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Doctoral Thesis

Understanding Compassion in Intellectual Disability Services

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Word count statement

Thesis section	Main text	Appendices (including tables, figures and references)	Total
Thesis Abstract	189	0	189
Literature Review	6450	1430	7880
Research Paper	6658	1079	7737
Critical Appraisal	3806	121	3927
Ethics Section	6386		6386
Total	23489		26119

Thesis Abstract

Section one of this thesis presents a systematic literature review which investigated the experiences of people with an intellectual disability of psychological talking therapy. Ten studies were included and reviewed. Eight main themes and three sub themes emerged. Developing new positive relationships along with learning new skills and confidentiality were important to people with intellectual disabilities. Negative aspects of therapy including both interpersonal problems with others in a group setting as well as process issues were difficult as was therapy itself. Clinical and theoretical implications are discussed.

Section two reports the findings from a qualitative, thematic analysis of staff's understanding of the concept of compassion. Ten participants who directly worked with people with intellectual disabilities in community support setting were recruited and took part in semi-structured interviews. Four themes emerged. The themes from the research mapped onto the appraisal model of compassion that could be used by services to support a compassionate culture

The third section is the critical appraisal which provides reflections on the research process and a discussion of compassion in care.

The fourth section contains the ethics application and approval documents for this thesis.

Declaration

This thesis represents work undertaken for the Doctorate in Clinical Psychology at Lancaster University's division of Health Research from September 2014 to July 2018.

The work presented here is the author's own, except where reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Elizabeth Hickman

Date: July 2018

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Finally, thank you to the participants who took part in the study, their insight and words were invaluable.

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Section Two: Research Paper

Section One: Literature Review

The Experience of Psychological Talking Therapies for Service Users with an Intellectual
Disability: A Metasynthesis.

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Abstract

Background

The aim of this study was to review the existing literature of people with intellectual

disabilities experience of psychological therapy.

Method

A Database search identified ten papers that met the inclusion criteria of the study. All ten

papers were qualitative using either thematic analysis or Interpretive Phenomenological

analysis (IPA) methodology. All studies were rated as similar for methodological quality, but

had large variation in the number of themes.

Results

Eight themes emerged with three subthemes. These reflected the importance of

connectedness between therapist and services and the person with an intellectual disability.

Conclusion

Findings from the research showed that developing new positive relationships along with

learning new skills and confidentiality were important to people with intellectual disabilities.

Negative aspects of therapy including both interpersonal problems with others in a group

setting as well as process issues were difficult as was therapy itself. The clinical implications

of this are discussed.

Keywords: *Intellectual disability, experience, therapy*

The Experience of Psychological Talking Therapies for Service Users with an Intellectual

Disability: A Metasynthesis.

People with intellectual disabilities are more likely to develop mental health problems than the general population. Studies that screened for psychiatric symptoms in people with intellectual disabilities report prevalence rates of between 20.1 and 40.9% (Taylor *et al*, 2004; Cooper *et al*, 2007) in the UK. This comorbidity of intellectual disability and mental health problems reinforces the need for services to offer therapeutic support. Since the publication of the Royal College of Psychiatrists' Council Report (2004) there has been a drive to increase and extend the use of psychological therapies for people with intellectual disabilities. This paper sought to refute the belief that individuals with an intellectual disability would not benefit from psychological therapies due to their cognitive impairment and understanding or that they were 'immune' to emotional difficulties (Bender, 1993). In the subsequent years, the needs of this population are better known and the development and introduction of programmes such as Improving Access to Psychological Therapies (IAPT) has made therapy more accessible to all groups (Beail, 2016).

People with intellectual disabilities are a disadvantaged and vulnerable group who are likely to encounter increased psychosocial threats and also barriers to accessing both physical and mental health care (Emerson & Baines, 2011). Health inequalities research shows that 12% of people with an intellectual disability had difficulty accessing health services compared to 3% of people who had no impairment (Allerton & Emerson, 2012). The barriers that people with an intellectual disability face accessing services include; transport problems, staff understanding of intellectual disability, people with an intellectual disability may have anxiety about attending especially if they don't know what to expect, and a lack of joint working from care providers (Heslop *et al*, 2013; Allerton & Emerson, 2012). There is

arguably a heightened risk of experiencing depression as these particular social circumstances and life experiences of people with intellectual disabilities result in them being socially marginalised and facing stigma in their day to day lives (Jahoda *et al*. 2006).

Traditionally, psychological interventions for people with intellectual disabilities have focused solely on skills training and behavioural management rather than talking therapy (Royal College of Psychiatrists, 2004). There is now an increasing recognition and use of talking therapies for people with an intellectual disability (Beail, 2016).

Cognitive Behavioural Therapy (CBT) is the most studied therapy for depression and has consistently been found to be an effective treatment for depression and other disorders such as anxiety (Butler, Chapman, Forman & Beck, 2006). A meta-analysis of randomised controlled trials of low intensity interventions to treat mild depression (Van't Hof *et al*, 2011) found a positive effect, especially with the use of CBT, compared to treatment as usual. The National Institute of Clinical Excellence (NICE) recommend that CBT is used for mild to moderate depression and that it is combined with pharmacology for the treatment of complex and severe depression (NICE, 2011). This reflects the increasing evidence base for the efficacy of psychotherapeutic approaches. Other therapeutic approaches have been found to be effective with NICE (2011) also recommending the use of interpersonal therapy (IPT) for moderate to severe depression and the use of Dialectical Behavioural Therapy (DBT) for people with borderline personality disorder.

Even with the difficulties that people with an intellectual disability may have with communication there is a growing evidence base that shows they can benefit from talking therapies if they are suitably adapted. Brown *et al* (2011) conducted a review of psychological therapies available to people with intellectual and development disabilities and concluded that psychodynamic psychotherapy, CBT, counselling and systemic family therapy can all be adapted to be accessible for people with intellectual and development disabilities

with positive outcomes reported, and some forms of therapy show particular promise with this group. For example, behavioural activation, which focuses on increasing meaningful activity and the reduction of avoidance, has less of a focus on verbal communication than other therapies, which is more difficult for people with an intellectual disability (Public Health England, 2016). This approach was adapted so that the therapist worked with both the service user and a family member or carer. Jahoda, Melville et al (2015) found a significant reduction in self-reported symptoms of depression using this approach.

Cognitive Behavioural Therapy (CBT) is the most frequently reported approach used with people with an intellectual disability (Lindsay, Jahoda, Wilner, 2013). A meta-analysis of psychological therapies for people with intellectual disabilities (Vereenooghe & Langdon, 2013) found that CBT was an effective treatment for anger and depression. However, the use of CBT is not just limited to the treatment of depression in people with an intellectual disability. It is a well reported approach in offender treatment programs in community and in-patient services and interventions for sex offenders without learning disabilities in prison and the community are frequently based on a group CBT model (Hanson *et al* 2002; Lambrick & Glaser, 2004; Brooks-Gordon *et al*, 2006). The adaption of these models for use with people with an intellectual disability shows promising results (Murphy & Sinclair, 2007; 2009). Boer, McVilly & Lambrick (2007) found that developing problem solving skills within CBT interventions was the only well evidenced treatment to reduce recidivism rates for people with an intellectual disability.

'Third wave' therapies have also been reported as applicable to people with learning disabilities. For example, Dialectical Behaviour Therapy (DBT) is a combination of cognitive and behavioural approaches with eastern philosophy. It has been found to be an effective treatment for individuals with an intellectual disability (Lew, Matta, Tripp-Tebo, & Watts, 2006) including forensic offenders (Sakdalan, Shaw, & Collier, 2010; Verhoeven, 2010),

people with additional challenging behaviour (Brown, Brown, & Dibiasio, 2013), and

adolescents (Charlton & Dykstra, 2011), and across a range of settings including the

community (Baillie & Slater, 2014) and high secure environments (Morrissey & Ingamells,

2011). Adaptions to the DBT model to make it more accessible to people with intellectual

disabilities include the simplification of language, the use of more visual materials, and

additional support for those in therapy (McNair, Woodrow & Hare, 2016).

The activity-based nature of Acceptance and Commitment Therapy may offer a more

accessible intervention model for intellectual disabled people than traditional CBT models

that are based on verbal reasoning skills. However, the interventions do require individual

adaptation for use in work with people with intellectual disabilities (Brown & Hooper, 2009).

The process and outcomes of therapy has been well researched in mainstream services

but significantly less so in the field of intellectual disabilities (Pert *et al*, 2013). In non-

intellectual disability services, the therapeutic alliance has consistently been found to be

important and having someone to talk to and who listens (Batchelor & Horvath, 1999; Ryan,

Guerin & Mcevoy, 2016; Shively, Simpson & Nunes, 2016). In intellectual disability

research, it is suggested that the process of having a therapist regularly sit with a person and

talk to them is just as important as the therapeutic model used (Beail, 1998). People with an

intellectual disability have more limited social networks so having someone, or a group of

people, who regularly talks to them about themselves could be beneficial in itself.

There is increasing reporting of process research in the field of intellectual

disabilities. Qualitative investigative approaches give us insight into what the important

processes are from the perspective of people with intellectual disabilities. This is important

because their experiences are likely to be different to those of people without an intellectual

disability. As previously mentioned people with intellectual disabilities have communication

difficulties which might impact on the process of therapy and the content of discussions

(Jahoda *et al*, 2009). Another potential factor that might affect how a person with an intellectual disability experiences therapy could be how involved they feel in the entirety of the process. Quite often they will not have been offered a choice about their referral for therapy and therefore their motivation to make any changes might well be very low (Wilner, 2005).

Until recently there has been a general paucity and gap in research examining the experience of service users accessing psychological talking therapy. Research has primarily focused on the experience of professionals or the process of delivering therapy. Valuing People (2001) highlighted that individuals with an intellectual disability faced discrimination in their everyday lives. Individuals with an intellectual disability were not being given fair and equal treatment and often faced barriers to accessing vital services. Since the publication of Valuing People (2001) there has been an emphasis on improving the care and treatment of people with an intellectual disability. However, it is important to review how the individuals themselves are experiencing this to ascertain whether policy has been put into practice and having an effect on people's lives. This review aims to address this gap in the literature.

Rationale for research

With the increasing use of adapted therapeutic approaches, it is important to capture the lived experience of those who are accessing therapy to ascertain how they view the approaches, process, and experience. A criticism of current intervention studies in intellectual disabilities is that they rarely explore which components of therapy are deemed by clients to be most meaningful and effective (Idusohan-Moizer et al., 2015), although service user views are increasingly important in research (Beail, 2016). Qualitative methods are an effective way to capture these views and experiences. There has been a recent growth in the number of published papers that explore these experiences, but a metasynthesis of the available research has not been completed to date.

Aim

The aim of this review is to synthesise current qualitative findings to produce an integrated understanding. The research question asks what the experience of assessing talking therapy has been for people with an intellectual disability.

Method

A constructivist approach allows for an understanding on how individuals construct and re-construct knowledge about a phenomenon (Guba & Lincoln, 1994). Meta-ethnography is one of several methods for synthesising qualitative research (Noblit & Hare, 1988) it provides a way of re-analysing and comparing the texts of published studies to produce a new interpretation. This approach was chosen over others as its methodology involves the interpretation of data and therefore is consistent and compatible with the epistemological position of this paper.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria should be recorded and applied with a rationale for the selection (Bondas & Hall, 2007).   In this review only papers in peer reviewed English language journal articles were included. Articles were restricted to first person accounts of service users, this was to avoid adding additional levels of interpretation, and therefore accounts that described what another party believed the experience of service users to be were excluded. Both qualitative and mixed methods studies were included for screening purposes. Studies that used perspectives of formal (paid staff members) and informal (family members) were included if service user views were also present, although only the data from the service user were analysed. Articles were limited to psychological talking therapies: creative therapies such as music and art therapy studies were excluded.
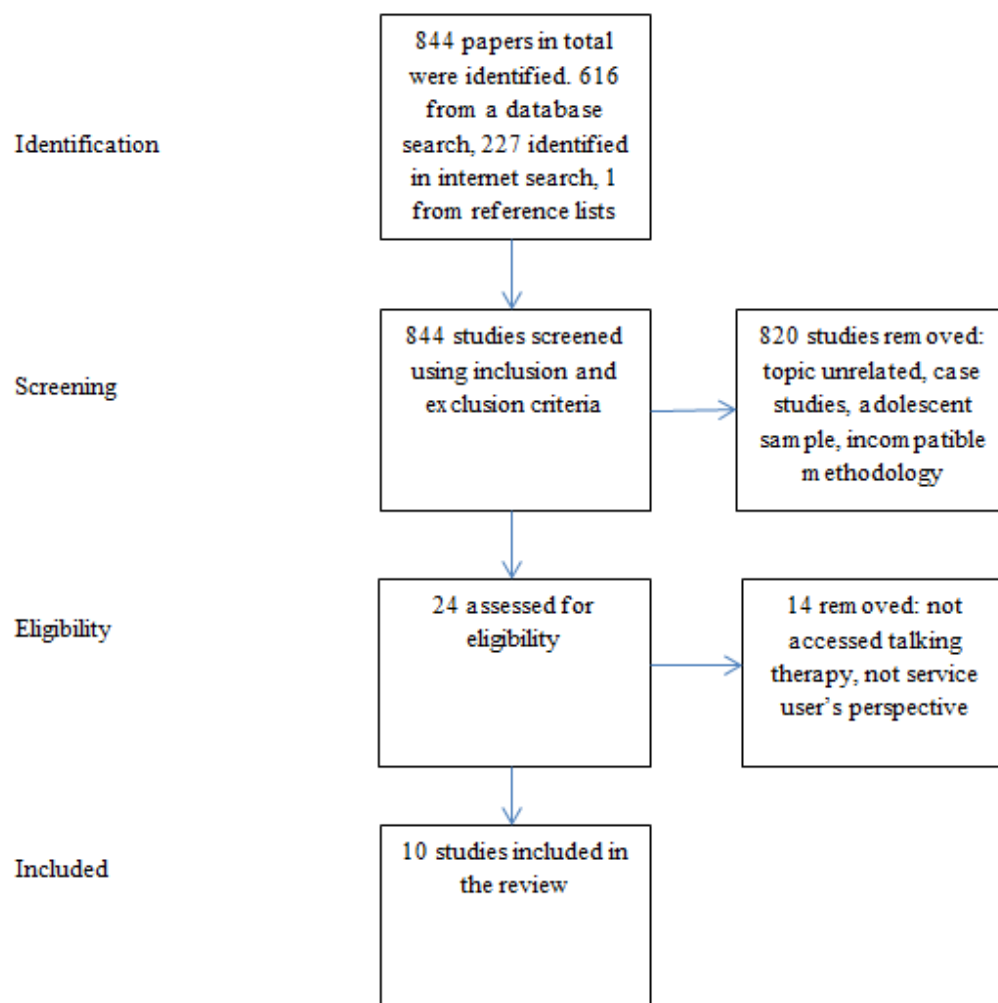
Search Method

The databases used for the searches were: PsycINFO, PubMed, and MEDLINE as these covered all aspects of psychology. The CINAHL database which covers nursing and allied health professions was used to broaden the scope of the search. The Web of Science database was searched as this was an all subject database. An internet search was also conducted including the use of Google Scholar. The terms 'intellectual' and 'learning' 'disabilit*' were used along with 'therap*', 'psychotherap*' and 'intervention'. These were combined with 'experience', 'perception, 'reflection', and 'views'. Hand searches of the references of relevant papers was undertaken to identify papers that might have been missed. The final search was undertaken on 8th August 2017.

The titles and abstracts of studies were screened for potential inclusion. Those with clear non-relevance were immediately dismissed and abstracts of potentially suitable studies were read for suitability. The full content of borderline or questionably suitable studies were read to maximise appropriate inclusion. Figure 1. outlines the stages of the selection process and the number of papers excluded at each stage.

Figure 1.

Flow Chart of Study Search and Selection Process. Adapted from Moher, Liberati, Tetzlaff, & Altman (2009)

Analysis Method

Noblit and Hare's (1988) meta-ethnographic synthesis method was applied in this review. Meta-ethnography is one of several methods for synthesising qualitative research but has the potential to retain the interpretation of the original accounts and reconcile different accounts across studies. Meta-ethnography attempts to use metaphor to bring cultural and individual differences together and that it is through this that those differences can be understood (Thorne *et al*, 2004). One method of meta-ethnography is reciprocal translation analysis (RTA). This is the process of translating concepts from individual studies into one another, thereby evolving overarching concepts (Noblit & Hare, 1988). This was followed in this study.

The synthesis was achieved through the following stages. First, following the literature search all identified papers were read thoroughly and repeatedly in order to identify the main concepts and themes from each of them. The information from each paper was summarised in the data extraction tables found in appendix B.

The next stage was translating the studies into one another and grouping common themes and concepts together. Themes began to emerge. Consideration was given to the quality assessment and the variation in the number of themes between studies. As some studies had in excess of 20 themes (including subthemes) and others only three. Therefore, themes were collapsed when there was considerable overlap between them. Finally, these initial themes were synthesised into meaningful translations of the concepts and expressed as final themes.

Critical Appraisal of Studies

The Critical Appraisal Skills Programme [CASP] analysis (Public Health Resource Unit, 2009). (Table 1) was used as a method of examining research papers to assess validity,

results and relevance (Hill & Spittlehouse, 2003). Papers were rated across ten areas such as clarity of aims and methodology on a scale of 0 to 4, with 4 being the highest score and each paper having a potential maximum score of 40. The papers identified had quality ratings ranging from 29 to 37 indicating moderate to high quality. No paper was given more overall weighting in the analysis than others however; there was a large variation in the number of themes between studies. They ranged between three themes in one study (Thompson & Johnson, 2016) to three superordinate themes with 17 subthemes and four superordinate themes with 11 subthemes in another (MacDonald, Sinason & Hollins, 2003). This has the potential for the latter study to dominate the themes. This was taken into consideration in the quality assessment and the weightings of themes was considered and adjusted accordingly as mentioned above. Subthemes that overlapped were collapsed into one theme.

Table 1. Critical Appraisal Skills Programme [CASP] analysis results

Study	Aims	Method-ology	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Total score
Anslow (2013)	3	3	3	3	3	2	3	3	3	4	30
Lewis, Lewis & Davies (2015)	4	4	4	4	4	3	3	4	3	4	37
MacDonald, Sinason & Hollins (2003)	3	4	3	4	3	3	3	2	3	3	31
MacMahon, Kroese, Jahoda et al (2015)	4	3	4	4	4	3	3	4	3	4	36
Merriman & Beail (2009)	3	3	3	4	3	3	3	3	3	3	31
Pert, Jahoda, Kroese, Trower, Dagnan & Selkirk (2013)	4	4	4	3	3	3	3	4	3	4	35
Roscoe, Petalas, Hastings & Thomas (2015)	3	3	3	3	3	3	3	3	3	3	30
Thompson & Johnson (2016)	4	4	4	3	3	3	2	3	2	3	31
Tomlins & Cawley (2015)	3	3	3	3	3	2	3	3	3	3	29
Vereenooghe, Gega & Langdon (2017)	3	3	3	3	4	2	3	4	4	4	33

*key: score 0 (lowest) to 4 (highest)

Results

Eight themes emerged with three subthemes. They are arranged in the order that they emerged from the analysis (See table 2.).

Theme 1: Building positive relationships and meeting new people in therapy.

Participants reported positive experiences of developing new friendships, connections, and networks. This went some way to fulfilling a social need,

"getting out…meeting all these different people" (Tomlins & Cawley, 2015)

and the development of new and improved relationships (MacMahon, Kroese, Jahoda et al, 2015). For the participants, this sense of inclusion contrasted with exclusion that they experienced elsewhere in their lives (MacDonald, Sinason & Hollins, 2003).

People with an intellectual disability have more limited social networks compared to the general population. This can be the result of the restrictions that are put around them when they are receiving care, particularly in inpatient services. The by-product of meeting new people, only when accessing group therapy, gave the participants the chance to develop friendships with others who were in a similar situation to them (MacDonald, Sinason & Hollins, 2003). The improved relationships were not limited to fellow peers in the group. Positive feelings were reported towards the psychologist (Lewis, Lewis & Davies, 2015) which combined, making therapy fun and enjoyable for participants (Lewis, Lewis & Davies, 2015). This is an additional, meaningful, relationship that they have in their lives.

Subtheme: Therapeutic relationship.

A distinct subtheme relating to new and improved relationships was the therapeutic relationship. Participants reported feeling valued and validated and being treated as an equal (Pert, Jahoda, Kroese et al, 2013). They felt included and used humour as a way of speaking about the therapist (MacDonald, Sinason & Hollins, 2003). Seven of the ten studies included in the review had themes relating to the therapeutic relationship and its importance in

therapy. The participants reported wanting to being able to talk face to face, and be listened to (Vereenooghe, Gega & Langdon, 2017).

The manner in which the participants experienced the therapist was important too. This was variously described as; feeling cared for and understood (Pert, Jahoda, Kroese et al, 2013), that the therapists were valuing of the participants (MacDonald, Sinason & Hollins, 2003), and that there was collaborative working between them (Lewis, Lewis & Davies, 2015). A focus on the positives as well as the negative was important,

"and that you talk about those issues, and they ask you some questions,

and you talk about things. But you also talk about the good times as well"

(Anslow, 2013).

Theme 2: The importance of confidentiality.

A theme from four of the ten papers was the importance of confidentiality and the challenges to this. Participant's from one study called this '*talking in private'* (Pert, Jahoda, Kroese, et al, 2013). Others mentioned that

"it's not the sort of thing I like to broadcast…they'd kill me if they knew

what I had done" (Merriman & Beail, 2009).

This appeared to stem from an awareness of the potential consequences if information was widely known from those participants who had engaged in offending behaviour. Participants were aware of the challenges to confidentiality (Lewis, Lewis & Davis, 2015). Those who had access to computer based therapy were aware of dangers of sharing personal information online and the need for assurance of privacy and confidentiality (Vereenooghe, Gega & Langdon, 2017).

Theme 3: Taking part in therapy is hard.

Seven of the ten studies had themes relating to the challenge of therapy. These included anxieties about attending,

"(I am) embarrassed about talking you know, talking about hearing

voices in my head around other people in the group and that" (Tomlins &

Cawley, 2015).

The expectations of what it might be like,

I was a bit nervous. I don't know what to say. I got a bit tight, scared of

what he might do to me (Merriman & Beail, 2009).

Once therapy had begun participants reported that talking can be difficult at first (Pert,

Jahoda, Kroese et al, 2013) and that talk is distressing (MacDonald, Sinason & Hollins,

2003). Participant's responses from Lewis, Lewis and Davies, 2015 supported this and they

stated that, *"therapy is hard"*.

Theme 4: Difficulties in communication in therapy.

The comprehension of therapy and engaging with the process was a problem in some

studies. There were difficulties understanding DBT,

"mmm I think it's good, mmm it's a bit, I am losing track of it know, I

don't know what I am doing and I am just writing anything…" (Roscoe, Petalas,

Hastings & Thomas, 2015),

and other more general communication difficulties in comprehension (Anslow, 2013).

This could be reflective of the communication and cognitive difficulties that are associated

with a person having an intellectual disability. The complex language and frequent use of

metaphors mean that therapy can be difficult to follow.

However, in other studies these barriers could be moderated by the utilization of

technology, overcoming barriers with verbal communication and alleviating discomfort when

speaking to a therapist (Vereenooghe, Gega & Langdon, 2017). The use of touch screen and

keyboard and mouse, symbols and sign language; games allowed participants to interact to

their satisfaction (Vereenooghe, Gega & Langdon, 2017).

Theme 5: Learning new skills and improving self-awareness.

Eight of the ten studies mentioned the positive development of skills and self-knowledge. The acquisition of new knowledge and new skills was something that the participants were proud of (MacMahon, Kroese, Jahoda *et al*, 2015) and others were able to articulate their improved self-awareness,

"so you recognise how, happy, sad, angry, ashamed or afraid you are, so you've got to focus on how you are feeling. Then only if you focus on how you are feeling will you be able to sort it out" (Thompson & Johnson, 2016).

For others, the benefits were in the avoidance and control of negative behaviours and helped them [men] resist the urge to offend (MacDonald, Sinason & Hollins, 2003). There was a greater awareness [of voices] and development of power and control (Tomlins & Cawley, 2015).

Theme 6: Negative aspects of therapy.

This theme was subdivided into two parts, but overall reflected the participant's experience of perceived negative aspects of therapy and its process.

Subtheme: Interpersonal Problems.

This related to the difficulties that those assessing group therapy had with others members. It was noted that other participant's distress is distressing (MacDonald, Sinason & Hollins, 2003). Hearing others speak about their experiences was difficult for those listening.

Other people in the group being perceived as dissimilar to themselves was also challenging for participants (MacDonald, Sinason & Hollins, 2003) and this could lead to group conflict [women only groups]. Participants also found the behaviour of the facilitators difficult,

"like they talk to one another, they don't look at us…a bit strange" (Anslow, 2013).

This contrasts with the experience of participants in the majority of other studies who felt included and valued. Other interpersonal problems were a dependant alliance on the therapist

> *"X sorts my problems out. I've had problems the last three weeks and he wrote them down and sorted it out. I leave him to sort it out"* (Merriman & Beail, 2009).

This inhibited the development of the participant's problem solving skills and left them reliant on the therapist to resolve issues. This would be of concern as the therapist will not always be available to act in this capacity.

Subtheme: Process and outcome dissatisfaction.

Participants from five studies expressed some dissatisfaction with outcomes and processes. There was questioning whether anything was different following therapy (Anslow, 2013) or what the group didn't change (MacMahon, Kroese, Jahoda *et al*, 2015). Another mentioned that any change that was made is fragile

> *I just take one step at a time and see how it goes. I can't really think that far ahead"* (Pert, Jahoda, Kroese, *et al* 2013).

There was a reluctance to engage in the idea of negative aspects of therapy or with therapists (Merriman & Beail, 2009).

In more practical aspects, the number of patients in a skills teaching group (Roscoe, Petalas, Hastings & Thomas, 2015) was a problem for some participants.

Theme 7: Access to therapy.

This theme relates not just to lack of treatments and services, but also the logistics of getting to therapy and what happens when the therapy ends. Frustration was clearly evident in participant responses such as,

"I came to see Y before X… It's easy to talk to X. He's all right. Yes we got on nicely right up to the end – pity he has to leave… bit like passing the parcel. Don't know who I will see now. I'm referred back to the Team. There's a one or two months' wait. I'll get [someone else] this time. Suppose I'll have to get used to it" (Merriman & Beail, 2009).

"When [the Hearing Voices Group] stopped I got a bit down and frustrated. That's when the voices played their part (Tomlins & Cawley, 2015).

This highlights the importance for participants of not just consistency of therapists and teams, but continued support as well. The logistics for those who were receiving staff support or who were in inpatient settings was relatively straightforward as they were supported to access therapy,

"it was easy to get to…(the staff) took me from here" (Tomlins & Cawley, 2015).

For those where access may be a problem Vereenooghe, Gega & Langdon (2017) reported that people with intellectual disabilities have access to different forms of digital technology, know how to use it, and like it. This type of technology could be utilised more in talking therapies.

Theme 8: Feeling listened to and able to talk.

For participants, just being able to talk to someone was particularly helpful, it may have been that they did not have anyone in their lives or networks that they felt able to discuss their feelings with, or any support that they have had in the past is not in place.

"it felt great when I started talking to him and getting things off my chest which I've done in the past to stop me doing it again. It was a great relief" (Merriman & Beail, 2009).

This 'talking' characterised what therapy was (MacDonald, Sinason & Hollins, 2003) and that being able to talk was what was helpful (Pert, Jahoda, Kroese, *et al*

2013). Being listened to and understood by the therapist was valued as was being encouraged to talk (MacDonald, Sinason & Hollins, 2003).

Discussion

The themes that emerged from the analysis show that people with intellectual disabilities value connectedness, not just with the therapist but with other people within therapy groups and the services that support them. Theme 1: Building positive relationships and meeting new people in therapy and the subtheme: therapeutic relationship reflects part of this. Theme 2: The importance of confidentiality demonstrates that for people with intellectual disabilities trust and confidentiality are important. Having someone that they can talk to in confidence without this information being needlessly shared with others. Theme 4: Difficulties in communication in therapy. As stated in the introduction, people with intellectual disabilities are likely to have communication difficulties and more work could be done to alleviate the problems in the area. Theme 5: Learning new skills and improving self-awareness further challenges the old myth that people with intellectual disabilities cannot benefit from talking therapy. Theme 6: Negative aspects of therapy. Subtheme: Interpersonal problems. Subtheme: Process and outcome dissatisfaction. Being in therapy is not always easy for people and they may not always get the outcome that they were hoping for. We can learn that continued support and connection is important so that people do not feel alone when therapy ends. Theme 7: Access to therapy. For people living in the community, rather than institutional or hospital settings, the logistics of accessing appropriate therapy could be a challenge. This is likely to be an increased issue with the introduction of the transforming care agenda, 'Building the Right Support' (2015) which aims to support people to live in the community and close to home. Theme 8: Feeling listened to and able to talk. Again, this links to a feeling of connectedness to others.

There was an element of 'feeling connected' that ran through the themes; with both its presence and absence being noted. When participants felt connected there was a generally positive view of therapy and the changes that had been made. Any barriers or interpersonal problems led to the sense of being disconnected from others and a more negative view of the therapeutic process. Overall however, therapy in general seemed to be well received and valued by the participants.

With relationships seeming to be so valued by participants and contrasting heavily with their experiences elsewhere it is important to think about why this is the case. We know that people with intellectual disabilities generally have more limited social networks than the general population (Asselt-Govert et al, 2015). These networks tend to be small and contact with people without intellectual disabilities is primarily limited to family members and professionals (Lippold & Burns, 2009). Accessing therapy is reported as offering meaningful relationships whether that be with the therapist, or with other peers if they have been a part of group therapy. Professionals are seen to be highly valued by people with a mild intellectual disability (Asselt-Goverts, Embregts & Hendriks, 2013).

People with an intellectual disability report that they are generally satisfied with their social networks, but three things that they identified as wanting to improve were; better contact with acquaintances and professionals, to develop social skills - particularly with acquaintances, and more contact especially with family (Asselt-Govert et al, 2015).

Participants liked feeling valued, included and listened to within therapy. Some explicitly said that this experience contrasted with their experiences elsewhere (MacDonald, Sinason & Hollins, 2003). Whilst it is of great importance that people should feel valued in therapy, it is of equal importance that they should feel this in other aspects of their lives. For example we know that, of individuals who are known to social care services in the UK, 5.8% are in paid employment, compared with 74% of non-disabled people (Hatton, 2016) and that

65 % of people with an intellectual disability would like to work but have not been successful in finding work (Department of Health, 2009). This inequality is further compounded for people with an intellectual disability by risk-averse service cultures that contribute to restrictive environments. This in turn means there are even fewer opportunities for these individuals to build a sense of self-efficacy and develop problem solving skills (Dagnan & Jahoda, 2006). This may limit the gains that people can make in therapy.

Participants also talked about access to therapy and some of the frustrations that they felt. For some this was not a problem if they were receiving significant support from staff. For those that weren't, or for those who had disruption to their care such as staff leaving, it was much more of a problem. The No Health without Mental Health document (Department of Health, 2011) sets out that people with intellectual disabilities should have fair and equal access to mainstream services. What the participants are saying in the studies reviewed here is that they need support when those services are not there, or for when therapy ends. They reported that change is fragile (Pert, Jahoda, Kroese et al, 2013) this suggests a need for more informal support for people when therapy ends to help them maintain the changes that they have made.

The 'No Health without Mental Health' strategy (Department of Health, 2011) and implementation framework (Department of Health, 2012) aimed to improve mental health and wellbeing in England. It stated that people with intellectual disabilities should be able to access mainstream services and that these services should have staff that have appropriate skills and could provide reasonable adjustments to meet their needs (NHS England, 2015).The National Institute for Health and Care Excellence (2009) recommends that people with a mild intellectual disability and a diagnosis of borderline personality disorder should have access to the same interventions as other people with borderline personality disorder without an intellectual disability. If this is to be successful staff will need to be trained and

have an awareness of the adaptions and specific needs of people with intellectual disabilities

to ensure that therapy is given every chance to be as successful as possible (Dagnan *et al*,

2016). Communication and the adaption of language, materials and method helped the

participants reviewed in this study. They were able to engage with therapy and develop skills

and self-awareness. Staff in mainstream services will need to be aware of and have access to

these materials. This would run alongside the 'Transforming Care' agenda, which is

beginning to build community service provision. The lack of this, or the location it was

provided in was highlighted by the participants in this meta-analysis as a logistical barrier to

accessing therapy. Under the Transforming Care agenda this could be provided locally, or

within people's homes depending on preference (2015).

Implications and recommendations for clinical services

Consideration should be given to setting up community support groups for people

with an intellectual disability. These may or may not need to have a therapeutic focus but

would offer peer support from experts by experience to others. This would enable people to

strengthen relationships that they may have made in therapy and develop social skills which

is something that people with intellectual disabilities hope for in relation to their social

networks (Asselt-Goverts *et al*, 2015). Helping and supporting people to access community

groups that are not necessarily targeted at the intellectual disability population should also be

encouraged, such as LGBTQ groups or sporting clubs. This would promote wider inclusion

and connection.

It is recognised that the therapeutic relationship is highly valued. Care should be taken

by psychologists and therapists to develop and nurture this relationship. It is an important part

of people's social network and practical and information support that is received from

professionals is more highly valued than it is from family members (Asselt-Goverts *et al,*

2013).

Reasonable adjustments to communication used in therapy should be made. People with intellectual difficulties have communication difficulties that might affect the extent to which they can engage in therapy. This could be supported with the use of augmented communication tools and the use of technology such as tablets and smartphones. There has been a growth in interactive apps that support therapy. These could potentially help people communicate and engage in the therapy process and is an area for future research.

Overall however, a more linked-up and continuous approach is needed. There are lots of areas of good practice as highlighted above, but these are often happening in isolation. For example, people have access to therapeutic interventions that they value and are adapted to their needs, but feel that they don't get enough support or connection to others when this is over. Given the high value that they attach to this and the need to maintain the gains that have been made in therapy, informal support could be offered over longer periods of time with the development of support and social networks. Communication between services could ensure valuable information is not lost, but giving people with intellectual disabilities ownership of this information, where possible, would allow for smoother transitions as this would stay with them.

Limitations of the review and future directions

This is still an emerging research area with a limited number of appropriate papers available. However, there has been an increase in the last few years allowing for this review to be completed, with 6 papers being published from 2015 to the date of this analysis. This review combined both community and in-patient therapy groups. Future research may seek to separate these groups out to ascertain if there are any differences between the two as those accessing therapy within in-patient services are often detained under the mental health act where therapy can be seen as necessary in order to be discharged into the community and is more likely to be mandated that people attend. It will also be valuable to see the impact of the

transforming care 'building the right support' model (2015). This will see the reduction of in-patient beds that are available and the investment in community services. There has been a shortfall between the development of community services and discharge of individuals who have forensic histories that form part of this change (Taylor, 2017).

If people with intellectual disabilities are accessing mainstream services then it is important that we get their views of their experiences of accessing this as well as the process and outcomes of therapy when it its delivered by non-specialist services. This would inform recommendations of how to support and improve this service. Further research into international interventions, particularly community psychology approaches would be valuable as the focus of these are inclusion and self-determination which this study has indicated are important to the lived experience of people with an intellectual disability. This review has taken a lot of information from the data that is available in the UK. This is due to the limited information that is published regarding therapy for people with an intellectual disability in other areas of the world. Community psychology approaches are often used in other European countries such as Norway (Meyer, 2009), but there is limited translated data on the therapy that is available to them. In middle and low-income countries, people with an intellectual disability are still viewed as 'incapable' and do not live independently with many people around the world placed in residential care institutions including Ireland, Israel and Finland (Scior, Hamid, Hastings, Werner, *et al,* 2015). In countries, such as South and Central America and Asia where people live with families, there is a lack of care available and consequently any data.

Conclusion

Generally, therapy is seen as difficult but valuable. There are negative elements, but these appear to be outweighed by the good. The relationships that people with intellectual disabilities form, particularly when engaged in therapeutic groups holds great value for them,

as does being given the chance to talk and feel listened to, valued and understood. This

review highlights that further support is needed for people with intellectual disabilities to

develop meaningful relationships in other areas of their lives and maintain any gains that they

make in therapy.

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Table 2. Summary information of the papers selected for the literature review

Study	Research question/aims	Methodology	Participants
Systemic family therapy using the reflecting team: the experiences of adults with learning disabilities (Anslow, 2013)	What are adults with learning disabilities experience of systematic family therapy using the reflecting team format.	IPA	5
'I don't feel trapped anymore… I feel like a bird': People with Learning Disabilities' Experience of Psychological Therapy (Lewis, Lewis & Davies, 2015)	To improve the service offered and to ensure that people receive the best possible care	IPA	6
An interview study of people with learning disabilities' experience of, and satisfaction with, group analytic therapy (MacDonald, Sinason & Hollins, 2003)	To elicit client's views on their experience of group analytic therapy. To identify both positive and negative aspects of clients' experience of group analytic therapy	IPA	9
'It's made all of us bond since that course…'–a qualitative study of service users' experiences of a CBT anger management group intervention (MacMahon, Kroese, Jahoda et al, 2015)	Capturing the participants lived experience of taking part in a CBT anger management group	IPA	11
Service user views of long-term individual psychodynamic psychotherapy (Merriman & Beail, 2009)	Explore the usefulness and value placed on the service by its users	IPA (Smith & Osborne, 2003)	6
Cognitive behavioural therapy from the perspective of clients with mild intellectual disabilities: a qualitative investigation of process issues (Pert, Jahoda, Kroese, Trower, Dagnan & Selkirk, 2013)	Explore the views of participants with an intellectual disability who were all attending individual CBT for emotional problems	IPA	15
Dialectical behaviour therapy in an inpatient unit for women with a learning disability: Service users' perspectives (Roscoe, Petalas, Hastings & Thomas, 2015)	Patient perspectives are needed to understand what makes treatment approaches more acceptable. Information from this research may be useful in informing future adaptions	IPA (Smith et al, 2009)	10

Table 2 cont. Summary information of the papers selected for the literature review

Study	Research question/aims	Methodology	Participants
Experiences of women with learning disabilities undergoing dialectical behaviour therapy in a secure service (Thompson & Johnson, 2016)	Look at the women's experience of undertaking a newly introduced therapy by asking them to share and elaborate on their experience.	IPA	7
'I didn't know other people existed who hear voices...' –qualitative perceptions of a hearing voices group for people with learning disabilities (Tomlins & Cawley, 2015)	How the group was experience by those who attended.	Thematic analysis	4 (from larger sample)
Intellectual disability and computers in therapy: Views of service users and clinical psychologists (Vereenooghe, Gega & Langdon, 2017)	Identify the functions and benefits, challenges and barriers, and required design features of computers in therapy for people with intellectual disabilities	Thematic analysis	3

Table 3. Summary of Themes

Theme	Key themes from studies	Source paper
Theme 1. Building positive relationships and meeting new people	Fulfilling a social need New and improved relationships	Tomlins & Cawley (2015) MacMahon, Kroese, Jahoda et al (2015)
	Inclusion contrasting with exclusion elsewhere	MacDonald, Sinason & Hollins (2003)
Sub-theme – Therapeutic relationship	Importance of the therapeutic relationship	Roscoe, Petalas, Hastings & Thomas (2015)
	Talk face to face and be listened to	Vereenooghe, Gega & Langdon (2017)
Theme 2. Importance of confidentiality	Talking in private	Pert, Jahoda, Kroese, Trower, Dagnan & Selkirk (2013)
	Challenges to confidentiality	Lewis, Lewis & Davies (2015)
Theme 3. Taking part in therapy is hard	Talking can be difficult at first	Pert, Jahoda, Kroese, Trower, Dagnan & Selkirk (2013)
	Anxieties about attending Expectations (nervous)	Tomlins & Cawley (2015) Merriman & Beail (2009)
Theme 4. Difficulties in communication	Overcoming barriers with verbal communication; alleviating discomfort when speaking to a therapist	Vereenooghe, Gega & Langdon (2017)
	Difficulties understanding DBT	Roscoe, Petalas, Hastings & Thomas (2015)
	Communication difficulties	Anslow (2013)
Theme 5. Learning skills and improving self-awareness	*"so you recognise how, happy, sad, angry, ashamed or afraid you are, so you've got to focus on how you are feeling. Then only if you focus on how you are feeling will you be able to sort it out"*	Thompson & Johnson (2016)
	Greater awareness of the voices and development of some power and control over their intrusive qualities	Tomlins & Cawley (2015)

Table 3 cont. Summary of Themes

Theme	Key themes from studies	Source paper
Theme 6. Negative aspects of therapy		
Sub-theme – interpersonal problems	Group conflict (women)	MacDonald, Sinason & Hollins (2003)
Sub-theme – process and outcome dissatisfaction	Number of patients in a skills teaching group	Roscoe, Petalas, Hastings & Thomas (2015)
Theme 7. Accessing therapy	Lack of treatments and services Staff leaving and therapy ending Positive approach – people with intellectual disabilities have access to different forms of digital technology, know to use it, and like it	Tomlins & Cawley (2015) Merriman & Beail (2009) Vereenooghe, Gega & Langdon (2017)
Theme 8. Feeling listened to and able to talk	Talking and listening Talking is helpful Talking being helpful	MacMahon, Kroese, Jahoda *et al* (2015) Pert, Jahoda, Kroese, Trower, Dagnan & Selkirk (2013) Merriman & Beail (2009)

Appendix A

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
Systemic family therapy using the reflecting team: the experiences of adults with learning disabilities Anslow (2013)	What are adults with learning disabilities experiences of systemic family therapy using the reflecting team format?	Semi-structured interviews and data analysed according to IPA guidelines	5 participants Age range 25 -34 1 man, 4 women Recruited via nomination from professionals at the family therapy clinic

Results

Therapist' focus on strengths and difficulties
And that you talk about those issues, and they ask you some questions, and you talk about things. But you also talk about the good times as well. (Paul).

Differences in metacognitive abilities
They go through each of us–what we said, what they think and what to do. (Tina).

Finding a voice in therapy
Martha: And…akaton, akaton, that's why…akaton…sometimes, sometimes it do help, akaton. I can do that well.
Interviewer: I don't know what akaton is…
Mother: Makaton.
Interviewer: Makaton. Makaton helps?
Martha: Yeah.
Interviewer: And does (Therapist 1) use Makaton?
Martha: Not really.

Frustration with the outcome of therapy
The big thing about family therapy, is I feel I go in there hoping for…how I put it? A big change…By talking…we talk, and talk, and talk, and they don't – in my eyes – I think they don't do anything. (Tina).

Managing an unusual experience
Like they talk to one another, they don't look at us…a bit strange. (Tina).

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
'I don't feel trapped anymore…I feel like a bird': People with learning disabilities' experience of psychological therapy Lewis, Lewis, and Davies (2015)	To improve the service offered and to ensure that people receive the best possible care	Semi-structured interviews and data analysed according to IPA guidelines (Smith *et al*, 2009)	6 participants 1 men, 5 women Age range 20 -43 Registered with the community learning disability teams

Results

Master theme 1: Setting up of therapy
Access to therapy
Preparing for therapy
Master theme 2: Content and process of therapy
Developing skills
Making therapy accessible
Process of talking
Indirect work
Master theme 3: Other positive aspects of therapy
Enjoying therapy and making therapy fun
Helpful experience
Master theme 4: Therapy being challenging
Challenges to confidentiality
Challenging but helpful
Therapy is hard
Master theme 5: Therapeutic relationship
Development of the therapeutic relationship
Collaborative working
Positive feelings towards the psychologist

Master theme 6: outcome of therapy
Positive changes

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
An interview study of people with learning disabilities' experience of, and satisfaction with, group analytic therapy Macdonald, Sinason, Hollins (2003)	1. To elicit clients' views on their experience of group analytic therapy 2. To identify both positive and negative aspects of clients' experience of group analytic therapy	Semi-structured interviews and data analysed according to IPA guidelines (Smith *et al*, 2009)	9 participants 4 men, 5 women Mean age 34

Results

Positive themes		Negative themes	
Superordinate theme	Subtheme	Superordinate theme	Subtheme
Non-specific positive comments	Nonspecific positive comments about the therapists Nonspecific positive comments about the group	General avoidance	General negative comments Talk is distressing Other participants distress is distressing Therapists are too confrontational
Communication	Talking characterizes therapy Feeling able to talk Talking about difficult experiences Ability to talk contrasting with other situations Being encouraged to talk Being listened to and being understood Helps resist urge to offend (men)	Negative aspects of group members Other	Negative reminders Negative patient behaviours Others in group dissimilar Group conflict (women) Other group members absent (women) Concrete problems Other
Inclusion	Group is inclusive Therapists valuing Humour in way of speaking about therapists Inclusion contrasting with exclusion elsewhere Separating from mothers (women) Similar to others in the group (women) Ability to help others Therapists are helpful		

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
'it's made us all bond since that course…' – a qualitative study of service users' experiences of a CBT anger management course MacMahon, Kroese, Jahoda *et al* (2015)	Capturing the participants lived experience of taking part in a CBT anger management group	Semi-structured interviews and data analysed according to IPA guidelines (Smith *et al*, 2009)	Eleven service users (eight men, three women). Age range 22 to 44 FSIQ 54-64 Community

Results

Superordinate theme	Subordinate theme
What it was like to take part	The fun of the group The challenge of participation The importance of relationships Talking and listening
The difference the group made to my life	A new me New knowledge and new skills New and improved relationships What the group didn't change
Presenting a positive self	Attributing responsibility for anger to the actions of others An expert in anger management: demonstrating new skills and knowledge

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
Service user views of long-term individual psychodynamic psychotherapy Merriman & Beail (2009)	Explore the usefulness and value placed on the service by its users	IPA (Smith & Osborne, 2003)	6 participants All male Age range 22 -45 Recruited from a health service clinic

Results

The referral process – clear understanding of why they had been referred to the service "I came because I offended" "I was hitting people. I think that was the reason"

The participants' experience of psychodynamic psychotherapy

Expectations "I was a bit nervous. I don't know what to say. I got a bit tight, scared of what he might do to me"

Talking being helpful "I felt great when I started talking to him and getting things off my chest which I'd done in the past to stop me doing it again. It was a great relief"

Dependant alliance on the therapist "X sorts my problems out. I've had problems the last three weeks and he wrote them down and sorted it out. I leave it to him to sort things out"

Therapy as private "It's not the sort of thing I like to broadcast. I don't know the reason why…they'd kill me if they knew. My name wouldn't be Y if they knew what I had done"

Positive and negative aspects of therapy

Pass the parcel – staff leaving and therapy ending, "I came to see Y before X… It's easy to talk to X. He's all right. Yes we got on nicely right up to the end – pity he has to leave… bit like passing the parcel. Don't know who I will see now. I'm referred back to the Team. There's a one or two months' wait. I'll get [someone else] this time. Suppose I'll have to get used to it.'

Reluctance to engage in the idea of negative aspects of therapy or therapists "I've liked everything about it'

Positive feelings about the therapist

Outcome

Positive behaviour change through therapy

Positive change in emotions through therapy

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
Cognitive behavioural therapy from the perspective of clients with mild intellectual disabilities: a qualitative investigation of process issues Pert, Jahoda, Kroese, Trower, Dagnan & Selkirk (2013)	Explore the views of participants with an intellectual disability who were all attending individual CBT for emotional problems	Semi-structured interviews and data analysed according to IPA guidelines	15 participants Age range 26 -52 8 men 7 women Recruited from three learning disability services

Results

Theme 1: talking in therapy
Talking is helpful
Talking in private
Talking can be difficult at first
Theme 2: Feeling valued and validated
Being treated as an equal
My problems are taken seriously
Feeling cared for and understood
Theme 3: therapy and change
Therapeutic goals
Change in therapy
Change is fragile

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
Dialectical behavioural therapy in an inpatient unit for women with a learning disability: service user perspective Roscoe, Petalas, Hastings & Thomas 2015	Patient perspectives are needed to understand what makes treatment approaches more acceptable. Information from this research may be useful in informing future adaptions of DBT for use in inpatients settings with individuals with a PD and ID	Semi-structured interviews and data analysed according to IPA guidelines (Smith *et al*, 2009)	10 women Age range 19 – 57 White British Recruited from two private hospitals

Results

Theme 1 understanding DBT
Difficulties understanding DBT
Mmm I think it's good, mmm it's a bit, I am loosing track of it now, I don't know what I am doing and I am just writing anything down . . .

Personal understanding of DBT
Participants showed evidence of having reached personal understandings and perspectives of the programme

Theme 2: DBT as helpful and beneficial
All of the participants spoke of how helpful and beneficial DBT had been for them

Theme 3: Engagement with the DBT process
Number of patients in a skills teaching group
Importance of therapeutic relationship
Motivation

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
I didn't know other people existed who hear voices…' – qualitative perceptions of a hearing voices group for people with learning disabilities Tomlins & Cawley (2015)	How the group was experienced by those who attended How the group was perceived by family members, professionals who did not attend Whether barriers existed which impacted on attendance at the group	Thematic analysis	

Results

Benefits of the hearing voices group
Greater awareness of the voices and development of some power and control over their intrusive qualities
Sharing voice hearing experiences, *'it takes the pressure off you, and they can take it all out of your system to tell them about what kind of voices you hear'*
Fulfilling a social need, *'getting out…meeting all these different people'*

Making the decision to attend
Logistics, *'it was easy to get to…(the staff) took me from here*
Anxieties about attending, *'(I am) embarrassed about talking you know, talking about hearing voices in my head around other people in the group and that'*
Personal motivation to attend, *'My voices bothered me that much that I definitely needed to go to the group'*

Positive and negative contributions to the voice hearing experience
Lack of treatments and services, *'when (the HVG) stopped I got a bit down and a bit frustrated. That's when the voices played their part'*
Input from other people, *'if people are winding me up they make my voices worse'*

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
Experiences of women with learning disabilities undergoing dialectical behavioural therapy in a secure service Thompson and Johnson (2016)	Look at the women's experience of undertaking this newly introduced therapy by asking them to share and elaborate on their experience	Semi-structured interviews and data analysed according to IPA guidelines	7 female participants In patient services

Results

How you do DBT
So you recognise how happy, sad, angry, ashamed or afraid you are, so you've got to focus on how you are feeling, then only if you focus on how you are feeling will you be able to try and sort it out.

The hardest part was] not being able to self-harm while you're doing the course

What we think about DBT
I was given a choice for the first place when they asked me, did I want to do DBT and they explained to me, but going back over it all again, will blow my mind right now, blow my mind personally, do you know what I mean?

Using DBT
I think it will make things better if everyone knows DBT, because they'll understand more 'cos, like some staff in the room were looking at me strangely that other day 'cos I was doing one of me DBT skills

Our homework it doesn't give you clear information on what you want to do, what to do on the homework, just tells you what to do and I just don't understand it.

Paper	Research question/aim	Methodology (data collection = one-to-one interviews unless otherwise stated)	Participants
Intellectual disability and computers in therapy: Views of service users and clinical psychologists Vereenooghe, Gega & Langdon (2017)	Identify the functions and benefits, challenges and barriers, and required design features of computers in therapy for people with intellectual disabilities	Thematic analysis	3 participants with ID, 3 Psychologists 1 man 2 women Previously taken part in computerised therapy skills training session

Results

1. **Confidentiality**

Aware of dangers of sharing personal information online and need assurance of privacy and confidentiality

2. **Communication**

Overcoming barriers with verbal communication; alleviating discomfort when speaking to a therapist

3. **Value of therapist**

Talk to people face to face and be listened to

4. **Access**

Positive approach – people with intellectual disabilities have access to different forms of digital technology, know to use it and like it

5. **Engagement**

Touch screen and keyboard and mouse, symbols and sign language; games

6. **Home practice**

Diary easier to write down on tablet and then bring it back to therapy and discuss it.

Appendix

Author Guidelines

Journal of Applied Research In Intellectual Disabilities

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The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the

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Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

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All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.
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Keywords: Up to six key words to aid indexing should also be provided.
Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.
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-Turn the hyphenation option off.
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-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
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Journal article

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. The American Journal of Psychiatry, 159, 483–486. doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain, 126*(4), 841-865. doi: 10.1093/brain/awg076

Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sec differences in developmental reading disability: New findings from 4 epidomiological studies. *Journal of the American Medical Association, 291*(16), 2007-2012. doi 10.1001/jama.291.16.2007

Book Edition
Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

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Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

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Section Two: Research Paper

Understanding Compassion in Intellectual Disability Services

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Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count: 7737

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Prepared for submission to: Journal of Applied Research in Intellectual Disabilities

Abstract

Background

Compassion is seen as a key element in effective and safe care. This study explored what staff understood compassion to be in an intellectual disability service.

Method

Participants were recruited who worked directly with people with intellectual disability in community support services. They were recruited from three services in the United Kingdom. Ten people consented to take part in the research. Thematic analysis was used.

Results

Four themes emerged: compassion was difficult to define, that knowing the person influenced responses, that there were barriers and inhibitors of compassion, and factors that support compassion. These mapped onto an adapted appraisal model of compassion.

Conclusion

The findings highlighted the support and training that staff needed to maintain a safe and compassionate culture. Psychological formulation was identified as a useful method to facilitate the staff's understanding of the people that they support.

Keywords: *Compassion, staff, intellectual disabilities*

Introduction

Compassion is seen as a key element of care (Darzi, 2008; Care Quality Commission, 2011), yet reports continue to show that it is lacking (Ballatt & Campling, 2011). In areas around the world there is still stigma and prejudice facing people with intellectual disabilities with discrimination prevalent and either institutional care is used, or there are a lack of services and people are reliant on the support of their family (Scior, Kett, Hastings, Werner, Hamid, *et al*, 2015)

Some sources have reported that the National Health Service [NHS] in the UK is facing what has been coined, 'a crisis of compassion' (Hedir, 2013). Whilst it is not always explicitly linked, deficits in compassion have been associated with poor practice. With the recent serious case reviews in UK services such as Winterbourne View (Department of Health, 2012a) and North Stafford Hospital and the publication of the Francis report (Department of Health, 2012b) delivery of care in services has been under the spotlight. The Francis report examined the failings at North Stafford and made reference to a 'negative and uncaring culture'. It called for a culture change in the NHS and made 290 recommendations for the future. These included 'improved support for compassionate care and stronger healthcare leadership'

Following the Francis report, in the UK the 6 C's nursing strategy was launched. This set out a shared purpose of nurses, midwives and health visitors to support the culture of compassionate care. The 6 C's are; Care, Compassion, Competence, Communication, Courage, and Commitment (Department of Health [DoH], 2012c). The NHS commissioning board (2012) published a three-year strategy for building a culture of compassion for care and nursing staff, 'compassion in practice'. This strategy was produced following additional consultation with 9000 nurses, care staff, stakeholders and patients from the draft document.

It states that organisational bodies should give the highest priority, 'to enabling the culture

for compassionate care' (p.14).

It has been recognised that this is a systemic issue. The follow up document, 'leading

with compassion' (NHS England, 2014) made the recommendation that interventions for

change needed to be targeted at the micro and macro level to support compassion in care. The

focus was, and still is, on changing the culture of services to foster compassion. Therefore, we

need to develop supportive, compassionate environments and the systems that surround them

In order to support compassion, we need to understand what it is. Various definitions of

compassion exist. The etymology of the word comes from the Latin, *compati,* meaning 'to

suffer with' (Oxford English Dictionary, 2014). Compassion as defined by the nursing 6 C's

is, 'how care is given through relationships based on empathy, respect and dignity – it can

also be described as intelligent kindness, and is central to how people perceive their care'

(Department of Health [DoH], 2012c, p13.).   This discussion has focussed on UK health

systems but similar issues have been identified in many health systems in other countries.

Scior (2011) reported on the societal responses to people with intellectual disabilities from

North America, Europe and Asia which reflected stigmatisation and discrimination. Scior

Kett, Hastings, Werner, Hamid, *et al* (2015) suggested that awareness and combating harmful

practice and prejudice for people with intellectual disabilities was highly variable across

countries. Compassion or the act of compassionate behaviour is also valued in many religions

such as Buddhism, Islam, Christianity and Jainism among others. In Buddhism it is seen as a

central component in the enhancement of wellbeing (Dalai Lama, 1995). Compassion from a

Buddhist perspective is defined as, 'a sensitivity to the suffering of self and others, with a

deep commitment to try to relieve it' (Dalai Lama, 1995).

Gilbert (2010) among others, (MacLean 1985; Geary, 2000; Preston 2013) suggests

an evolutionary advantage to compassion. Evolutionary perspectives of compassion have

seen it, with sympathy, as an emotional experience that enables the protection of the

vulnerable from suffering (Goetz, Keltner, & Simon-Thomas, 2010). Their appraisal model

of compassion suggests the decision-making process that might underpin the setting

conditions for compassion. The model proposes that certain cognitions and resources need to

be available in order to facilitate compassion. Compassion focused therapy supports a

respectful, supportive and generally kind approach to people (Gilbert & Leahy, 2007) which

is common across all therapies (Allen, Fonagy & Bateman, 2008). Despite there being a lack

of a general consensus on the definition of compassion and its differentiation from other

concepts such as empathy or pity, the use of the word 'compassion' is prevalent in the

literature surrounding health care. Terms such as compassion fatigue and compassion

satisfaction are often used when describing the impact of care giving behaviour (Yoder,

2008; Stamm, 2005).

　　　There is a scarcity of research specifically in the field of intellectual disability and

compassion. Most of the more recent existing literature on compassion (Corso & Div, 2012;

Halifax, 2011; Van der Cingel, 2011) explores the concept from a nursing and palliative care

perspective covering compassion fatigue and compassion satisfaction. This is particularly

interesting as compassion is important in the care of more vulnerable people, such as people

with intellectual disabilities. A literature search of various library databases yielded three

relevant studies in the combined fields of compassion and intellectual disabilities. Of these,

one was an opinion piece of compassion in psychotherapy (King, 2005); the others took a

spiritual, religious focus of compassion (Turnbull, 2005; Gramenz, 2007).

　　　This reflects the variance in how compassion is considered within health care. One of

the challenges in intellectual disability services is that normalisation based approaches, such

as the person-centred approach, may introduce similar issues to compassion (such as respect)

and, whilst admirable, the nature of these concepts has not been explored or operationalized

so staff may not be clear on what it is they are being asked to do and how this is different to their current practice. This could potentially make it difficult to embed in practice and change the existing culture of care. If people are unclear about what it is they are being asked to do, then it makes it harder to implement and measure outcomes. This is reflected in the considerable overlap of terminology used in the existing research, predominantly with the terms compassion, sympathy, empathy and pity. There are some studies that touch on empathy and sympathy (Waite, 2011) but the shared meaning of these for people is not always clear, and what these represent as conceptual constructs. There is considerable overlap in the definitions of empathy, pity and compassion. This demonstrates that the concept of compassion can mean different things to different people, depending on the context. For example, demonstrating pity when working with people with intellectual disabilities has the potential to be seen as patronising them for simply having an intellectual disability. One of the few studies that attempts to conceptualise compassion specifically (Condon, Feldman & Barrett, 2013) used video clips of situations that were assessed by the researchers to show compassion and compassionate behaviour. It is important to explore what compassion means to staff working in intellectual disability services so they can be effectively supported to deliver compassionate and appropriate care.

The importance of supporting staff is not just to promote good care for service users but also for the emotional wellbeing of staff. Compassion fatigue can result in staff members feeling helpless or angry in their work (Yoder, 2008) and has been linked to staff burnout (Stamm, 2002). Compassion fatigue is defined as '*indifference to appeals of those who are suffering people, experienced as a result of the frequency or number of such appeals*' (Oxford dictionary, 2017), although this definition does not encompass the aspect of available resources, whether these are individual or organisational for example lack of time or sufficient staff. This would understandably have an impact on service users and the care that

they receive. If staff are feeling burnt out and helpless, they are going to find it increasingly difficult to offer compassion to others. Staff may have to take time off from work as the result of these stressors which impacts on staffing levels and the availability of care for services users

Compassion satisfaction has been defined as pleasure in being able to do one's work effectively, if work is of a caring nature (Stamm, 2005). A significant negative correlation has been found between compassion satisfaction and burnout in healthcare workers working in hospice and palliative care however. This suggests that the potential problems that are associated with burnout and compassion fatigue could be alleviated with the systemic support of compassionate cultures and working environments for staff.

Why This Research is Warranted

Compassion is featured in health care strategy and may be seen as an outcome, or indicator of how well an organisation is working. There are relationships between compassion fatigue and burnout (Stamm, 2002), and high-profile failures in healthcare have been due to a number of factors which have included a lack of compassionate care. However, compassion, its meaning and how it can be transferred into practice is not clear (Dewar, 2013). There is significant overlap with definitions of empathy and pity, therefore, one of the core elements of defining compassion is that it needs to differentiate from other similar concepts. Much of the existing literature has been in the fields of general nursing or palliative care. There is a research gap in the field of intellectual disability services. The key practical and psychological aspects of compassion are not well researched in mental healthcare (Brown, Crawford, Gilbert, Gilbert & Gale, 2014). If compassion in services is to be effectively supported it is important to have an understanding of what care staff believe it is and the setting conditions in which it can be maintained.

Aim of Research

This research aims to investigate what intellectual disability service care staff understand compassion and compassionate care to be so this can be most effectively supported and maintained.

Method

Design

The design and plan for this study has been informed by a constructivist epistemological position. A constructivist perspective postulates that meaning is socially produced rather than inherent within individuals (Burr, 1995). As this is an initial exploration of compassion in intellectual disability services and in the absence of clear established models of compassion, an interpretive descriptive framework will be used.

Participants

Ten participants were recruited from residential and day services and multiple providers of care for people with intellectual disabilities. Nine participants were female and one was male with an age range of 26 to 58. Five were recruited from day services, following these interviews a decision was made to purposely recruit the next five participants from residential supported living services. This decision was made in order to obtain a more global picture of support services.

Inclusion Criteria: Participants must have had contact with service users and be involved with their care. All had been working for a minimum of six months.

Three services were approached with the information sheet about the study (see ethics section) prior to asking participants to take part in the study. All ten participants volunteered to take part and the information sheet was revisited with them prior to them being asked to sign consent forms. The interviews lasted between 40 and 55 minutes.

Data Analysis

The data were subject to thematic analysis (Braun & Clarke, 2006) to identify,

analyse and report patterns and themes of interest. Thematic analysis is regarded as an

accessible and theoretically flexible research method for analysing and working with

qualitative data (Braun & Clarke, 2006). This is particularly useful when looking for

common themes within research material as the potential range of things that can be explored

is greater due to this flexibility.

Inductive, content driven analysis utilising an ideographic approach was used, the

specifics of each transcript in turn were analysed and codes generated from this which were

further assimilated into subsequent common themes (Guest, 2011). Table 1. shows

exemplars from the transcripts of how quotes were assigned codes. Once each paper was

coded, the codes were grouped into themes. The themes were refined with the addition of the

codes from each paper in turn until meaningful and complete themes were formed. Table 3.

(Appendix A) shows the quality assurance process that was followed to improve the rigour of

this process.

Ethical Issues

Clearance to undertake the study was granted by the Lancaster University ethics

committee. It was possible that participants may communicate, or become visibly distressed

during interviews. If this was to have occurred then the procedure for halting the interview

would have been followed. As participants were asked to talk about times when compassion

has been missing, or has been more difficult, there was the potential for poor practice to be

disclosed which would have led to breaking the confidentiality agreement.

Procedure

Multiple independent supported living providers were approached to gain permission

to approach staff to inform them of the proposed research project. Staff were informed of, and

invited to take part in the research by the distribution of the participant information sheets by

either the field supervisor or the chief investigator (see ethics section). The contact details of

the chief investigator were contained on the participant information sheet. They were asked to

contact the chief investigator to express an interest in taking part in the research.

Interviews were audio recorded and took place at the participant's workplace,

although they were offered the option for the interviews to be at Lancaster University to

further protect anonymity if they wished. Before the interview began verbal and written

consent (see appendix 2) was checked and participants were reminded of their right to

withdraw consent, without giving a reason, up to two weeks after the interview had taken

place.

Staff were asked not to give names of service users in the interviews. Pseudonyms

have been assigned to the participants.   The interviews adopted a semi structured style with a

topic guide for questions and explorations (see ethics section). The questions have been

adopted from Bramley and Matiti (2014) to act as a prompt for the chief investigator.

Table 1. Development of themes

Quotes	Codes	Themes
"Being aware of somebody's distress and responding to it without making that person feel more distressed or embarrassed" (Fiona).	Recognising and responding to distress	Difficult to define. The duality of compassion: both a reaction to distress and a continuing component of care.
"I think it's just being as understanding and supportive to somebody and showing TLC and that people do care…not being judgmental" (Rachael).	Caring, support and non-judgmental	
"Somebody is upset and sit down and, you know, have a cuppa. They are the obvious compassionate things, but I think that it covers…I think that compassion is in absolutely everything that we do" (Rachael).	Compassion as underpinning all aspects of care	
"having that sort of level of judgement when somebody needs support or comfort, or on the other hand, knowing when to step back and realising what they need right now is space and some alone time" (Debbie).	Assessing the situation, what is the person trying to communicate	"knowing" the person influences compassionate response.
"everybody's needs are different…I know that not everybody likes what I would want to do, so maybe sit calmly with them or ask them what they want, you know, if they know" (Joan).	People have different needs and not everybody will want the same response to a behaviour/communication	
"Someone who doesn't kind of reach out for compassion, or doesn't look as if they would really welcome it…even just saying to them, shall I go and make you a cuppa, or shall we go and put your slippers on? That is still showing some form of compassion" (Rachael).	Compassion can be simply offering a distraction	
"It may be hard if people create a perception that somebody is simply squeezing as much as they can, that they are attention seeking" (John).	Attributions of behaviours	Barriers and inhibitors of compassion.
"it's hard, sometimes you can become too emotionally involved and you have to find that working relationship, especially when you are working in such close proximity like most of the staff are" (Grace).	Emotionally draining	
"Tiredness, patience, work demands…those types of things are real…not knowing someone very well" (John).	Practicalities of everyday support	
"It was just the talking about it and, 'how do you do it?' or 'how do you manage?' again through understanding of different bits of training over the years and the experiences of other people" (Sophie).	Learning from others and having their support	Factors that support and maintain compassion
"I think that some people are more naturally compassionate and more in touch with their emotions than other people" (Sarah).	'naturally' Compassionate people are drawn to the care profession	
"Try and find a light-hearted side to stuff rather than a criticism, you know, it's just one of those things that are going to happen" (Rachael).	Internal coping strategies to manage emotions	

Results

Four themes were generated from the data, which are summarised in Table 2 below.

Table 2. Summary of themes

Main Theme	Key Aspects
Difficult to define – the duality of compassion	A reaction to distress
	A continuing component of care
'Knowing' the person influences compassionate response	A compassionate response will be different depending on a person's needs
Barriers and inhibitors of compassion	Attributions of behavior and staffs internal and external resources affected compassionate response.
Factors that support and maintain compassion	Individual and organisational strategies that helped them to understand the people that they were working with

Theme 1: Difficult to define. Participants responses reflected a duality of compassion: both a reaction to distress and a continuing component of care. All of the participants in the research paused to consider what they thought compassion to be. It was a word that they used, but they had never thought about what that meant in reality.

"It's one of them confusing words I think. It is…I think that people have different understandings like, if I was to say what compassion is I would say…I've never really thought about it…being there for someone, respecting someone, what they need and what they want and being able to go alongside that with respect, with like a degree of friendships compassion" (Jessica).

For the participants,

"Compassion is about having sympathy and empathy for someone who is having a difficult time. A difficult time might be about grief, it might be about loss, it might be any human condition where somebody is struggling" (John). It was also

"Being aware of somebody's distress and responding to it without making that person feel more distressed or embarrassed" (Fiona).

To do this they had to be

"able to identify the needs emotionally to be able to support that individual with their emotional needs" (Grace).

The participants felt that it wasn't just responding to an incident of distress when a person may be obviously upset; compassion was something that ran throughout their practice.

"Somebody is upset and sit down and, you know, have a cuppa. They are the obvious compassionate things, but I think that it covers…I think that compassion is in absolutely everything that we do" (Rachael).

For others, they thought

"it's just being as understanding and supportive to somebody and showing TLC and that people do care…not being judgmental" (Rachael).

Compassion is a way of connecting with people in the here and now and,

"Maybe putting yourself in that person's position a bit" (Sophie). *"It can be quite poignant really…because it's sort of like – that's human kindness there"* (Fiona).

Theme 2: "Knowing" the person influences compassionate response. This theme reflected that compassion may be different depending on a person's needs. Participants noted that they needed to use reflection and

"having that sort of level of judgement when somebody needs support or comfort, or on the other hand, knowing when to step back and realising what they need right now is space and some alone time" (Debbie).

Sarah said that her and her team,

"are very sensitive to her needs and we try and help her with every aspect

of her life that she needs supporting with, whether that be that somebody has

upset her or maybe it's a bill that's come through that she needs to deal with".

One method that participants used for getting to know the people that they support

was learning from observation,

"I like to think that I learn by watching…I am learning how they respond

to a situation as well, rather than me just going in and someone saying, no I don't

want that" (Joan).

They would,

"Sit down beside them; maybe put (an) arm around them, depending on

who it is and what they like" (Sophie).

There was a recognition that

"everybody's needs are different…I know that not everybody likes what I

would want to do, so maybe sit calmly with them or ask them what they want, you

know, if they know" (Joan).

Because of this recognition their responses would change,

"based on how [service users] respond in a situation so you vary that

accordingly…tuning in to them as an individual" (Carol).

The participants were acknowledging both the psychological and environmental

factors and their impact on the service users.

Most participants mentioned that not everybody welcomes compassion and that

judgement was needed in what a person might want or need, Autistic Spectrum Conditions

(ASC) were often mentioned in this context and how a more direct approach was needed or

less physical reassuring contact.

"so yeah, I didn't go in and just give her a hug because I didn't think it was the right thing to do and I had to sort of step back and think, how is she going to react if I go in like that? So, I just sat and talked to her for a minute" (Joan). *"Someone who doesn't kind of reach out for compassion, or doesn't look as if they would really welcome it…even just saying to them, shall I go and make you a cuppa, or shall we go and put your slippers on? That is still showing some form of compassion"* (Rachael).

Participants were suggesting in their responses that explicit compassion is not always helpful, managing an immediate crisis and needing to keep people safe may require a more directive approach. However, this was still deemed as compassionate as it was recognising this was what the person needed to keep them safe.

Theme 3: Barriers and inhibitors of compassion.

Attributions of behaviour, particularly if service users are perceived to have behaviours that challenges services, can affect the compassionate response.

"I think that sometimes the staff can think that she is playing on it, she doesn't need that much compassion today" (Sarah). *"It may be hard if people create a perception that somebody is simply squeezing as much as they can, that they are attention seeking"* (John). *"There is still a perception that one or two people enjoy misery and that's become a behavioural thing rather than an emotional need"* (John). *"It is more difficult to be compassionate to those…you perhaps don't bond with as well"* (Rachael).

These quotes locate the responsibility of behaviour that challenges within the person with an intellectual disability. Service users are seen as having control over their behavioural and that they are acting in a specific way to elicit a specific response as suggested by the term 'behavioural thing'. This behaviour is seen as less deserving of compassion.

"I did lots of things with them and (they were) quite humorous, but at times they were challenging in a physical way. I know I was on the receiving end of that a few times and for me I struggled with that bit because there were times I would go in to support them and it was that kind of internal battle thinking, well you have done this really horrible thing to me and I'm hurt" (Sophie).

This participant had acknowledged that compassion was a struggle sometimes, especially if staff had been the victim of verbal or physical violence. What they are demonstrating is reflective skills of recognising their own internal battle about their emotional response and the needs of the person that they are supporting.

Participants demonstrated insight that their own state of mind and internal resources and that will impact on how able they were to be compassionate.

It depends on what mood you are in yourself um…you might be less compassionate if you were in a particularly bad mood or you were upset yourself" (Sarah). *"Tiredness, patience, work demands…those types of things are real…not knowing someone very well"* (John). *"There are times when, you know, staff can be tired. You have x, y and z to deal with and it has been quite an emotionally and physically draining shift and I can understand how people's level of empathy can drop"* (Debbie).

Staff changes can affect people's capacity for compassion

"people need supporting around safeguarding, so if you are having to relieve people from that and you have to find somebody else to do that…it depends how your budget is looking" (John).

Staff rely on each other to support themselves, this is harder when staff are working on their own or there are not enough staff.

Compassion can be draining for people

"it's hard, sometimes you can become too emotionally involved and you

have to find that working relationship, especially when you are working in such

close proximity like most of the staff are" (Grace).

Staff have become emotionally invested in the people that they support. When they are

spending long periods a day on a shift that can last 12 hours or more, they understandably

develop strong connections and relationships with service users and are affected by their

discomfort and distress

"I was on a sleep-in and he wasn't very well and then I was just worrying

and I was trying to sleep, but I couldn't sleep because I was worrying so much,

yeah them times. Then you go home and you think, oh I hope they are alright"

(Jessica).

Whilst not explicitly mentioned, burnout is a real possibility for the participants

"After the third major crises of the day and somebody um…you know,

somebody sort of trashing the place. Perhaps the first time you are like, come on

we'll get your hanky now, second time: I'll go and get a hanky, third time: do you

want a hanky?" (Rachael).

Repeated exposure to difficult events means that people may become frustrated with

the situation in front of them, which in turn affects their response. over time this will leave

people feeling stressed and demotivated.

Theme 4: Factors that support and maintain compassion.

Most participants thought that having support plans in place helped them to

understand the people that they supported. These were practical strategies that the service had

put in place.

"We have very structured policies and strategies…there are strategies for how the other member of staff responds…all written in to the support plans as I say, the team that work with her are very aware of the support needs" (Debbie).

Positive attributions or understanding the functions of behaviour helped participants work positively with service users,

"you don't take it personally and she can't help, it's part of her illness and her disability and her challenging behaviour. Once you can get past that and it's not personal then (Grace)".

This is a method that could be used for staff who are struggling with behaviour that challenges. We have seen that in theme three, attributions of behaviour to personal control and gain are seen as less deserving of compassion. If these behaviours could be psychological reframed with formulation and/or functional analysis it would support a fuller understanding of a person's behaviour and needs.

Personal experiences and characteristics influence development and display of compassion.

"I think that some people are more naturally compassionate and more in touch with their emotions than other people" (Sarah). *"my instinct was just to get up and give her a hug and she just cried on me and my boss came and said she couldn't do that, it wasn't in her instinct to be able to do that"* (Joan).

Participants demonstrated a high degree of emotional intelligence

"If you grow up in an emotionally rewarding environment then it is more likely that you will be empathetic and compassionate with others" (John).

This is reflective of attachment theory which is a useful way to understand how patterns of interacting with others develop through life. The warmth that the participant's felt

about the people that they supported was evident in the language they used when talking

about the people that they supported,

> *"I absolutely adore working with her"* (Debbie). *"that's what I love the*
>
> *most, it's rewarding. If I didn't get paid I would still probably work. It's just that*
>
> *rewarding. I love it. I am happy to go to work"* (Jessica).

 This was serving as reinforcement for staff to feel happy in their work and enable

them to offer compassionate, caring support.

Having a strong and cohesive team was protective and positively supported the care

that participants felt that they were able to give.

> *"You (staff) have to be able to work together. You all have different*
>
> *personalities; you all have different strengths…so being able to use it together"*
>
> (Joan).

They were able to use these differences to their advantage and having a different

perspective helped people make sense of what happened.

> *"Try and find a light-hearted side to stuff rather than a criticism, you*
>
> *know, it's just one of those things that are going to happen"* (Rachael).

They used the knowledge that they had gained over the years from experience and

training and combined it with peer support.

> *"It was just the talking about it and, 'how do you do it?' or 'how do you*
>
> *manage?' again through understanding of different bits of training over the years*
>
> *and the experiences of other people"* (Sophie).

They respected one another and would be there to offer support to those that needed

it.

> *"We are all very much so close knitted; there is only six of us and we all*
>
> *kind of work alongside each other"* (Jessica). *"We have got a really good team*

here and if anybody is ever sort of struggling we will always find someone and

talk about it" (Debbie).

Managing the feelings that participants had from difficult experiences was a way for them to recover and therefore feel able to offer compassion and care again. John talked about being able to ask the team for help,

"I can't do this today; can you do it? I'm up to here…and that will

happen because we all have lives, we all have crises and we have own needs for

maybe being at work".

Sophie also felt that it was,

"from colleagues really. It was from colleagues talking, that they had

common experiences. I think that you talk about the difficulties, you know this has

happened and I have got to come in and carry on and be normal and be

professional and do my job".

Discussion

Four themes emerged that linked together. Theme one: Difficult to define – the duality of compassion. It was both a reaction to distress and a continuing component of care. Theme two: 'Knowing' the person influences compassionate response. A compassionate response will be different depending on a person's needs. Inaction might be the most compassionate thing a person can do in the moment, that is let the person have some space on their own, in other words, compassion can also be inaction, which is interesting because the literature uniformly states that compassion is an active role. Theme three: Barriers and inhibitors of compassion. Attributions of behavior and staffs internal and external resources affect compassionate responses. Theme four: Factors that support and maintain compassion. Individual and organisational strategies that helped them to understand the people that they were working with. The themes from this research map onto the appraisal model of

compassion (Goetz, Keltner & Simon-Thomas, 2010). Compassion is the culmination of the

process (see Figure 2).

Fig 2. Model of compassionate care (adapted from Goetz, Keltner & Simon-Thomas, 2010)
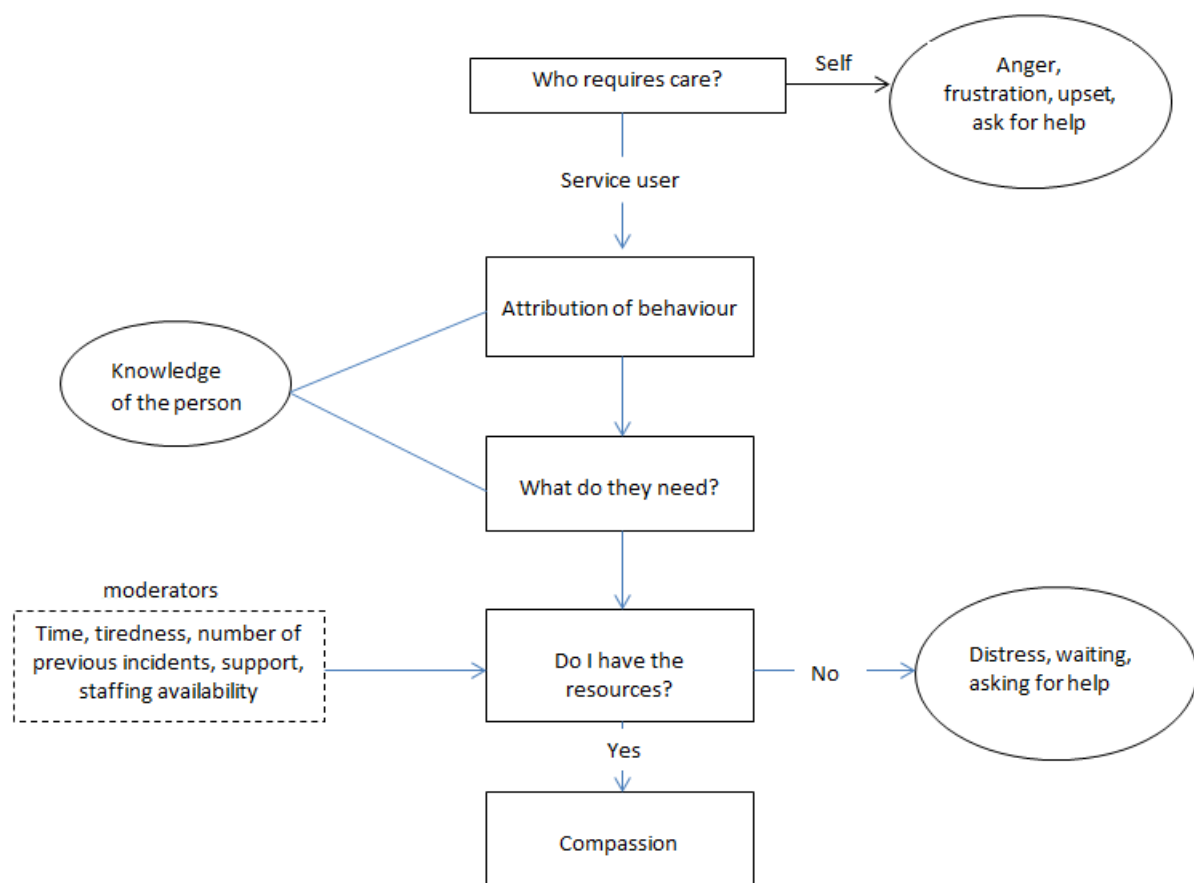
Compassion was a word that participants initially found difficult to define. For them it was an act that they could describe, but it was also part of their daily practice of care. This reflects the challenge of explicitly embedding compassion within care. If the concept of compassion is elusive, then it becomes harder to be able to practically support it as part of the positive culture of service.

Staff needed to feel supported and receive compassion from managers in order for them in turn to feel able to give compassion to others. The explicit act of compassion was in addition to normal caring practice and required time and emotional space from the staff member. If this not available it is possible for compassion to be missing. Participants reported that compassion could be draining, particularly if a service user is unwell or there have been multiple incidents during the course of one shift. Participants were often left feeling upset themselves by these events. Currently they found talking to one another an effective management strategy for these emotions so it is important that this continues to be supported and maintained by teams and their managers.

The theme of knowing the person fed into the attributions that staff make about the function of a person's behaviour and what they might need as a response from staff. If the behaviour is seen as communicating distress then the person would attempt to alleviate this and prevent further distress. This characteristic involves the member of staff being able to reason what is needed and behave in an appropriately kind and warm manner (Brown, Crawford, Gilbert, Gilbert & Gale, 2014). However, staff felt that the person was 'attention seeking' or that it was a 'behavioural thing' then they reported that they felt less motivated to give a compassionate response. Weiner's attribution model (1985) postulates that if a person's behaviour is seen as being under their control, such as 'attention seeking' in this example, then the responding person is likely to experience anger and therefore less likely to offer support or help in that situation. Dagnan and Cairns (2005) found that in a group of

carers, sympathy was the only significant predictor of helping intention. If a person was thought to be responsible for behaviour that challenges, then sympathy was less likely. With sympathy being linked by the participants in this study to compassion it is highly possible that they were experiencing something similar here.

Considering the impact that knowing and understanding the person's needs has on how care staff may offer compassion, it supports the use of formulation with service users, particularly if the person may exhibit behaviour that challenges services and teams. A collaborative formulation could be used as a framework within peer support and reflective practice sessions to enable staff to think through behaviour. If it can be seen from a different perspective and that perhaps the person is acting as a response to long standing patterns of behaviour it might make it more understandable and elicit a compassionate response from staff. There are case examples where the use of sharing formulations with staff have reduced negative perceptions of behaviour (Ingham, 2011) and that team formulation can reduce frustration, promote the understanding of factors that can affect a service user's presentation, and help staff to find other ways to approach difficulties (Johnstone, 2015, Roycroft, Man, Downie, Gale, Armstrong, *et al*. 2015). Team formulation has the potential to change attributional thinking and increase staff empathy towards service users (Whitton, Small, Lyon, Barker & Akiboh, 2016). Ingham (2011) used the '5P's' approach to formulation, which focuses on a person's **P**re-disposing factors, **P**recipitating factors, **P**erpetuating factors, **P**rotective factors and the **P**resenting issue. This structured approach has the benefit of being accessible to both service users and staff when adapted to suit need. However, in order for team formulation to be successful the service and culture of the team would need to be open and receptive to it. Time would need to be allocated to facilitating this and staff released to attend as this is one of the barriers that is anecdotally identified by staff and services.

There were various moderators that were identified by the participants that affected the availability of external and internal resources that supported compassion. These moderators included whether or not the resources were available, for example an external resource would be if a staff member was available to offer support. If the staff member was helping somebody else they may not be able to immediately support another person. The internal resources of a person could be impacted if the participant felt tired and had faced multiple incidents of behaviour that challenges. To manage this in the moment, they may have had to ask the service user to wait a while or they have had to ask other staff members for help. But the effects of these incidents could lead them to feel distressed, frustrated and tired. This is a risk factor for burnout, emotional exhaustion and depersonalisation (Leiter & Maslach, 2000). Mills and Rose (2011) found a positive correlation between challenging behaviour and burnout. It is also suggested that exposure to violence predicts emotional exhaustion, but self-efficacy acts as a moderator between emotional exhaustion and depersonalisation (Shead, Scott and Rose, 2016). The long-term effects of this impact not only on the care that is offered to service users but the psychological and physical well-being of the staff that are supporting them (Leiter & Maslach, 2000). Implications would include the potential for the staff member's health to suffer requiring them to take time off work to aid their recovery. Burnout has been shown to be related to service users' perception of poor care (Vahey, Aiken, Sloane, Clarke & Vargus, 2004).

Theme four showed the factors that participants believed supported them being able to be compassionate. A large part of this was having a team around that that could be relied upon to offer help when needed and that was led by a good managerial team. This reflects the culture of not just the immediate care team but the system that is around them. When staff feel cared for by their employers, they are better equipped to provide exceptional care (West & Dawson, 2012). The positive relationship between staff members was identified as a

protective and supportive factor. Blumenthal, Chien and Singer (2018) also found a significant positive relationship between the perception of team dynamics and perception of safety culture in primary care. When people feel engaged they are more likely to put increased energy into interactions with service users (Salanova, et al, 2005).

Clinical Implications

Participants talked about the benefits of team working when they felt supported by each other and by the wider system. The participants reported that in teams that are working together to deliver good quality care, being able to rely on others for help and support greatly facilitated this. It also acted as a moderator for drains on internal and external resources. This is something that should be promoted and supported in other services to enable a change in culture. The teams supporting people need to feel that they are listened to and that they are fully involved. The adapted model identifies areas that services could target for change, such as additional support in the form of occupational health services being available for staff that might minimise the impact of moderating factors such as stress.

Supervision and training for staff teams is essential. Participants spoke about using the knowledge that they had learned over the years and how this had helped them. Theoretical models would offer a framework for staff to understand how and why people act and feel the way they do. Attachment theory is an example that emerged through the analysis and would help staff to understand interactions and relationship patterns. This could be considered through the importance of having a safe and secure base in order to build positive relationships (Bowlby, 1973). It is interesting that this was evident in the research as it links with the recommendations from the Francis report of the importance of a safety culture (Francis, 2013). Using the framework of attachment theory combined with psychological formulation could be effective methods in the promotion of this safety culture as it will

facilitate staff's understanding of the people they support and consequently further enable compassionate responses.

This research would support the use of team formulation in a systemic way in order to promote and maintain compassion within all aspects of care for service users and provide support for staff teams. Practically, clinical psychologists and therapists can be involved in developing shared formulations collaboratively with service users and the teams that work with them. The formulation can provide a working hypothesis as to why a person may think and behave the way they do in certain situations (Weerasekera, 1996) and challenges negative attributions. It would also provide information for Positive Behavioural Support plans that inform care in many intellectual disability services. This would help staff consolidate their knowledge of how best to support service users and the attributions that they make about behaviour that challenges. A formulation also provides a framework to think about service users progress and frustrations that both staff and service users might have (Butler, 1998). This could be especially useful in staff support sessions that and would further enable staff to feel that they are being listened too.

Limitations

The group of people that were part of this research may have valued compassion highly. All participants talked about the need for care staff to have personal values that included compassion to be able to do the job that they were in. In addition to this, participants were asked to volunteer to take part in the study; staff that are 'more' compassionate might be drawn to take part in a study. This may have had an effect on the responses that were given in the interviews.

Future Research

This study highlights the value of team working, knowledge sharing, and a compassionate culture within the whole healthcare system. Future research could look at the

impact of introducing a framework model, such as the one adapted in this study on staff wellbeing and resilience.

Conclusion

Whilst compassion might be difficult for people to verbalise in a definition, how they support and talk about service users demonstrates care and compassion. Feeling connected to other members of staff and the people that they support promotes compassion. Barriers and moderators to providing this do exist, but if the wider system and culture can respond these effects can be minimised which benefits both staff and service users. The adapted model of compassionate care can be used as a framework for services to enact change and sustain good practice.

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Appendix A

Table 2. Quality assurance for thematic analysis (Braun & Clarke, 2006).

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed - interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other - the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done - i.e., described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

Section Three: Critical Appraisal

A Critical Appraisal of the Thesis Research Process: Understanding Compassion in Intellectual

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Critical Appraisal

The aim of this critical appraisal is to provide an overview of the research process, including my reflections on why I chose this topic area, why I chose thematic analysis as a methodology and to comment on the strengths and limitations of the project. There will be a discussion of some of the challenges presented and how they were managed. I will outline my epistemological position and how that influenced methodological choices. I will discuss the results of the research and my reflections on the process and how this has informed my clinical practice.

I wanted to conduct research with people with intellectual disabilities as this was most relevant to my clinical practice. My pre-training experience had been working with this client group and it was the area that I wanted to work in post qualification. I have always enjoyed working with this client group and find it extremely rewarding.

My interest in compassion in intellectual disabilities was triggered through my experience of working in a variety of services, both community and in-patient during the time that Winterbourne and the problems at North Staffordshire were taking place. I remember the shock that was felt, not just by myself, but by my colleagues as well, that abuse like that was still taking place. It was hard to believe that people who were employed in a caring capacity could act in this way and that it had gone unnoticed for so long. There was almost a blissful naivety that we had learned the lessons from previous inquiries and that there were safeguards in place to protect people from this happening again. Myself and my colleagues acknowledged a sense of collective shame that we too worked in intellectual disability services and we thought that the general public would associate us with the scandals. I reflected upon why we felt this way. I believe it was because we cared about the people that we supported and wished to protect them from abuse. We saw them as people, as equals, who needed support and should be treated with respect. I did not want to be seen in the same way as those who had perpetrated the abuse. This was partly a reaction to how all services were portrayed by the

media response. Emotive language filled the headlines and it was uncomfortable reading. It was also the understandable reaction from commissioning monitoring services. There was an increased scrutiny of the care that people were receiving. This was of course to protect service users, but it left me feeling as if we had done something wrong too.

We believed that we were treating service users with care and respect but from watching the Panorama documentary (BBC, 2011) of the abuse that took place in Winterbourne view, a private hospital in the south of England that supported people with intellectual disabilities, the service users were certainly not treated this way. They were almost de-humanised. Perhaps more shockingly though, was that staff were watching this take place in front of them and did nothing to stop it.

This was when I first began to wonder what it was that was different about services that were compassionate and caring like the one that I worked in, and those that abuse was rife in. From my observation and experience there was a distinct difference in the culture and atmosphere of the 'good' and 'bad' services. I was happy in my job and so were the majority of those around me, I felt supported by colleagues and management. I believed we were caring and compassionate.

The outcomes and recommendations of the serious case reviews and the Francis report (2013) identified compassion as a key component in safe and effective care, so this seemed like a good place to start. Were we compassionate because it came naturally or were we supported to maintain compassion? It was an interesting concept to me and I will discuss this further in relation to the results of my research later in this paper.

Because of my desire to work in intellectual disability services post qualification, conducting research in this area has further developed my research skills and awareness of potential challenges. As the majority of the 'write up' aspect of this research has taken place whilst I have had a full-time job. I have developed skills in managing the competing demands of research and clinical work which will be of enormous benefit for any research that I undertake in the future.

Having an awareness of current research is vitally important in the area that you work, as is keeping up to date with government and local policy. This increases knowledge and understanding, and further develops skills in applying theory to practice. This process has enabled me to do this.

Methodology and Epistemology

I decided to collect data from a sample of staff who worked with people with intellectual disabilities in the community. The reasons for this were that I wanted to explore their understanding of what compassion was. They are being asked and expected to work with compassion, but what does that mean to them? I chose community services rather than in-patient as care staff in community settings work with more autonomy and are distanced somewhat from health professionals and their support. This autonomy can mean that people are often working by themselves or in small teams. That isn't to suggest that they are less likely to be compassionate, but that it is important to capture their understanding as they are the ones who are responsible for the delivery of care. Before we ask people to act compassionately we need to understand what they believe compassion to be in order to effectively support its maintenance and development.

In the beginning, I considered what methodology would be most appropriate to answer my research question. Essentially, the correct methodology is the method that will answer the research question (Holloway & Todres, 2003). As this was exploratory research, it was deemed appropriate to use a qualitative methodology to explore participants' understanding of compassion.

Thematic analysis is a method that highlights themes derived from a person's experience and understanding (Braun & Clarke, 2006) and was selected for use in this study. Thematic analysis is not connected to existing theory so is ideally suited to initial exploratory research. It is also useful for informing policy development (Braun & Clarke, 2006). This is a major advantage for this type of research as it allows the findings to support changes in service development which was partly the

inspiration for conducting the research.

Other methodology such as Interpretive Phenomenological Analysis (IPA) was considered. This approach was closely aligned with my epistemological stance for this research. It involves making interpretations about the interpretations of the participant (Smith, Flowers & Larkin, 2009). However, its stance of phenomenological epistemology (Smith et al, 1999) was not entirely consistent as it prioritises peoples lived experience in greater detail (McLoed, 2001). This was rejected as an option as I wanted to ascertain what people believed the experience and concept to be before their lived experience of it was explored. I felt that that was more suited to the follow up or second stage of this research, once we understood what the concept was. As this was an exploratory study I felt it was more important for the views of the participants to be prominent so this method was dismissed.

Challenges arising during the research process

The first challenge faced was the ethics of asking people for examples of times when they believe compassion has been missing in care. Whilst ethical approval had been granted for the research, care and sensitivity were needed when asking this question. I had to be mindful that my question was not accusatory and that the participant did not feel that I was questioning their practice, but I felt it was important to explore what factors were present or absent when compassion was missing. Another potential problem could have been if a participant had disclosed uninvestigated or unknown abuse. I had been clear for the beginning that if any information was disclosed that I believed meant that someone was at risk, I would have to report this. This did not happen, but there were still descriptions of events that had clearly distressed the participants as they had become frustrated, angry and upset by the circumstances they were working or with the people that they supported. During this process, it was important to remember my position as a researcher, rather than a clinician. The purpose of the interview was to gather information not to offer clinical supervision for difficult experiences. This was slightly uncomfortable for me as outside of a research context I would take a much more active role as a clinician. Separating these roles is difficult and Orb,

Eisenhaur and Wynaden (2000) suggest that people may experience discomfort and what they find as the contrast of the passivity of the researcher role. To manage this discomfort without overstepping boundaries I demonstrated empathy in my body language and facial expressions. This allowed the validation of the participants experiences making them feel heard and understood without offering comments that would alter the research.

One of the major challenges for me in completing this research was the length of time taken to complete the work. The research and analysis was completed before I finished my formal classroom training. However, when I began working full time after the course had finished time quickly became limited for what I could manage to do in terms of completing of the write up and editing in a week. Combined with a very stressful job and unfortunate life events I found the work overwhelming. For a period of time I felt that I could not continue with the research and became very anxious. This took a toll on me and for the benefit of my health I took a break, which helped me to work through the stressors that I was experiencing in my life. I also had support from others which was invaluable and to whom I am grateful.

When I returned to the work it seemed much more manageable but with the passage of time I had to reacquaint myself with the research. As I was doing this it became apparent that my original literature review was no longer viable. Other authors had written papers that were similar on the topic I had chosen of people with intellectual disabilities accessing health care. I felt this was no longer a novel area for review. It was still possible to conduct a review but it covered a very broad area and would not have been as meaningful as I had hoped. I considered the other review options and decided to conduct the one that I had actually originally hoped to do but had been unable to because there was very little research in the area at the time. Since leaving the course a further six papers had been published making it a much more feasible option for a literature review. After a discussion with my field supervisor, who has been very supportive through this process, I decided to proceed with a review of the experiences of therapy for people with intellectual disabilities. I believed this linked

with my research of the care and support of people with intellectual disabilities as an overall theme of the thesis.

In practical terms, what this meant was that I had to completely re-write my literature review. Which was a huge piece of work and very time consuming. On reflection, this was actually helpful to my research process. I was able to immerse myself fully from start to finish in a topic that I was passionate about. I think that the review benefits from this.

I didn't have so much difficulty with the empirical paper as this was much more fully developed before I took a break. With this paper, I did have to spend considerable time reacquainting myself with it. Whilst it needed updating, it did not require major revisions and was more manageable.

This process was not without anxiety. I was still working full time so I had to be very structured when it came to my own personal time management. There was a lot of work still to do and I could easily have felt overwhelmed with it all again. This was managed by focusing on one section at a time, then considering the whole paper one at a time. I also benefited from supervision to talk about the process of the research with my field supervisor. I was lucky enough to be well supported by my employers who have always encouraged me to complete the work.

Strengths, Limitations

A limitation of this study is that the sample consisted of a homogenous group of people, who were predominantly female and were all white and British. They all worked in community intellectual disability settings. Future research should try to capture staff from a wider variety of backgrounds to represent any cultural or spiritual differences in the understanding of compassion.

All participants volunteered to take part in the study. As they knew that they study was asking

about compassion it is possible that the participants were already very good at compassion as those that weren't avoided taking part. Whilst this is a limitation of the study, it could also be considered a strength. Being able to understand what they thought compassion was and how they were able to support it gives valuable insights into how this can be generalized into other services. Participants were still able to identify barriers to compassion, but they also had their own solutions. This information was incorporated into the adapted appraisal model (Goetz, Keltner & Simon-Thomas, 2010).

A further strength of this study was the identification of the clinical implications from the themes. It highlighted the importance staff support and training in theoretical models and supported the use of psychological formulation to help staff to understand the people that they support.

Reflection on Results

The research has given an exploration into the understanding of compassion of staff in intellectual disability services. Participants were extremely thoughtful about the subject and gave careful consideration to their responses. The themes mapped onto the appraisal model of compassion (Goetz, Keltner & Simon-Thomas, 2010). Compassion was the culmination of the process of attribution of behavior, knowing what was needed and whether available resources would facilitate a compassionate response. This was moderated by level of knowledge of the individual and interpersonal and systemic factors such as tiredness and staffing availability. Thinking back to what originally got me interested in this subject it becomes clearer to why the service I had worked in the at the time of Winterbourne was able to be compassionate. We did have some of the barriers, I believe most if not all services will struggle with staffing level problems and staff fatigue, we were able to work through these.

After the research interviews had been completed most of the participants reported finding it beneficial to share their experiences. They talked about how they felt listed to and that the process had been a positive experience for them. There are acknowledged benefits from taking part in

qualitative research that include participants feeling empowered, acknowledged, and having an

opportunity to voice their opinion (Hutchinson, Wilson, and Wilson,1994). This is particularly

interesting as it connects to the themes within the research. If people feel supported and listened to

then they are more likely, or feel more able, to be compassionate. What these comments show is the

importance of having a safe, boundaried space that they can talk about their practice. This need

would usually be met through clinical supervision. All the participants had access to supervision and

stated that they were using this. However, it was having someone independent from the service to

talk to that they said was a refreshing change.

This research goes some way to suggesting ways in which compassion can be supported in

services. I remain curious about how situations such as Winterbourne came about. It is difficult, if

not impossible to infer what happened in those services with certainty without all the information

about the particular circumstances of the service and the people that worked there. However, suffice

to say that a complexity of factors was a play. There was a culture in place that allowed abuse to go

unchallenged, or in the case of the whistleblower, ignored. Compassion was evidently missing, but it

also was not able to thrive in the service as well. The serious case review (Department of Health,

2012a) found a number of failings such as lack of supervision, training and poor communication.

These are all things that were found to be moderators of compassion in this research. Without these it

is harder for staff to feel able to be compassionate to the people that they are supporting and their

colleagues.

I chose to focus on frontline staff in this research as they are the ones who are directly giving

care. But the findings of the research are generalisable to organisations as a whole. Front line staff

need to feel supported and have adequate resources to be able to do their job and this is also true for

the next tier of staff who are supporting them. Staff in all levels of the organisation need to feel

supported listened to in order to build and sustain a safe and compassionate culture.

Impact on my own practice

Conducting this research has had a significant impact on my own practice. Firstly, I have reflected on my use of formulation. I have always been aware of the importance of co-producing formulations where possible with the service user. In intellectual disability services, this means that language and presentation of the formulations need to be adapted so that the person can readily understand them. The research has reinforced the idea to me of knowing the audience that I am writing reports and formulations for. If reports and formulations are to be helpful, not just to the service user but to the staff that they are working with, they need to be easy to understand. I have reflected on the language that I use and recognise that I can use terminology that is degree level. I have become more aware of the need for language to be simple to understand but still convey the information needed. An obvious pitfall in the communication of information is that if it is not understood, then it cannot be used effectively.

The second impact this has had on my practice is the use of formulation in group staff supervision sessions. The service that I work in supports a number of service users who have behavior that challenges services. Staff can find this difficult to work with and it is important that they feel they are supported themselves. To do this group supervision sessions are offered where we talk through the incidents using the formulation, which they report are helpful. It promotes everyone's understand and allows me to talk through the formulation and for people to be able ask questions if they don't understand anything that I have written. We can also add or change things (if appropriate) depending on what staff bring making it a live document. It can become a place for us all to check that we have a shared understanding of the person we are supporting.

It has also given me a greater understanding of compassion and its importance in the care of vulnerable people, such as those with intellectual disabilities. I am currently working in a service that is undergoing huge organisational change so a number of the barriers to compassion, such as a high turnover of staff and many staff leaving are prominent factors. This increases the demands that are

placed on the remaining staff as there is a pressure to do 'more with less'. This increased pressure will dramatically increase the risk of burnout and compassion fatigue (Yoder, 2008). I am able to apply what I have learnt though conducting this research to support myself and my colleagues through this process. I am to share my findings with the wider team so that we can work together to promote a safe and compassionate culture in the face of change. The adapted appraisal model will help to identify key areas of additional support that staff might need, including gaps in training or clinical supervision.

Conclusion

In conclusion, my interest in the subject was piqued by personal professional experience and a desire to understand this better. To explore this thematic analysis was deemed the most appropriate methodology as it suited the exploratory nature of the research. The results of the study mapped onto the appraisal model of compassion that showed the process of which compassion is the end result with various moderators affecting the response. This gave some useful insights that could be used to identify areas for managers and clinicians to focus on and to inform policy in intellectual disability organisations

There are various limitations of this research, the participants were a homogenous group so future research could consider staff from different cultural backgrounds. Secondly, as the participants were volunteers they may be drawn to the research because they are compassionate people. However, this is also a strength as it allows for the research to show how compassion can be nurtured. The process of this research prompted me to consider my own practice and how I communicate formulation, training and supervision as this needs to be done in a meaningful and easily understood way. It has allowed me to develop no just my research skills but my clinical skills as well. I hope to continue developing these skills post qualification through additional research opportunities.

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Section 4: Ethics

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Thesis Protocol

Doctorate in Clinical

Psychology Research

Title: Understanding Compassion in Intellectual Disability
Services

Name of Applicant / Principal Investigator: Ellie Hickman, Trainee Clinical
Psychologist,   Lancaster University, Lancashire Care NHS Foundation Trust

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Internal Supervisor ████████████████████████████████
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Understanding Compassion in Intellectual Disability Services

Research Protocol

Current Climate

With the recent serious case reviews at services such as Winterbourne View (Department of Health, 2012a) and North Stafford Hospital and the publication of the Francis report (Department of Health, 2012b) there has been an increasing emphasis on the promotion of compassion within services in order to prevent such events happening in the future. Some sources have reported that the NHS is facing what has been coined, 'a crisis of compassion' (Hedir, 2013). The NHS commissioning board (2012) published a 3 year strategy for building a culture of compassion for care and nursing staff. This strategy was produced following additional consultation with 9000 nurses, care staff, stakeholders and patients from the draft document. It states that organisational bodies should give the highest priority, 'to enabling the culture for compassionate care' (p14).

Definitions of Compassion

Various definitions of compassion exist. The etymology of the word comes from the Latin, *compati,* meaning 'to suffer with' (Oxford English Dictionary, 2014). Compassion as defined by the nursing 6 C's is, 'how care is given through relationships based on empathy, respect and dignity – it can also be described as intelligent kindness, and is central to how people perceive their care' (Department of Health, 2012c, p13.). Compassion from a Buddhist perspective is defined as, "a sensitivity to the suffering of self and others, with a deep commitment to try to relieve it" (Dalai Lama, 1995).

Literature

A literature search of various library databases (PsychINFO, PsycARTICLES,

AMED, MEDLINE, CINAHL) yielded three relevant studies in the combined fields of

compassion and intellectual disabilities. Of these, one was an opinion piece of compassion

in psychotherapy (King, 2005); the others took a spiritual, religious focus of compassion

(Turnbull, 2005; Gramenz, 2008). This reflects the variance in how compassion is

considered within health care.

One of the challenges in intellectual disability services is that normalisation based

approaches,   such as the person-centred approach, may introduce similar issues (such as

respect) and   whilst admirable, the nature of these concepts have not been explored or

operationalised. This could potentially make it difficult to imbed in practice and change the

existing culture of care.

One of the few studies that attempts to conceptualize compassion generally

(Condon, Feldman Barrett, 2013) used video clips of situations that were already deemed

to show compassion and compassionate behaviour. There are some studies that touch on

empathy and sympathy (Waite, 2011) but what these represent as conceptual constructs

that have a shared meaning for all is not always clear. There is considerable overlap in

their definitions of empathy, pity and compassion.

Most of the more recent existing literature on compassion (Corso & Div, 2012:

Halifax, 2011: Van der Cingel, 2011) explore this from a nursing and palliative care

perspective covering compassion fatigue and compassion satisfaction.

Compassion in a Wider Context

Compassion or the act of compassionate behaviour is also valued in many religions

such as Buddhism, Islam, Christianity and Jainism among others. In Buddhism it is seen as a

central component in the enhancement of wellbeing (Dalai Lama, 1995).

Compassion focused therapy supports a respectful, supportive and generally kind approach to people (Gilbert & Leahy, 2007) which is common across all therapies (Allen, Fonagy & Bateman, 2008).

Evolutionary perspectives of compassion have seen it, with sympathy, as an emotional experience that enables the protection of the vulnerable from suffering (Goetz, Keltner, Simon- Thomas, 2010).

Compassion Fatigue and Compassion Satisfaction

Despite there being a lack of a general consensus on the definition of compassion and it's differentiation from other concepts such as empathy or pity, the use of the word 'compassion' is prevalent in the literature surrounding health care. Terms such as compassion fatigue and compassion satisfaction are often used when describing the impact of care giving behaviour.

The importance of supporting staff is not just to promote good care for service users but also for the emotional wellbeing of staff. Compassion fatigue can result in staff members feeling helpless or angry in their work (Yoder, 2008) and has been linked to staff burnout (Stamm, 2002).

Compassion satisfaction has been referred to as pleasure in being able to do one's work effectively (Stamm, 2005). A significant negative correlation has been found between compassion satisfaction and burnout in healthcare workers working in hospice and palliative care however, there is no conceptual framework that looks at the dynamics between compassion satisfaction, fatigue and burnout (Slocum-Gori, Hemsworth, Chan, Carson & Kazanjian, 2011)

Why This Research is Warranted

Compassion is featured in health care strategy and may be seen as an outcome, or indicator of how well an organisation is working. This has been driven both by reports that there are relationships between compassion fatigue and burnout (Stamm, 2002), and that failure in healthcare are due to a number of factors which have included what is called a lack of compassionate care. However, Compassion, it's meaning and how it can be transferred in practice is not clear (Dewar, 2012). There is significant overlap with definitions of empathy and pity, therefore, one of the core elements of the definition of compassion is that it needs to be differentiation from other similar concepts. Much of the existing literature has been in the fields of general nursing or palliative care. There is a research gap in the field of intellectual disability services. If compassion in services is to be effectively supported it is important to have an understanding of what care staff believe it is and the setting conditions in which it can be maintained.

Aim of Research

This research aims to investigate what intellectual disability service care staff understand compassion and compassionate care to be. It is important that we understand what staff see compassion as so this can be most effectively supported and maintained.

Research Question

- What direct care staff in intellectual disability services understand compassion and compassionate care to be.

Method

Design

This is a qualitative study utilising a semi structured interview technique. As this is an initial exploration of compassion in intellectual disability services and in the absence of clear established models of compassion, an interpretive descriptive framework will be

used.

Practical issues / costs / logistics

There are limited costs associated with the study. Mileage to interview locations and postal costs accrued for sending out participant information sheets will also be covered by University. There are no other expected financial costs associated with this study.

Participants

Participants will be recruited from staff teams in the independent care sector providing supported living services for individuals with an intellectual disability. A minimum of 10 and a maximum of 15 participants will be recruited. A saturation based approach will be used. It is anticipated that there will be a range of ages from 18-65, with a mix of male and female participants.

Inclusion Criteria:

Participants must have contact with service users and be involved with their care.

Potential participants will be given an information sheet about the study (see appendix 1) prior to being asked to consent to participation. Appropriate consent will be sought (see appendix 2) and reassurances of safe storage provided on the consent form. A snowball method of sampling will be used through multiple independent service providers.

Procedure

Multiple independent supported living providers will be approached to gain permission to approach staff to inform them of the proposed research project.

Staff will be informed of, and invited to take part in the research by the distribution of the participant information sheets by either the field supervisor or the chief investigator (see appendix 1). The contact details of the chief investigator are on the participant information sheet. They will be asked to contact the chief investigator to express an interest

in taking part in the research. The chief investigator will then liaise with them to arrange a convenient time to gain consent and conduct the interviews.

Interviews will be audio recorded and last up to one hour. Interviews will take place at either the participant's workplace or Lancaster University. This is so participants can be offered the choice to be interviewed away from the workplace to further protect their anonymity. When working off site the researcher will follow the lone worker policy guidance (see appendix 4). Before the interview begins verbal and written consent (see appendix 2) will be checked and staff will be reminded of their right to withdraw consent, without giving a reason, up to two weeks after the interview has taken place. Staff will be also be reminded that although the information from the interviews will be anonymous, this is limited if they disclose poor practice that leads the chief investigator to believe that the participant or others are at risk. In this instance the chief investigator will inform the field supervisor immediately. If possible, the chief investigator will inform the   participant before they do this. If signs of distress are observed or communicated at any point during the interview, the interview will be halted and the participant will be given time to recover. After they have recovered they will be offered the option to stop the interview, or to continue if they wish. Sources of support are included on the participant information sheet. Staff will be asked not to give names of service users in the interviews. The interviews will adopt a semi structured style with a topic guide for questions and explorations (see appendix 3). The questions have been adopted from Bramley and Matiti (2014) to act as a prompt for the chief investigator.

All data stored will be anonymised at the stage of transcription. Sound files will be transcribed and uploaded to university drives via the virtual private network (VPN) M drive as   soon as possible following interviews, and then deleted from the Dictaphone. No identifying information will be used on the recordings and they will be anonymised before

storage.

Transcribed files will be kept in a password protected document on the university M drive while the project is on-going, and then saved onto an encrypted memory stick and stored by the Doctorate in Clinical Psychology Research Administrator until the end of the storage period.

Following transcription all digital recordings will be erased from the digital recorder. Any paper copies of transcripts (used for analysis) will be stored within the home of the chief investigator in a locked filing cabinet. Storage at the chief investigator's home address will only be for the duration of the analytical procedure and following this long-term storage will be at Lancaster University archives in the department of clinical psychology. This will be arranged by the administrative team at the department and will be in line with the data protection act 1998. Furthermore the analysis procedure will be undertaken at the home address of the chief investigator and at Lancaster University department of clinical psychology.

Data Analysis

The experience is being studied with a view to identifying what staff members understand and recognise compassion to be in an intellectual disability service. The data will be subject to thematic analysis (Braun & Clarke, 2006) to identify, analyse and report patterns and themes of interest.

Thematic analysis is regarded (Braun & Clarke, 2006) as an accessible and theoretically flexible research method for analysing and working with qualitative data. This is particularly useful when looking for common themes within research material as the potential range of things that can be explored is greater due to this flexibility.

Inductive analysis utilising an ideographic approach will be adopted, looking at the specifics of each transcript in turn and generating codes and then into subsequent

common themes (Guest, 2011).

Ethical Issues

It is possible that participants may communicate distress during interviews. If this occurs
then the procedure for halting the interview (outlined above) will be followed. As
participants may also be asked to talk about times when compassion has been missing, or
has been more difficult, there is the potential for poor practice to be disclosed. The external
supervisor will be available for emergency supervision should a situation arise during the
data collection period. When the external supervisor is not available, appropriate cover
will be provided. Circumstances may arise that necessitate confidentiality to be broken,
This would be when the chief investigator has a reasonable belief that the participant may
be at risk of causing harm to themselves or others or if a suggestion that abuse has been
taking place. If this occurs, the field supervisor will be informed immediately and further
advice sought.   At the end of each interview the researcher will debrief the participant and
provide them with an opportunity to reflect on the interview process and any associated
feelings.

Timescale

November 2014 - Ethics application. Information gathering for literature review.

December 2014 - Ethical approval

December 2014 - Introduction and method write up –

February – March 2014/5 - Data collection and analysis

November - December 2014 - Literature review

January 2015 – Literature review and results

March/April 2015 - Results and discussion April

2015 - Draft

July 2018 - Submission

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Participant Information Sheet

Understanding the Concept of Compassion within Intellectual Disability Services

My name is Ellie Hickman and I am conducting this research as a student in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
The purpose of this study is to investigate what members of staff who work in intellectual disability services understand and recognise compassion to be. Developing a shared understanding of what compassion is can help us to work together therapeutically with service users and will contribute to the development of ways in which compassion and compassionate care can be maintained and supported within services.

Why have I been approached?
You have been approached because the study requires information from members of staff who work in intellectual disability services.

Do I have to take part?
No. It's completely up to you to decide whether or not you take part. Even if you decide to take part and then later change your mind, you can withdraw from the study up to two weeks after the interview takes place and your information will not be used.

What will I be asked to do if I take part?
If you decide you would like to take part, you would be asked to contact the principal researcher, Ellie Hickman (details below). We can then arrange a suitable time to meet for an interview about your experiences. This can be done in your working hours if this is most convenient for you. Alternately, the interview could be done at your workplace or Lancaster University prior to or following working hours. If you would prefer a different option then please get in touch and we can discuss this. Please note that choosing to participate during working hours will require you to make any necessary arrangements for this with your manager; however your data will still be anonymous and confidential. The interview will last for approximately one hour and will be audio recorded and then it will be transcribed. In the interview I will ask you to talk about what you understand compassion to be, and times when you have witnessed compassion in the workplace.

Will my personal data be identifiable?
The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be stored securely as an encrypted file on a password-protected laptop. The principal investigator (Ellie Hickman) will transcribe the interviews from these recordings and these transcripts will be anonymous.
- Hard copies of the interview transcripts will be kept in a locked cabinet until the study has been completed and will then be destroyed.
- At the end of the study, electronic copies of transcripts and audio recordings will be kept securely by Lancaster University for 10 years, which is the standard data management policy.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

Is there anything else I should know?

- There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and follow the organisation's Safeguarding Policy. If possible, I will tell you if I have to do this.
- You are asked not to discuss other members of staff or service users by name or in a way that otherwise may identify them. I will remind you of this at the start of the interview if you choose to take part.

What will happen to the results?

The results will be summarised and reported in a dissertation as part of assessment for the Doctorate in Clinical Psychology programme and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress during participation you are encouraged to inform the researcher as we can postpone the interview or you can decide to withdraw from the study. The contact details of two support services can be found at the end of this information sheet if you wish further help or advice.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee and approved by the University Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

Please keep this information sheet for future reference. If you have any other questions about the study, please contact the principal investigator

Ellie Hickman
e.hickman@lancaster.ac.uk
(Department of Clinical Psychology)
Lancaster University
Lancaster
LA1 4YG
Tel: 01524 592754

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

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Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

British Institute of Learning Disabilities
www.bild.org.uk

Turn2Me (online support and counseling)
www.turn2me.org

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

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Consent Form

Understanding the Concept of Compassion within Intellectual Disability Services

We are asking if you would like to take part in a research project that aims to understand how people understand the concept of compassion within intellectual disability services. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Ellie Hickman.

Please initial box after each statement

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.

2. I confirm that I have had the opportunity to ask any questions and to have them answered.

3. I understand that my interview will be audio recorded and then made into an anonymized written transcript.

4. I understand that my participation is voluntary and that I am free to withdraw up to two weeks following the interview without giving any reason.

5. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.

6. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.

7. I consent to information and quotations from my interview being used in reports, conferences and training events.

8. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with her research supervisor.

9. I consent to Lancaster University keeping anonymous audio recordings and electronic transcriptions of the interview for 10 years after the study has finished.

☐

10. I consent to take part in the above study.

☐

Name of Participant_____**Signature**_____**Date** __

Name of Researcher_____**Signature**_____**Date**_____

- -

Initial Draft of Interview Schedule

- What does compassion mean to you?
- Can you describe a situation where you have witnessed compassionate care?
- What was happening at the time?
- What was said?
- What was the person doing?
- What else was happening at the time?
- Please will you tell me how it felt?
- Can you describe a time when you think compassion has been missing?
- What was happening at the time?
- What was said?
- What else was happening at the time?
- Please will you tell me how that felt?
- Are there times when it is easier to be compassionate?
- Are there times when it is harder to be compassionate?
- Do you think it is important to be compassionate?
- What would help to maintain or improve compassionate care?
- How do you think this could be achieved?
- Is compassion different in intellectual disability services than other healthcare services?
- Is there anything else that you would like to tell me about compassion or compassionate care?

These are non-fixed questions and may be subject to change. Follow up questions and inferential chaining will be used to explore participant's responses in further detail.

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Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research involving
direct contact with human participants

Instructions *[for additional advice on completing this form, hover PC mouse over 'guidance']*

1. Apply to the committee by submitting:

    a. The University's **Stage 1 Self Assessment (part A only)** and the **Project Questionnaire**. These are available on the Research Support Office website: LU Ethics

    b. The completed application **FHMREC form**

    c. Your full research proposal (background, literature review, methodology/methods, ethical considerations)

    d. All accompanying research materials such as, but not limited to,

        1) Advertising materials (posters, e-mails)
        2) Letters/emails of invitation to participate
        3) Participant information sheets
        4) Consent forms
        5) Questionnaires, surveys, demographic sheets
        6) Interview schedules, interview question guides, focus group scripts
        7) Debriefing sheets, resource lists

    Please note that you DO NOT need to submit pre-existing handbooks or measures, which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submit all the materials electronically as a **SINGLE email attachment in PDF format** by the deadline date.

3. Submit one collated and signed paper copy of the full application materials in time for the FHMREC meeting. If the applicant is a student, the paper copy of the application form must be signed by the Academic Supervisor.

4. Committee meeting dates and application submission dates are listed on the FHMREC website. Applications must be submitted by the deadline date, to:

5. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application.

6. Attend the committee meeting on the day that the application is considered, if required to do so.

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1. Title of Project: Understanding Compassion in an Intellectual Disability Service

2. Name of applicant/researcher: Ellie Hickman

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3. Type of study

☒ Includes direct involvement by human subjects.

October 2014

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. Please complete the University Stage 1 Self Assessment part B. This is available on the Research Support Office website: LU Ethics. Submit this, along with all project documentation, to Diane Hopkins.

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4. If this is a student project, please indicate what type of project by marking the relevant box: (please note that UG and taught PG projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐   Masters dissertation ☐   DClinPsy SRP ☐   PhD Thesis ☐   PhD Pall. Care ☐

PhD Pub. Health ☐   PhD Org. Health & Well Being ☐   PhD Mental Health ☐   MD ☐

DClinPsy Thesis ☒

Applicant Information

5. Appointment/position held by applicant and Division within FHM   Trainee Clinical Psychologist, Doctorate in Clinical Psychology (DClinPsy)

6. Contact information for applicant:
E-mail: e.hickman@lancs.ac.uk   Telephone: 01524 592754 (please give a number on which you can be contacted at short notice)
Address: Programme Office, C16 Furness College, Lancaster University, LA1 4YG

█ Project supervisor(s), if different from applicant: █████████

8. Appointment held by supervisor(s) and institution(s) where based (if applicable): Research Tutor

9. Names and appointments of all members of the research team (including degree where applicable)

██

The Project
NOTE: In addition to completing this form you must submit a detailed research protocol and all supporting materials.

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10. Summary of research protocol in lay terms (indicative maximum length 150 words):

With the recent serious case reviews at services such as Winterbourne View (Department of Health, 2012a) and North Stafford Hospital and the publication of the Francis report (Department of Health, 2012b) there has been an increasing emphasis on the promotion of compassion within services in order to prevent such events happening in the future.

However, there is a huge variance in what compassion is understand to be and this can vary across services, culture and religious background.

There is a lack of research in the area of compassion and intellectual disabilities. If compassion is to be imbedded and supported within services it is important that we explore what staff understand by what it means to be compassionate in an intellectual disability service.

11. Anticipated project dates (month and year only)

Start date: February 2015   End date June 2015

12. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

A minimum of 10 and a maximum of 15 participants will be recruited. A saturation based approach will be used. It is anticipated that there will be a range of ages from 18-65, with a mix of male and female participants. Participants will be recruited from staff teams in the independent care sector providing supported living services for individuals with an intellectual disability.

13. How will participants be recruited and from where? Be as specific as possible.

Multiple independent supported living providers for people with intellectual disabilities will be approached. These will be based in the ████████████. Staff who are involved in the direct day to day care of people with intellectual disabilities will be provided with the participant information sheet regarding the proposed study by either the field supervisor or the chief investigator. They will be asked to contact the chief investigator if they are interested in taking part in the study in order to arrange a mutually convenient time to obtain consent and conduct the interview.

14. What procedure is proposed for obtaining consent?

Participants will initially self-select on the basis of interest in taking part, having been provided with information about the study aims and procedure. At this stage they will be given any further information, have the opportunity to ask any questions and sign a consent form that details the information and procedure already provided and indicates acceptance of these. Participants will be made aware that they can withdraw consent at any stage prior to the study being submitted for assessment to the Lancaster University Doctorate in Clinical Psychology programme. Participants will be informed that may be able to withdraw consent for their information to be used for a period of two weeks following the interview. After this point it will not be possible for the data to be withdrawn. This is detailed in the consent form that participants will be asked to sign.

15. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks.

It is not expected that the discussion topic will cause inconvenience or danger to participants. Participants will be encouraged to notify the chief investigator if they experience any discomfort. Participants will be provided with the details of two support services.
If signs of distress are observed or communicated at any point during the interview, the interview will be halted and the participant will be given time to recover. After they have recovered they will be offered the option to stop the interview, or to continue if they wish. The contact details of two support services are provided on the participant information sheet should they wish to access them. These are the British Institute of Learning Disabilities and Turn2Me (online support and counseling).

16. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

It is possible that the researcher may hear examples of poor practice. If this is the case, the external supervisor will be available for emergency supervision should a situation arise during the data collection period. When the external supervisor is not available, appropriate cover will be provided. Interviews will be offered at either the participant's workplace or at Lancaster University. This is to allow the participant to choose to be interviewed away from their workplace and further protect anonymity. When the chief investigator is working away from the university base, the university's Lone Worker Guidance (field work) will be followed (see appendix 4)

17. **Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.**

There are no direct benefits to participants from taking part in the study, although involvement may be interesting and the results may have wider benefits for the employing service.

18. **Details of any incentives/payments (including out-of-pocket expenses) made to participants:**

Travel expenses may be reimbursed in the event of data collection taking place outside of participants' normal working hours and thus requiring additional travel.

19. **Briefly describe your data collection and analysis methods, and the rationale for their use. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.**

Individual, semi structured interviews will be conducted with participants. Data will be collected using a Dictaphone, and then transcribed. All data stored will be anonymised at the stage of transcription, all identifying information will be removed and the participants will be assigned pseudonyms. Transcription will be carried out by the chief investigator. Transcriptions will be analysed using thematic analysis. The rationale for this method is that it allows for the identification, analysis and the reporting of patterns within data but is not theoretically bounded.

A proportion of the audio transcriptions will be listened to by the university project supervisor in addition to the chief investigator and compared to a transcription in order to confirm the accuracy of the transcription. Additionally, the university project supervisor will have some input in terms of the coding of data. A peer supervision group within the cohort will also provide an opportunity to have additional input on the coding and analysing of already anonymised data.

There are limits to confidentiality and these will be explained to the participant and are outlined in the participant information sheet. Confidentiality may be broken If the chief investigator feels that the participant has indicated that they may cause harm to themselves or others such as suggesting abuse has taken place. This will then be discussed with the field supervisor.

20. **If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.**

A member of ███████████████████████████ provided feedback at the initial project proposal presentation.

21. **What plan is in place for the storage of data (electronic, digital, paper, etc.)? Please ensure that your plans comply with the Data Protection Act 1998.**

Any paper copies of transcripts (used for analysis) will be stored within the home of the chief investigator in a locked filing cabinet. Storage at the chief investigator's home address will only be for the duration of the analytical procedure and following this long-term storage will be at Lancaster University archives for the clinical psychology programme for a period of ten years. This will be arranged by the administrative team at the department and will be in line with the data protection act 1998. Furthermore the analysis procedure will be undertaken at the home address of the chief investigator and at Lancaster University department of clinical psychology. Transcribed text files will be kept in a password protected document on the university drives while the project is on-going, and then saved onto an encrypted memory stick and stored by the Doctorate in Clinical Psychology Research Administrator until the end of the storage period of 10 years.

22. Will audio or video recording take place?   no   audio   video
If yes, what arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Interviews will be transcribed, encrypted and uploaded to university drives via virtual private network (VPN) as soon as possible following interviews. Following transcription all digital recordings will be erased from the digital recorder. No identifying information will be used on the recordings and they will be anonymised before storage

23. **What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.**

The findings will be initially presented by the chief investigator as part of the assessment process for the Lancaster University's Doctorate in Clinical Psychology programme. Publication in a peer-reviewed journal will be pursued,

a s will further presentation at any relevant conferences.

24. What particular ethical considerations, not previously noted on this application, d
the proposed study? Are there any matters about which you wish to seek guidance fr

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It is possible that participants may communicate distress during interviews. If this occurs then the procedure for halting the interview (outlined above) will be followed. As participants may also be asked to talk about times when compassion has been missing, or has been more difficult, there is the potential for poor practice to be disclosed.

If this occurs then the field supervisor will be informed immediately, where possible the participant will be made aware that this will happen. Following this the safeguarding policy of the organisation that the participant is employed by will have to be followed. be clear about the limits of confidentiality at the outset

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Signatures: Applicant: ████████████████████

                               Date: ████████████████████

                               *Project Supervisor (if applicable): ████████████

                               Date: ████████████████████

*I have reviewed this application, and discussed it with the applicant. I confirm that the project methodology is appropriate. I am happy for this application to proceed to ethical review.

Research and Enterprise
Services Division

Lancaster
University

Applicant: Ellie Hickman
Supervisor: ███████████
Department: DHR

02 March 2015

Dear Ellie ███████

Re: Understanding Compassion in an Intellectual Disability Service

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, ████████████████████ ████████████ if you have any queries or require further information.

Yours sincerely,

Secretary, University Research Ethics Committee

Cc ██████████ University Secretary, ████████████████ (Chair, FHMREC); ██████████ ████████ Chair, UREC).

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