A Year in the Life of a Bereavement Counselling and Support Service for People with Learning Disabilities

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What is This?
A year in the life of a bereavement counselling and support service for people with learning disabilities

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Abstract  This paper addresses the specific needs of a minority group that historically have not had their grief needs acknowledged, addressed or accommodated: people with learning disabilities. Action research was initially used to introduce, and facilitate the development of, a bereavement counselling and support service designed specifically for people with learning disabilities and integrated into a well-established voluntary organization in North Staffordshire, England. The paper focuses upon a 12 month 'snap-shot' of this service which incorporated a qualitative perspective, where focus groups were used to capture constructive feedback from the bereavement counsellors involved in the project. In addition, descriptive statistical data of the service are presented to corroborate the perceived needs and challenges of the bereaved individual who has learning disabilities. Specific characteristics of a bereavement service that can constructively accommodate the bereavement care needs of such a client group are identified.

Keywords  bereavement counselling; grief; learning disability

Introduction

For many years people with a learning disability have had forgotten deaths, forgotten grief and have often become forgotten people when it comes to meaningful support over the death of a loved one. (Read, 1997, p. 5)

As a result of changes in care legislation from an international and national perspective (Department of Health, 1971), local care provision for people with learning disabilities has now drastically altered, with many large institutions closing in favour of small community-based home settings. As a result of such closures, many individuals are experiencing enormous changes in both their lives and lifestyles. Changes often involve losses, and
such losses are sometimes difficult to cope with: 'the bigger the loss the bigger the pain' (Martin and Weston, 1998, p. 1). With many people with learning disabilities now physically integrated into mainstream society, they too have access to the mainstream services that non-disabled individuals enjoy: these include GP and primary care services and bereavement counselling and support. Nevertheless, as Conboy-Hill (1992) has advocated, not many services (or indeed counsellors within these services) fully understand the bereavement counselling needs of this client group and access to such services is limited.

Despite all the advances made in changing attitudes towards people with learning difficulties, it appears that in the area of loss and bereavement they are still not receiving enough consideration, or the appropriate support that they require (Oswin, 1991, p. 26).

People with learning disabilities are often perceived as being ‘forgotten people’ with regard to loss and bereavement for a variety of social and practical reasons (Conboy-Hill, 1992; Kitching, 1987; Oswin, 1991). Yet it is known that such people do experience grief, do respond to the death of their loved ones, and often respond in a very profound way (Bonell Pascual et al., 1999; Conboy-Hill, 1992; Emerson, 1977; Hollins and Esterhuyzen, 1997).

In some parts of the United Kingdom, services are now awakening to the bereavement needs of this client group, are addressing the special considerations required and are proactively responding in a professional manner.

The fourfold aims of this paper are to:

1 introduce and describe an established bereavement counselling and support service for people with learning disabilities
2 evaluate the uptake of the service for a 12 month period (1 April 1997 to 31 March 1998)
3 explore the identified challenges inherent in offering such a service
4 identify the characteristics of a bereavement counselling and support service for people with learning disabilities.

Establishing a specialist bereavement counselling and support service
Mindful of the perceived needs and the rights of people with learning disabilities experiencing loss and change, a bereavement project was initiated in April 1995 specifically to address the neglected bereavement care needs of this client group. The project is called SHOULDER (Supportive Help Offering Understanding to people with Learning Disabilities Experiencing Recent
or long-standing bereavement) and was established as a triadic venture between three local statutory, voluntary and educational organizations (the Learning Disability Directorate, NHS Combined Health Care Trust; North Staffordshire Bereavement Care; and Keele University respectively).

The project is located within the voluntary organization, Bereavement Care, which has been established since 1984 and enjoys an excellent local and national reputation. Bereavement Care is a very dynamic organization, which has always shaped the service it provided to meet the needs of the local community of North Staffordshire. Hence the voluntary organization has developed a fairly broad range of specialist counselling services over the years, incorporating counselling and support for bereaved adults; counselling and support for those facing serious illness (the Dove Service); and counselling and support for children and young people. The SHOULDER project is the most recent development, and initially offered bereavement counselling and support to individuals with learning disabilities experiencing a general loss (such as transitional loss associated with relocation), and bereavement specifically; and also to those individuals facing serious illness either personally or amongst their family or friends. Offering support for general loss issues was a significant change in direction for the voluntary agency, which had previously only offered counselling for loss due to death or anticipatory death. The general loss counselling was offered in support of recognized local transitions from institution to community living and would cease 6 months after the local institution had finally closed. Prior to this closure the voluntary organization would offer consultancy only to individuals and/or their carers in recognition of the importance of this type of loss.

Bereavement Care is an organizational member of the British Association of Counselling, and works well within their ethical and supervision guidelines. Every counsellor has a personal supervisor whom they see on a fortnightly basis and the SHOULDER project offers a monthly support group that is open to any counsellor working with this client group. The ongoing supervision of the bereavement counsellors and the counselling work being undertaken is seen as crucial to sound, professional and healthy counselling practice.

Action research approaches were introduced in an effort to fill what presented as a 'gap' in this dynamic, voluntary counselling service.

**Action research approaches**

Action research approaches (Hart and Bond, 1995; Lewin, 1946) were initially employed to identify and respond to deficits in the voluntary organization in an effort to accommodate the special needs of people with learning disabilities.
Action research has been described as an approach to research rather than a specific methodology (Meyer and Batehup, 1997) and is 'concerned with doing research with and for people rather than on people' (1997, p. 175); it has been used effectively in industry, education and nursing (Cormack, 1991). Action research may attract nurse researchers because 'it offers the possibility of working with people in a way that is non-hierarchical and non-exploitative, that it may be used to make changes, and that it closes the theory–practice gap' (Webb, 1990). Action research:

- is educative
- deals with individuals as members of social groups
- is problem oriented, context specific and future oriented
- involves change intervention
- aims at improvement and involvement
- involves a cyclic process in which research, action and evaluation are interlinked
- is founded on a research relationship in which those involved are participants in the change process (Hart and Bond, 1995, pp. 37–8).

There was a perceived 'gap' in the bereavement counselling service, but the professionals involved did not know how, or in what ways, the service needed to be adapted in order to accommodate this client group. Consequently, action research was identified as being an appropriate approach in the establishment of this service and the identification of pertinent practical and philosophical issues as they arose. Within the action research cycle (Susman and Evered, 1978) various organizational and practical challenges were identified; options were addressed; action was taken; the change was evaluated; and the findings were disseminated to others within the voluntary organization. At times there were several small changes simultaneously being addressed at different stages of this cyclical process.

Such developments included the piloting of two-stage assessment formats to elicit the appropriateness of bereavement counselling; the development of pictorial leaflets about the service to promote communication and facilitate accessibility; the development and piloting of consent protocols and packages incorporating pictorial representations of concepts (such as counselling and research); the revisiting of existing referral protocols; and the conversion of written letters to words with common associated symbols (using the Widgit, 1996 software) and/or sign language (using the Makaton, 1999 software).

These initial developments were important elements of the project, and are presented to provide the paper with a contextual background on which the current service and its evaluation were based. Once established, the project has gone from strength to strength.
Care Innovation in Practice Award in 1996 and has gained national recognition for both its specialist focus and its integrated development.

Method
Statistical information was gathered over a 4 year period (1995-8) by using a generic evaluation form that was completed with all client groups throughout the bereavement counselling service and which was regularly reviewed. Fourteen bereavement counsellors were involved over the 4 year period, some seeing occasional clients with a learning disability, others seeing such clients on a regular basis. The counsellors (as befits many voluntary organizations) had a variety of skills and qualifications in counselling (minimum of Certificate level; some had MAs in counselling), with the majority having limited experience of working with people with learning disabilities.

In addition, focus groups (Barbour and Kitzinger, 1999; Morgan, 1997) were used to constructively engage with the counsellors involved and to explore issues from a counselling practice perspective. The focus group contributions were audiotaped, transcribed and analysed for key themes, which are presented for discussion. Although such focus groups were generated purely from a research perspective, the bereavement counsellors themselves enjoyed the opportunity to discuss and address issues in a constructive way, and also to receive written feedback (a copy of the transcript) of their interview.

Ethical issues were reviewed through the multi-disciplinary Bereavement Research Forum, established within the voluntary organization. Process consent (Beaver et al., 1999) was used throughout the counselling encounter, and practice protocols were established, evaluated and implemented to constructively support the consent process. Process consent involves the counsellor referring back to the client at regular intervals throughout the counselling process to ensure that the client still wishes (for example) to see a counsellor. Process consent is perceived as ongoing clarification of willingness to participate in the counselling process.

Results

Demographic and service data
Table 1 presents descriptive statistical information regarding the uptake of services (N = 145); the number of counselling sessions; the venue at which the bereavement counselling took place; and finally the nature of the referrals undertaken over a 4 year period.

The period evaluated in this study was 1 April 1997 to 31 May 1998, and
the uptake of services is shown in the 1997–8 column in Table 1. This period was selected because it contributed to an ongoing PhD research study.

Bereavement Care is a relatively large voluntary organization, and saw nearly 900 clients, incorporating over 3000 counselling sessions, during this period. The SHOULDER project is currently the smallest (and newest) client group.

For the 41 new referrals identified in Table 1:

- 27 percent had additional impairments (sensory/physical)
- 60 percent were aged 49 or below
- the average counselling session lasted for 50 minutes
- 90 percent of the sessions were community based (day centre, home, community home, workplace)
- of the seven facing serious illness, three related to personal illness (mixed cause, e.g. cancer, renal failure, degenerative disease) and four related to friends and relatives (two friends, two parents, all associated with cancer)
- the loss issues incorporated were either relationship or relocational losses
- 94.5 percent were third-party referrals (over 80 percent involving health and social services)
- 12 counsellors were actively involved in the project
- 61 percent of referrals were male.

### Qualitative analysis

Two focus groups (N = 5 and N = 6) were conducted which involved asking the bereavement counsellors five questions related to their bereavement
counselling work. The results are represented as Tables 2, 3 and 4. The trigger questions included what they liked and disliked about working with this client group (Table 2); what the similarities and differences were in comparison to other identified client groups (Table 3); and finally what they felt were the challenges involved in supporting people with learning disabilities from a bereavement counselling perspective (Table 4).

In Table 2, simplicity of approach relates to the creative and practical methods used (for example, drawing, memory books, life story work, reminiscence) in an effort to facilitate the counselling relationship and explore the grief world from the client's perspective.

Dealing with compliance and confidentiality will always be a challenge when working with vulnerable people in all manner of contexts, but especially so with this client group as they harbour a history of disempowerment.
It is important for the counsellor to establish that the client does indeed want to work with the bereavement counsellor, and is not doing so purely because they have been told to, or because the counsellor turns up regularly to see them. A two-stage assessment process was developed to enable the counsellor to establish whether bereavement counselling was appropriate at this time and if the client wanted someone to talk with about their bereavement. The bereavement counsellor was encouraged to work alongside the client, and at the beginning and end of every counselling session to spend time recapping on what has been done, and to check if the client wanted to see the counsellor again. Consequently 'process consent' (Beaver et al., 1999) was used throughout the bereavement counselling encounter: clients were actively encouraged to make simple decisions regarding the methods used, and more complex decisions such as when counselling should cease.

Although the bereavement counsellor may promote active engagement through the use of more concrete methods within the counselling process, dialogue accompanies any method used. Hence counsellors identified how tiring working with this client group might be as the counsellor talked through activities, encouraging the client to think and reflect upon personal situations and often-repeated words and phrases in an effort to ensure concrete understanding and to promote reciprocal communication. The parallel with older people from an ending of counselling perspective relates to the feeling of isolation and inherent sense of abandonment experienced by the counsellors on finishing, when a fruitful and reciprocal counselling relationship had been established and nurtured. Such feelings are often echoed by bereavement counsellors who work with the elderly population; such people often have a limited social circle and are subsequently lonely.

Assessment of the therapeutic value of counselling continues to challenge counsellors who work with all client groups. Measuring the process and outcome of such approaches remains problematic.

The challenges identified highlight the perceived vulnerability and
uncertainty of the bereavement counsellor; the lack of concrete resources; and the difficulties of the specifics of counselling, such as dealing with endings effectively.

Discussion

Working with the bereaved individual who has a learning disability may offer additional challenges as the bereavement counsellor seeks to positively overcome an inherited legacy of practical, emotional and attitudinal difficulties. Prevailing negative attitudes (Oswein, 1991), low expectations and stereotyping (Kitching, 1987) and a complex combination of limited cognitive abilities, attention span and limited emotional vocabulary (Conboy-Hill, 1992) have served to affect the development of appropriate services and the delivery of effective bereavement counselling to this client group.

The voluntary organization, Bereavement Care, made a conscious decision early in the project to see people with learning disabilities in a setting of their own choice wherever possible. Largely this was in their own homes, in hospitals, in the workplace or at day centres if there is an appropriate (quiet, uninterrupted and comfortable) space available. This had implications for the voluntary organization since the majority of the clients (nearly 60 percent) attended the main centre for counselling. Having clients attend the centre was very effective in terms of both time and cost from a counselling and organizational perspective, but attending the centre may have been a daunting experience for some bereaved individuals. Many people with learning disabilities may associate offices with negative consequences, and hence may feel very uncomfortable attending the main centre, however comfortable and thoughtful the layout.

Additionally, many of the care homes had minimum staff and other resource issues may have taken priority when a client needed support to attend a bereavement counselling appointment.

The researcher's average mileage for the project was approximately 3000 miles per year, and this is an important resource consideration for developing similar projects. Interestingly, a notable increase in clients electing to visit the centre during 1997-8, coincided with the voluntary organization's move to a bigger, more central and more accessible venue.

During the year analysed, bereavement was the main reason for referral (73 percent) followed by Dove referrals (17 percent) and lastly loss issues (9.7 percent). Issues relating to people with learning disabilities accessing primary care generally (Rodgers, 1993) and palliative care specifically (Read, 1998) are an increasingly popular development for discussion. The Dove referrals in Table 1 echo the growing importance of this somewhat neglected area of care, where individuals are faced with their
own death, or the pending death of close friends or relatives. People with learning disabilities do experience palliative illnesses and, because they are now living in community settings, are accessing ordinary primary care services (for example GPs, hospices, district nurses) for their palliative care needs. Counselling and support will continue to be an important part of effective, holistic palliative care. However, more research is required to firmly establish such needs, and to identify the professional development needs of those who may be caring for such people (for example district nurses, hospice staff, and GPs).

Whilst Kerr et al. (1996) have identified that over 50 percent of people with learning disabilities have significant communication impairments, Prout and Stromher have suggested that ‘the less articulate client with mental retardation may feel uncomfortable in verbally orientated sessions’ (1994, p. 7). The client uptake for 1997–8 identified that 27 percent of the clients referred had additional impairments. Communication is the key to effective understanding within the bereavement process and counsellors need to be aware of the creative resources available to promote concrete communication with this client group (Read, 1999). Many of the emerging themes identified centre around effective communication. More direction and the establishment of the effectiveness of these communication tools (for example, life story work, poetry, drawing, photographs and picture books) are necessary from a bereavement counselling perspective.

For those clients for whom counselling was deemed inappropriate (for example due to profound complex and/or communication challenges) support was always offered through the carers by training and/or ongoing support.

Issues surrounding consent and boundaries are crucial within the bereavement counselling processes if client-centred approaches are offered and a confidential relationship is to be both established and maintained. The bereavement counsellor needs firm guidance (both written and verbal) to ensure that reciprocal consent to counselling and/or research has been given. Many ethical committees are concerned with promoting the rights of individuals whilst simultaneously addressing the ethical principles of providing beneficence and non-maleficence (Beaver et al., 1999). People with learning disabilities have positively contributed to the research arena (Robinson and Simmons, 1996; Walmsley, 1990; Whittaker, 1997). Inviting the client to participate in bereavement counselling research has to be done with sensitivity and openness, as ‘Consent to research is regarded as fundamental to sound research practice’ (Behi, 1995, p. 61). Process consent (Beaver et al., 1999) is perceived as being appropriate for this client group and the development of more concrete communication tools to assist the counsellor in explaining the research process would be helpful.
Interestingly, 61 percent of the clients with learning disabilities referred during this period were male; and this ratio is fairly consistent throughout the 4 years, with the exception of the first year of the project. At Bereavement Care generally, females are referred more frequently, and consistently so, than males. One might construct plausible explanations as to why men are referred more often than females. First, one of the main reasons for referrals is behavioural changes (either of frequency or of intensity); it may be that professional carers are anticipating such changes from their male clients. Second, the professional workforce is predominantly female; it may be that these carers are sensitive to the client’s potential needs from a bereavement counselling perspective. Robust research to further explore issues of gender within this group is advocated.

A common emerging theme was the need for specific written guidance and support, regarding learning disabilities and bereavement counselling. Many of the perceived inadequacies identified by the bereavement counsellors in Tables 2-4 could be addressed by more concrete direction. A significant development within research into training in counselling and psychotherapy has been the introduction of systematic training manuals as a means of codifying and disseminating new approaches to practice (Bergin and Garfield, 1994; McLeod, 1994). Bereavement counselling for people with learning disabilities is a new and evolving area, and bereavement counsellors involved in this study have identified the need for specific written guidance, both overtly and covertly within the focus group discussions. Such a manual would not replace traditional training, supervision and support but would serve to complement existing work, and to offer a consistency of approach and direction.

A therapeutic counselling manual has subsequently been developed in conjunction with the counsellors involved, and is currently being piloted to enhance, guide and promote good practice. This manual currently has six sections:

1. A bereavement counselling guide in a manual format
2. Perspectives on bereavement counselling
3. Counselling begins
4. Creative ways of working when exploring the bereavement counselling process
5. References
6. Appendices.

Each section is colour coded for ease of access. The manual is not used in the traditional manner (i.e. prescriptively); it contains options and ideas for the counsellor to reflect upon and consider, and is more like a recipe book. It also contains a wealth of contributions from clients and counsellors in...
the form of case stories, poems and drawings. Every section relates specifically to people with learning disabilities and associated conditions from a counselling and therapeutic perspective.

Service providers can learn much from immersing themselves in the data presented to discover the characteristics of a bereavement counselling and support service for this specific client group. Any bereavement service for the individual who has learning disabilities needs to:

• adopt a willingness to address the challenges
• be flexible, adaptable and amenable to change
• listen and respond positively to the bereavement needs of the client group
• be mindful of practical considerations
• recognize the development needs of the bereavement counsellors involved (Read et al., 1999)
• be able to respond quickly and effectively
• be realistic
• have firm aims with regards to what the service can or cannot offer
• offer broader support in addition to counselling specifically
• develop a team of specialist counsellors.

Conclusion

This paper has introduced and described an established bereavement counselling and support service designed specifically for people with learning disabilities. Demographic information about the development and integration of this service has been presented. The evaluation period outlined in this paper (1997–8) was chosen because of its contribution to the ongoing PhD study. It both helped to shape the development of that work and also identified issues in practice that needed to be addressed.

This paper has identified and explored the challenges inherent in developing such a service throughout, and a range of specific issues have emerged. These included developing a means of ensuring informed consent by the development of simple written consent forms and concept-related, laminated cue cards to complement the written word, in an effort to explain difficult concepts in a simple and concrete way. These cue cards have now been further developed with the help of a professional illustrator.

A counselling manual has also been developed to act as a guide for practice and to offer a consistent, accessible and meaningful resource for the bereavement counsellors involved.

The use of focus groups was invaluable in accessing the counsellors’ dilemmas and ‘ideal for exploring peoples experiences, opinions, wishes
and concerns’ (Barbour and Kitzinger, 1999, p. 5). They will continue to play an active role throughout the completion of this PhD research study, as a means of tracking the bereavement counsellors as they continue to be involved in the research.

An apparent omission from the work has been the concrete involvement of the client from a practice partnership perspective (Ward and Simons, 1998). Lack of feedback from the client’s perspective indicates the need for the development of a simple written, pictorial evaluation sheet that could be used both before and after counselling, in an effort to establish and explore the client’s perspectives and experiences. The client’s stories are also important, as they offer valuable insight into unique personal experiences. The invitation for clients to tell their stories will be an important element of the research, and such participatory approaches (McClimens, 1999) are seen as a fundamental and crucial element of the main research study. Generally bereaved people feel a deep sense of disempowerment when faced with the death of their loved ones; for many bereaved people with learning disabilities this sense of disempowerment is often total, as they may experience multiple losses associated with the death of (for example) a primary carer. Such stories can be simple and yet incredibly powerful, and can teach us much.

The weaving together of several research methods aids the exploration of the bereavement counselling experience from both a client and a counsellor perspective. However, a tool to measure the therapeutic outcomes of bereavement counselling will support clinical effectiveness. Such a tool has been developed (entitled ‘Responding to bereavement: a checklist for people with learning disability’) and piloted and incorporates 91 questions from a pre- and post-bereavement counselling perspective.

When working with bereaved people who have a learning disability, bereavement counsellors often witness profound sadness that they can perceive but may never fully comprehend. Knowledge of resources currently available (and the development of new resources in the future) may help them to connect with their clients more readily, and ensure concrete, reciprocal understanding when working with individuals with learning disabilities. Such resources need to be identified, readily available and easily accessible in an effort to aid the bereavement counsellor. All such issues help to identify what is involved in offering a bereavement counselling and support service to this client group. The characteristics of such a service have been identified in this paper to encourage other professional groups to embrace the challenges, and rewards, of such a bereavement service.
References


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