Loss, death and learning disability: Creative approaches for meaningful support

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Aims

• Clarify key concepts of loss, grief and mourning

• Identify the challenges when supporting people with learning disabilities experiencing loss and grief

• Critically explore the concept, nature and meaning of support associated with loss, death and bereavement for people with complex needs

• Identify recommendations for supporting loss in secure environments
Defining learning disability

DH (2001) describe people with learning disabilities as having a reduced ability to understand new or complex information, or to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood and with a lasting effect on development.
Definitions

Clearly this definition describes individuals who may have a whole range of different presenting competencies in communication, social skills, social functioning and/or behaviour.

“People with learning disability are amongst the most socially excluded and vulnerable groups in Britain today” (DH, 2001:14).
People with a learning disability are more likely to “...function on a developmental level that is inconsistent with their chronological age” (Lavin, 2002:314), and carry a history of marginalisation, devaluation and stigma.
People with a learning disability have more similarities to us than differences from us, particularly from within the loss, death and bereavement context.

(Read, 2005; Cartlidge & Read, 2010)
When we are born
When old age approaches
When death approaches

“Death is not the enemy, Doctor. Inhumanity is.”

(Bertman, 1991)
Living with loss

Life is characterised by movement, change and development, therefore by transitions, losses and grief.

(Thompson, 2002)
Importance of loss

“I thought that it sometimes seems as if all our lives we are trying to cope with loss – either the fear of it, or the memory of it or its raw immediate presence.”

(Oswin, 1991: 15)
Loss

Loss is a sense of being deprived or being without, and such losses can be expected or unexpected.

– Developmental loss
– Circumstantial loss
– Invisible grief (Machin, 2009)
When expectations about the course of life are not met, people experience inner chaos and disruption. Such disruptions represent a loss of the future. 

(Becker, 1997:4)

Shattered dreams (Bowman, 2001)
Loss

• Death is the ultimate loss but people grieve in other circumstances

• Loss can be physical, emotional, psychosocial, spiritual  (Worden, 2008)

• Loss always occurs in a social context  (Read & Elliot, 2006)
Duel process model of grief

Loss Orientated
Grief work
Intrusion of grief
Breaking bonds and ties
Avoidance of restoration changes

Restoration Orientated
Attending to life changes
Doing new things
Distractions from grief
New roles, identities and relationships

Stroebe & Schutt (1995)
Grief: A responses to loss

“Grief is an emotion prompted by change and readjustment”
(Parkes, 1993)

“Grief….a response to loss…a struggle in which release from pain may be achieved either by evasion or confrontation”.
(Machin, 1998)

“A response to loss that can be physical, behavioural, social and / or psychological”.
(Machin, 1998)
To clarify

• Bereavement is what happens to you

• Grief is a response to loss

• Mourning is what you do
‘If we understand the different ways people react to loss, we understand something about what it means to be human...

...something about the way we experience life and death, love and meaning, sadness and joy.’

(Bonanno, 2009:3)
Bereavement and learning disability

• People with learning disabilities do experience grief (Oswin, 1990; 2000; Hollins & Esterhyuzen, 1997)

• Impact of grief is varied and often complex (Conboy-Hill, 1992; Hollins & Esterhyzen, 1997; Sheldon, 1998; MacHale & Carey, 2002)
Bereavement and learning disability

“...response to bereavement by adults is similar in type, though not in expression, to that of the general population” (Bonell-Pascual et al, 1999).

Prone to multiple and successive losses (Oswin 1991; Elliott, 2003)

Cultural differences in bereavement support (Dodd et al, 2005)
Why hearing the words is difficult

• Cultural and societal taboos generally

• Emotional needs often remain neglected (Arthur, 2003)
  • Perceptions of ability to grieve (McLoughlin, 1986; Elliot, 1995; Read, 1996)

• Cultural and societal taboos: death and disability (Oswin, 1991)

• Over protectiveness (Deutsch, 1985)

• Carers feelings of fear, inadequacy and uncertainty (Emerson, 1976; Thurm, 1989; Oswin, 1991)
Why hearing the words is difficult

“...failure to recognise the impact of loss on people with learning disabilities arises from our need to see such people as lacking in effective emotional apparatus.....this conveniently feeds our own need to avoid discussion of pain and grief and so the cycle of ignorance and inaction has been perpetuated”

(Conboy-Hill, 1992: 151)
Challenges to bereavement support

Communication (Kerr et al, 1996)

- Often the individual lacks an appropriate verbal repertoire
- Support person may not know how to communicate effectively
- Uncertainty around what has been absorbed / understood
- Counselling is perceived as a ‘talking therapy’
Challenges to bereavement support


- Parents and carers tending to focus upon the symptoms rather than addressing the cause (Crick, 1988)

- Lack of appropriate specialist education, training and supervision (Read, 1996)

- How death is conceptualised.
Challenges to bereavement support

- Combination of cognitive ability, attention span and limited emotional vocabulary (Conboy-Hill, 1982)
- Low expectations, stereotyping and stigma (Kitching, 1987)
- Limited experience of grief and grief rituals (Cathcart, 1985)
Challenges to bereavement support

Vulnerable from a death and dying perspective:

– Actively excluded from death and dying (Read & Elliott, 2003)

– More complex the needs, the less likelihood of being involved (Read & Elliott, 2003)

– People usually experience sudden as opposed to anticipatory grief (O’Nians, 1993)

– Have an external locus of control (reliant on so many for so much).
Disenfranchised grief
(Doka 1989; 2002)

“...the grief that persons experience when they incur a loss that cannot be openly acknowledged, publicly mourned, or socially supported...”

- The relationship is not recognised
- The loss is not recognised
- The griever not recognised (1989)
- The ways that individuals grieve
- The circumstances surrounding the death (2002)
Responding to disenfranchised grief
(Doka, 2002)

- Acknowledging the loss/ *legitimise* the emotional pain
- Active *listening*
- **Empathy** (making sense of life experiences by interacting with others, sharing and supporting)
- Meaning making (finding *benefits*)
Losses associated with living in restricted environments are likely to be diverse and vast, yet there is limited empirical research that explores the loss experience of people with learning disabilities living in secure forensic environments.
Loss is widely acknowledged as a potential explanation for behavioural and mental health problems for people with LD (Dodd et al., 2005; Hollins and Esterhuyzen 1997; O’Hara and Sperlinger 1997).

having an LD itself is recognised as a significant predictor of mental health problems following bereavement (Bonell-Pascual et al., 1999)
Hobson, Read & Priest (in press)

• People with LD who live in secure environments are more likely to have mental health problems than those who do not (Hobson and Rose 2008; Gore and Dawson 2009)

• compounded by the fact that they often experience diverse losses throughout their lives (Isherwood, Burns, Naylor and Read 2007; Gore and Dawson 2009)
When losses go unacknowledged and unsupported, self-harm and challenging behaviour can sometimes result (Blackman 2003; Brown and Beail 2009).

creating a vicious cycle of dependency and disenfranchisement
Loss in the forensic setting

• Can be multiple and successive (Elliott 2005)

• Usually include:
  – loss of freedom from being detained
  – being separated from important relationships (Schuengel and van Ijzendoorn 2001)
  – emotional trauma
  – loss of the ideal self (Isherwood et al., 2007)
  – Not knowing when they may leave

Hobson, Read & Priest (in press)
Loss in the forensic setting
Hobson, Read & Priest (in press)

• We designed and conducted a grounded theory study to generate a **framework** about the loss experiences of people with LD in a low secure environment

• The ultimate aim of undertaking this study was to **understand** the nature and impact of these losses so that we could identify recommendations for future practice in forensic settings
Loss in the forensic setting
Hobson, Read & Priest (in press)

- Ethical approval from NHS and University Ethics committee
- Individual interviews (N=8)
- Participants encouraged to bring along any items that had personal meaning regarding loss
Loss in the forensic setting
Hobson, Read & Priest (in press)

• To **develop** interview questions, check the accessibility of information, and add to the credibility of the information produced (Chiovitti and Piran 2003), a focus group was conducted with in-patients at a low secure hospital in England.

• Participants **suggested:**
  • **adding** questions about having the opportunity to talk about loss and what people had learnt from loss
  • recommended using **scenarios** to make questions clear
  • using different coloured paper and using **pictures** to support understanding
Grounded theory and ‘lived experiences’ (Charmaz 2006):

- Robert, in his twenties, had been in a medium secure hospital and community homes both as an adult and a child. He said that he had been raped a number of times throughout his life and felt like taking his own life. He missed his mum but was able to talk to her on the telephone.

- Beth, in her forties, said her biggest loss was her child who had been removed from her care. Following the adoption of her child to another family, she committed her index offence. She still thinks of her child often, especially on important anniversaries.
Data analysis revealed a series of critical interactions, primarily between the key categories of:

- loss
- being heard
- identity

How individuals made sense of their loss was influenced by how they constructed the meaning of loss based on who they were (their identity); In turn, their identity was affected by how they made sense of the loss and also by whether or not they felt ‘heard’. Therefore the process of making sense interacting between each category, was seen as a key factor.
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

Learning about loss:

• profoundly affected participants’ lives
• shaping who they were
• influenced their identity and how they thought of the future
• loss included bereavement
• losing out on everyday experiences from being in a secure environment
• the effects of abuse and trauma in early life
• loss was an everyday occurrence as well as an historical fact from the past
• participants continued to experience loss from being in a secure environment whilst attempting to deal with previous losses
Talking about loss:

- Being heard by someone else
- Being able to ‘get things off one’s chest’ was seen as helpful
- Participants valued the opportunity and the experience of talking about loss, especially to a person not employed in the organisation
- Participants found being heard a difficult process
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

Talking about loss:

• Whilst it was emotionally upsetting to talk about loss, the participants felt they weren’t being heard by others.

• Staff were sometimes unable to recognise or acknowledge losses.

• Staff may have felt ill-prepared or uncomfortable talking about such issues.

• Staff may not have had the time to talk.

• Staff may not have felt it was part of their job role.
Coping with loss:

- Not being heard often led to participants trying to deal with loss on their own in inappropriate ways or in ways that were helpful only in the short-term, such as self-harming, using drugs or alcohol, or becoming physically aggressive.

- However, they were able to recognise this and wished to learn alternative ways of coping, despite the difficulties of dealing with loss in a setting which may have emphasise on behaviour rather than dealing with distress.
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

Control:

• Participants described having little control over many things, and about experiencing loss of previously-held controls

Beth spoke of losing her access to the kitchen to make herself a drink: ‘I made myself a hot drink and then the work top was a bit wet ... and then [member of staff] said that night for me not to go in after then ... and staff made me my drink then’.
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

- Participants talked about controlling their own feelings and behaviour, and using strategies to get control in an environment where they had limited control.

- Some participants tried to regain a sense of control through self-harm or aggressive behaviour, although this often resulted in them having less control as staff sought to manage their behaviour.

- Being controlled by others or losing control due to loss or bereavement had a disempowering, and ultimately disenfranchising effect.
Loss in the forensic setting
Hobson, Read & Priest (in press)

• Corr (2002) argues that mourning can be disenfranchised when loss rituals are dismissed or discouraged.

• Similar to other detained populations (Hendry, 2009), participants in this study reported being unable to attend funerals of loved ones as they were detained in hospital or prison.

• It is worth noting, however, that while participants commented on identifiable rituals associated with bereavement, no other such rituals were identified for other losses (for example, having a child removed or abstract losses such as freedom, future, childhood or adulthood).
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

Story telling:

• Telling the story of loss was an important part of the process of being heard

• Participants told stories of their losses, re-living their experiences

• Carol described her step-father’s death in detail: ‘... the ambulance crew came and started resuscitating him but there was no response and [they] started shocking him ... and he didn’t comply to the shock so they said they’re going to stop now, so they said time of death’

• Storytelling was not simply about telling the story; it was about being heard and having a witness to their loss and pain.
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

Recommendations:

• A clear implication of this study’s findings is the importance of therapeutic work around loss with people with LD in a low secure environment (Read and Bowler, 2007; Dowling et al., 2003); Blackman, 2002; Watters et al., 2012)

• A thoughtful and compassionate approach to working with this client group in this setting is required which acknowledges the losses experienced throughout life and from being detained, even at the initial assessment stage

• Consider where loss fits within the ethos and discourses of secure services, and promoting that discourse in a meaningful way
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

• We need to be mindful of the potential dangerousness of individuals and the need for security (Inglis and Dale 2011)

• similarly, the effects of dealing with aggressive, violent behaviour and administering physical restraint may leave care staff with negative feelings towards an individual (Howard et al., 2009; Sequeira and Halstead 2004).

• consequently it may be difficult for care staff to acknowledge, empathise and be compassionate about someone’s loss
Loss in the forensic setting: Results
Hobson, Read & Priest (in press)

Recommendations:

• Reflective groups, supervision or team meetings where staff can openly acknowledge difficulties and tensions may allow for the person to be heard within the secure environment

• Creative approaches to self-expression can help alleviate distress and produce tangible outcomes (such as drawings, pictures, storytelling or poetry)

• For those individuals who need specific help and support with their loss, external agencies and independent counsellors can offer that ‘safe space’ for cathartic conversations
How we can help

Helping people to understand about loss using proactive and reactive education:

– Group work (Read et al 2000; Read & Papakosta-Harvey, 2004)

– Openly sharing feelings and responses to loss

– Retaining tangible memorise (life story work)

– Telling and sharing stories (Jennings, 2005)
How we can help

Nurturing a healthy grief response:

• Using naturalistic opportunities to talk and express feelings generally

• Developing and using a variety of accessible resources
How we can help

Good support following a loss or death:

– Active listening
– Assessment of needs: finding out what the person wants
– Incorporate loss as part of any assessment
– Communicating in a meaningful way
– Offering consistent support
– Normalising the grief response
– Referring on when appropriate
To conclude...

Loss, death and dying remain sensitive issues for everyone, but can be more challenging for some.
To conclude...

- Marginalised groups (such as people with learning disabilities) often experience disenfranchised grief.

- Disenfranchised grieveres may need extra support to express their grief in a meaningful fashion.

- Forensic environments need to consider how they may best support their clients with the range of potential losses.
To conclude

- Addressing practice issues e.g. Breaking bad news and grief rituals (Raji & Hollins, 2003), record keeping, policies and procedures

- Actively looking for grief responses (Kitching, 1987)

- Adopting a proactive approach to loss

- Having carers who are confident, skilled, knowledgeable and comfortable:
  - Explicit guidelines and directions
  - More empirical research
  - Education and training
Any questions…

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