dark tunnel and no way out, can't see a light, all me thoughts are negative
		Anger	7	When you feel like that, when you want to hurt yourself, you're that angry or frustrated… mainly frustrated more than anything
		Frightened or anxious	5	Moira gave a number of examples of feeling 'scared'. She said that it was like being frightened of a wasp. She also identified 'scared' as being when people are laughing at her, or when she is laughing at others. She indicated that when people are screaming she feels scared, and then bites her hand and screams herself.
		Excited	1	Feeling excited could also lead to Moira biting her hands
		Confused	2	There were voices going on in my head and that and I didn't know where they were coming from, so I used to harm myself, you know
		Overwhelmed	8	I felt really bad, everything was getting on top of me, I couldn't see a way out of it, and I did it
		Bottling up	2	then you end up either getting angry and angry and bottling it up inside … you end up firing chairs or firing things across the floor or hitting something off the wall in your bedroom or cutting yourself
		Release	4	Whatever I'm sad about it's steam coming out. A rush of stuff, stuff inside.
		Diversion of pain	2	It was just like diverting it to pain so then I chilled out a bit.

		Masks physical experience	3	Well, one thing with self-harm, y'see, you don't feel the pain. Then you can cut cut cut cut cut and you just don't feel t'pain while afterwards y'see. [Right…and what's it like for you afterwards?]. Oh it's awful
		Expect to be cut	1	Your body gets addicted. And when you get angry, when you get angry it expects, when you get angry your body expects to be cut
		Feel better after	6	It gets all my feelings out and you come back and you are happy.
		Pleasurable sensations	2	Wendy: What's swallowing about? Catherine: Suffocate. You get a trip to hospital, get an operation, I like the feeling of general anaesthetic, makes you go to sleep. I love that feeling.
		Bad feelings return or worse	4	'I'm fed up with doing it (self-harming)…'
		Worried about consequences	1	'I get upset……after I get upsets sometimes….I just do, 'cause … I get upset 'cause things are going through my mind sometimes of what's going on….what's gonna happen and … 'cause I don't want that to happen, but it's going through me head what's happening and what I keep doing at home and what I've done'.
	Way you feel about your self	Negative self-image	5	'I didn't like myself, I didn't wanna know and I hated my body, the way it was
		Critical about self-harm	4	It's not normal behaviour
		Angry or disgusted at self	3	The fact I've threatened a woman again and I said I'll never, I'll never do that again…it, it hurt like….i was gonna end up like…threatening women again and again and I said I'm not, like I said I'm not, not a woman beater, never have been, never will be…and the reason that I did that (shows injury) is because I threatened a woman
		Wanting change but not knowing how	2	I went to anger management, I thought that would work but it never…I don't know who to go to, I do want to get out of it…I don't know how I get out of it, I really don't.
		Lacking confidence in ability to use other skills	3	I had paranoia of doing skills wrong…
		Suicidal	4	A terminal situation, I wasn't thinking, oh, I'll self injure to get their attention…I got to the stage where I thought **** it, I don't want to put up with all this shit…It got to the stage where I didn't care to live… it was the lowest moment in my life

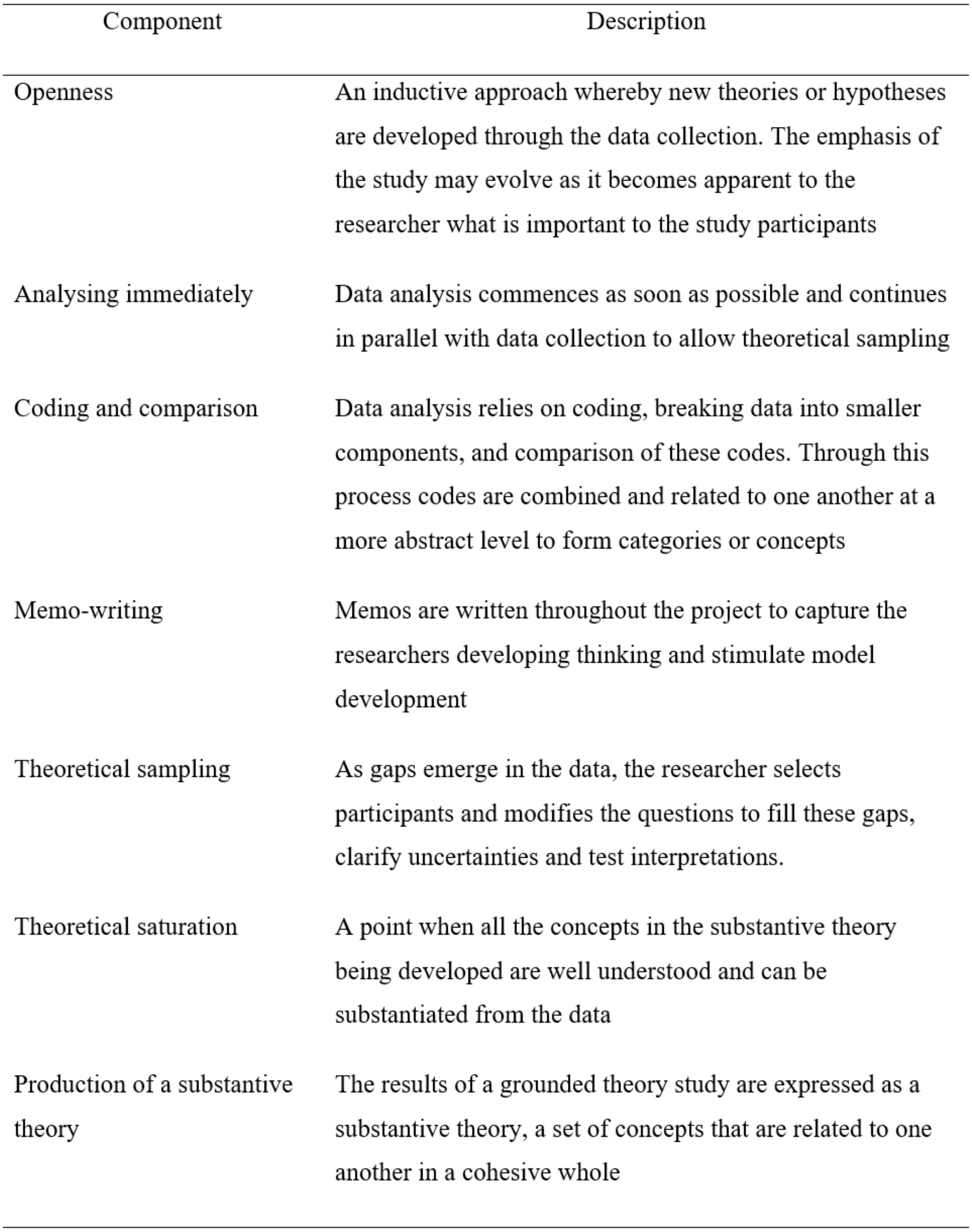
		Unable to cope	3	Of what help you get, if you can’t address those problems yourself, and you can’t find any other coping mechanisms without self injuring you get to the state where you resort to self-injury
		Punishment	1	I used to feel like I had to punish myself, for being dirty. I was dirty so I had to punish myself. Some days I still feel like that.
		Physical health	1	Sometimes, when I start building up to a seizure I start bashing myself there, there, on my neck, on my body, on my arms, I get my teeth and bite myself
		Shame	4	I can’t wear tops anymore. I’ve got to keep me trousers on and keep my tops, because; see my arms, its bad enough to see them in the bath. What’s it like for you, when you see them?] I just don’t like it [Can you tell me any more about it?] No, I just don’t like it. No. I keep them covered because I don’t like it. I don’t like my body cos I’ve done it, what I’ve done to it
	Interpersonal	Demands from others	4	Well if someone says that, I’ll do it
		Interpersonal conflict	3	‘I don’t like being with Emma (support worker)…I slap myself. I don’t like her louder voice. Louder voice’
		Others unkindness	2	The nursing staff would be described as ‘winding them up’ and would at times tell participants to ‘play with their toys’ or ‘go and do it’,
		Feeling threatened	2	It’s all because she threatened me if I didn’t go to Roseton with her again, I’d get put in the assessment centre….and that’s when I self-harmed’
		Direct at self than others	4	I already have [made changes]. I don't blow up no more. I don't hit out. I don't hit the staff. I don't hit me friends. I just hurt meself
		Other residents enable self-harm	1	Wendy: Do you think it has got worse over the years? Catherine: Well it depends what ward I am on, some wards are worse. Wendy: In what way are they worse? Catherine: Well some people give you things, other residents. So I like to be on my own.
		A private act	1	I do it in me room where there’s nobody around so people won’t be able to see what I’m doing
		Seeing others distress	3	Well, house was unsettled, there were all people kicking off, and things like that. [What was that like for you?] I always do scratch meself if its...I always scratch meself when house is un, when house in’t stable
		The impact of self-harm on others can make you feel worse	2	Catherine: I like them not to make such a fuss, just to treat me and then forget about it. They shouldn’t panic and that. Wendy: How does that make you feel, when people panic? Catherine: I feel worse inside, feel daft. Every time I look at the scars then I feel bad, messing people’s lives, it’s horrible.

		Self-harm makes others angry	4	It's like because you pissed them off so much, because they've got to do all the ****** paperwork, how's this person managed to cut himself, though they were on a one to one type of thing and they are going to get into trouble with the managers.
		Others can't cope with self-harm	4	They didn't cope with it at all. They didn't have a clue what to do with me.
		Causing others distress	4	They were always just like, 'Oh what are you doing to us? You're upsetting us.'
A different response	Action from others	Restrictive interventions can be helpful	7	I've had a lot of help with it. Like my self-harm and things. Like the razor. I know I have to keep it in there now.
		Offered rewards	1	I was told if I wasn't getting into bother I'd get my leave.
		Caring for physical injuries	2	They change my bandages and ring the doctor's to get an appointment.
		Allowed to self-harm	3	Housing that accepts self-harming – mild cutter or banger, where not judged.
		Wanting staff intervention	2	Sometimes I hope, when I'm in the middle of doing it, I hope that somebody will come up and talk to me before I do it, but it doesn't happen
		Building trust	3	She would talk to me and tell me to stop it and all…she talks to me a lot better than other people. I trust her more'.
		Encouragement from other	2	and then with great help from (ward staff names). I think they give you aspects of life to think about, like what could be out there for you once you leave here, giving you goals to aim for. There are better ways.
		Not the only one	2	Having self-harming groups for people to talk about their feelings about it.
		Having others around	3	I know if I was let out with my mum, I wouldn't do anything, because I know she's ill. .
		Feeling understood	1	Sometimes I'll just do it automatically and then when I tell them they'll say, 'Well what have you done that for…but no I think they're pretty caring, they just say, 'Well just try and not do it.' But yeah they're very understanding
		Space to talk	6	A psychologist. Talk about past things. [long pause] That helps.
		Others who listen	1	Well it was somebody you could talk to, and she would listen. But she wouldn't do all the talking, she would let you talk
		Comfort from others	4	I keep a picture (of a previous carer) and that seems to help me. When I feel bad I get both of them out and that helps me

		Knowing others care	5	I had a good experience once. Security guard was getting rude with me. Doc said 'Let her go right now, take your hands off her.' He stitched it up, got cream and I left. Told them [the doctor told the security guard] they can't do things like that.
		Involving professionals	5	I had my psychologist (name) at the time help me and talking to me and saying what's this about? What's that about? And generally talking to me, and counselling through that way,
		Sharing self-harm	3	Int.: When I first knew you, when you got angry you used to self-harm. You say you don't do that so much now. So what do you do when you feel angry now? D: I tell someone…the staff
		Remembering connections	4	I just put my mind to it, all sorts of stuff, I think about getting out of here. Getting off my section. Getting free time. Getting on with staff and living near my family.
		Picking up on others emotions	1	Some people, some of the staff…are just like chilled all the time so then that helped chill me
	Taking personal responsibility	Blocking it out	3	I just go to sleep. I just cover myself over. I've got a giant sized big blanket. I just cover it over my face.
		Teaching others	*2*	It's like an easy reference for people. Like I wear quite blacky clothes, and if I came down in a pink flowery skirt or a pair of wacky trousers they'd probably pick me up for the wacky trousers, whereas the pink flowery skirt would be the real alarm bell ringer, 'cause I wouldn't wear it, but then they'd know if they looked … and it'd save me telling everybody and explaining things
		Keeping busy	4	It blocks things out yeah…if I'm busy I can't think' me
		Writing	2	Just putting it down helps…I write it down. Just how I feel. […] It gets it out of your head quicker. And talking quicker.
		Gaining confidence	3	I've lost some weight…helped to give me some confidence back.
		Using music or music therapy	3	When I feel sad or angry, any music I like, I put it on and it helps
		Managing own risks	5	I could get an infection there and have me arms chopped off or something
		Talking self out of it	4	I stay calm and I say to myself, 'You're not going to do it. Do nothing, you're not going to self-harm.' I talk to myself in my head, ignore stuff.
		Time alone	4	I kinda keep calm and I I kinda go to my room and I stay out of it

		Alternative physical release	2	Especially the one with the tea towel, you put ice in a tea towel and you bang it against the table - that gets quite a lot of the anger out of you. Time you've done that you are totally shattered really. You can't be bothered to even think about self-harming.
		Taking time to calm down	1	It's like I've gotta try and….calm down a little bit, and then normally when I've calmed down I'm normally OK; it might take me an hour, it might take me two hours.
		Changing behaviour	4	I already have [made changes]. I don't blow up no more. I don't hit out. I don't hit the staff. I don't hit me friends. I just hurt meself.. And that's all. And that's something I'm learning, I'm learning a little bit how not to do it.
		A personal choice	4	I think as a self-harmer you should be entitled to what you do to your body as long as it's hurting no-one else's but your own.
		Acceptance of self-harm	2	it's just life
		Proving others wrong	1	And I was like, Right. Screw you, I'm not doing it again, I'm gonna prove you wrong. So that's what I did… I was like,
		Understanding own emotions	3	If I'm stressed and anxious then I sit down and think, well what am I stressed and anxious about?
		Seeing not self-harming as good	1	I've still been good and not self-harmed or anything.
		Apologising	1	Then I apologised to all the staff for having a go at them, and swearing and things like that at them

Appendix F: Fundamental components of grounded theory (Corbin and Strauss, 2015)



Component	Description
Openness	An inductive approach whereby new theories or hypotheses are developed through the data collection. The emphasis of the study may evolve as it becomes apparent to the researcher what is important to the study participants
Analysing immediately	Data analysis commences as soon as possible and continues in parallel with data collection to allow theoretical sampling
Coding and comparison	Data analysis relies on coding, breaking data into smaller components, and comparison of these codes. Through this process codes are combined and related to one another at a more abstract level to form categories or concepts
Memo-writing	Memos are written throughout the project to capture the researchers developing thinking and stimulate model development
Theoretical sampling	As gaps emerge in the data, the researcher selects participants and modifies the questions to fill these gaps, clarify uncertainties and test interpretations.
Theoretical saturation	A point when all the concepts in the substantive theory being developed are well understood and can be substantiated from the data
Production of a substantive theory	The results of a grounded theory study are expressed as a substantive theory, a set of concepts that are related to one another in a cohesive whole

Appendix G: Research advert

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent, TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Research Advert

How do residential support staff understand and respond when individuals with learning disabilities harm themselves?

Hello. My name is Libby Ilett and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study.

The aim of this study is to develop a theory to understand the experience of staff working alongside people with learning disabilities who harm themselves and how you, as staff members, respond.

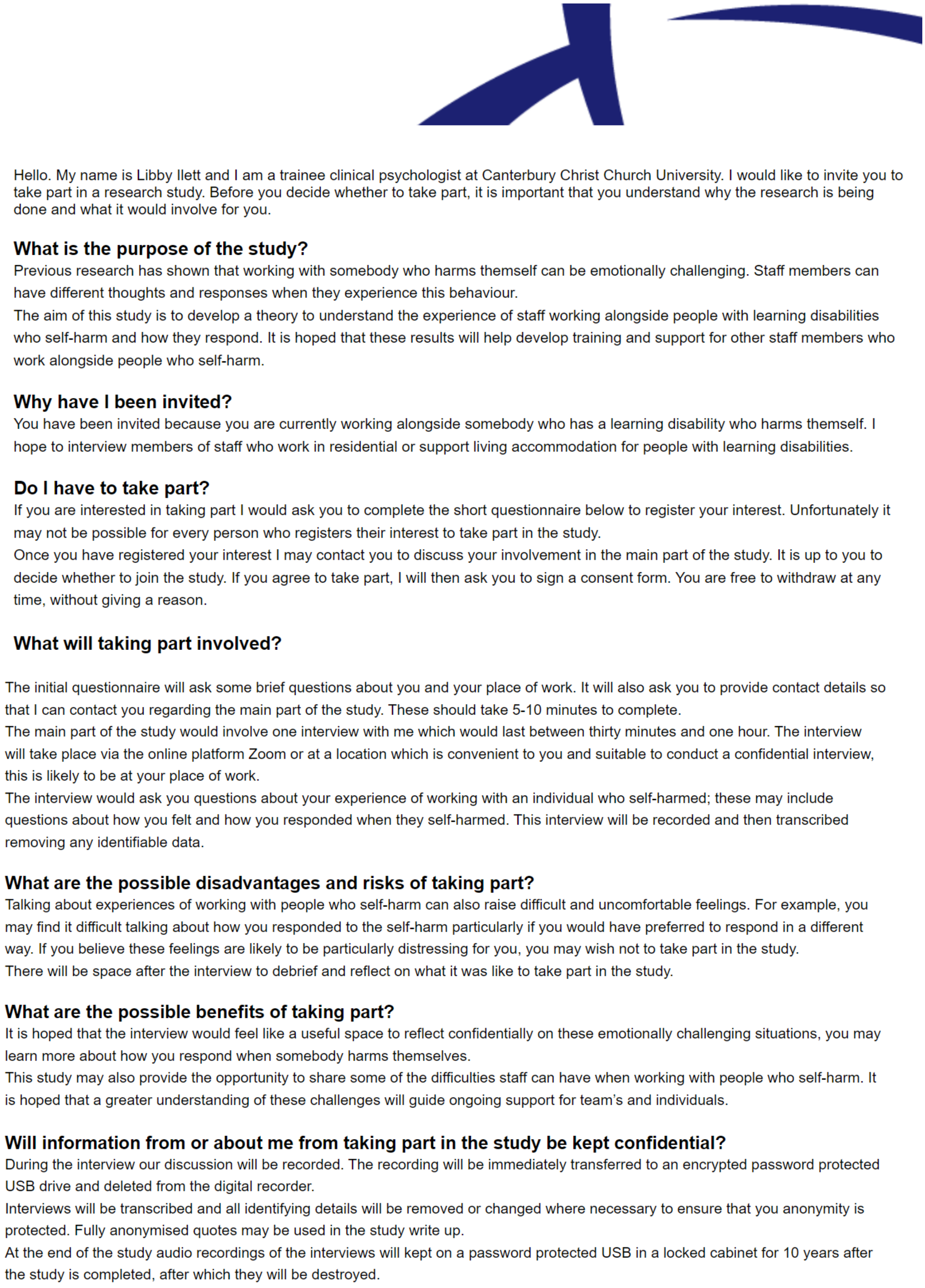
I hope to interview members of staff who work in residential or support living accommodation for people with learning disabilities and, who work with somebody in these settings who "self-harms". Self-harm might include head banging, cutting, scratching, pinching or biting themself.

This study would involve one interview with me which would last between thirty minutes and one hour.

If you are interested in taking part, please follow the link below to find out further information and register your interest. Unfortunately, it may not be possible for every person who registers their interest to take part in the study.

https://tinyurl.com/me9z7kvs

Appendix H: Screening questionnaire hosted by Qualtrics



Hello. My name is Libby Ilett and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

What is the purpose of the study?

Previous research has shown that working with somebody who harms themself can be emotionally challenging. Staff members can have different thoughts and responses when they experience this behaviour.

The aim of this study is to develop a theory to understand the experience of staff working alongside people with learning disabilities who self-harm and how they respond. It is hoped that these results will help develop training and support for other staff members who work alongside people who self-harm.

Why have I been invited?

You have been invited because you are currently working alongside somebody who has a learning disability who harms themself. I hope to interview members of staff who work in residential or support living accommodation for people with learning disabilities.

Do I have to take part?

If you are interested in taking part I would ask you to complete the short questionnaire below to register your interest. Unfortunately it may not be possible for every person who registers their interest to take part in the study.

Once you have registered your interest I may contact you to discuss your involvement in the main part of the study. It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will taking part involved?

The initial questionnaire will ask some brief questions about you and your place of work. It will also ask you to provide contact details so that I can contact you regarding the main part of the study. These should take 5-10 minutes to complete.

The main part of the study would involve one interview with me which would last between thirty minutes and one hour. The interview will take place via the online platform Zoom or at a location which is convenient to you and suitable to conduct a confidential interview, this is likely to be at your place of work.

The interview would ask you questions about your experience of working with an individual who self-harmed; these may include questions about how you felt and how you responded when they self-harmed. This interview will be recorded and then transcribed removing any identifiable data.

What are the possible disadvantages and risks of taking part?

Talking about experiences of working with people who self-harm can also raise difficult and uncomfortable feelings. For example, you may find it difficult talking about how you responded to the self-harm particularly if you would have preferred to respond in a different way. If you believe these feelings are likely to be particularly distressing for you, you may wish not to take part in the study.

There will be space after the interview to debrief and reflect on what it was like to take part in the study.

What are the possible benefits of taking part?

It is hoped that the interview would feel like a useful space to reflect confidentially on these emotionally challenging situations, you may learn more about how you respond when somebody harms themselves.

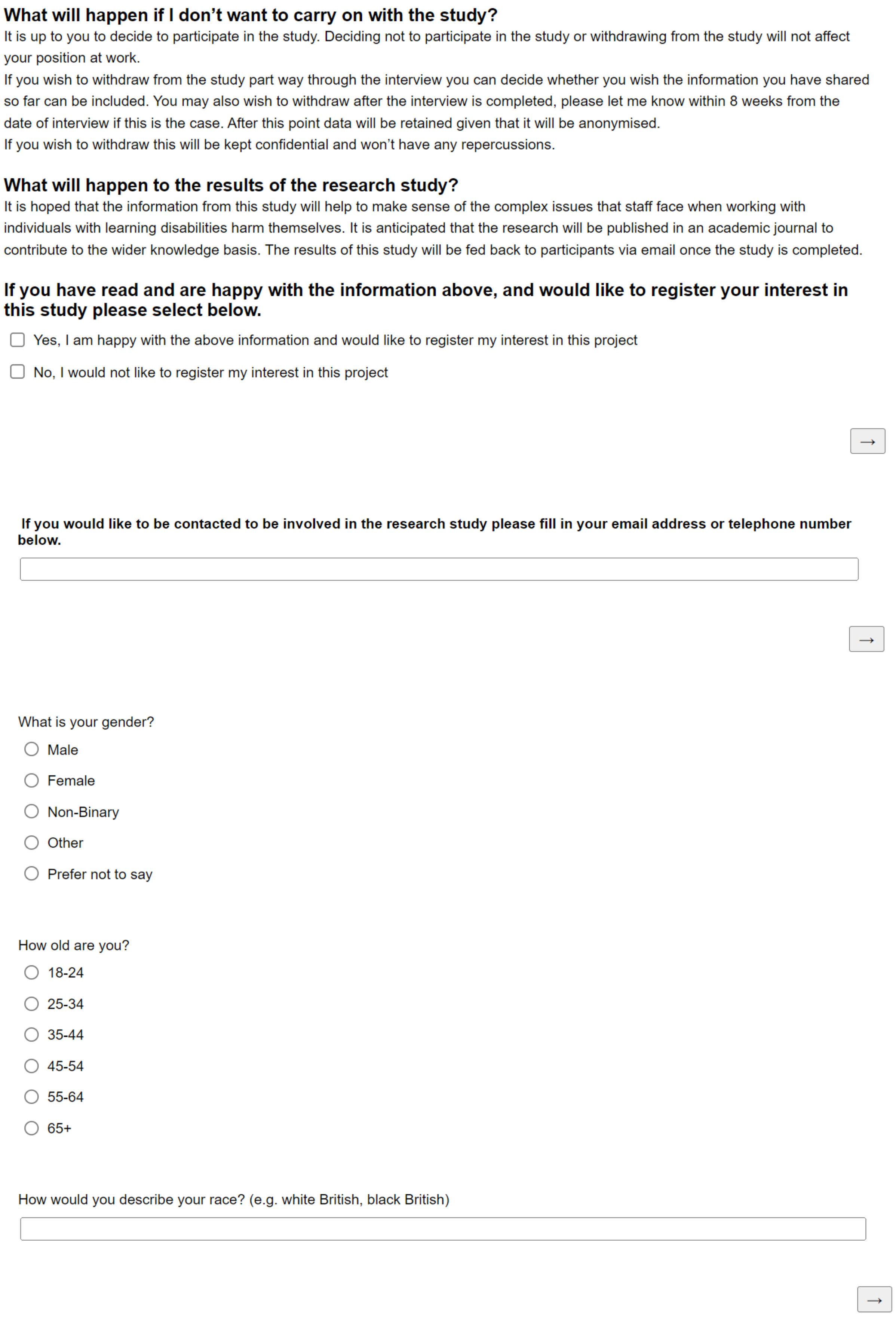
This study may also provide the opportunity to share some of the difficulties staff can have when working with people who self-harm. It is hoped that a greater understanding of these challenges will guide ongoing support for team’s and individuals.

Will information from or about me from taking part in the study be kept confidential?

During the interview our discussion will be recorded. The recording will be immediately transferred to an encrypted password protected USB drive and deleted from the digital recorder.

Interviews will be transcribed and all identifying details will be removed or changed where necessary to ensure that you anonymity is protected. Fully anonymised quotes may be used in the study write up.

At the end of the study audio recordings of the interviews will kept on a password protected USB in a locked cabinet for 10 years after the study is completed, after which they will be destroyed.



What will happen if I don't want to carry on with the study?

It is up to you to decide to participate in the study. Deciding not to participate in the study or withdrawing from the study will not affect your position at work.

If you wish to withdraw from the study part way through the interview you can decide whether you wish the information you have shared so far can be included. You may also wish to withdraw after the interview is completed, please let me know within 8 weeks from the date of interview if this is the case. After this point data will be retained given that it will be anonymised.

If you wish to withdraw this will be kept confidential and won't have any repercussions.

What will happen to the results of the research study?

It is hoped that the information from this study will help to make sense of the complex issues that staff face when working with individuals with learning disabilities harm themselves. It is anticipated that the research will be published in an academic journal to contribute to the wider knowledge basis. The results of this study will be fed back to participants via email once the study is completed.

If you have read and are happy with the information above, and would like to register your interest in this study please select below.

☐ Yes, I am happy with the above information and would like to register my interest in this project

☐ No, I would not like to register my interest in this project

If you would like to be contacted to be involved in the research study please fill in your email address or telephone number below.

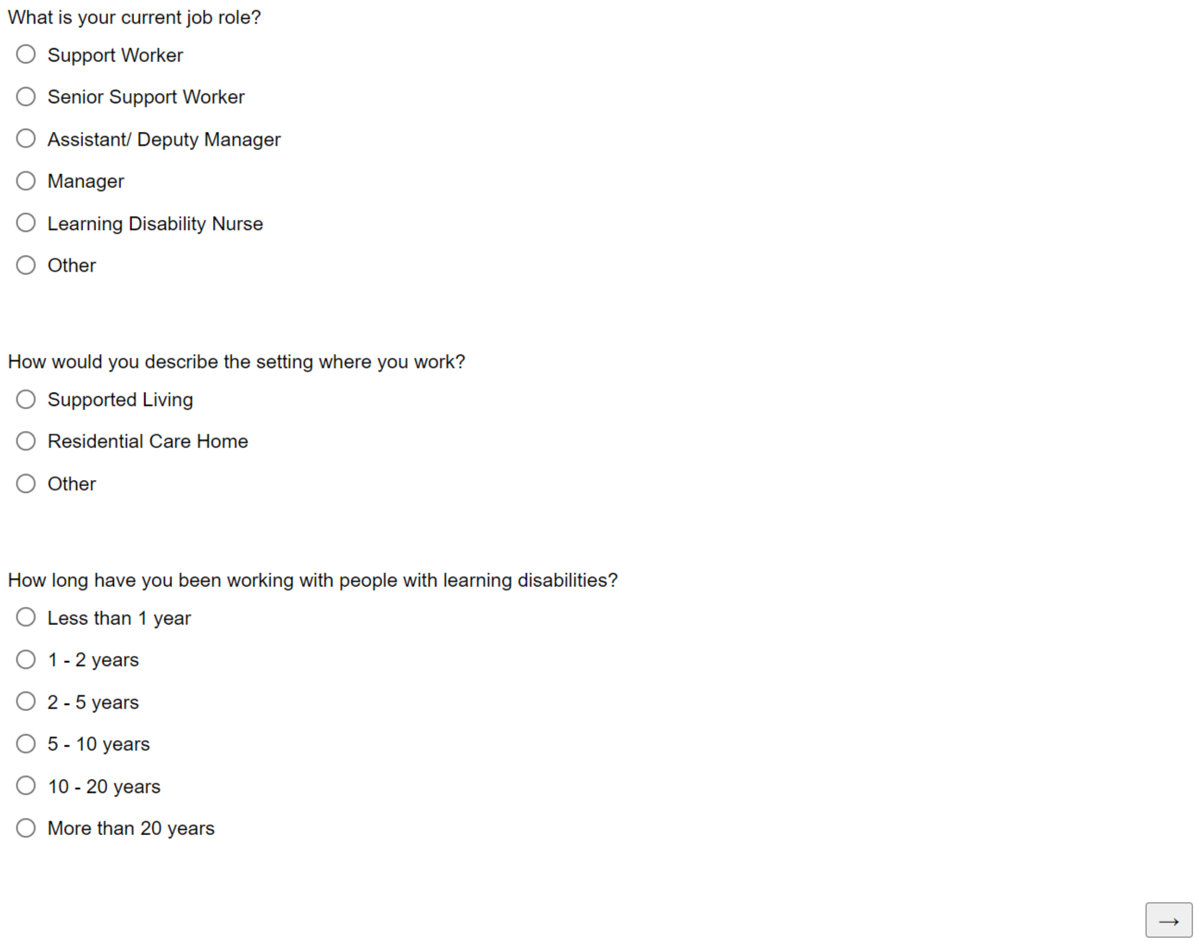
What is your gender?

○ Male
○ Female
○ Non-Binary
○ Other
○ Prefer not to say

How old are you?

○ 18-24
○ 25-34
○ 35-44
○ 45-54
○ 55-64
○ 65+

How would you describe your race? (e.g. white British, black British)



What is your current job role?

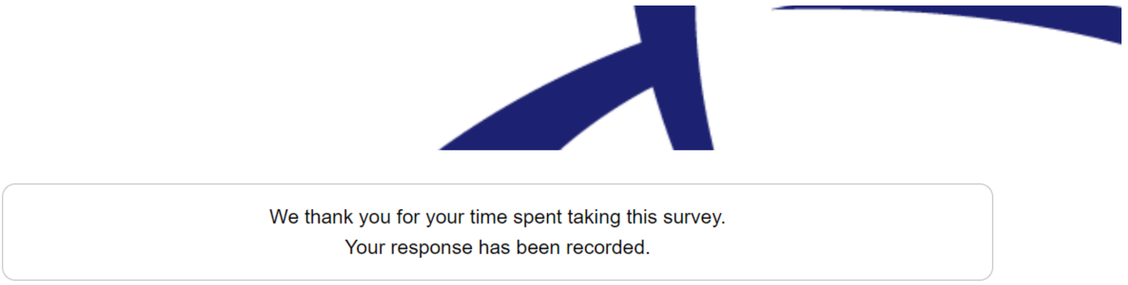
- ○ Support Worker
- ○ Senior Support Worker
- ○ Assistant/ Deputy Manager
- ○ Manager
- ○ Learning Disability Nurse
- ○ Other

How would you describe the setting where you work?

- ○ Supported Living
- ○ Residential Care Home
- ○ Other

How long have you been working with people with learning disabilities?

- ○ Less than 1 year
- ○ 1 - 2 years
- ○ 2 - 5 years
- ○ 5 - 10 years
- ○ 10 - 20 years
- ○ More than 20 years



We thank you for your time spent taking this survey.
Your response has been recorded.

Appendix I: Ethical approval

This has been removed from the electronic copy

Appendix J: Information sheet

Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

How do residential support staff understand and respond when individuals with learning disabilities harm themselves?

Hello. My name is Libby Ilett and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

What is the purpose of the study?

Previous research has shown that working with somebody who harms themself can be emotionally challenging. Staff members can have different thoughts and responses when they experience this behaviour.

The aim of this study is to develop a theory to understand the experience of staff working alongside people with learning disabilities who self-harm and how they respond. It is hoped that these results will help develop training and support for other staff members who work alongside people who self-harm.

Why have I been invited?

You have been invited because you are currently working alongside somebody who has a learning disability who harms themself. I hope to interview members of staff who work in residential or support living accommodation for people with learning disabilities.

Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

Before you take part, I would encourage you to discuss your involvement with somebody else. This could be somebody at home or work who you feel like you could turn to for support if needed.

What will taking part involved?

This study would involve one interview with me which would last between thirty minutes and one hour. The interview will take place via the online platform Zoom or at a location which is convenient to you and suitable to conduct a confidential interview, this is likely to be at your place of work.

The interview would ask you questions about your experience of working with an individual who self-harmed; these may include questions about how you felt and how you responded when they self-harmed. This interview will be recorded and then transcribed removing any identifiable data.

If you agree, as a follow-up from the interview I will contact you via email to explore whether the results of the study fit with your understanding of working with individuals who harm-themselves.

What are the possible disadvantages and risks of taking part?

Talking about experiences of working with people who self-harm can also raise difficult and uncomfortable feelings. For example, you may find it difficult talking about how you responded to the self-harm particularly if you would have preferred to respond in a different way. If you believe these feelings are likely to be particularly distressing for you, you may wish not to take part in the study.

There will be space after the interview to debrief and reflect on what it was like to take part in the study.

What are the possible benefits of taking part?

It is hoped that the interview would feel like a useful space to reflect confidentially on these emotionally challenging situations, you may learn more about how you respond when somebody harms themselves.

This study may also provide the opportunity to share some of the difficulties staff can have when working with people who self-harm. It is hoped that a greater understanding of these challenges will guide ongoing support for team's and individuals.

Will information from or about me from taking part in the study be kept confidential?

During the interview our discussion will be recorded. The recording will be immediately transferred to an encrypted password protected USB drive and deleted from the digital recorder.

Interviews will be transcribed and all identifying details will be removed or changed where necessary to ensure that you anonymity is protected. Fully anonymised quotes may be used in the study write up.

At the end of the study audio recordings of the interviews will kept on a password protected USB in a locked cabinet for 10 years after the study is completed, after which they will be destroyed.

When would confidentiality be broken?

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else. If this were the case, I may need to report to other professionals involved in safeguarding.

What will happen if I don’t want to carry on with the study?

It is up to you to decide to participate in the study. Deciding not to participate in the study or withdrawing from the study will not affect your position at work.

If you wish to withdraw from the study part way through the interview you can decide whether you wish the information you have shared so far can be included. You may also wish to withdraw after the interview is completed, please let me know within 8 weeks from the date of interview if this is the case. After this point data will be retained given that it will be anonymised.

If you wish to withdraw this will be kept confidential and won’t have any repercussions.

What will happen to the results of the research study?

It is hoped that the information from this study will help to make sense of the complex issues that staff face when working with individuals with learning disabilities harm themselves. It is anticipated that the research will be published in an academic journal to contribute to the wider knowledge basis. The results of this study will be fed back to participants via email once the study is completed.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Salomons Research Ethics Committee, Canterbury Christ Church University.

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me [Libby Ilett] and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology fergal.jones@canterbury.ac.uk

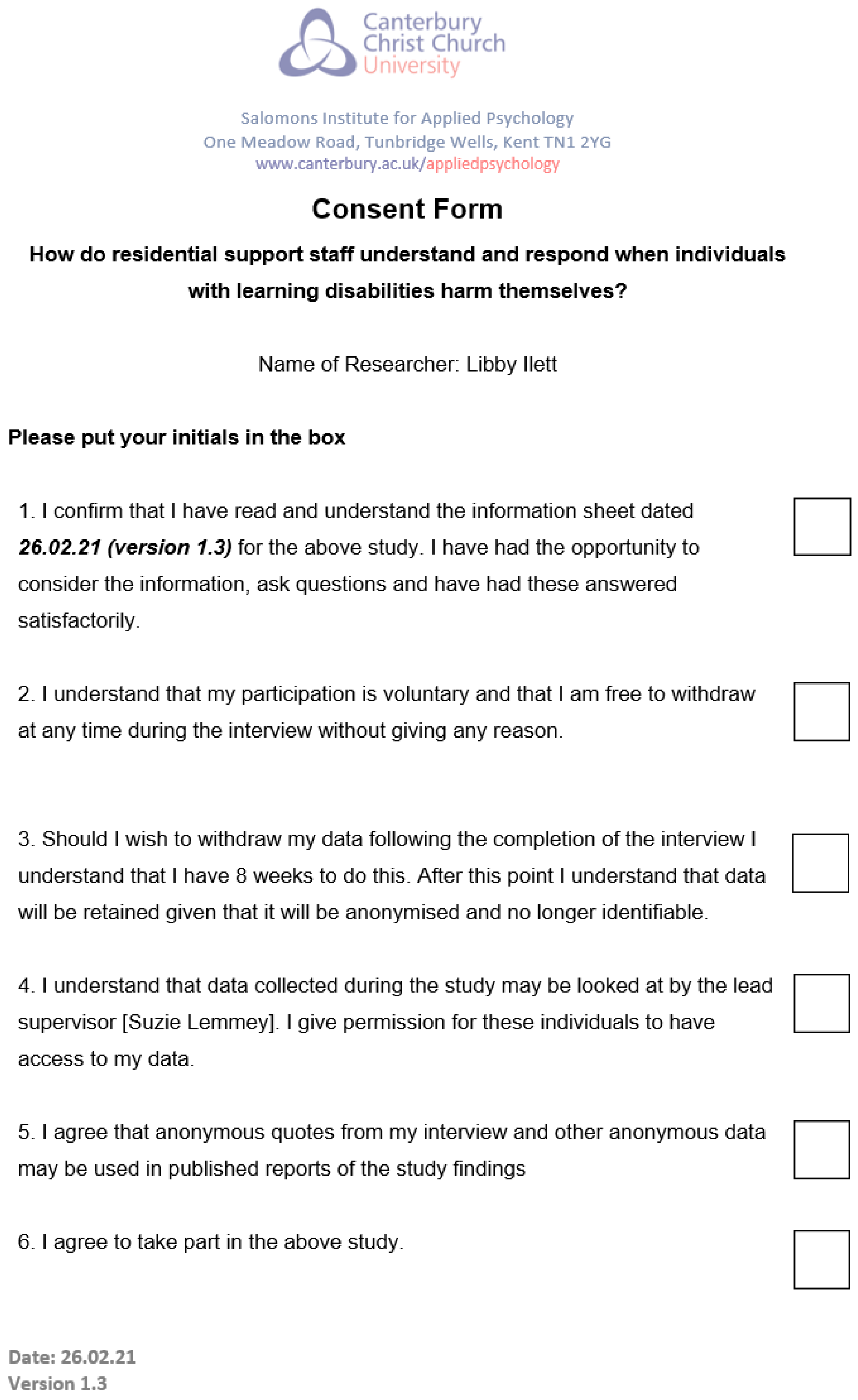
Further information and contact details

If you would like to speak to me and find out more about the study of have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Libby Ilett] and leave a contact number so that I can get back to you. Alternatively, you can email me at l.ilett62@canterbury.ac.uk and I will respond to you as soon as possible.

Thank you for taking the time to consider this information sheet.

Date: 26.02.2021
Version 1.3

Appendix K: Consent form



Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Consent Form

How do residential support staff understand and respond when individuals with learning disabilities harm themselves?

Name of Researcher: Libby Ilett

Please put your initials in the box

1. I confirm that I have read and understand the information sheet dated ***26.02.21 (version 1.3)*** for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time during the interview without giving any reason. ☐

3. Should I wish to withdraw my data following the completion of the interview I understand that I have 8 weeks to do this. After this point I understand that data will be retained given that it will be anonymised and no longer identifiable. ☐

4. I understand that data collected during the study may be looked at by the lead supervisor [Suzie Lemmey]. I give permission for these individuals to have access to my data. ☐

5. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings ☐

6. I agree to take part in the above study. ☐

Date: 26.02.21
Version 1.3

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

7. I agree for my anonymous data to be used in further research studies [OPTIONAL] ☐

8. I agree to be contacted via email to comment on the results of the study [OPTIONAL] ☐

Name of Participant____________________ Date________________

Signature ______________

Name of Person taking consent ______________ Date_____________

Signature ____________________

If you would like to be contacted with the results of the study please write your email address below:

____

Date: 26.02.21
Version 1.3

Appendix L: Interview schedule with modifications

Interview schedule

Can you tell me about yourself and your experience of working in your current job

- How long have you been working here?
- Can you tell me a bit about the client group you work with? (Version 1.2)
- Can you tell me a bit more about the type of service? (Version 1.2)
- What sort of things would you do in a typical day?
- What do you like?
- What is hard?
- How did you get into the job? (Version 1.4)

Can you tell me about a person you have worked with who has(intentionally) hurt themselves?

- Tell me about your experience of working with them
- What is *the person* like?
- Can you tell me a bit more about their disability?
- How do you support this person in a typical day?
- Can you tell me about your relationship with this person?

Can you tell me about a time this person has (intentionally) hurt themself?

- What was happening before?

Why do you think they were doing this/ did this?

- How did you come to understand it in this way? (Version 1.3)
- Do you think your way of understanding was similar or different to others? (Version 1.5)
- Was this how you understood the self-harm at the time or has this changed? (Version 1.4)
- Why do you think your understanding has changed? (Version 1.4)

Can you talk me through what happened and what you did?

- What went through your mind when this was happening?
- How did you respond?
- How did you feel?
- How do you manage these feelings (Version 1.5)
- What effect did this have on you?

What happened after this event? (Version 1.2)

Why do you think you responded in this way?

- Was there anything that contributed to you responding in this way?
- Did you respond in a way that was similar or different to others? (Version 1.5)

- What enabled this response? (Version 1.5)
- Was there anything that made responding in this way more difficult?

Thinking about the situation now is there anything that you would have done differently?
- Do you think the way you respond to self-harm has changed? In what way? (Version 1.3)
- Do you think your understanding of self-harm has changed? In what way? (Version 1.3)
- Why do you/ don’t you think this has changed? (Version 1.3)

Have you received any training about self-harm?
- If so what did you think about it?
- Is there any further training you would like?

Appendix M: Extracts from research diary and memos illustrating the development of the research schedule

13.03.21- Research Diary

Had the feedback from my ethics review and am very pleased that it got passed. They suggested a couple of things about the wording in my interview schedule so I have made those changes (Version 1.2). I have also been thinking with Suzie about how to make the participants feel; comfortable at the start of the interview (I have my first one coming up really soon). We thought it might be helpful to just add a couple more background questions, maybe to know a bit more about the client group and service as well would be helpful (Version 1.2).

08.06.21- Memo

Concept: understanding the behaviour

Giving a reason behind the behaviour is a very general category that links all the explanations (is this staff formulating). Could it be more helpful to separate types of behaviour or reasons. QUESTION FURTHER- how do you develop these ideas?

08.06.21- Memo

Concept: Understanding SH

Moving to code interview 2 and I'm struck by the start where he seems very concerned about pinning down the cause of behaviours.

"that's understanding the behaviours of the people that I support and sort of trying to…get to the crux of why they are getting upset and, and really trying to analyse what is it I've done, what is it that people around me may have done that could have caused this escalation behaviours."

I feel like interview 1 was less concerned about that (more thinking about link to emotional state and what SH enables e.g. a way of getting support)? Is that something that changes over time? With experience? With different training? Interview two is also more focused on what he or others may have done to "cause" the behaviour rather than interview 1 thinking about the persons context more generally. Again, is that something that changes over time or with different training?

08.06.21- Research Diary

From doing the first two interviews I am interested in exploring further how does response/ understanding to SH change over time. There appears to be some differences between interview 1 and 2 in how they understand and respond with interviewee 2 looking for more certainty (e.g. in finding trigger, in how they should respond) and I am wondering whether this is linked to having less experience. It could also be the type of SH (e.g. he witnessed it directly while interview 1 did not) so trying to keep an open mind but I think I've got questions for that. Experiential learning also seems important and I'm curious about how this might affect response. I guess a question about how participants came to understand it in a certain way would be helpful to try and tap into this and maybe more of an exploration about whether or not it has changed (Version 1.3).

25.11.21- Research Diary

I think the added questions about how people understand and respond to self-harm were useful. She spoke about it going from being more personal (either for causing the behaviour or worrying about the consequences) to being more detached with experience/ seniority which is something I have thought about before (but certainly is in line with my personal experience). I think interview 2 (who was new to the career) seems to fit this pattern so I am interested to explore this more. Wonder if it is more about experience or seniority as well?

06.11.21- Memo

Concept: giving a reason for the behaviour

This is more of a descriptive category rather than anything more analytic- what reason's do people give for the SH taking place: Emotions (particularly anger and anxiety), change (e.g. due to lockdown), a specific trigger (e.g. loss of skin) and a way of communicating. I guess the question is what purpose does giving a reason for the behaviour serve? What does it mean in terms of what happens next? What happens before to lead people to this way of making sense of things?
I wonder if this sense making has happened before or after? If I didn't ask the question would people even bring it up. Do different job roles affect how different people make sense of things (e.g. depending on their training). What other people work in these settings that I could possibly interview?

06.11.21- Memo

Concept: Seeking certainty

Looking for a specific reason for the behaviour also seems linked to this concept. Hypothesis that less experienced staff want a specific reason while more experienced staff can accept they might not know the reason or there might be multiple reasons?

06.01.22- Memo

Concept: Understanding SH as a way of seeking control

As this was my main research question about how do staff understand SH I think it is important to highlight this concept. Not sure at this point what led this person to have this understanding compared to others, the participant reported that the self-harm had happened after an additional restriction/ change was put on the person. This might be linked to the idea of **powerlessness** this time for the service user and SH is a way of seeking control (exerting authority?)
They also acknowledge the limits to their own understanding and recognising that there could be lots of different things that contribute to self-harm. I guess that I have been noticing that throughout my memo's that I really want people to pin their idea about self-harm to one thing and actually its way more complicated than that- maybe there is something about ***accepting multiple meanings***
Erm, (sighs) so yeah I there was, I think that although it's difficult to pin point what exactly motivates each individual act of self-harm that he will engage in, because there's so many different things that could contribute to it I think that definitely played a part
Could I ask more questions about how meanings change? Or what people think of all these different meanings?

07.01.22- Research Diary

By the end of the day today I've got my summary of concepts from the first few interviews and they feel manageably grouped (although I do worry about missing stuff). I think I could be more curious about the "understanding" self-harm part so I want to add a couple of questions. Like do people actually try to understand SH in the moment or is it something that happens after? (Version 1.4)

13.01.22- A summary memo

There is a second concept that seems related to the participant. Its about their values and what keeps them in the job. Their values (e.g. making a difference) seem to shape how they go about day to day interactions. Do they also have direct influence on how they respond to SH (e.g. risks vs restrictions)? They might also influence the relationship that is built with the service user. The person's job role/ length of time in the service also seems related to this concept with seemingly less experienced staff finding self-harm more personally challenging (through what process?); it could also be that they witnessed it directly rather than observed. Participant 3 also had her own diagnosis of autism, and participant 1 had been a carer when younger- I wonder if there are other people with personal experiences and how these shape understanding or response to SH. What do people perceive their job role to be (e.g. participant 1 it is about taking care of the team as well (mental health) and this will influence the environment). Is this something which enables people to respond in a different way?

13.01.22- Research Diary

She spoke about the impact of witnessing SH and the fact that its not "normal" despite being accepted as that. She spoke about how people pretend they are ok but actually it is quite horrible to witness, particularly for newer staff members. I would be really curious to interview some of those people. Because she was less involved she had more time to think and understand the self-harm. I wonder if people's understanding changes from when they are in the action to alter when they reflect on it- might add a question like this. I think this links to what I was interested in above, whether the understanding of self-harm comes in the moment or comes after (Version 1.4). The model at the moment isn't suggesting that this understanding is what drives the response to self-harm but more the emotions. This would suggest that maybe the understanding comes after?

11.02.22

Concept: Different responses to SH

Interview 8 talks about SH being different between people she has worked with. This is in terms of the risk, or possible risk (serious consequences) which makes it more anxiety inducing to work with some people. She sess the function as the same- a way of managing or expression of stress or distress!

13.02.22

Concept: Sitting with it

Participant 9 is the first who I think talks about just "waiting it out" the SH and not necessarily trying to stop it. Obviously there are things that she tried to do but when she can't find a way to help, its sort of like just being with the person and sharing in their distress. For participant 9 this is because she is really against physical interventions. I think another participant also talked about accepting self-harm

13.02.22- Research Diary

Re-listening to interview 9 (and coded 8) and few things struck me from the interview, first she was new to working in care and had been quite worried because of the restrictive interventions which were very against her ethos- it was interesting to explore why. She spoke about how they are just expected by many and (although I know its not my job to challenge in these interviews) I guess I could have been more curious about why people chose to use them rather than just taking it at face value. She didn’t go with the restrictive interventions even though she was told to? What enabled that? I think I might amend my interview schedule again before later today (Version 1.5).

Appendix N: Key themes and reflections from bracketing interview

Some of the assumptions I am holding before going into the project:

- That self-harm and self-injurious behaviour are understood by most people as separate entities (i.e. with different causes). I think my relationship has shifted and now see them more as the same thing (what I have read that people with LD see them as?), maybe I need to hold this idea more loosely (no right or wrong)
- Self-harm has the potential to be quite a distressing topic for people to talk about, I think that sometimes I can forget this because of quite a lot of personal experiences of working with (desensitized?). Thinking about my response it would probably be to do with risk assessment and safety which has been shaped by my professional roles. I remember really clearly though the first time I witnessed *child name* self-harming and how anxious I was- it was like a real physical response. I think I was able to deal with it quite well (supportive team?) but I know that this might not be the case for everyone so I need to be sensitive about that?
- That our responses to self-injury for people with LD are not always that helpful, when I think about *child name* now at *previous place of work (school)* feel really sad (thinking of it as a challenging behaviour and not thinking enough about the distress). It was interesting to notice how my own idea's have shifted and I guess on reflected suggests that the organisation can have a big influence. Am I going into interviews therefore assuming that staff are going to have responded in an unhelpful way and how might this influence my questions? Try to hold more systemic ideas (not being expert, ideas that are more or less helpful)?
- That staff are not responding to self-harm in the way in which people with LD would want them to. This comes from some of the literature about what people with learning disabilities say is helpful/ unhelpful and what they report has happened to them. Also I think what you hear in the media as well has an influence (e.g. Winterbourne view) and also I think sometimes from what I have personally witnessed. I'm aware that I might think I could do a "better" job but also that that position sits quite uncomfortably with me- I think I need to be able to own this position so I can be aware how it might influence the interviews
- That being a carer is a very stressful job, they lack training and support from management structures , might lack skills, might not care (media, personal experiences). Again how might this influence the interviews and what I am looking for in the text?
- Reading about the models that there are so far e.g. locus of control, still find myself wanting to hunt out these patterns. Noticing myself wanting to find clear concrete understanding (cause and effect models) and my own anxiety going into the unknown. Actually these models have not been shown to fit so must be something else going on….what could it be, I guess that's the exciting bit about grounded theory

Appendix O: Example of initial coding

This has been removed from the electronic copy

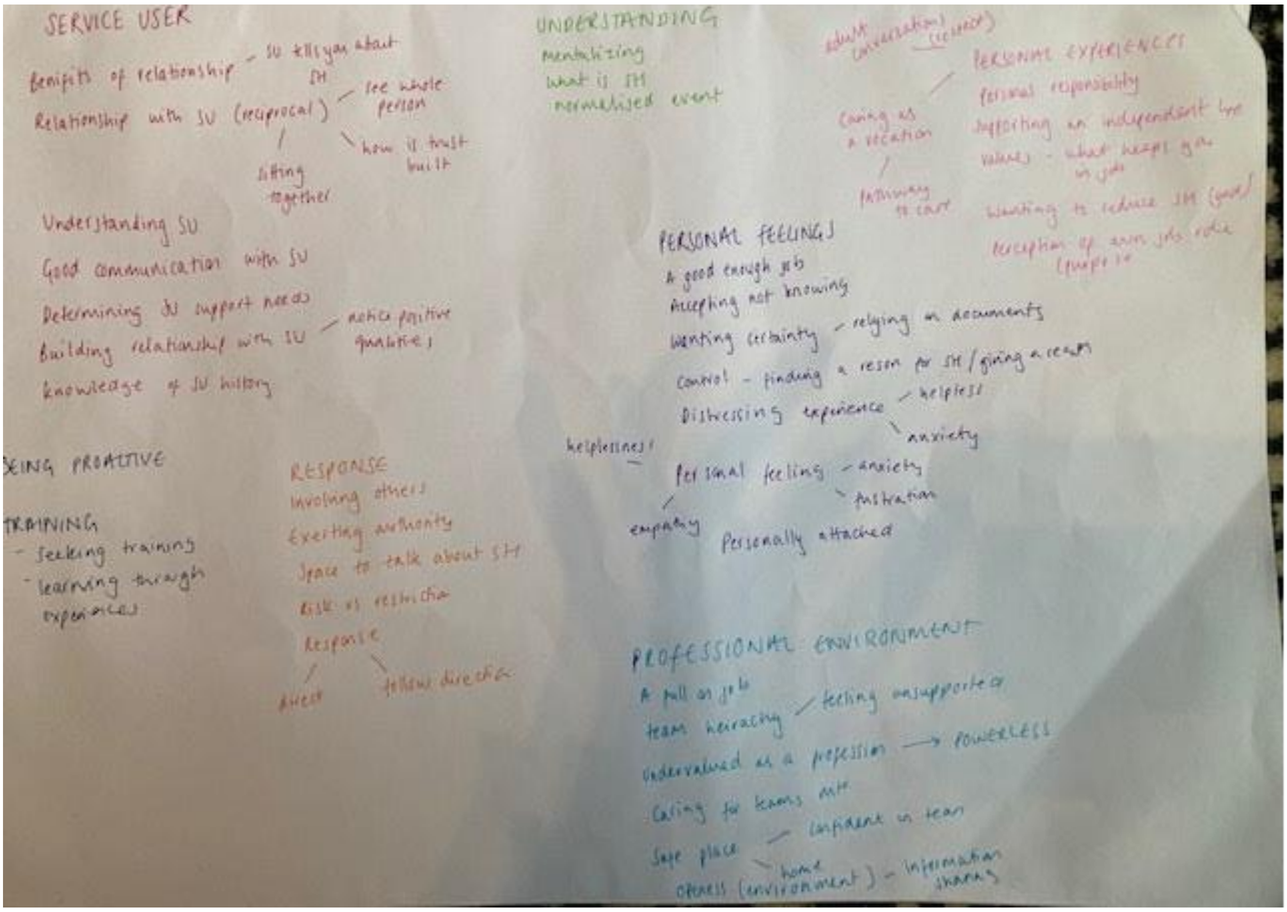
Appendix P: Audit trail of data analysis

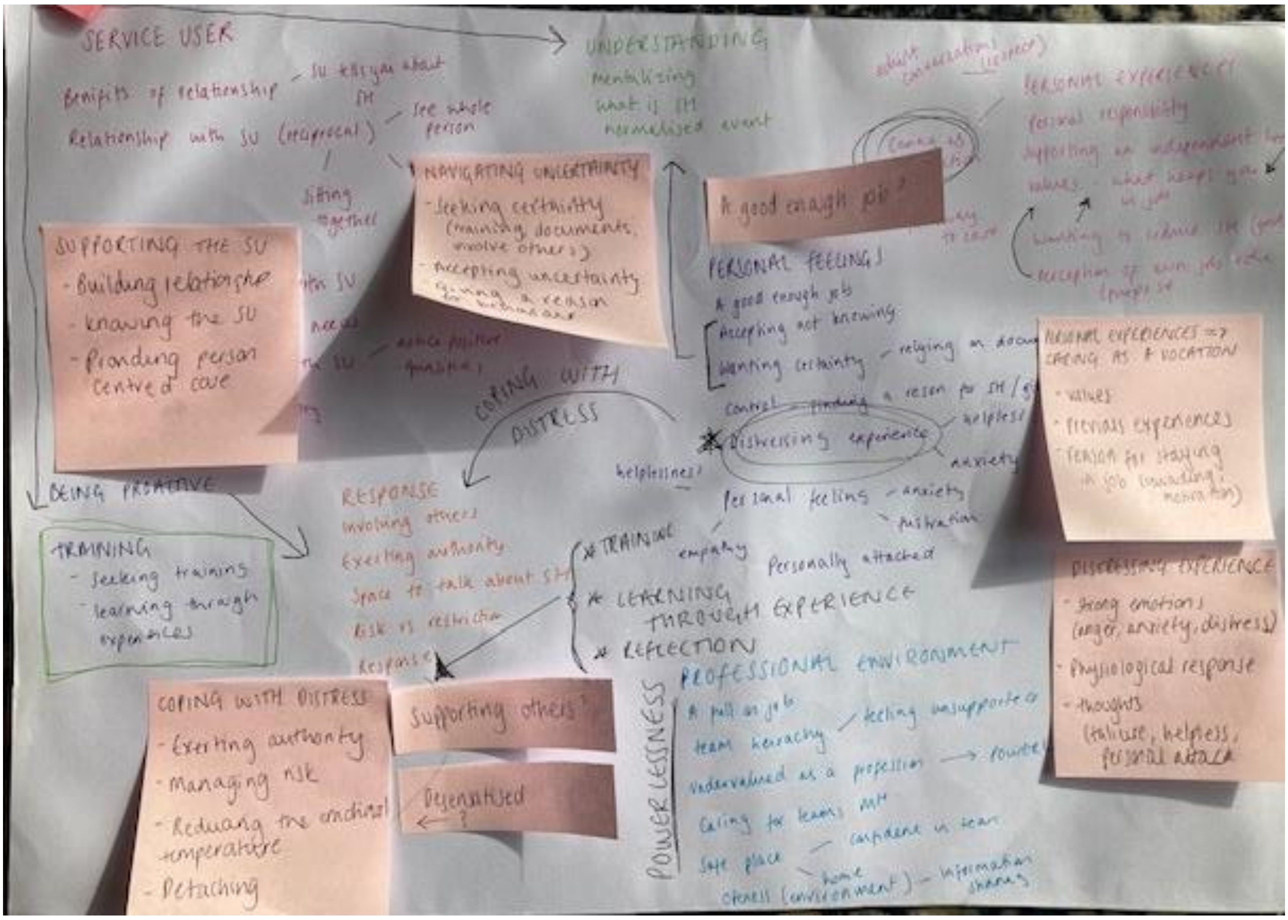
Open to focused coding: The table below illustrates the process of development of example focused codes. These were continually refined through the data analysis process

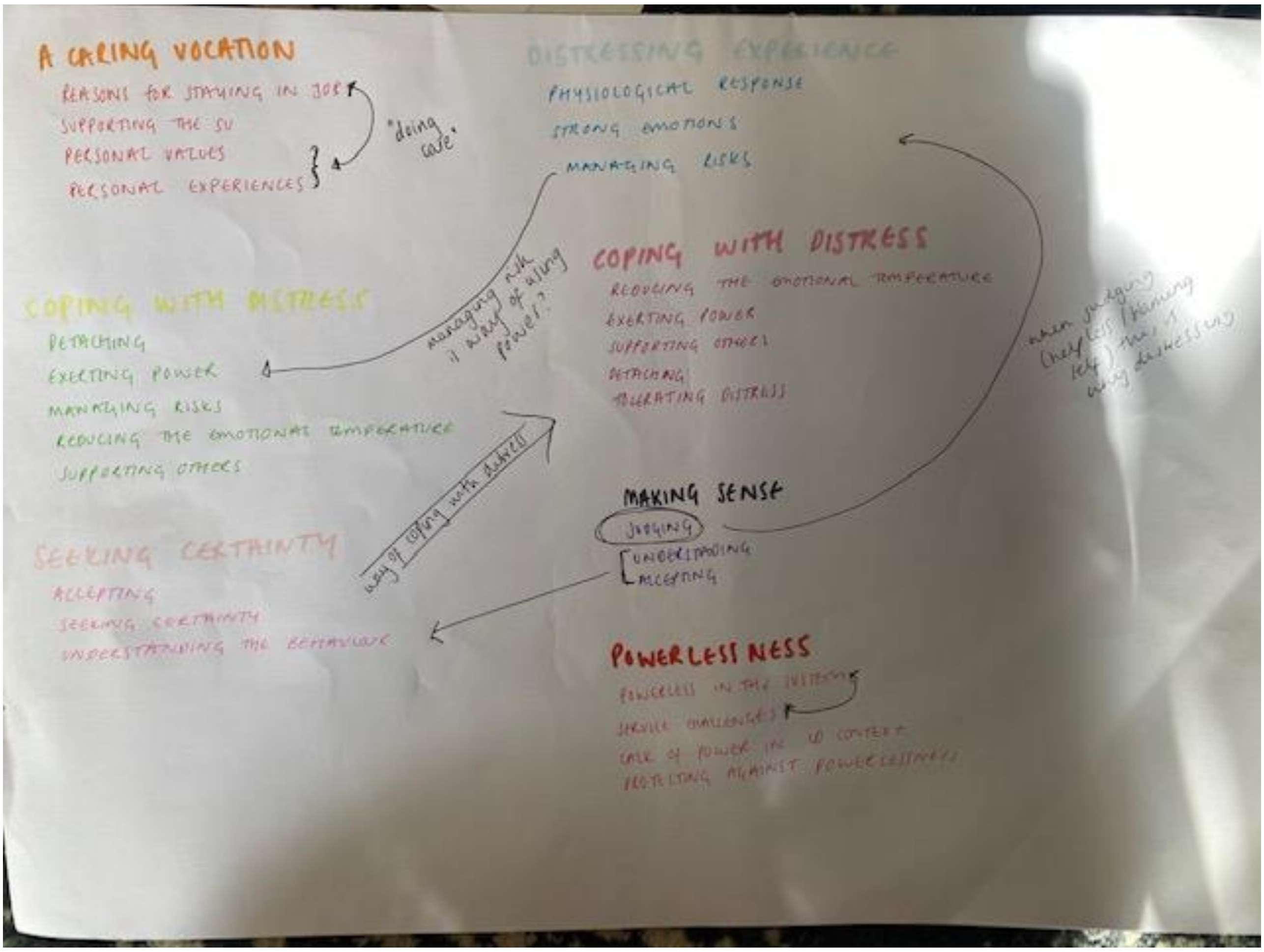
Open codes (examples)	Focused codes 12.12.21	Focused codes 20.02.22
Attributing getting to know SU as reducing SH Trust enables truth Getting to know SU enables better recognition of change in mood Knowing client well helps manage risk Good relationships useful in SH response Knowing SU to find strategies to suit them Knowing the “golden nuggets” to provide the best support	‘Knowing’ SU enables better support	Knowing the SU
Having historical information to understand Making sense of SH using current and historical information Reflection on how SU lack of historic support may affect current beliefs Awareness of historic risks to other	“Knowing” the SU history to understand present	
Noting SU positive qualities Seeing strengths Seeing the positive side of being full on Seeing the whole person Understanding SU specific interests	Seeing SU strengths and interests	
Creating parity Creating equality Empowering people Enabling independence Supporting independence Vocation driven by values to support others Wanting to change lives for the better	Values: empowering people	Personal values: Changing lives for the better
Seeing alternative coping strategies working Knowing strategies are working due to hearing less about SH Having confidence that strategies will work Seeing change in SU over time Staying in the job- seeing the difference You know you are doing the job right when you can see them results	Witnessing change (motivating)	Witnessing change (motivating)
Desensitization Getting used to it with time SH becomes normalised Emotionless description	Become desensitized to SH	Detaching
Making a referral due to risk Connecting with CP in wider network CP willing to be involved Involving a clinical psychologist due to risk of suicide	Involving others due to risk	Seeking certainty through involving others
Involving social care team when feeling stuck Involving multiple professionals to make the right decision Network helpful- determining placement needs	Involving other in decision making	

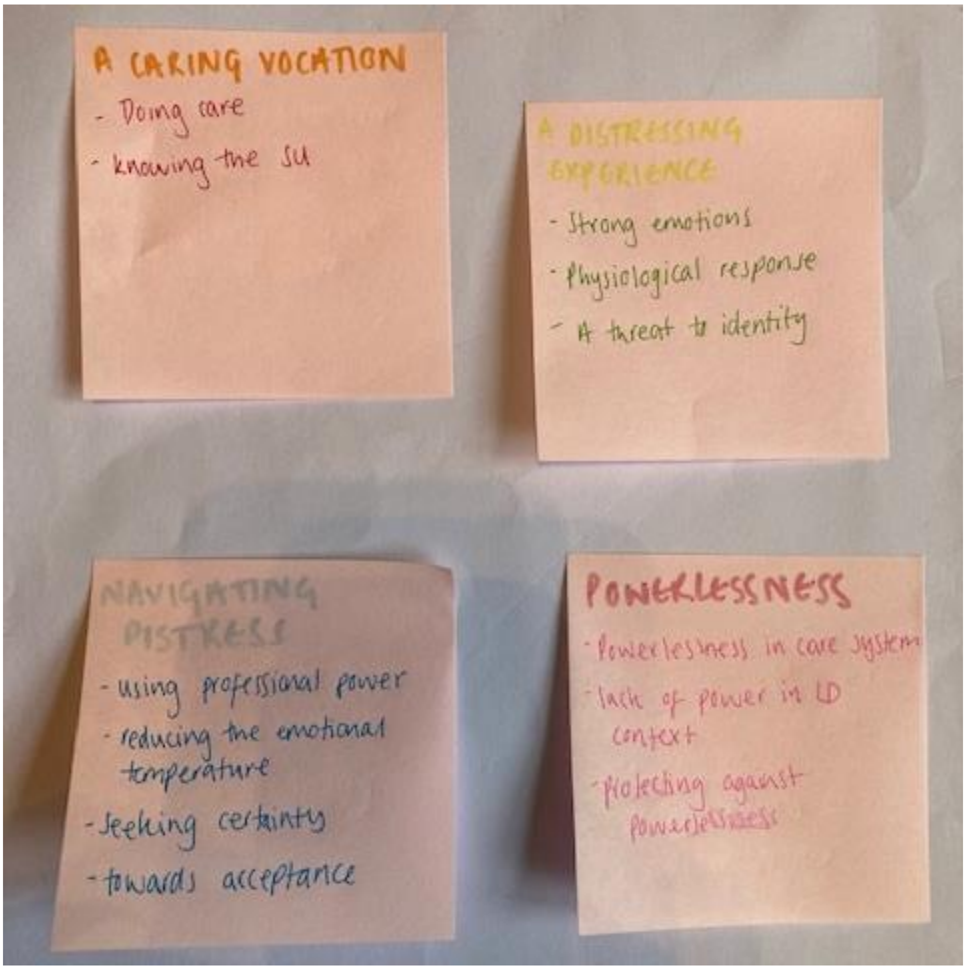
Clinical psychologist providing space for SU to speak about SH Connecting with other members if network Increasing contact with CP Involving CP to understand reasons Deciding to involve CP due to history and knowledge Communication in network improves understanding	Involving others to support understanding	
Accepting uncertainty about reason for behaviour Giving multiple reasons Acknowledging limits to own understanding Trying to keep an open mind about reasons for SH	Accepting uncertainty	Accepting uncertainty
Job requires patience Requiring bravery Requiring resilience Requiring responsibility	Need certain characteristics to do the job	Innate skills
Analyzing behaviour is in support workers blood Seeing care and compassion as natural instincts Skills required for care work innate Good at coping in a crisis Caring more than a job, it’s a vocation	Innate skills	
Seeking certainty through training Formalizing training about an individual Wanting greater certainty about responding to SH	Wanting certainty in SH response	Seeking certainty through training
Wanting first aid training tailored to individual Verbalising the support plan to help remember	Wanting individualised training	
Childhood caring experience Connecting family history to skills needed for job	Personal experiences of caring	Using personal experiences

Selective coding: The process of selective coding involved the organisation of focused codes into conceptual categories and subcategories. Again this was an iterative process with concepts continually refined through data analysis. The diagrams below illustrate this process at several stages






A CARING VOCATION
REASONS FOR STAYING IN JOB
SUPPORTING THE SU
PERSONAL VALUES
PERSONAL EXPERIENCES
"doing care"
DISTRESSING EXPERIENCE
PHYSIOLOGICAL RESPONSE
STRONG EMOTIONS
MANAGING RISKS
managing risk a way of using power?
COPING WITH DISTRESS
REDUCING THE EMOTIONAL TEMPERATURE
EXERTING POWER
SUPPORTING OTHERS
DETACHING
TOLERATING DISTRESS
when judging (helpless / blaming self) this is very distressing
COPING WITH DISTRESS
DETACHING
EXERTING POWER
MANAGING RISKS
REDUCING THE EMOTIONAL TEMPERATURE
SUPPORTING OTHERS
way of coping with distress
MAKING SENSE
JUDGING
UNDERSTANDING
ACCEPTING
SEEKING CERTAINTY
ACCEPTING
SEEKING CERTAINTY
UNDERSTANDING THE BEHAVIOUR
POWERLESSNESS
POWERLESS IN THE SYSTEM
SERVICE CHALLENGES
LACK OF POWER IN LD CONTEXT
PROTECTING AGAINST POWERLESSNESS



A CARING VOCATION

- Doing care
- knowing the SU

A DISTRESSING EXPERIENCE

- Strong emotions
- Physiological response
- A threat to identity

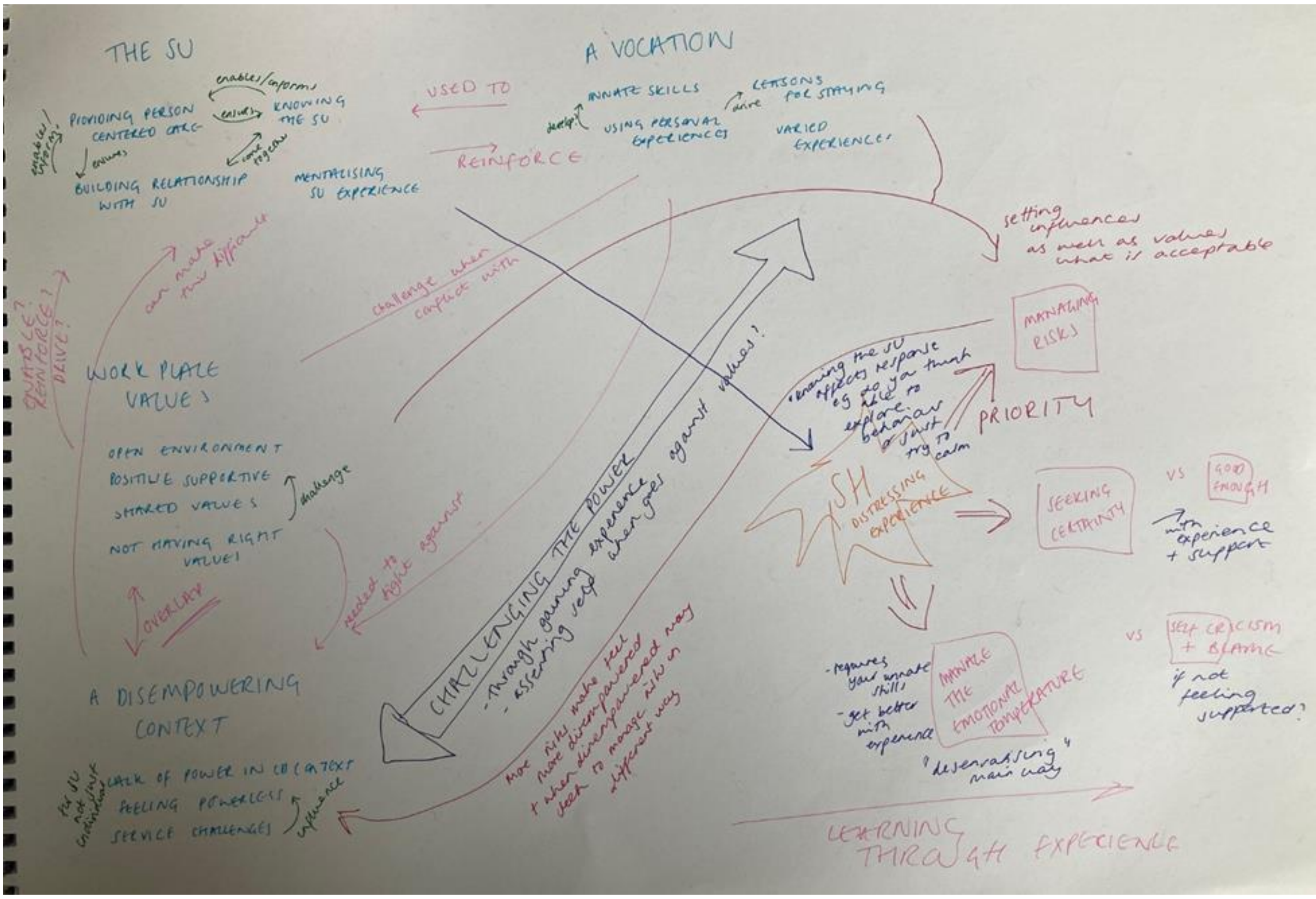
NAVIGATING DISTRESS

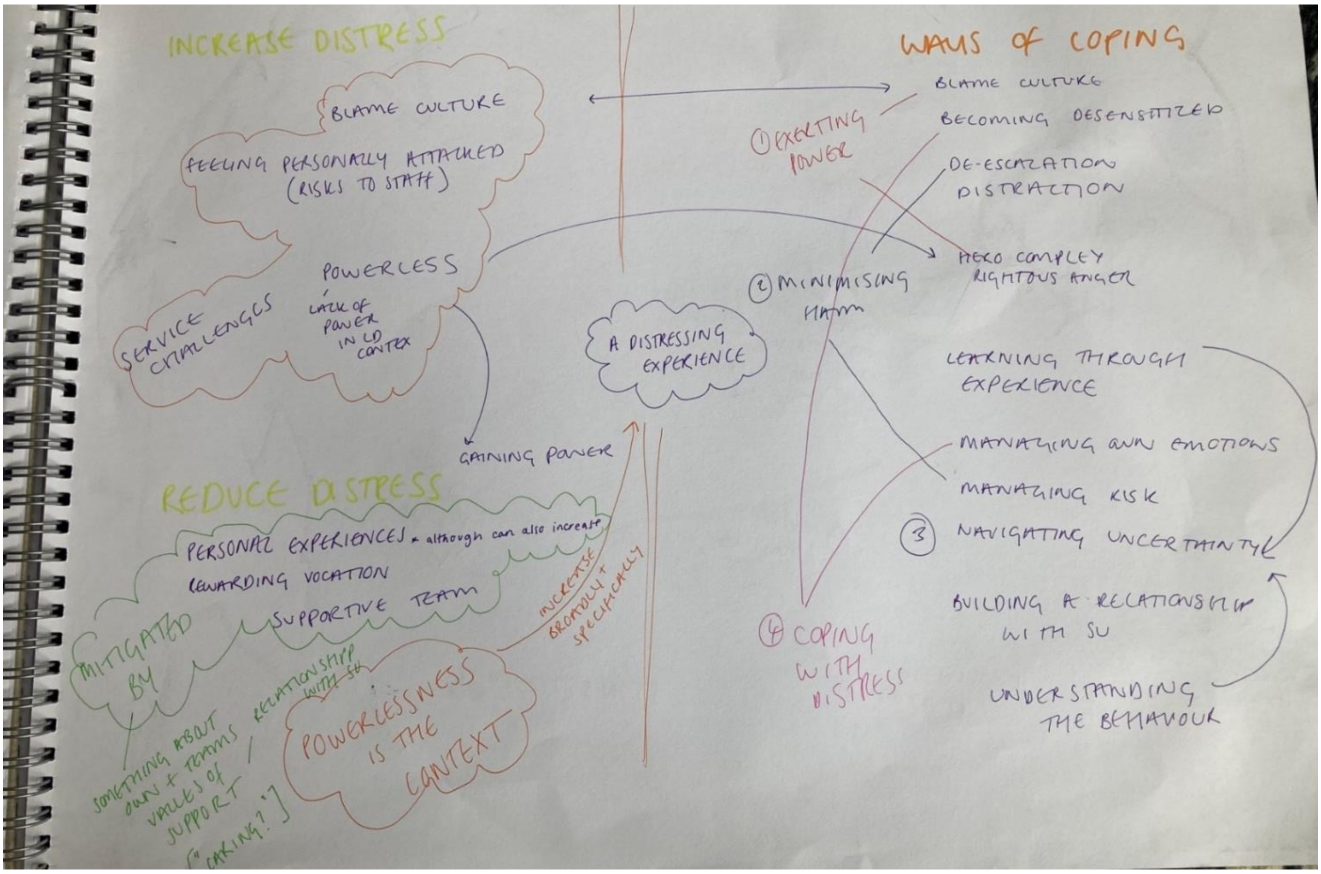
- using professional power
- reducing the emotional temperature
- Seeking certainty
- towards acceptance

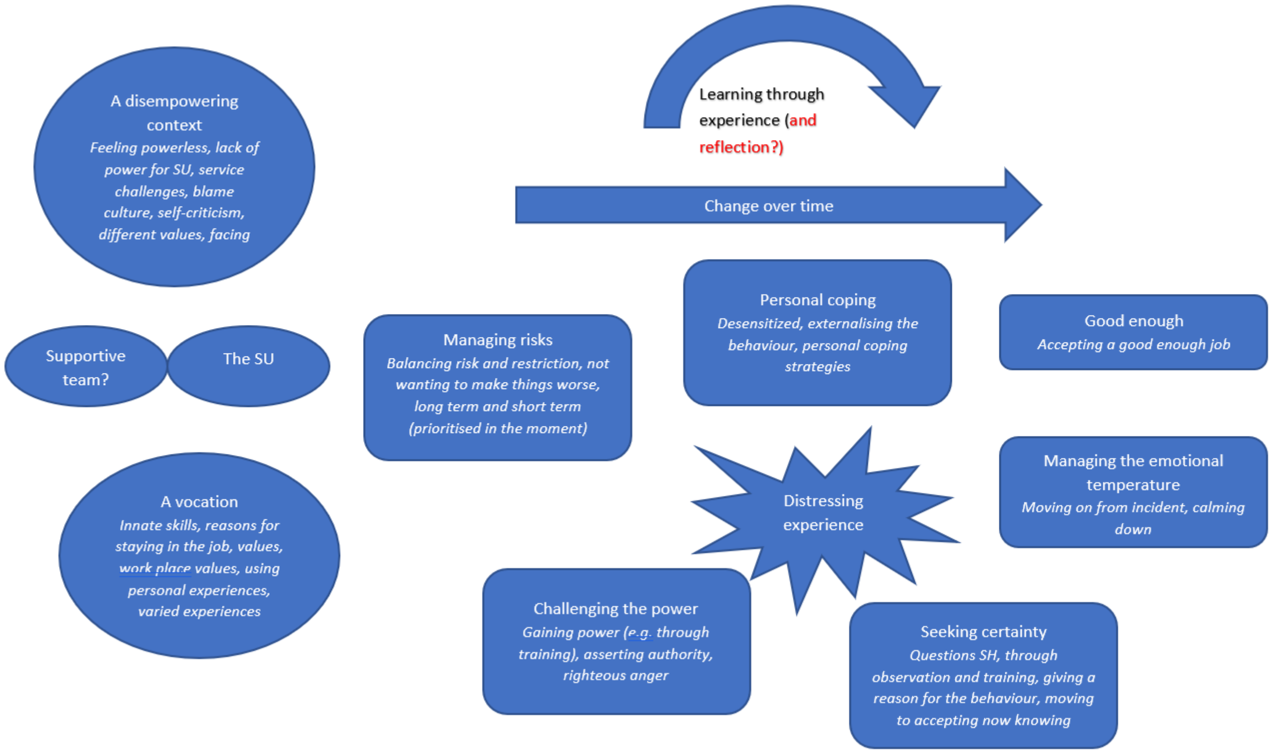
POWERLESSNESS

- Powerlessness in care system
- lack of power in LD context
- protecting against powerlessness

Diagram/ theory development







A disempowering context
Feeling powerless, lack of power for SU, service challenges, blame culture, self-criticism, different values, facing

Supportive team?

The SU

A vocation
Innate skills, reasons for staying in the job, values, work place values, using personal experiences, varied experiences

Learning through experience (and reflection?)

Change over time

Managing risks
Balancing risk and restriction, not wanting to make things worse, long term and short term (prioritised in the moment)

Personal coping
Desensitized, externalising the behaviour, personal coping strategies

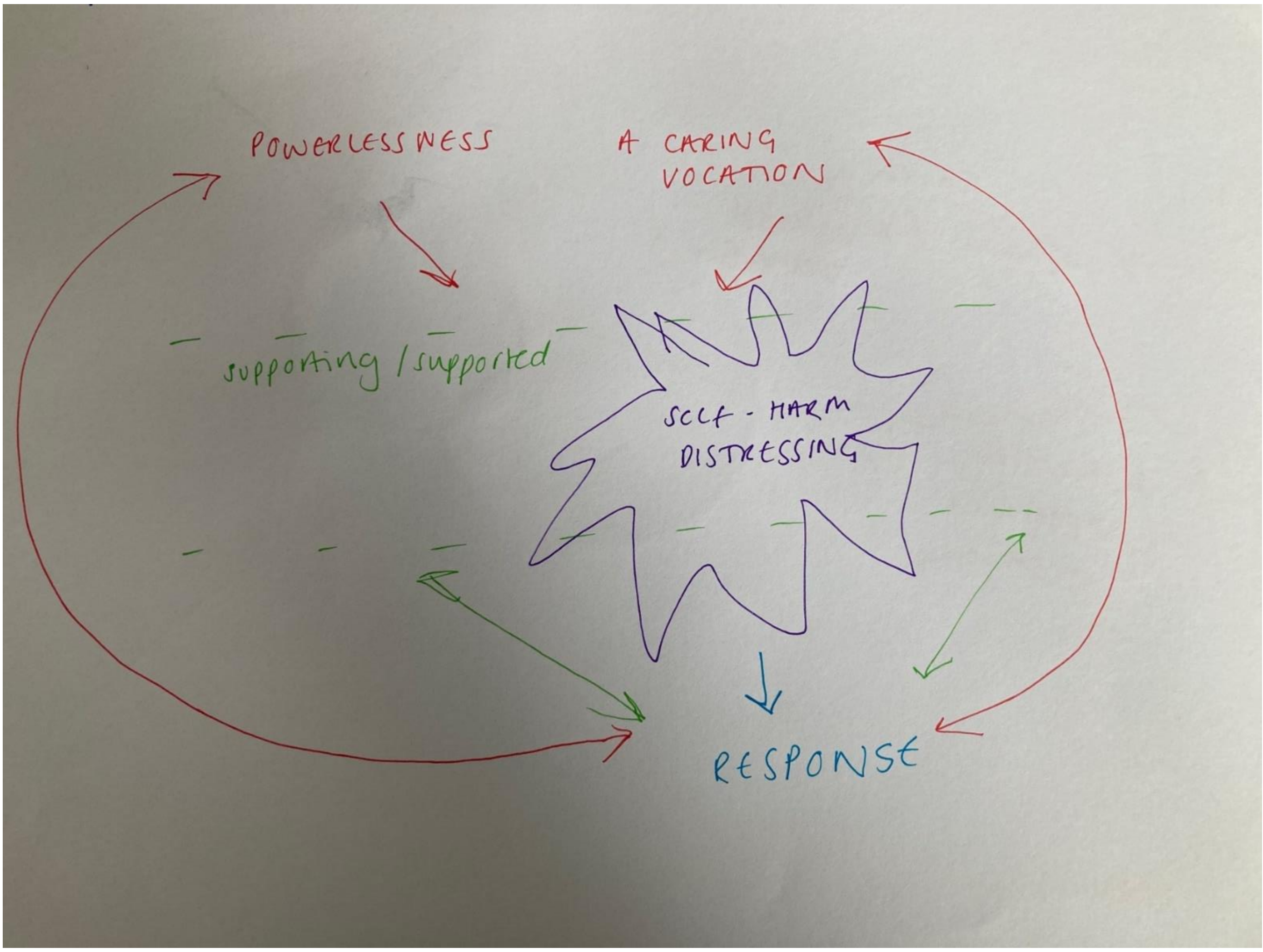
Good enough
Accepting a good enough job

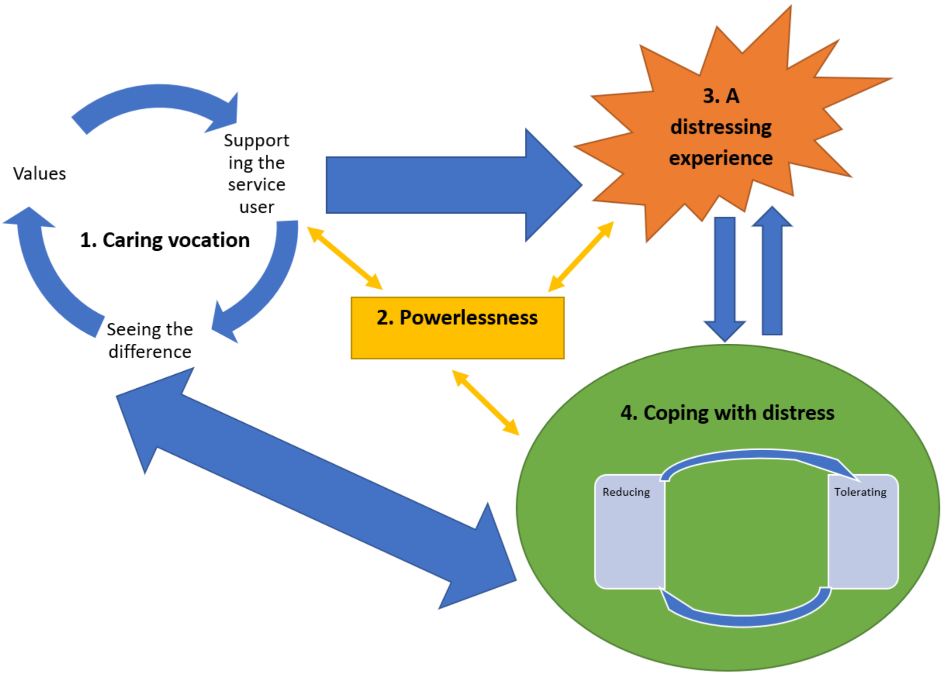
Distressing experience

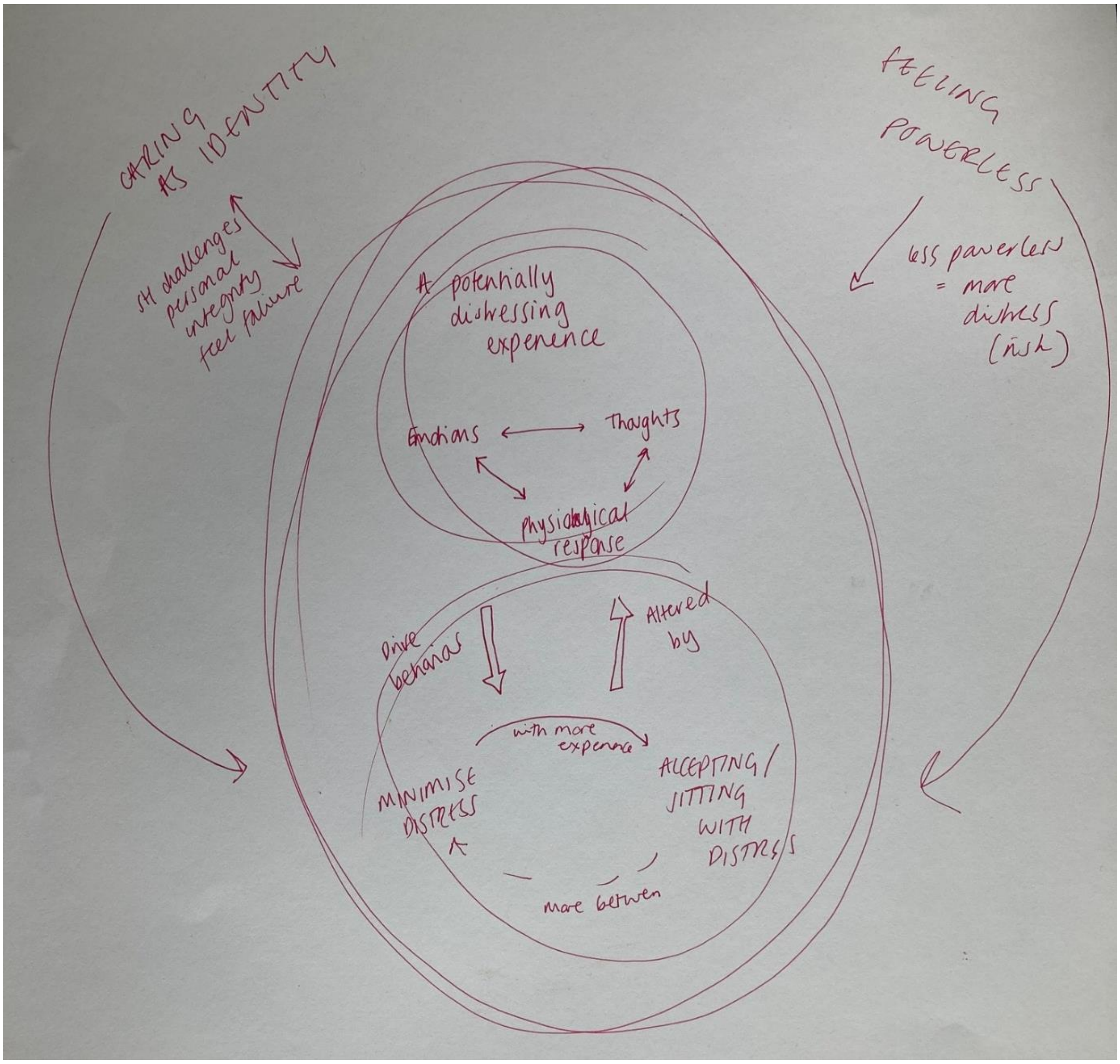
Managing the emotional temperature
Moving on from incident, calming down

Challenging the power
Gaining power (e.g. through training), asserting authority, righteous anger

Seeking certainty
Questions SH, through observation and training, giving a reason for the behaviour, moving to accepting now knowing




Values
Supporting the service user
1. Caring vocation
Seeing the difference
2. Powerlessness
3. A distressing experience
4. Coping with distress
Reducing
Tolerating


CARING AS IDENTITY
SH challenges personal integrity feel failure
FEELING POWERLESS
less powerless = more distress (risk)
A potentially distressing experience
Emotions
Thoughts
Physiological response
Drive behaviours
Altered by
with more experience
MINIMISE DISTRESS
ACCEPTING / SITTING WITH DISTRESS
More between

Appendix Q: Example memos

04.11.21 Concept: involving others
I have noticed that two of the interviews talk about deciding when to involve other professionals (these are both slightly more senior that the other interview so something that may be linked with job role?). How does the decision to involve other professionals come about? What shapes that decision? What is the process? Interview 1 suggests this may happen when thinking about placing restrictions on person's life, particularly in grey area's of capacity? Risk?
"Erm but we've got a young gentleman at the moment who's just really struggling with being in the community, what is appropriate, what isn't, erm…we need to do because we can only do so much because they are independent and have capacity then you really need that support from the social team to be able to move that forwards"
Involving other professionals to increase certainty?

06.11.21 Concept: relying on documents
More reliance on support plan for participant 2? Younger? Less experiences? Less time working with individual? Does this happen day-to-day or is this in interview as not wanting to get things wrong with me

06.11.21 Concept: a distressing experience
It is clearly quite distressing for participant two to talk about the SH incident. Wonder if this is because he witnessed it more directly (for participant 1 talking about the suicide attempt in prison also seemed distressing). Or had less experience? Wonder about the long term effects of this (PTSD?). But also in the moment how does this effect response or understanding of the behaviour. Note how helpless he feels in the interview and wonder if this contributes to distress- or the distress contributes to feeling helpless.
Comparing to everyday experiences to help try and make sense of things? Knowing about SH (e.g. through support plan etc) is clearly different from witnessing it.

06.11.21 Concept: Reflecting on own role
Through the process of talking about SH participant 2 moves from thinking they don't do much because of own inexperience to recognising their own role in incident and seeing that they were helpful(?). Wonder if this occurs through other processes as well e.g. supervision. There seems to be a kind of acceptance here? Goes against the blame culture which is talked about in some other interviews.
Talking with other members of the team about incident. Witnessing it for the first time as "coming of age". Is there a temporal process in staff experiences of SH (changing over time)

06.11.21 Concept: Seeking certainty
Particularly for the less experienced participant there was a real want to be "certain" whether that was in what he was telling me (what did he think the consequences would be if he got something wrong?) and in the field. This might be linked to his experience in his other job which he feared getting the blame if something went wrong. Certainty was sought through training- which he wanted to be really explicit. This contrasts with participant 5 who with more experience and seniority talked about adapting plans on the spur of the moment and trying something new? Does that come more with experience? Authority? Or something else?
Looking for a specific reason for the behaviour also seems linked to this concept. Hypothesis that less experienced staff want a specific reason while more experienced staff can accept they might not know the reason or there might be multiple reasons

06.11.21 Concept: Feeling personal responsibility
Again this is only spoken about by the less experienced participant who feels personally responsible through reflection on his own actions. Is this related to being less experienced? Is it that he is less senior and has worked in settings where he feels he gets blamed. Or is it more about his proximity to the self-harm i.e. he was actually there when the self-harm took place (and had been involved in that persons care on the day) rather than hearing about it. Would be good to contrast these experiences to see.

06.11.21 Concept: A PTSD response (distressing)
Maybe more of a description but the way in which the incident is talked about sounds very distressing, participant 2 in particular can vividly describe the events leading up to the incident and finds it distressing to talk about. It seems like the memory of the incident stays (at least for new staff) what happens when you have witnessed hundreds of events? Do only some stay in your mind. What is the effects of this? Or how do people protect themselves against this?

14.11.21 Concept: reflecting on own response
The process of reflecting on own response seems to happen after the incident. Individually? By talking to others? I also think that the process of the interview helps people reflect on their experiences as well. Is there a difference between reflecting on self or others. Reflecting can be in quite a detached way- e.g. what was the outcome- and this seems to help cope with the impact of self-harm. Or it can be more focused on the individual e.g. what did I do? What could I have done better? Does this lead to the feeling personally responsible. What about feeling you have done “a good enough job” (below)

14.11.21 Concept: A good enough job
This concept reflects the process of moving towards accepting you have done a good enough job (rather than feeling you are personally responsible?). There seems to be two parts accepting the inevitability of the SH/ or your power to control it and accepting your own response to it. Is this easier for more senior or experienced staff members? E.g. when you have seen it enough times it just becomes something “normal” (should it be? What is the impact of that? Stop trying to change things?). What happens if you cant accept you’ve done a good enough job? Do you just stay blaming yourself forever? What impact does this have- eventual burnout? Can you go the other way and think you did an excellent job so stop being reflective and stop learning.

12.12.21 Concept: Accepting not knowing
An acceptance that you are not going to know and understand everything (maybe linked to doing a good enough job). Participant one seems quite comfortable with not knowing (comes with experience?). This feels like it is in contrast to participant two who very much wanted certainty at the start of the interview at least wanted certainty about why- did the process of reflection through the interview enable this acceptance of not knowing. What are the other opportunities nor this acceptance to take place. What are the implications of this acceptance of not knowing- less blaming of self?

12.12.21 Concept: Feeling helpless
Both participants acknowledge this feeling. For participant 1 it is because she cant do what she said she would due to lockdown (powerlessness?). For participant 2 it seems more linked to not knowing what to do in the moment of SH i.e. how to support the individual (make the behaviour stop?)

12.12.21 Concept: Feeling undervalued as a profession
Pretty self-explanatory but there is a sense that working in care is undervalued. Seems to come from all levels of the profession but wonder if this changes as you get more senior? Think there are a few parts to it: firstly that the skills and training required aren't recognised (nobody knows how hard the job is), secondly that the pay and the title reflect this feeling of being undervalued. NB. Most people in the study so far have been white British, wonder whether there would be any cultural differences? I wonder what impact if any this has on their work, could be linked into values so if values underpin the reason they are doing this job perhaps feeling undervalued has less of an impact? Possibly links to concept of powerlessness from interview 3.

06.01.22 Concept: powerlessness
Yeah that's restriction had already been introduced, that was going to happen very soon because they finally believed us about him being a potential threat to children and animals. They said he needed to have a male accompaniment wherever we went in case he needed to go to places like public toilets. Its, it's understandable but the fact that we've been fighting this for a year you can imagine how frustrated we all were
Erm, trying to get this recognition and being told its completely imaginary and then without any kind of time for him to process what the hell is going on they introduce new restrictions and taking away certain members of staff which hasn't gone very well
I think this is another example of the **powerlessness** and particularly highlights how this is similar between staff and the individuals that they support

06.01.22 Concept: A challenging place to work- under attack (powerlessness again?)
I was frustrated at the nurse I thought the way that she handled both situations wasn't helpful to him or us. There had been a lot of almost personal attacks on the staff before, erm, where that team, so it wasn't just the nurse, it was the social worker and that before
Under attack- in this case this concept seems to be relating to feeling under attack from other professionals. I wonder if this is related to what was said earlier and this participants want to get qualifications, I guess it also links onto the powerlessness. The word 'attack' is quite a powerful one and here it is being used to describe a verbal attack. When she talked earlier about being 'attacked' by the service user that was obviously a physical attack but what still seemed to be most difficult was the last of support from management (another attack?) I wonder if self-harm ever feels like an attack?
Could be the same things as **powerlessness** again which is coming up a lot. Which can also lead to these feelings of anger and frustration. For this person this seems to drive them to exert their authority to other professionals. I wonder what other people would do? Could there be an alternative response i.e. give up? How might this sense of powerlessness be different between different professionals as well?

13.01.22 ***A summary memo***
The first main concept seems to be about the working environment, it helps understand the context in which self-harm takes place. There are maybe two sides to this. Firstly that it is challenging- its busy, there are lots of demands on the team (more for more senior managers who need to split their time?) but its also a challenge because other people don't really appreciate the role and people feel undervalued and powerless. Possibly related to the complexity of the network (challenges exist as part of the wider network as well as the immediate environment). I'm not sure that it's the flip side but the other related concept s having an open environment (an open home?). This is largely seen as a positive thing: people "check in" on each other, communication is good, and it sounds a more fun,

happy place to work. Its both metaphorical (e.g. sharing information) and physical (actually leaving the door open) and impacts both staff and the people they work with. I guess “the blame culture” (which participant 2 experiences in his other setting) would be the opposite to this. I wonder if a negative environment is likely to add to more negative experiences for the service user and contribute to SH.

There is a second concept that seems related to the participant. Its about their values and what keeps them in the job. Their values (e.g. making a difference) seem to shape how they go about day to day interactions. Do they also have direct influence on how they respond to SH (e.g. risks vs restrictions)? They might also influence the relationship that is built with the service user. The person’s job role/ length of time in the service also seems related to this concept with seemingly less experienced staff finding self-harm more personally challenging (through what process?); it could also be that they witnessed it directly rather than observed. Participant 3 also had her own diagnosis of autism, and participant 1 had been a carer when younger- I wonder if there are other people with personal experiences and how these shape understanding or response to SH. What do people perceive their job role to be (e.g. participant 1 it is about taking care of the team as well (mental health) and this will influence the environment). Is this something which enables people to respond in a different way?

The characteristics (?) of the service user themselves also seem an important concept. Two different responses to self-harm mostly about how much space is given to talk about it rather than “moving on” seem to be related to the individuals level of “functioning” and/or verbal communication. What other differences might there be (not necessarily immediately related to SH). There is also the person’s relationship with the SU which comes up- having a relationship enables openness. Having a relationship seems important (because of participants values), is this what enables you to see the whole person (strengths as well as difficulties). This relationship shapes how they spend their time together although influence on SH directly is less clear.

What actually happens when somebody self-harms feels less clear because its not just response in the moment but before and after. Maybe this concept could be “action”. How do carers support Sus day to day (e.g. supporting independence, routine, enjoyable activities, connecting to the community)? How does this shape whether or not SH takes place. There’s an observing or looking out for warning signs that things might not be ok and intervening early if possible. Then what do people actually do while the SH is happening- in the moment this seems mostly focussed on risk (and reducing the risk). And then after, trying to understand (“sitting with”), connecting with other people in the network, or “moving on” (trying to distract).

- There seems to be a process of reflection that takes place (privately, through talking to others or during the interview) when people judge the actions they took and whether they would do anything differently next time. How much does the outcome of the situation affect this. Probably the environment as well (blame culture) and their own personality (i.e. are they self-critical)
- There is also a process of learning either by going back and reviewing what happened (another type of reflection) or by observing. This seems to change what action is taken
- People seem to want training or think it will be helpful. Not actually clear whether it would change action though. Maybe a question to ask is how do you use your training?

Another important concept seems to be the participants emotional experience. It is a really distressing incident to witness (particularly for less experienced staff and then it becomes more normalized? Through what process?). I wonder how long this lasts and how people manage this (probably where a good team/ environment is important). What might be the long term consequences? There seems to be worry/ apprehension which can hold people back from acting? (helpful or unhelpful) and I wonder what other influences there is. Participant 3 also talks about frustration which maybe comes from feeling “under attack” (by SU and others), leads to attempts to exert authority. What about positive emotions as well- link back to the persons values and are what keeps the person in the job.

Understanding SH is my final main concept at the moment, how do people understand SH. My sense is that there a multitude of reasons, even within each interview participants talk about a range of reasons (that may be related or not) for why they think the person may have self-harmed. Some are very concrete like there was this incident and then they did this but the emotional impact of an even it talked about as well. So far it doesn’t seem to drive action (at least immediately that is driven by risk) and afterwards its more about the persons “functioning”. I guess when I started this project I was hoping for a clear this is how they understand SH and therefore this is the response but it’s a whole lot less clear than that. Interestingly I think this might be what happens for participants as well they start off wanting to find a specific cause (participant 2) and then through the interview (participant 2) or with experience (participant 1) are more accepting of a range of reasons or not knowing. Maybe less participant 3 (ASD diagnosis = more black and white? Other emotions e.g. frustration stop reflection?).

17.01.22 Concept: Emotionless description (desensitization?)

So yeah I suppose he just started kind of shouting and screaming very, very quickly and slapping his face, which you know when he’s kind of more on the kind of (sighs) less in control, I guess, erm, when he does kind of go for physical aggression at the same time as well. So, he ran outside to the car park and when he does, often he’ll like run at ya, but stop just before and start hitting himself but then when it gets to another level when its like, its like built up too much, when he runs at ya he’ll like hit you with his arms. So he kinda like does that and then

Not sure exactly how this concept fits (part of the PTSD response- NB I really want to change the name of that as I think PTSD response could be too strong?) but basically when people describe the self-harm they describe some pretty horrific things in a very neutral way. In interviews I don’t experience particularly strong emotions when I hear it (because I have worked/ witnessed things myself, because I don’t know the client) which I guess is also interesting. Participant 2, 7 and 8 are maybe the exceptions- finding it quite hard to talk about (I’ll need to double check)- again linked to a lack of experience. Do we talk about these things in unemotional terms to protect ourselves.

27.01.22 *Drawing together again*

Because “Action” felt like it wasn’t really working I went back to the codes and took them apart a bit again. The problem is I feel like I have grouped things thematically now but lost the more analytic way of understanding and the process that takes place. At the moment I have just grouped all the actions under response:

- Connecting: building relationship with SU; connecting with others in the network
- Controlling: about managing risk; also using punitive measures
- Empowering (the SU): creating a meaningful life, supporting alternative coping strategies
- Exploring: with the SU (or I guess through looking at notes etc.) the reason for SH
- Fixing: trying to find solutions (not very full)
- Involving (others; actually very similar to connecting)
- Mentalizing: trying to understand the SU- maybe its less a response but just a reflective process that takes place
- Sharing: Speaking with others in the team (a learning process)
- Soothing: trying to manage own emotions, soothe the SU, and moving on to a normal day
- Supporting: Very similar to empowering

So, yes maybe helpful for me holding the data in my mind but what are the main processes that actually take place.

1. A move from observing to acting to directing. Maybe directing is too harsh a title (guiding?). Comes with experience and seniority in job role. Learning through experience as well and being directed by others enables this process (benefits oh having an open environment). Requires safety? What gets in the way- own anxieties, sense of powerlessness. Observing is actually important all the way through (always come back to it to try and understand).
2. Normalization. Initially the SH is seen as very scary but becomes normalised over time, this reduces the anxiety response. Some memories remain which were particular threatening? As it becomes normalized it enables this move from observing to directing? Sharing in the team also enables this process? And a need to be able to soothe and process own emotions.
3. Towards "a good enough" job, the move to accepting that you can't do everything right. Compared to when you are blaming self, and others, for not going a good enough job. Again supportive environment helps (to not blame self and if you feel supported by others you will not blame them). Happens in parallel to number one?
4. Accepting uncertainty, a circular not linear process but people going from not knowing the cause (and panicking about it) through observation, asking the SU, reflection, learning and training to identifying a "cause" and then moving to noticing multiple understandings and accepting that they might "not know" (before going back to identifying again!). "knowing" and relationship with the SU is important here.
5. Balancing risks with restrictions. A process which seems to be the daily challenge. On the one hand its about empowering SU but there are restrictions placed on their lives. This is highlighted in incidents of SH

The overall model then becomes more Understanding and working with people who SH?

29.01.22 Concept: A distressing experience

Although mostly this is about SH because this is what I am asking about I think it is worth acknowledging that its not just SH which is a distressing experience but also there are other quite difficult things that staff have to deal with (e.g. threats to themselves) which can make it a challenging place in general. Again I'm just noticing the parallels with SU's and what they have experienced. At the moment these things are quite separate but could they be bought together (e.g. The SU and the work place?). Possible similarities: importance of relationships, feelings of powerlessness, importance of openness and empowering, providing support? I guess its interesting that I was trying to maybe separate the person with Ld- reflecting my own biases in seeing difference

03.02.22 Concept: Power

Following my interview with supervisor today there were a few interesting conversations that got me thinking about power

- Is powerlessness of staff increased because of working with undervalued group? This is something I could be curious about if I manage to do any further interviews but would also be something to look back over past interviews about
- My own power in interviews- Is this why people choose to use "professional language" or worry about what experience to talk about (a way of exerting their own power). If they are feeling powerless how might this affect what they say or don't say
- Splitting in the team (the blame culture) as a way of asserting power?

One thing I'm really conscious of though is separating the ways of doing things into "good" and "bad" with the idea that power= bad and so things that attempt to reduce power are inherently good and things which increase it are "bad". I'm not sure that that is necessarily the case and besides who am I to decide, I will only be judging this from my own perspective. Maybe a more helpful way of thinking about it would be “balancing power”. I’m also slightly conscious of the word power in itself having negative connotations. What else is it…control? Certainty? Safety? Knowledge? In a way I think it is all these things and maybe is the right word. Why is it that I am so aversive myself?

03.02.22 Concept: Seeking certainty

But its, it does, it really, it’s a weird feeling, a really weird feeling. You know I was questioning myself as a manager, “am I in the right job? How could that have happened?” you know, once, once you drill down to it, we then found out it was literally, the workman had been in and left a torch (interview 5)
Wanting to find a cause as part of the blame culture? If can find somebody else to blame it on can stop blaming self?

03.02.22 Concept: powerlessness, seeking certainty

Yeah, you know, what are your classic questions, you know from psychiatrists and therapists there. Yeah, how are you feeling? You know how you really feel then? How does any bloody person, though how they're feeling, I mean that what ridiculous question to sort of ask, especially when you're in a in a hospital base, and I think so you say things as a tick box exercise don’t you? “Yeah, I'm feeling really good”, you know? Yep, Yep no. Knowing that actually if I'm OK I might be able to get out next week in the in the in the mini bus, you know? (interview 5)
I think here again it is about how asking questions (a way of seeking certainty either about understanding or in this case risk) is used as a way of gaining power for the person asking but can maintain the lack of power for the person being asked. Its driven by your values…why are you doing this? Is it in the SU best interests? And even then to some extent its about the perception of the person who is experiencing the questions.

05.02.22 A summary memo

The immediate response to self-harm seems to be about managing the risk. This response might vary depending on if the SH is witnessed first hand (but even when it’s not its about first aid). Its then about calming down/ attempting to escalate (both yourself, your team and the SU)- this might include just moving on with the incident and pretending its ok. Finally its about understanding- asking the SU directly or by looking at notes, records, debrief etc.
Personal factors: values, experiences (including personal and professional), personality.

- Risk: Values will affect how you decide to balance the risk vs the restriction; may use past experience to justify why you are using some strategies; how experienced you are will depend whether it is your responsibility to involve others; asserting your authority may again come with experience or may be driven by values
- Emotion: Personal experiences of not being supported / blamed in the past may lead you to expect this from other; with experience become more desensitized; personality will also affect how you choose to cope with experiences; harder for newer staff to manage the emotional temperature
- Uncertainty: with experience become less reliant on following specific behaviour plans and more able to move towards accepting uncertainty (although this is flexible); role of more experienced people to involve others

Perception of SU factors: relationship, perception of abilities, ‘knowledge’ of history

- Risk: Knowing what has worked for SU in past helps manage risk; balancing the risk vs restriction is determined by relationship with SU and knowing what is important for them so can shape strategies to suit them; perceptions of “disability” determines what ways of managing risk is deemed appropriate; knowledge of SU past experiences of trauma may drive you to exert authority (with values)

- Emotion: Perception of disability determines choice to “talk about” SH or just move on with day; can become desensitized if behaviour is seen as part of SU; if tricky relationship with SU may lead to blaming them; relationship with SU may affect emotional impact for self
- Uncertainty: Giving a reason for the behaviour shaped by perception of disability and knowledge of history

Organisational factor: values, support

- Risk: again organisational values drive the management of risk and how this is balanced with restriction; whether you assert you authority may be determined by whether you feel supported by others?
- Emotion: Being in an organisation who’s values are in line with own and feel supportive drive seeking or giving support to others; when these not in line may feel blamed or blame others (blame culture)
- Uncertainty: the type of support the organisation provides may shape the way in which you seek uncertainty (e.g. through training, involving PBS practitioner); talking about things with the team requires an open environment with good communication; asking the SU also requires an open environment where they feel able to talk

All this takes place within a context of power where staff feel powerless and so do people with LD. All the main concepts (risk, emotion, uncertainty) could be seen as dimensions of power e.g. managing risk increases staff power but reduces it for SU; managing emotions again increased staff power as feel more in control?; seeking certainty is a way of exerting power (“being all knowing”). But its not just always about seeking power the persons values etc mean that they want to increase the power for the person they work with as well. I keep coming back to this idea of balancing the power

10.02.22 Concept: Feeling helpless

Is this linked to a lack of power- feeling powerless to do anything to stop the SH. Which obviously contributes to it being a more distressing experience

Erm, and…yeah, and just really because I haven't worked with them for that long, uhm, it kind of just made me like, it kind of just made me like I really need to, we need to do something and I need to help them where I can, if that makes sense?

I wonder why being new to working with this person made her really feel like she needed to do something? Seems to suggest that you are more likely to feel helpless if you are inexperienced? (although she had been in the service for longer so maybe not about the system in that way?) Does it link back to what she perceives her job role to be (reducing this behaviour) and therefore because she is new to working with this person feels she needs to prove her value in this way?

Erm, I mean, throughout the day they kind of go in cycles of, of doing this, asking lots of questions, engaging in self interest behaviour and then they would go outside to self regulate and then they would be OK for a couple of hours and then it would like come up again and that would happen to the entire day up until kind of UM, kind of at night where they, they settled down and they slept and then the next morning waking up kind of when not in that they were not in that, sorry excuse me, they're not in that state anymore.

Also what seems to be important is although some things are helpful these seem to be things the SU is doing (“self regulate”) or out of her control (“sleep”), so even though these things are helpful they still leave her feeling quite powerless.

13.02.22 Concept: Sitting with it

Participant 9 is the first who I think talks about just “waiting it out” the SH and not necessarily trying to stop it. Obviously there are things that she tried to do but when she can’t find a way to help, its sort of like just being with the person and sharing in their distress. For participant 9 this is because she is really against physical interventions. I think another participant also talked about accepting SH.

18.02.22 Concept: Lack of power in LD context
This is actually something one of my supervisors had been curious about in a previous meeting- because people with LD can be such a powerless group themselves (experiences of stigma, control, abuse) whether the people working with them experience this powerlessness more. A few people had alluded to it in their interviews but it really struck me in the interview today with participant 11
I think the potential that these people have is incredible and they're just just because they're they have a learning disability that just kind of usually just put to one side and told that they can't amount to anything.
And they obviously had a, uh, a thing like he'd never change, which was something I hear quite a lot about people learning disabilities.
I think the thing that's really struck me is how forgotten about and how like kind of side-lined people learn disabilities are, and the fact that uhm, you know they're, they're kind of not given the same opportunities and then put into situations where uhm, any of us would would make bad decisions I think and and and then locked away for a very long time, much longer then other people would be for for that, for those kind of decisions so yeah
I think it just really demonstrated how the lack of power for people with LD can also affect staff's feelings of powerlessness e.g. through a lack of resources, lack of support from others, a lack of hope for change in the system. He also alludes to the fact that this might create reposes like self-harm or 'challenging behaviour' which then can obviously increase he feelings of powerlessness for staff

24.02.22 Concept: coping with distress
Think I need to have a re-think about this concept because at the moment it feel like the sub-concepts are organised descriptively but don't necessarily reflect the process. This is how the concept is currently broken down.
I think there is two things to thing about firstly how things happen with time so some things happen straight away and somethings take longer, and also whether it is about minimising the distress or sitting with it. It's a kind of balancing act that sort of varies at different points in time. Maybe I'm trying to make this two complicated though. Maybe it is just that people use these different ways of coping at different points in time and they move between wanting to minimise the distress, or being able to tolerate it a bit more. Maybe it's a gap for further research to identify more about the specific time line and the factors which shift people between these different ways of coping.
Also as I'm writing this I'm really aware that I don't think that one way of coping is better than another necessarily and that we should try and make people cope in one way. It actually seems helpful when people move between these ways. Maybe what is unhelpful is when people get stuck or focused on one

09.04.22 Concept: Uncertainty and power
Looking back over my memo's the two concepts that seem to come up a lot are power and uncertainty. There is definitely powerlessness in the system (risk, working with other professional, undervalued as a job, powerlessness for people with LD). This can affect how distressing SH is (e.g. if you have been previously hurt or unsupported) and also witnessing SH adds to this feeling of powerlessness (e.g. participant 2 helplessness). One of the ways of coping with SH is for staff to use the power they have in different ways : managing risk, reducing the emotional temperature, detaching. As I said before I don't necessarily think this is a bad thing but might explain why sometimes coercive or punitive methods are described in the literature. Participants in this study seem to show an awareness of this balance of power between themselves and SU (could this be linked to their values?).

“Erm, and then after that she had to have consistent visual which was awful for her but equally we just couldn’t take that risk until it reduced.” (Participant 1)]

Also this sort of using power is also used to support others to empower the service user or other members of the team. Awareness of the power can also stop the ‘blame culture’.

The other process that seems to be going on is about accepting uncertainty. In this caring vocation professionals talk about wanting to “know” the service user so they can support them (a way of managing uncertainty) however things cant be certain and the SU might SH. Again power is used in some ways to manage this uncertainty (managing risks longer term) but also so is knowledge (seeking certainty). With experience (desensitization as well?) people are able to accept greater uncertainty (e.g. what causes SH) and tolerate the distress/ feelings of powerlessness

Appendix R: Research diary extracts

13.10.21

So have now transcribed all three of my first interview and coded the first two (twice!). Initially coded them by hand and then transferred that to the computer. Am finding it hard to know how to manage all this data and worries I will "loose" something important. I am also noticing that I am being very critical of my own initial coding and really feeling a sense of wanting to get it right. Trying to remind myself that there is not a "right" way of doing things and use memo's where possible to record the decision making. Feels hard and overwhelming though!

11.11.21

Just swapped and reviewed coding with one of my peers. Was feeling a bit worried before that would have got this all wrong but it was reassuring to find out the feeling was mutual. Our coding was relatively similar which was also reassuring but we spoke about how this may be influenced by us coming from similar positions (e.g. both white, female, trainees at Salomons). I think that this is where the bracketing interview was really helpful.

One of the differences that arose from my coding was whether to code what the SU being described is doing (e.g. using SH to manage emotions) or what the interviewee is doing (e.g. Understanding SH as a way of managing emotions). I generally went for the latter which I think fts better with the research questions but worth bearing in mind what might be missed.

We also spoke about the challenge of going from psychologist to researcher and how this shapes the way you interview, for example how much do you summarise, how do you point out contradictions in what the person has said etc. It was interesting to notice how the process of asking questions really does shape the other persons answers and maybe their thoughts and beliefs as well. I think I noticed participant 2 alluding to this about how reflecting made him remember more- wonder whether this will become part of the model.

09.12.21

I just completed my sixth interview, he was passed on the details from somebody I interviewed previously and is hopefully going to pass it on again to his team which hopefully is a helpful way of recruiting. I was slightly conscious of rushing through some of the questions, particularly the first ones because after the very long interview last time I wanted really to focus more on the experiences of self-harm. I also think I felt the need to less rigidly stick to the script in order. Partly as I become more confident in knowing the questions off hand so can fit them more naturally to the flow of the conversation, and partly because he began talking early about how his response to SH has changed through his career and as this was something I was interested in previously I wanted to make sure we talked about that. I noticed as well when he said "reflection" I really went into that, probably a trigger word for psychologists! In contrast with some of the previous interviews, he was quite focussed on the "triggers" for behaviour and I don't think really talked about emotions at all. The client's he talked about were non-verbal so perhaps it may be associated with that, he also seemed to have had previous and current experiences working in quite PBS led services, and (massive generalization but its on my mind) was also a man?

17.12.21

Feeling really "in the thick of it" now and really feeling the pressure of getting Part A done before Christmas. Everything just takes so much time but the coding for the thematic synthesis has made me feel a little bit more confident in coding again so hopefully helpful in part B.

Did my final interview for before Christmas so now have done seven which is what I had hoped, and have two more scheduled for after the break. Don't think this interview went particularly well, the internet was unstable so we had our camera's off and it was hard to establish a sense of connection. I think I might have compensated for this by giving too many reflections or summaries to make her feel heard but was cautious of trying not to put words into her mouth. She linked the SH to anxiety and I think I asked a follow up question about how SH 'functions' for the individual (I guess this was influenced by the current coding of my part A) but this led to her talking about it being an emotional regulation strategy or way of blocking out so maybe would be useful to include in the future.

11.01.22

It feels like there has been a shift in the project from being quite specific how do staff understand and respond to SH to a wider question- maybe how do staff work with people with SH. I don't think the SH incident can be looked at in isolation and it really is about how the wider context of what is going on affects things. For me I have become less concerned with trying to pin things down to a specific cause and effect and more able to sit with and accept this uncertainty and complexity (interestingly that also seems to be the process participants go through as they get more experienced). – "safe uncertainty" What drives safety? What drives certainty?

14.01.22

The 10 interview milestone has been reached!!! Think I need to get a bit more analysis under my belt before going back to see if I need more interviews. I feel like I now know the first three participants and there interviews really well but have sort of lost the ones in the middle.

27.01.22

Feel like I am really going round in circles today, revisiting some of my codes and feel like I am creating more of a mess! The more I re-look at categories, the more I take them apart and then I am back at my initial codes again. It feels like this will be never ending, like you'll always be able to unpick and re-arrange things in a different way. It feels like there is two things making this messy 1. Is there is no clear separation of time- I want things to be before, during, after the event but they are not (so I guess it's a more circular process). 2. I also want action to be separate but its not its linked to context and understanding, and not just that these things influence action but also understanding is a process in itself! Feel like I'm loosing focus and just making things worse and worse.

29.01.22

Just coded interview 7 and I have to say it's the first one that hasn't taken me ages. This might be because it was slightly shorter but I also noticed that I wasn't creating hundreds of new codes or having to do loads of rearranging. This has made me start to feel that maybe now my concepts are starting to make sense and I am starting to add to the evidence rather than discovering more gaps. One thing I've noticed as I go through the interviews either completing them or transcribing them is that I seem to be sharing more of my personal story. Firstly I think this is because I have seen that it really makes people feel more comfortable. The coding I think has highlighted to me the power dynamic in the interview and so I really want to try and equalise that by being transparent and sharing my own experiences. I think also being aware of this, we had a lecture recently about therapist self-disclosure, means that when I do disclose something there is some thought behind it and its quite a conscious decision. Also I think through the coding I've seen how much my own experiences and lense is going to shape how the data is collected and analysed anyway , its impossible to be a blank slate. Sharing a bit more of myself feels more authentic to the type of researcher and therapist I am going to be.

Coming to the end of coding today I'm struck by the way in which I've been really trying to separate out the experiences of people with learning disabilities from the other staff. To be honest I'm a bit ashamed of myself because I feel like it reflects this unconscious "us and them" bias. Actually the challenges and what's important is similar (and why wouldn't it be!)

03.02.22

Had a meeting with my supervisor today and it was really helpful to just speak aloud some of the things that have been going on in my head. We though about how the question has shifted from a more linear process driven question (how to staff understand and respond to SH) to a more circular(?) or at least broader process (how do staff work with people who SH). I think this shift is partly my own more to accepting greater uncertainty and not needing to find this clear 1, 2, 3 process. Its also been making be think what data might be less relevant (to this model) and therefore ok to let go of; talking out loud made me realise quite how much I still want to cover and reflect on how I can make this simple and relevant for the participants.

We reviewed the coding of the transcript we had both done as well. This was quite reassuring because although the initial line by line codes were not the same the broad concepts that these codes could relate to were similar- it maybe made me not stress so much about the line by line coding.

Talking about the codes really made me think about my own power in the process, for example in the professional language the participants chose to use. How might I represent the MDT and the lack of power they feel to them. What does this mean they say or don't say e.g. how might they choose which experience of self-harm to share. I hope I am making people feel comfortable, I guess this might be why I've noticed myself sharing some personal anecdotes as a way of minimizing this power dynamic.

07.02.22

One thing I've noticed through coding and transcribing is that I haven't paid that much attention to the context of covid. In interviews it has been mentioned a little bit (increasing daily tasks, changing activities and creating anxiety for the people they work with) but not that much- maybe this is because in my questioning I haven't gone into it in too much detail. I have also noticed I had maybe coded it on early on but these codes have been sort of lost into broader categories. I'm really interested as to why this is because I am well aware of the difficulties carers are facing in the context of covid and for example with my recruitment am really holding onto how difficult things are and hence why people might not want to take part. I guess I have been doing more of the coding when Covid (or at least the rules) are lessening so maybe I just don't want to think about it and am pushing it away; maybe that is the same for the people I have been interviewing. It reminds me of a quote from one of the participants who said something about dealing with it now and processing it later- maybe because covid is still around I (and participants) are also not wanting to process it.

12.02.22

Transcribing and re-listening to interview 10 and to be honest its really quite touching to hear just how much he cares. I think with the media its so easy to "demonise" care worker's but honestly throughout the interviews everybody I have spoken to really does care and really does do this job because of that. Interview 10 just really reminded me of why I wanted to work in this area in the first place (and to be honest sometimes why I was put off psychology because you get too detached)- really for me its about like he said giving somebody a nice birthday! It also makes me angry as well because I do think it is such a hard job, that demands so much of you and it is just so so so undervalued. But really until you do it I just think that you can't get a sense of that (it's a bit like how participants talk about how training can never prepare you for seeing sH), you just don't know how hard it is to be a carer until you do it

18.02.22
Met with my supervisors today to discuss the data analysis and the model development. I think trying to articulate it out loud is helpful and I can notice the bits that are a bit sticky to articulate and where any gaps might be. I've put this in a memo (18.02.22). Mostly though I think it made sense and with a few names for the concepts changing I think this will help people to make more sense of things. Although it still would be helpful to interview somebody who did not like the job/ did not share the values of care I think this is going to be very difficult. Talking the model through made me feel a bit more confident that I might be starting to have enough participants.
Its starting to feel like now new concepts are emerging. In fact it was really helpful because I think that he was articulating some of the links between concepts that I was making and hearing it back to me really made sense; I don't think I was asking him questions that were too leading to get him to say things either. Actually, one thing I have noticed is when I first started asking questions I was really hoping for certain answers, I don't know what I wanted to say but I think I wanted people to just closely, and neatly, answer the question. But that's not what happens, people go off one hundreds of tangents and that's really what has bought some of the main concepts of my data (e.g. powerlessness). I think as I have gone on I've been more relaxed about this and just been generally curious about what people say. The last few interviewee's have commented "what a good question" and although I don't think the questions have changes or are particularly good this must reflect my genuine curiosity and their comfort in then really being able to reflect. I hope that the space for reflection has been interesting and useful to people, it has been for me to hear and I also think it has produced richer data.

04.03.22
I am in the writing up stages now, really is the final push. But its interesting even as I am writing, and therefore reviewing my memo's I think the way that I want to group some of the data is changing again. I guess it sort of reflects this critical realist perspective like there is something happening in the real world which I am trying to capture (e.g. the process of people becoming more "accepting" of self-harm) but I am deciding how this should be captured in the model and the language I use to describe it will to a certain extent (or not) accurately reflect this!

Appendix S: Model sent to participants

Email cover letter

Dear [NAME],

I hope you do not mind me contacting you again.

As you will probably recall you took part in an interview exploring how staff work with people with learning disabilities who self-harm. I have now analysed the data from your interview, alongside interviews from other participants, and would like to ask your opinion of the proposed results so far.

I have attached a diagram and short explanation of the proposed theory. Please let me know if you have any questions or would like further detail about the model. I am particularly interested in whether you think the theory reflects the comments you made in the interview and also, whether, in your opinion, the theory reflects more generally the experiences staff have working with people with learning disabilities who self-harm. Please note that this is not necessarily a final version of the theory and may be subject to change.

You are welcome to email me back with any comments or questions you have about the proposed model. If you would prefer, we could arrange a brief follow up meeting, please let me know when would suit you best.

Finally, I’d like to thank you again for your time and participation in the study, I really do appreciate the time you have given to take part.

With best wishes,

Libby Ilett

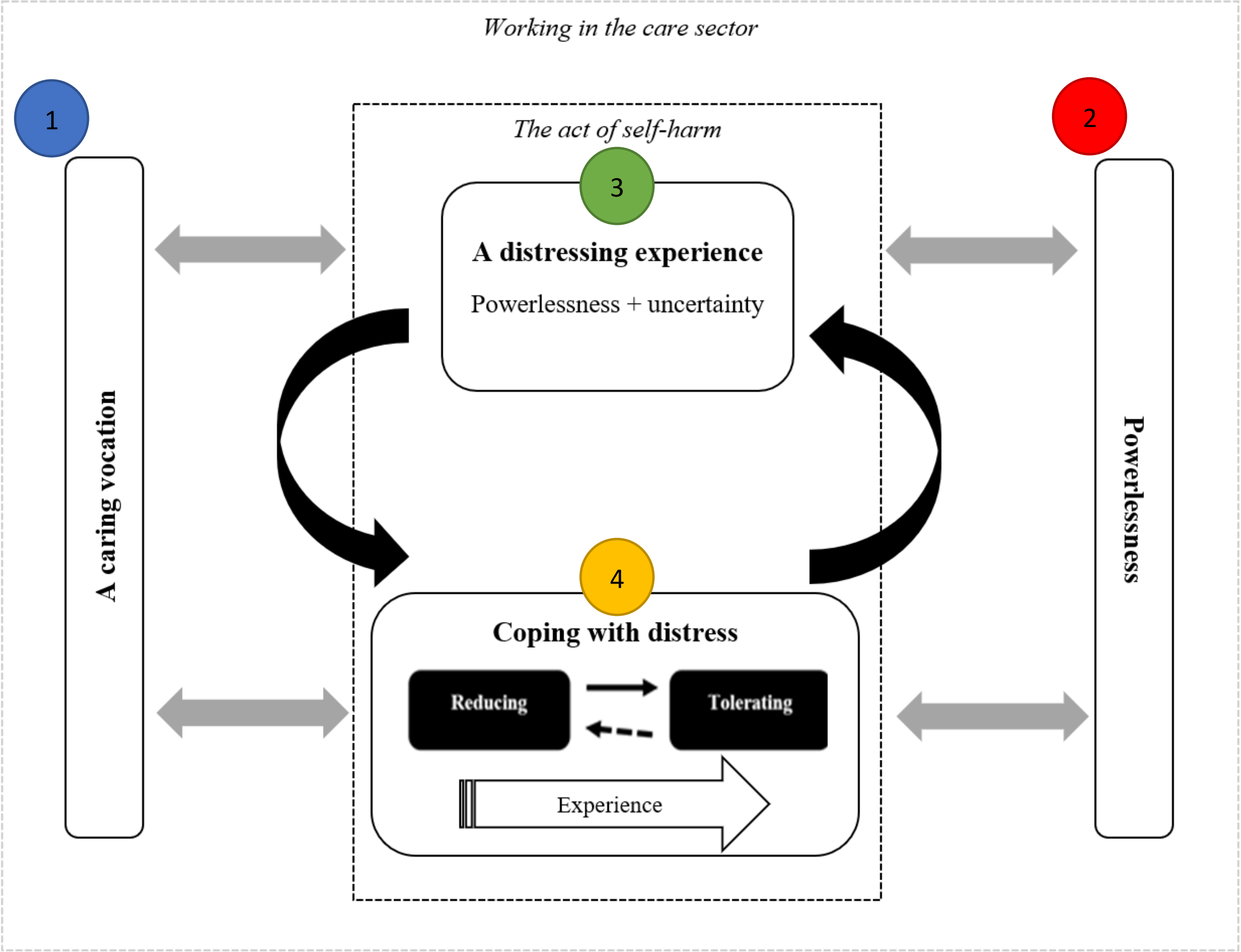
Trainee Clinical Psychologist

Summary of model

Navigating distress: A theory of how care professionals work with people with learning disabilities who self-harm

NB. Please note this is not the final version of the study results. The full report will be accessible at a later date.

The model below displays a theory about how care professionals work with people with learning disabilities who self-harm in community or supported living settings. It comes from analysis of your interview alongside the interviews with other participants.



The model highlights the importance of understanding the experience of working with people with learning disabilities who self-harm within the wider social care context.

1 Working in social care was often described as more than a job, it's a **caring vocation.** People draw on their personal values and experiences which shape the care that they provide. Ultimately, the job is about supporting the service user. To provide person-centred care professionals use their knowledge and experience, as well as their relationship with the service

user, to ‘know’ how best to support them. Seeing the difference that that support is making can motivate people to continue in the job.

2 However, its also a very challenging vocation and people can often feel very **powerless** working in the system. Care work is often undervalued and the skills it requires may not be appreciated by other professionals. Resources are limited and there might be a fear of getting blamed if things go wrong. Moreover, people with learning disabilities are often felt to be an overlooked group and experience a lack of power in their own lives. This could make it even harder for care professionals in this context because of the way society treats this group of people. More positively, people talked about how they can feel less powerless by having a supportive team and gaining professional qualifications.

3 When self-harm occurs it is often a **distressing experience** for professional who work with the service user. It can raise strong emotions in those witnessing it, including anxiety, helplessness, anger and uncertainty (particularly when the reason for self-harm, or how to respond appropriately is unknown). For some people it might make them feel as if they have failed at their job. People will experience these emotions to different degree’s and intensity.

4 These emotions could drive people to find ways of **coping with distress**. Sometimes this is trying to actively reduce the distress for yourself, the service user or other staff members. With experience people become more able to also tolerate the distress as well. Strategies include:

- Using professional power- Attending to risk is often the first priority during an incident of self-harm, staff use their professional power and responsibility to do this. Longer term staff are aware of how they use their power and the need to balance risk and restrictions on the life of the service user. Professionals also need to use their authority to get the service user the support they need (even when they feel quite powerless); this might be easier for people who feel more experienced. Sometimes the strong emotions that self-harm evokes, particularly when people feel angry or personally attacked, could mean people try to assert their power in other ways by blaming others, including the service user.
- Reducing the emotional temperature- in the moment people try to reduce the distress for the service user (e.g. through distraction) and ultimately themselves. Supporting other staff members seemed important following an incident of self-harm, particularly for more senior staff members. Empowering the service user to find alternative coping strategies also appeared important to reduce incidents of self-harm (and distress) longer term. People may cope with their own distress by trying to compartmentalise. Over time people seem to become de-sensitized to self-harm through repeated exposure to it.
- Seeking certainty- Self-harm creates lots of anxiety, when we are anxious we might want things to be certain. For example, we might want to know the exact reason for the self-harm and how we should respond in every situation. People described trying to seek this certainty, or create it for others, through observation, paperwork and training.
- Acceptance- people also spoke about becoming more accepting of self-harm, by understanding why the person may do it, and accepting that they may not always understand it or know exactly how to respond. On reflection most people felt that they had done a “good enough” job at coping with the self-harm and through experience are able to cope a little better with the distressing experience that self-harm is.

Appendix T: Categories, subcategories and example quotations

Concept	Sub-category	Focused codes	Example quote
A caring vocation	Doing care	Reasons for staying in the job	That really bought home, you know, just how her life has changed and how I have been privileged to sort of be part of that [P5]
		Innate skills	Erm, we are naturally built to analyse to why something has happened and why are they feeling that way, erm, its just built into your blood I suppose isn’t it [P1]
		Personal values	So I, I really like kind of being able to make that difference and making them feel like, like (a) they're, they're kind of part of the community, part of us, and (b) make, make, making sure that they have a life that is, you know, to, to, to their own beliefs and their standards, kind of worth, you know worth kind of getting out of bed for. [P10]
		Using personal experiences	I’ve told people when I was younger, when I first started in the industry that I was autistic, I saw it as a strength, erm, you know I’ve been a carer since I was nine I knew I had the skills, I saw it as an additional strength, especially when I was working in an autism specific service. [P3]
		Personal experiences make it more difficult	It's almost like seeing my little brother have a a challenging episode and get really upset over it, I take that very much to heart. [P10]
	Knowing the service user	Building relationship	Like I don't I I try not to be too formal with the like….obviously I have boundaries, but I try not to be too formal the the people I support because that that just draws up more like walls, I think. So I go in like casual clothes and I have a chat and if there's anything I want to discuss, I like I mean there's specific session or session work I go through, but I discuss it in a more informal way. 'cause then it allows him to connect with me a little bit more I think yeah. [P11]
		Knowing the service user	So its took time again to get to know NAME, to find out you know this, this sort of erm, information from her and the swallowing of the batteries was very much in the early days and then it was a lot of time, I mean I invested a lot of time sitting with NAME, spending time, seeing how she reacted [P5]
		Providing person-centred care	

			Seeing what like their goals are, that sort of that sort of thing. And then just general, support like and if they can't drive taking them places or helping them with cooking, every now and again, that that sort of thing, yeah [P7]
A distressing experience	Strong emotions	Anger and frustration	Erm, so when she said that to him and the self-harm happened, it was very…youre frustrated because your like, im going to swear sorry, just “for F***sake” basically (laughs). Erm, frustrated for him, frustrated for yourself, frustrated that we, we’ve made, raised these concerns so many times and nothings been done and then all of a sudden everything is going a million miles an hour when this gentleman needs time to process stuff [P3]
		Fear or anxiety	I was worried, because she was really hitting her head against the wall it was, it's worrying because you don't know what sort of damage you're going to do? But yeah, it, yeah, it's worrying. [P8]
		Distressing	And he was very distressed by that, very and oh I felt awful, I mean just watching him sort of melt down [P2]
	Physiological response	Bodily response to a distressing experience	I probably didn’t, I probably, you get a bit of an adrenaline rush to kind of like manage the situations [P4]
		Can vividly recall details	Its, its not something that I’ve forgotten all these months later [P2]
	A threat to identity	Failure	Erm, so I suppose in my younger days, like when I first started, it was like if I had a day where he didn't do that [self-harm] throughout the day, I'd be like, “Oh yeah”, you know “I've nailed that day” and then I'd really like beat myself up when he did [P6]
		Helpless	Sometimes in those instances you don't really know what to do, there isn't a right or wrong, there's not, you know, sometimes things happen that you've never dealt with before, and you don't really know what to do [P9]
		Personal attack	On a bad day it can be very stressful because he will trash his house, he’ll self-harm, he’ll make allegations, he’ll get right in your face and very angry and say things that are meant to hurt you, especially the more that you get to know him if he gets annoyed in any way he will take it out on the people he feels safest with, erm, which is quite a common response but he can be very manipulative in that context and he will say things to try and get a reaction. [P3]

Navigating distress	Using professional power	Managing risk	Because this individual is so far off baseline, he doesn’t resonate with his own safety, so he he doesn't recall some long term consequences of what it would be if he hit his head that severely. So it’s what we’re there for hence why we have to use these techniques that we did. [P10]
		Asserting yourself	So I had a couple of battles in that sense, like in terms of advocating for the need of the input, not just specifically around self-harm, but around every kind of everything. [P11]
		Blaming	'cause I was a little bit annoyed with some other people responses. And you know it either got played down or not much use really. 'cause I was really concerned. Erm when I did approach someone who was on on shift that night they weren't really too fussed, didn't really help, didn't come, didn't like look at the situation and kind of was just like, Oh well, that's kind of what he does. And I was like it's not! [P9]
	Reducing the emotional temperature	De-escalation	Like even then I probably wouldn’t talk to him about it because he’s not listening like then, you have to like get him to a calmer state and then... And then actually if you were to go “tell me what’s really the problem” like when he was calmer, he probably, if he trusted you, he probably would blurt something out that wasn’t even what he was shouting about [P4]
		Detaching	I have kind of a quite strict rule with myself that as soon as I finish during the day, uhm. I have to stop thinking about things, I have to stop thinking about work and and my partner is very good at reinforcing that. So so I mean, it's difficult, it is, but I've kind of practised it over a period of time 'cause I've worked in these kind of services for like 5 or 6 years now. Erm, and that kind of helps me just it's almost compartmentalising. [P11]
		Supporting the service user	We can do things about communication, you know. Colour coded communication Things to stop activities and stuff like that. That's that's some stuff we put in for him [P6]
		Supporting the team	Uhm, but it was and it was hard for staff as well, I remember at the time. Erm, to have had a significant incident to then carry on and go back in and get their confidence back up. [P5]
	Seeking certainty	Seeking certainty (interpersonal)	So that you can have multidisciplinary meetings to make the right decision with the individual. [P1]
		Seeking certainty (paperwork)	Like people starting…unclear…then we've had to do like a behaviour scale as well to say about like giving them clear criteria’s of when like maybe you should intervene, when you should report, you know all that kind of stuff [P6]

		Understanding the situation	It's like when you think about something very, very uncomfortable and something that you really don't want to be thinking about, something that makes you feel bad, sometimes we all do it in like small, small ways, erm like I pick like my pick my nails, but for some people that, that like displays itself in a different kind of behaviour, like a more intense behaving like that self-injurious, so I can escape from like those thoughts that bad feeling that we're feeling [P7]
		Identifying a reason for the behaviour	So I don't know and I think it's a release of tension…I've heard anyway. So I don't know for certain...She hasn't ever said why she's done it [P8]
	Towards acceptance	Accepting uncertainty	You know you're not always going to know everything about them [P1]
		Accepting unable to manage all risks	But, there was an element of failure because I hadn't thought that far ahead, but you just you, you just don't prepare for every eventuality. You don't, you know, and you've got to learn to look at that as a lesson learned. [P5]
		Accepting why people might self-harm	Erm, but just like a greater understanding, awareness of all the different types of self harm erm and it would be hard to do it as, in general but, the like why someone would do it in in a general… but personal would be better, but even generally seeing all the different kinds of reasons erm, that you don't have the time to look at, sometimes. [P9]
		"Good enough"	I guess, I guess not, I mean, I think it would be naïve to say that everything that I did was amazing and perfect, no one can ever say that about anything can they, but I, I suspect that being in that scenario I probably did as well as I could have expected myself to [P2]
		Tolerating distress	Sometimes I go in there and he'll jump up and I'm like for the staff, "oh is he going to the toilet" like i'm not sure and you know and I'm trying to say to people like it's the same like I feel like that sometimes and but maybe just trust in the process I guess. [P6]
Powerlessness	Powerlessness in the care system	Blame culture	I think it's some staff teams feel under pressure that you know they might say "Well, you said we should leave this person now he's hurt" and you know that kind of stuff, so that's been A bit of a difficult one to balance up. [P6]
		Undervalued as a profession	but that never gets recognised. Erm and I think that it is a profession at the end of the day and it should be recognised as a profession [P1]

		Service challenges	Erm and then, throughout COVID, we've had like new staff who've learned, who've started in the middle of the pandemic and learn off the current staff that are there and pointing out the guidance 'cause then we got like a new manager who probably didn't know him well enough to give that stuff, so they're learning it from the current staff. [P6]
		Risks to staff	Erm, even if there is the possible challenge of us getting hurt in the meantime, we can deal with kicks, scratches, erm you know falls, rolling around in brambles, we can deal with that, its what we sign up for its what we're trained for. [P10]
		Powerless to make change	Not always being able to do what you want to do basically. You, you…it's kind of like always a little bit of a losing battle you know, every day, you want to do all these things, you know you need to do all these things. I've got them all in my head, I've got them all written down on a to-do list, it's just getting bigger and bigger and bigger erm and it's impossible, it's impossible to do it all. But then also trying to do things, but then not being able to maintain [P9]
	Lack of power in the learning disabilities context	Awareness of service user power	I think the thing that's really struck me is how forgotten about and how like kind of side-lined people learn disabilities are, and the fact that uhm, you know they're, they're kind of not given the same opportunities and then put into situations where uhm, any of us would, would make bad decisions [P11]
		Stuck in disempowering systems	Then I get to the other stage when I'm quite angry because you know the lady that we've just moved out in LOCATION B, when you look through her life, erm, you know, six, seven years of being in a hospital, two years, you know after the first two years she should have been discharged, another five years on top, some of the medication can be top heavy as well [P5]
	Protecting against powerlessness	Gaining power through professional status	And yeah, so I've kind of worked as like a behaviour, behaviour analyst and a PBS practitioners positive behavioural support and I've seen quite a lot of individuals with a range of disabilities and I supported them all really. [P7]
		A supportive team	Erm, I suppose, I don't…I like seeing things work, I guess. So I like it when the staff teams are cohesive and you can see things kind of being done right and in a nice way and morale is positive and things like that so…yeah. Erm, I suppose just seeing everything kind of going as it should and people being happy to work here [P4]

Appendix U: British Journal of Learning Disabilities authors guidelines

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Appendix V: Summary report for ethics panel

Dear Professor Margie Callanan,

Navigating distress: How care professionals work with people with learning disabilities who self-harm

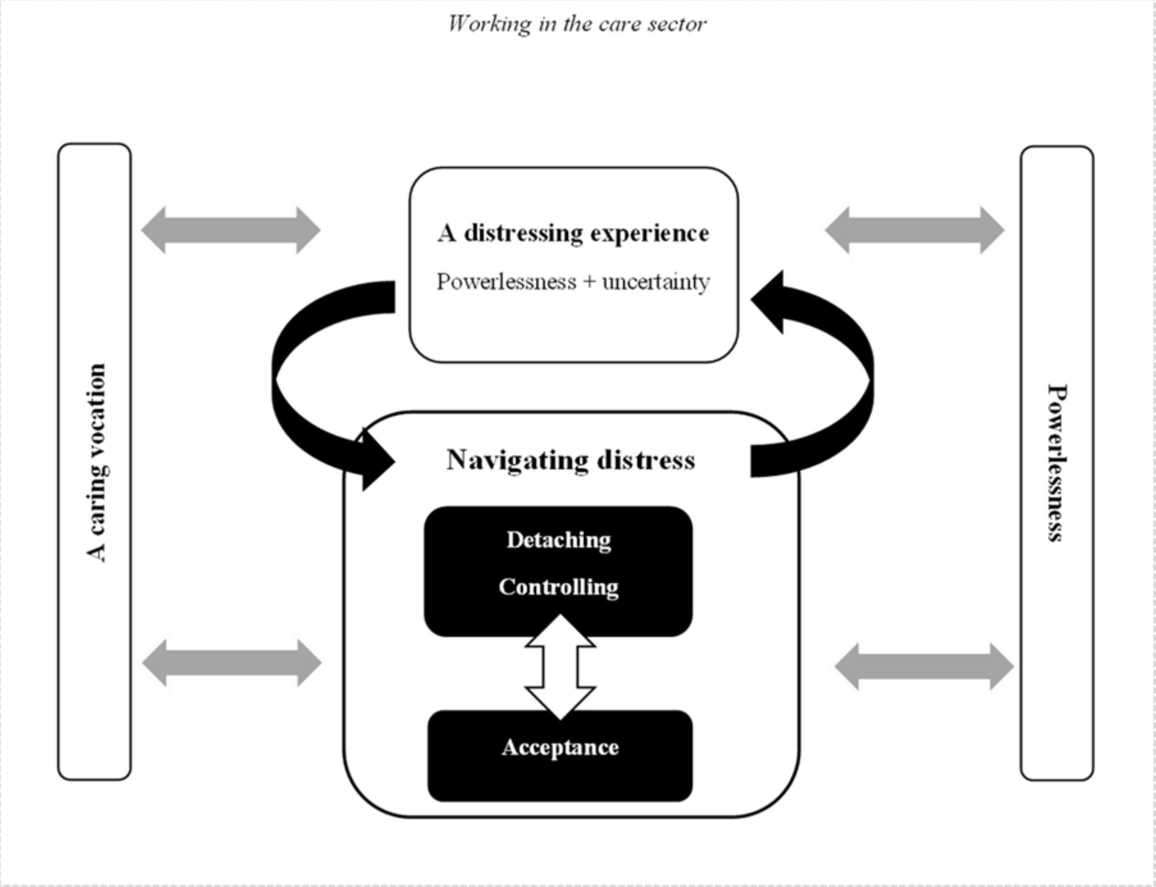
I am writing to you, as chair of the Salomons Ethics Panel, to inform you that the above Major Research Project is now complete and will be submitted for marking.

Background: Working with people who self-harm is emotionally challenging for professionals. These emotional responses, and attitudes towards self-harm, have been found to influence professionals' response to the people they are supporting. Self-harm is perhaps more prevalent in people with learning disabilities. Research also found that working with people with learning disabilities who self-harmed was emotionally challenging however how this affected professionals' response to self-harm was unknown. This study aimed to better understand the way in which social care professionals worked with people with learning disabilities who harm themselves in residential or supported living settings.

Method: 11 participants were recruited and interviewed about their experiences working with people with learning disabilities who self-harm. Grounded theory was used to analyse the data and propose a model to understand how care professionals navigate distress when working with people with learning disabilities who self-harm in community or supported living settings.

Results: The model portrayed how professionals identified caring as their vocation. Professionals sought to 'know' the service user, by drawing on their experiences and relationship with the individual, to ensure certainty in the support they provided ('a caring vocation'). Self-harm evoked feelings of powerlessness which was experienced as a threat to professionals' values and caring identity. Uncertainty about the reason for the self-harm, and how they should respond, heighted participants distress ('a distressing experience'). Professionals moved between attempting to reduce or control the distress and learning to tolerate or accept the strong emotions that self-harm evoked ('navigating distress'). Through experience, professionals developed their understanding of self-harm and moved towards greater acceptance of the uncertainty around self-harm; this reinforced their positive identity as a carer. Experiences of powerlessness in the context of the care system for people with learning disabilities, influenced professionals distress and the coping strategies they utilised ('powerlessness').
The findings build on previous research about the emotional impact of self-harm and the way in which professionals' emotional response and understanding of the behaviour may

shape the response. Limitations included possible selection bias and lack of diversity within the sample.



Implications: This study highlighted the emotional challenge of working with people who self-harm in the already demanding context of social care. Sharing the challenging nature of this work and the difficult emotions it can bring up was deemed helpful as a way to manage the distress and the move towards acceptance of uncertainty appeared helpful. Embedding supervision, reflective practice, or mindfulness into care organisations would be helpful to encourage professionals to talk about these experiences and tolerate uncertainty.
Further research may seek to test the fit of the current model with a broader range of professionals working in social care. Studies that track professionals' experiences over time, might further investigate factors that influence the shift towards tolerance of distress, uncertainty, and acceptance of self-harm.

Yours sincerely,

Libby Ilett
Trainee Clinical Psychologist

Cc: Dr Suzie Lemmey (Supervisor); Dr John McGowan (Supervisor)

Appendix W: Summary for participants

Navigating distress: How care professionals work with people with learning disabilities who self-harm

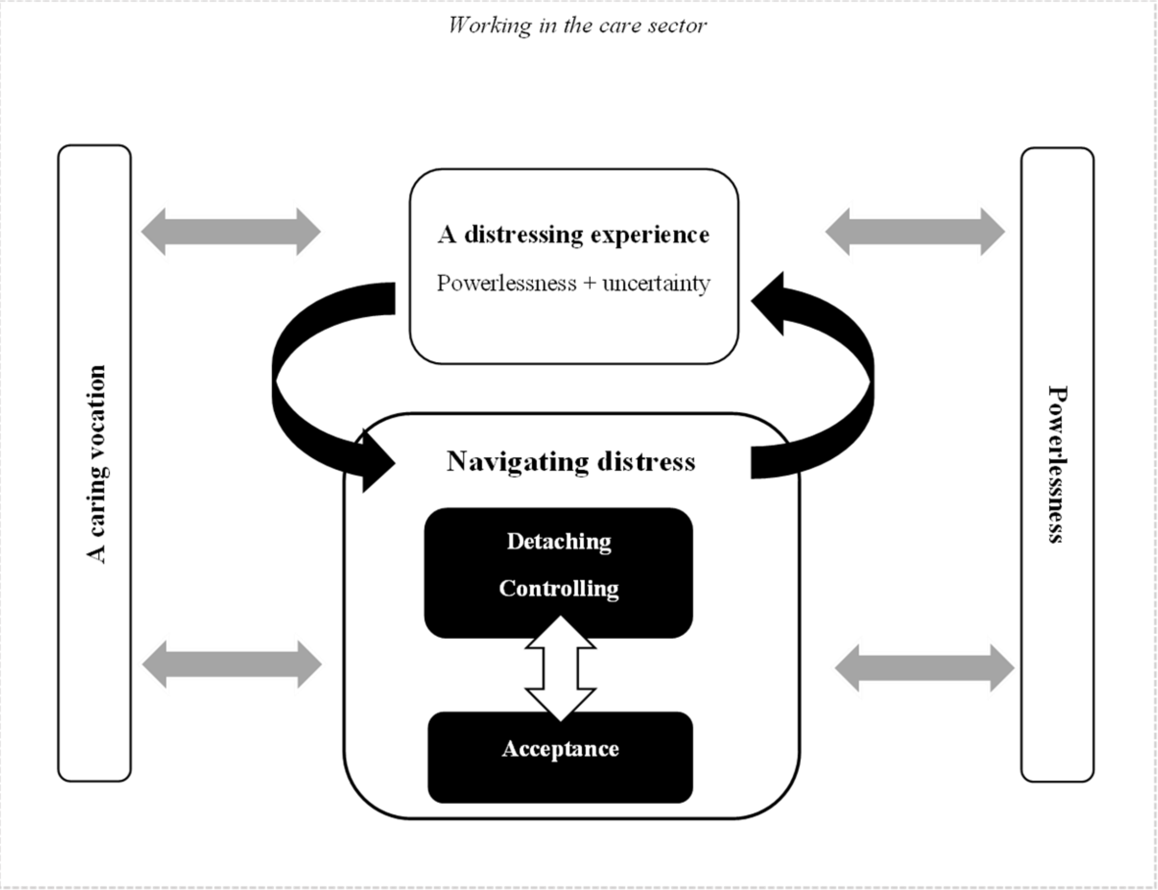
Background:

Working with people who self-harm is emotionally challenging for professionals. These emotional responses, and attitudes towards self-harm, have been found to influence professionals' response to the people they are supporting. Self-harm is perhaps more prevalent in people with learning disabilities. Research also found that working with people with learning disabilities who self-harmed was emotionally challenging however how this affected professionals' response to self-harm was unknown. This study aimed to better understand the way in which social care professionals worked with people with learning disabilities who harm themselves in residential or supported living settings.

Method:

11 participants were recruited and interviewed about their experiences working with people with learning disabilities who self-harm. Grounded theory was used to analyse the data, explore and propose a model to understand how care professionals navigate distress when working with people with learning disabilities who self-harm in community or supported living settings.

Results:



The model portrayed how professionals identified caring as their vocation. Professionals sought to 'know' the service user, by drawing on their experiences and relationship with the individual, to ensure certainty in the support they provided ('a caring vocation'). Witnessing self-harm was a distressing experience. It evoked feelings of powerlessness which were experienced as a threat to professionals' values and caring identity. Uncertainty about the reason for the self-harm, and how to respond, heighted participants distress. Professionals moved between attempts to control and manage distress for self and the service user and finding ways of tolerating distress ('navigating distress'). Different strategies were utilised depending on a range of factors including individuals' values, experience, level of risk, personal characteristics, relationship with the service user etc. Through experience, professionals developed their understanding of self-harm and moved towards greater acceptance of the uncertainty around self-harm; this reinforced their positive identity as a carer. Experiences of powerlessness in the context of the care system for people with learning disabilities, influenced professionals distress and the coping strategies they utilised ('powerlessness').

The findings build on previous research about the emotional impact of self-harm and the way in which professionals' emotional response and understanding of the behaviour may shape the response. Limitations included possible selection bias and lack of diversity within the sample.

Implications:

This study highlighted the emotional challenge of working with people who self-harm in the already demanding context of social care. Sharing the challenging nature of this work and the difficult emotions it can bring up was deemed helpful as a way to manage the distress and the move towards acceptance of uncertainty appeared helpful. Embedding supervision, reflective practice, or mindfulness into care organisations would be helpful to encourage professionals to talk about these experiences and tolerate uncertainty.

Further research may seek to test the fit of the current model with a broader range of professionals working in social care. Studies that track professionals' experiences over time, might further investigate factors that influence the shift towards tolerance of distress, uncertainty, and acceptance of self-harm.

Acknowledgements:
I would like to take this opportunity to thank the participants who took part in this research study.