Clinical psychologists' response to bereavement in adults with intellectual disability

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Abstract: This study aimed to explore the current clinical psychology approach in supporting bereaved adults with intellectual disability (ID). As the literature in this area is limited, report of real clinical practice may enhance our understanding of the usual role of clinical psychologists, and any factors which may shape this. Semi-structured interviews were carried out with six clinical psychologists and the resulting data analysed thematically. Findings identified the approach of participants when supporting bereaved adults with ID, as well as some factors affecting this, such as the impact of grief across support systems and the complexity of best practice in the absence of clear guidance. This absence of an evidence base to guide the clinical response in supporting bereaved adults with ID was identified as a source of professional concern for participants. Further guidance and resources, derived from high-quality research, are urgently required in order to address this issue.

Keywords: intellectual disability, bereavement, intervention, clinical psychology

Introduction

The topic of grief in relation to people with intellectual disability (ID) is one which has evolved considerably in recent decades. Grief (here understood as the psychological reaction to the loss of a significant other, often but not exclusively through death; Stroebe, Hansson, Stroebe, & Schüt, 2001) was once frequently viewed as largely irrelevant where cognitive difficulties were present, as some believed such difficulties prohibited the experience of deep emotions (Kloeppel & Hollins, 1989). Currently, while grief is acknowledged as perhaps at times socially 'disenfranchised' (Doka, 1989) in persons with ID, it is recognised that even where profound levels of cognitive impairment are present, a grief response may be experienced (Meeusen-van de Kerkhof et al., 2006).

Grief is psychologically understood according to varied theoretical models: for example, Worden's 'tasks' of mourning (2009) include accepting the reality of the loss and adjusting to a world without the deceased, while

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Stroebe and Schüt's dual-process model (1999) posits that grieving persons will oscillate between tasks focused on their loss and tasks focused on restoration of life in the absence of the person who has died. However, grief is usually only conceived of as a clinical issue where it falls outside of the perceived typical range, such as in complicated grief; this has been defined as including symptoms of separation distress (such as yearning for the deceased person and intense loneliness) as well as symptoms of traumatic grief (for example intrusive thoughts and numbness (Tolstikova, Fleming, & Chartier, 2005)). Complicated grief has been identified in some persons with ID (Dodd et al., 2008), and indeed Brickell and Munir (2008) deemed that this population may be more vulnerable to complicated grief, as a result of cognitive difficulties and life circumstances.

Unfortunately, where a grief process does warrant psychological input, there is no apparent consensus within the literature regarding how this should be carried out with people with ID, with documented therapeutic techniques ranging from creative modalities such as music therapy (eg Bright, 1999) to attachment-based psychotherapy utilising cognitive-behavioural techniques (eg Wetherell, 2012). However, one study has found that clinicians may work directly, or indirectly through frontline staff, to provide education, support participation in grief rituals, facilitate the grief response, and provide therapeutic intervention where required (Irwin, O' Malley, Neelofur, & Guerin, 2017). Unfortunately, the efficacy of any such supports cannot be determined by the existing literature; for example, studies have frequently failed to employ formal outcome measures when evaluating therapeutic interventions, while no identified studies have utilised a no-treatment group so as to control for natural changes in grief symptoms known to typically occur over time (Currier, Berman, & Neimeyer, 2008). Therefore, clinical psychology as a field lacks an evidence base on which to build its role in supporting grief in persons with ID.

An additional matter of relevance to psychology's role, which has been highlighted in the literature, is that of the broader systemic and professional context, such as resource limitations and the involvement of professional and non-professional support persons. For example, Gilrane-McGarry and Taggart (2007) noted a case wherein the use of an external counselling service resulted in a lack of continuity, with frontline staff uncertain how to integrate the therapeutic work within the ID service. Therefore, in determining the role of clinical psychology in supporting grief for persons with ID, potential factors which may affect that role, for example in the settings and systems within which it will be enacted, must also be considered.

The aim of this paper is to determine how clinical psychologists currently support bereaved adults with ID; in the absence of an evidence base upon which to develop practice, this may comprise a type of practice-based evidence, although not empirically-derived. This paper will therefore aim to identify what clinical psychologists currently do to support grief in persons with ID, while accounting also for factors in the professional setting which may impact or shape this role.

Method

Design

This study uses a phenomenological approach; Creswell (2007) states that this involves the exploration of the meaning, for several people, of their '*lived experiences* of a concept or a phenomenon' (original emphasis, p. 57). Creswell recommends both the experience of the phenomenon and the contexts or situations affecting the experience are addressed, therefore this approach was considered well-suited to the aims of this research.

Participants and sampling

The inclusion criteria for participation were that the person be qualified and employed as a clinical psychologist within an ID service in the Republic of Ireland, and that they have experience of working with bereaved adults with ID. No exclusion criteria were stipulated. Participants were recruited through indirect and snowball sampling through email distribution by professionals not involved with the study.

There were six participants; four were female. Three had qualified as clinical psychologists within the previous 10 years, one within 20 years, and two within the previous 30. Four had completed their clinical training in the Republic of Ireland and two in Asia. All were currently employed as a basic grade, senior or principal clinical psychologist, within a public or private ID service, and there was considerable geographical spread. Employment in the current service was reported to be from six months to more than 25 years.

Measures

An information and consent sheet was compiled along with a recruitment email. A semi-structured interview schedule was developed, which focused on participants' opinions of the clinical needs of adults with ID after bereavement, how they as psychologists respond to these, and factors affecting this response, such as within their setting and service.

Procedure

This study was granted exemption from full ethical review through the University College Dublin's Human Research Ethics Committee. On receipt of signed consent, interviews took place by telephone in five cases and face-to-face in one. These lasted on average 60 minutes and were audio-recorded and later transcribed for analysis. Any potentially identifying details were omitted during transcription.

Data analysis

Thematic analysis (Braun & Clarke, 2013) was deemed the most appropriate approach to analysing the data; this is not exclusive to a particular framework or theoretical underpinning, and has previously been applied to phenomenological studies, wherein it has been reported to be useful in conserving the social reality of participants without enforcing the researcher's own constructs (Joffe, 2012).

At key stages of the analysis, the co-authors provided additional perspectives and facilitated credibility checks. The initial task was the development of a coding framework using thematic analysis; in applying this framework to all data, inter-rater reliability was calculated using approximately 15-20% of the data set, which had been randomly selected. Consensus was found to exceed the minimum acceptable level of 70% (as per Guerin & Hennessy, 2002).

Finally, a secondary analysis involved the identification of overarching themes within the findings; the final thematic framework was reviewed and concepts which appeared to recur across the topics and/or themes were identified. Deeper interpretation at this stage of the analysis allowed for some inferences to be drawn at a more detailed level than in the thematic analysis.

Results

The reported role of clinical psychologists in responding to grief among people with ID was captured during primary analysis; the overarching themes, then, comprise the secondary, more in-depth analysis.

Primary analysis: the role of clinical psychologists in supporting bereaved adults with ID

Seven themes were identified which related to the specific tasks of the clinical psychologist in supporting bereaved adults with ID (see Table 1).

The first theme alluded to the role of the clinical psychologist in guiding others to prepare and inform the person with ID about a death or an impending death; an emphasis was placed on providing information in a manner which the individual can comprehend. '*All the information is needed like, so-and-so's going to have to go to hospital … the doctors think that next step will be this*'. (CP1). This links to the task identified by all participants as part of their role, that of ensuring understanding of the death for the person with ID. As seen in the second quote in Table 1, provision of concrete and specific information about the concept of death was deemed

Table 1. The role of clinical psychologists in supporting adults with ID when bereaved: list of themes and sample quotations

Theme	Sample quote
1 Guiding others to prepare & inform	*'The question was whether we should inform [her] about dad's illness … my view was … we should but in a … communicable language.'* Clinical psychologist (CP) 5
2 Ensuring understanding	*'Understanding … how the person died, that it wasn't their fault … I'd be very specific, we don't know where they're gone, some people say it's heaven but they never come back.'* CP6
3 Individual therapeutic sessions	*'I … do some psychotherapy with some adults with intellectual disability … obviously I'm not liaising with their keyworkers 'cos … their therapy is private … I'm kind of following their lead and just helping them process it verbally.'* CP3
4 Remembering & continuing bonds work	*'Part of it was … a memory box, which they would decorate and fill with whatever they wanted that would remind them of … their parent.'* CP1
5 Guidance & psycho-education to staff	*'I wouldn't do as much of the hands-on work like let's say doing a memory book with the person … but I'd give the keyworker the skills to do that. Kind of training.'* CP3
6 'A consistent answer and consistent explanations'	*'The role would be kind of, co-ordinating to make sure that family … keyworker in the day service, or keyworker in their residential house … that everyone is … using the same approach.'* CP3
7 Normalising & reassuring	*'To know how … grieving can present itself … things like oh, they mightn't seem to have registered at all and then, in like six to eight months' time they can suddenly start acting quite differently and … don't panic or start thinking they're having a breakdown or it's … dementia, like, okay it could be but it also can be … delayed grief or it sinking in. So psychology for me it would be around spreading that information.'* CP3

important; for people with limited verbal communication, picture books, social stories and cultural rituals such as lighting candles next to a photograph of the deceased are aids to giving information.

All participants offered individual therapeutic sessions occasionally, although this was typically only with persons with strong verbal communication skills. Two participants incorporated a cognitive-behavioural approach, with mindfulness also noted by one; the focus of sessions was on supporting the processing of grief, providing a space to talk, and building up a tolerance for difficult feelings. A theme identified the frequent use of continuing bonds work (Klass, Silverman, & Nickman, 1996) also, including looking at photographs, considering the ongoing relationship with the deceased person, and monthly bereavement groups which act as long-term settings in which to remember the deceased.

A key role for most participants was providing guidance and psycho-education to frontline staff. A factor contributing to this common way of working was the need for more frequent supports than psychology sessions could provide, with frontline staff being equipped by psychologists to '*support the person … in their natural environment … work and residential*' (CP4). As well as advising on how to respond to the grief of the service user, the provision of information to staff about the process of grieving and how it may manifest was a key area of psychological input.

The sixth theme captured the report by most participants that ensuring consistent explanations are provided is imperative. The need for all those involved to employ the same language and provide the same information to the person with ID was deemed important for the person's understanding, with the quote in Table 1 identifying the co-ordination of this as part of the role of the clinical psychologist.

The final theme pertained to the role of psychologists in 'normalising and reassuring'; as seen in the quote in Table 1 this included positioning grief responses within a framework of what is typical, as well as reassuring both the person with ID and those around them of the normality of many symptoms or feelings which may appear unusual or be unexpected, such as guilt and anger.

This level of analysis identified the tasks completed by clinical psychologists in supporting bereaved adults with ID, and provides a context in which the overarching themes can be considered. These overarching themes, which comprise a deeper analysis of the entire thematic framework, will now be described.

Secondary analysis: identification of four overarching themes

1: The importance of context in understanding the grief response

The first overarching theme highlights that a grief response in people with ID must be understood contextually, within the settings and systems in which it occurs. It was expressed that there is a common human need at a time of bereavement for everyone, regardless of cognitive ability; however, the expression of this may be somewhat different where an ID is present: '*I don't think they're different, I think they've got the same range of emotions … the same ability to experience loss, but how they show you that … is slightly different*' (CP6). The potential for behavioural changes not to be recognised as potentially representative of grief was noted:

> *'Relatively quickly people were … going, "oh she's still crying all the time, why is that happening?" Or … "she keeps wanting to … not do … her training course … " and "she's tearful", and "she's clingy" and … "she's difficult" and "she's non-compliant" and there's all these kind of horrible words being used.'* (CP1)

Changes in behaviour then, rather than recognised grief, often lead to referral for psychology: '*People would be referred to me for "challenging behaviour" … then you'd find out in the last year maybe a mum or a dad died"*' (CP6). This frequent misinterpretation of grief as challenging behaviour was noted by two participants as inappropriate, while another regularly delivered staff training on grief within a challenging behaviour training programme.

Therefore the grief response in persons with ID may at times be expressed and/or perceived differently from that of non-disabled persons, despite a shared emotional experience. This was attributed to aspects of the ID such as difficulties with comprehension and communication, which may affect the management of strong emotional states; one participant quoted a client stating '*people are telling me my mum is dead and I hate it and I attack them*' (CP6). However, this difference was also partially ascribed to the various systems around the person with ID; for example, a 'normal' grief response in persons with ID may be poorly-tolerated by others, with the '*need for the person not to be too sad*' (CP6) potentially leading to withholding of information by families, even over several years: '*protecting people and … not upsetting them … that "they wouldn't know about that and it's better that they don't know" and … "we'll allow them to have all the happy things, but we won't allow them experience the other side of it"*' (CP6). This protectiveness, while well-intentioned, is unhelpful for people with ID both personally and culturally, perpetuating a misunderstanding that '*people with ID … are different from us*' (CP4). Unsurprisingly then, lack of choice and agency for persons with ID was also identified:

> *'When you're in the general population you can choose. You can choose if you want an intervention … you have the right … not to deal with*

> *it…to be…flailing in it, if that's how it is for you. If you've a disability, everybody has an opinion on what you should and shouldn't do'.* (CP1)

Another theme noted that the relationship between staff and service users, which can be an uncommon mix of an emotionally close and yet a professional relationship, may at times lead to role confusion: '*I suppose at times of bereavement or loss or when somebody's really distressed it's really hard not to lean into that…and then you're going to have to pull back and then that's another loss*' (CP1). Concurrently, the person with ID's needs may conflict with the family's; for example, a person with ID may require increased supports, such as frequent repetition of information about the death to facilitate their understanding, which may be highly distressing for grieving family members to provide. In some such instances this can also lead to families not disclosing the death: '*She said "No…I'm not going to tell her, I'm not able, I'm still grieving"*' (CP6). At other times, the family's needs were deferred while the person with ID grieved, with a referral at times made to psychology in the hope of hastening the grief process:'"*They* [the person with ID] *need to be okay, cos then* I *can grieve*"' (CP1). Simultaneous and shared grieving is therefore not always possible within these families, due to difficulties balancing the role of caregiver with active grieving. This struggle may be particularly pertinent due to a frequent absence of other non-professional sources of support, as it was identified that ID services' unique 'cradle-to-grave' input can impinge on the development of natural support networks.

Culturally, then, there may also be an impact on the grief process of people with ID: a theme noted the importance for clinicians and others to be cognisant of '*some aspects of their* [people with ID] *experience that are very relevant…to…how they go through the world and…how others relate to them*' (CP3). The cultural experience of being a person with a disability was noted as likely to contribute to a '*feeling of loss of…not being seen, not being heard, not being understood*' (CP6).

One participant referenced many of the themes identified here as collectively contributing to an exacerbated bereavement experience: '*The lack of information, the dependence on others, the exclusion from rituals, the overprotectiveness, the lack of personal supports, and isolation from the family just adds to the whole trauma of bereavement*' (CP6). It is clear that grief in people with ID, then, must be considered not in isolation or in terms only of the individual, but within this framework of family, staff, services, and wider societal and cultural factors this population may be exposed to, and must therefore not be pathologised unduly. Indeed participants advocated for people with ID to be allowed to exhibit signs of grief without clinical intervention, as those in the general population typically are: '*If it's just…sadness cos somebody's died, don't lose sight of that that's appropriate*' (CP1).

2: The impact of grief across systems

This theme relates to both the ripple effect of grief across the involved support systems, as well as to inter-systemic relations. Participants described the need to '*keep the spotlight on the person*' (CP6), reporting that the involvement of multiple systems in the provision of bereavement supports can result in the overshadowing of the perspective of the person with ID. It was deemed important for interventions to be person-focused and, where possible, informed or chosen by the person themselves:'*I will always start with the person whether it's a severe ID, profound, whatever, I start the intervention with them, see…what they might need*' (CP6). A theme noted that, at times, the person with ID's needs may conflict with the family's, with a potential role for psychologists in managing this difficulty so as to promote the needs of the individual: '*Even though the* [family member] *is grieving, I'm still asking them to support the person with ID…I might feel horrible about that, but that's my role*' (CP6).

The impact of systemic relations on the psychology role comprised a theme; as clinical psychologists often work indirectly through both frontline staff and family, and as frontline staff members comprise the most common link between the family and the multidisciplinary team, it is perhaps unsurprising that psychology work is impacted by the quality of relationships between these systems. For example, the relationship between clinicians and the frontline team could at times comprise a source of stress, such as where expectations are unclear: '*It can flip from "why aren't you* [the psychologist] *fixing them?" to "but sure they don't even need it"*' (CP1).

The individual systems also require their own supports: a theme identified that frontline staff need reflective supervision in supporting bereaved people with ID, so as to be able to '*reflect on your practice…to ground…to have some kind of mindfulness*' (CP6). Similarly, a theme emerged indicating that clinical psychologists need supports, with one person relating this to '*the toll on you working through relationships*' (CP6). Most participants felt generally well-supported in their current service, citing supervision and peer support as particular areas of benefit. The provision of such supports was attributed to psychologists' own initiative in seeking them, as well as to clinical governance: '*I'm supervision-ed out of it! So that I don't do any kind of harm to other people…and…to prevent burnout…there's a certain expectation…that you* [the psychologist] *will manage that*' (CP6). At the organisation level, however, such support was not seen to be sufficiently valued for some participants: '*We kind of* *have a somewhat peer supervision structure but it would be nice if that was…seen as important and valued'* (CP1).

Supports for family and frontline staff, then, were deemed to be best provided externally to the ID service, with participants reporting that it was not the role nor within the resources of the psychology team to offer direct support to these groups. Instead, these parties were advised to seek emotional support through their GP or employee assistance schemes, while reflective supervision for frontline staff was noted to be better sought within the professional body rather than the organisation. The impression here was therefore of multiple systems working together to support the individual with ID, each with their own associated emotional or professional needs, but with no clear structure in place to support these needs.

3: 'ID is a little footnote in things'

The above quote (CP1) was felt to summarise an issue relating to a general lack of higher-level clinical focus on the topic of bereavement in ID. Most participants had not received input during their professional training on this topic, nor did they feel any support in their work from measures such as national directives or policies; indeed, one participant expressed that these have often been unhelpful and personally '*soul-destroying*' (CP6) in their tendency to focus on 'challenging behaviour' and restraint procedures.

This clinical marginalisation of the topic, and perhaps of the ID population in general, was further identified in a theme around the lack of tools and literature, with agreement among participants that this can be problematic in clinical work: '*I've used some scales and some people look at it and go "that's not the best way of communicating that concept" - but that's the only validated thing I have…things are adapted but they're never validated*' (CP1). A lack of guiding literature, particularly of large-scale research, was also noted. One clinician expressed a sense that the field was '*stuck…we are not growing*' (CP5).

Furthering this sidelining of clinical ID services, the poor ability of mainstream services to address the needs of persons with ID was captured in a theme. Participants disagreed as to the appropriateness of adults with ID accessing mainstream psychology services for bereavement supports, although none were of the opinion that this is currently a viable option. Only persons with milder levels of ID and good verbal communication skills were felt to be potentially suited to mainstream supports in their current format: '*There are very few services that are capable of dealing with people who are…significantly…cognitively compromised…they don't have the experience of…the time it takes and the sort of methodology that you might use*' (CP2). One participant pointed out that many common mainstream bereavement interventions, such as creative therapies, may not require significant adjustment for people with ID, while another felt that the absence of a theoretical understanding of what it is to have a disability would render any intervention unhelpful. One participant observed that clinicians in mainstream settings may experience a '*confidence issue*' (CP1) in relation to ID, which inhibits their inclusion of these people. The significant responsibility on clinicians in ID services as a result of the unavailability of mainstream specialist services (such as for dementia) to people with ID was noted: *'They're* [specialist services] *thinking "…the disability organisations will sort them out", but…you can't be expert on everything!'* (CP6). Another concerning outcome of this isolation of ID services was reported as an absence of clinical governance: *'There's nobody…saying "here's what you should be doing" there's nobody…checking you're doing a good job either'* (CP1).

This overarching theme may reflect a wider cultural treatment of people with ID, with broader social marginalisation of this population perhaps echoed in the lack of clinical attention. Allowing this topic to remain a 'footnote' clinically may perpetuate this issue culturally; however, it remains unclear whether the topic of bereavement in ID should best be given greater specialist clinical focus, or be incorporated into mainstream services.

4: The complexity of 'best practice'

The final overarching theme reflects psychologists' difficulties in determining best practice in supporting bereavement in people with ID. Professional discomfort and uncertainty was apparent among participants as a result of the lack of training or literature to guide their practice in this area. One theme identified the sense of being somewhat isolated in their work due to the lack of a consensus approach: '*it feels like you're in a vacuum*' (CP1). Several psychologists expressed curiosity regarding what others find useful, with the aim of informing their own clinical practice; indeed, there is a potential role for such collaboration in increasing clinician confidence in the absence of a sound evidence base: '*Is there some way of capturing…practice-based evidence…what's being done, are groups okay…when are they okay, for whom, for how long?…is it okay to not intervene yet?*' (CP1).

Perhaps unsurprisingly, participants expressed some concerns around the efficacy of their work: one noted that not having a specific therapeutic model to follow was *'very hard'* (CP2), while another expressed concern that their interventions may appear '*woolly*' (CP1) due to the lack of supporting literature. It was identified that, in response to this absence of an evidence-based therapeutic model for people with ID, clinicians tend to rely instead on modifying evidence-based general population approaches. Although much trial and error may be required in adapting an approach to meet the needs of the person with ID, such modification was yet felt to be the most acceptable option available to psychologists, with one participant noting: '*I feel happier doing that, because all I'm doing is concretising it*' (CP6).

An additional area of clinical uncertainty was around the topic of clinical specialism, or whether mainstream supports could be a suitable option for people with ID. Three participants stated that clinical expertise and experience working in ID is important for supporting those with moderate, severe, or profound levels of ID:

> *'You'd need to have … the practical … method of delivering but I think … the key thing that … maybe clinicians who don't work in the ID area wouldn't have would be … the overarching broader … framework or theories around intellectual disability'.* (CP3)

Another participant expressed a need to avoid ongoing segregation under '*the guise of specialism*' (CP6), noting that while there is some specialism warranted, psychologists should provide this from mainstream settings, thus '*supporting people with ID to be belonged* [sic]' (CP6) by promoting community involvement and intervention. One participant recommended collaboration between ID and mainstream services to share expertise and resources so as to provide a unified service: '*to kind of go … what are your resources and what are our resources … can we meet in the middle and open this up to everybody?*' (CP1).

The pathway of referral to psychology was also a source of difference in practice, although the most common referral pathway was via staff within the organisation. While one participant referenced the importance of open access to psychology and even self-referral, another reported accepting referrals from GPs only, noting the need to first rule out physical issues which may present as emotional (such as undiagnosed thyroid problems mistaken for anxiety), so as to avoid misdiagnosis and misuse of clinical time. Another participant noted that GP referral would appropriately parallel typical psychology referral pathways for the general population.

Ensuring best practice was also complicated by the service settings, with limitations in resources (for example in funding for psychology posts) restrictive of what psychologists could offer clinically, and at times leading to outsourcing staff training and family supports, as well as delegating tasks not specifically requiring psychological skills. These limitations, although perhaps not specific to the field of ID, were problematic for best clinical practice, with increased resources likely to allow psychologists to provide a '*more structured and more timely approach*' (CP4) to bereaved service users.

Discussion

The aim of this study was to explore the role of clinical psychologists in supporting bereaved adults with ID. The findings included a description of the role as reported by participants, as well as a deeper analysis of the thematic framework which identified some factors affecting this role.

The findings of this study suggest that the role of clinical psychologists in supporting grief in adults with ID is highly varied, and approximately parallels the findings of a previous study (Irwin et al., 2017). Individual therapeutic input is relatively infrequent, with those already closely engaged with the person with ID viewed as more appropriate sources of emotional support. The role of clinical psychology appeared instead to predominantly involve the co-ordination of supports, as well as consultation and collaboration with loved ones and frontline staff. Clinical formulation involves the integration of theoretical knowledge with specific information about the person so as to make sense of the unique presentation of the individual (BPS, 2011); although certainly not unique to clinical psychology, this may be viewed as a core skill of the profession (BPS, 2011). It is such formulation which appears to be a key contribution of clinical psychologists when an adult with ID is bereaved: although family and staff members closest to the person with ID typically provide the direct support, this is often guided by a shared and psychologically-informed understanding of the person's presentation and needs.

This study also aimed to capture factors which participants may experience as impacting on their role. A key feature in ID services is the involvement of multiple systems, including family members and frontline staff teams. In supporting staff and families to facilitate the grief of the person with ID, challenges were noted to arise; for example, family members may struggle to provide care and support at times when they are also grieving, while frontline staff may be tasked with finding a suitable manner in which to offer emotional support to the person with ID while also maintaining appropriate professional boundaries. The subsequent need for all parties to have their own emotional and/or professional supports available in these situations was highlighted; however, this was identified as a matter which ID services do not currently address. However, poor outcomes where supports are implemented by persons who are themselves stressed have been reported elsewhere (Dowling, Hubert, White, & Hollins, 2006); as such, it seems vital to attend to the needs and wellbeing of these key support persons, in order to optimise the outcome for the individual with ID. Clinical supervision, multidisciplinary Schwartz rounds (The Schwartz Center for Compassionate Healthcare, undated) and family peer support groups are just some of the forums in which staff and family members may be supported in their respective roles by the organisation, with varying levels of required input.

Finally, there was a prevalent sense among participants of inadequate professional attention being given to the field of ID. Limited training opportunities, scarcity of suitable measures and resources, the absence of an evidence base on which to ground their work, and the inaccessibility of mainstream specialist services to people with ID were some of the key difficulties clinical psychologists experienced. Such obstacles render it impossible to work according to the scientist-practitioner model, in which participants were probably trained; this may understandably then contribute to the clinical uncertainty expressed by them. Some participants expressed concerns about the validity of their work, while several reported curiosity regarding other psychologists' clinical practices. The accompanying lack of clinical governance in this field was noted as a worry by one participant, and the potential for poor clinical work to be carried out without detection is perhaps a concerning consequence of the lack of an evidence base against which to measure practice.

Methodological strengths and limitations

This study holds both strengths and limitations which must be acknowledged. A key limitation is the sample size, which is smaller than was hoped for; however, participants represented psychologists of differing levels of experience, employed in varying ID services and across a large geographical area. Therefore, the representativeness of the findings, although significantly limited by the number of participants, may be improved by this diversity in the sample.

The use of interviews may be considered subjective and biased due to their employment of individuals' opinions and exploration of their experience; however, the aim of this study was to understand and explore clinicians' perspectives and practices, while maintaining a focus on real practice within clinical settings, and so such subjectivity was intentionally sought and is not considered a weakness here. This study has identified not just the role of clinical psychology in supporting this specific population, but also several professional factors which may shape or constrain this role. An understanding of such factors may be critical to comprehending real clinical practice, and so the inclusion and identification of these is a key strength of the 'real-world' research approach utilised (Robson, 2011). However, caution is warranted in considering the relevance of the data to a wider population.

Finally, the data analysis procedures used here included validity checks and the involvement of a second person at key stages of the analysis, which allowed for the inclusion of an additional perspective and avoided undue bias by the primary researcher.

Future research

In terms of future research, this paper has noted some areas of need. A paucity of large-scale research around clinical input for bereavement in people with ID has been noted to impact on clinicians' practice and professional confidence; indeed this paper may depict the dissonant state experienced by clinical psychologists, who are typically trained according to a scientist-practitioner model, when their clinical practice is unfounded in evidence or involves the use of measures outside of the population they were validated with. The noted potential for poor clinical practice where the specifics of 'best practice' are impossible to identify highlights the urgency with which additional research in this area is required. Therefore, large-scale research studies looking at specific grief interventions are required to inform as to what factors are associated with positive outcomes for people with ID; such studies should include control or comparison groups, and employ specific and appropriate outcome measures (although indeed the lack of validated measures may comprise a difficulty here). Until such research is available, practice-based evidence by clinicians may be a helpful interim measure; consistent implementation of outcome measures pre- and post-intervention with clinical clients, and compilation of clinical reports which recount the interventions clearly, would entail invaluable information in the absence of any comprehensive literature on current practice.

Conclusion

This study has provided an insight into clinical psychologists' current response to bereavement in adults with ID; various clinical concerns and difficulties have been noted as they may affect this role, and suggestions made as to how these may be addressed. This study highlights a need for additional research of a high quality on this topic. ■

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