Loss and grief in later life: 
A theoretical model describing the experiences of adults with cerebral palsy and complex communication needs

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Loss & Ageing

• An experience of loss is a normal, expected and necessary part of life (Ambler Walter & McCoyd, 2009).

• Older age has been identified as a time when multiple, gradual and cumulative losses occur (Garrett, 1987; Raphael, 1984).

• People with lifelong disabilities experience the same patterns of growth, development, maintenance and eventually loss of skills and function as people who do not have a disability (Turk, Overeynder and Janicki, 1995)

• Loss or change in skills, function and identity may result in feelings of grief for some people ageing with a disability
Grief

• Loss is a personal experience that is shaped by individual experiences, familial, community and cultural factors (Genevro, Marshall, & Miller, 2004).

• Different individuals will attach different meaning and significance to loss events (Bruce & Schultz, 2001; Neimeyer, 2001).

• Grief and grieving encompass varied and diverse procedures for transforming and evolving meanings about the source of the loss and reorganising and adapting to a new reality (Hagman, 2001).
Cerebral Palsy and Ageing

- There is evidence to suggest that as people with cerebral palsy age, changes / losses may be associated with:
  - **Health and Wellness** (Turk, 2009)
  - **Function and independence** (Haak, Lenski, Cooley Hidecker, Li and Paneth, 2009)
    - Motor function
    - Pain and fatigue
    - Communication
    - Swallowing and nutrition
  - **Psychosocial factors** (Haak et al., 2009; Horsman, Suto, Dudgeon, & Harris, 2010; Svien et al., 2008)
    - Social networks
    - Participation
    - Quality of life
• To date there has been no research exploring the experience of loss and grief for adults with cerebral palsy and complex communication needs as they age

• As many more people with cerebral palsy will now experience older age it is important to understand how loss and grief will affect their lives and the supports they utilise

• The perspectives of people with cerebral palsy themselves can add valuable information about topics that have little or no research
Method

• A qualitative study was conducted using constructivist grounded theory (Charmaz, 2006)

• 20 participants with cerebral palsy and complex communication needs aged over 40 years were interviewed about their experiences of loss and grief

• Interviews were examined for themes and allocated codes

• A theory and model were developed from the data

• My interpretations were verified with individual participants
The theory

- Loss and grief feels like “Life is getting smaller”

- This happens because of a feeling of diminishing control over Physical, Cognitive, Social, Emotional areas of life.

- There are three things that affect the experience of loss and grief in either positive or negative ways:
  - The ability to communicate
  - Support Structures
  - Making Meaning

(Dark, 2010)
Model of loss and grief for older adults with cerebral palsy and complex communication needs (Dark, 2010)
1. Diminishing Control

• It is important to hold on to physical skills and abilities as these contribute to independence

• Many people with cerebral palsy need assistance from others on a daily basis, but it is important to be involved in decisions about how that assistance is provided

• It is very important for people with cerebral palsy and communication difficulties to “stay in the loop”. This includes being given information and being asked for information
• Participants described loss around their relationships, particularly those with able bodied people.

• It was important to have a meaningful occupation such as employment, attending a day program, doing volunteer work

• Some participants described a feeling of loss when they retired from work. This was because they felt their contribution was not acknowledged or there were significant changes to their lifestyle and daily routine following retirement
“I feel myself not yet completely gone down hill but a little bit each week I feel like I'm going down hill … you might not notice it but I can tell myself”

“My surgery has really changed my life style from being well… not totally independent but reasonably independent to being to being totally dependent. Although people would disagree with me because I get out and about and I look independent but really I’m only independent as long as my electric wheelchair works … and it is a big loss and a big point of grief for me because I can no longer go do things when I want to but when I’m told”

“If I don’t make all my choices now and keep the way I have been going I’m going to lose all that independence and my abilities. While I’ve got it I want to keep it and when it’s gone it’s gone and there’s nothing I can do about it”

(Dark, 2010)
2. Communicating through loss

• Communication is essential for managing loss and grief

• It is important to have the right words to talk about loss and grief; this includes access to words and symbols on AAC systems

• Managing loss and grief involves choosing who to talk to, when to talk to them and what to say
• With older age, participants described loss or change in their communication skills. These included:

  ▪ Expressive skills (e.g. speech intelligibility)

  ▪ Receptive (understanding) skills (e.g. loss of hearing or vision; cognitive changes)

  ▪ Changes in social networks and opportunities to communicate with others
“It frightens me … a lot of things are crammed up my brain, I just want to get them out. What will I do if I don’t have words?”

“This might sound stupid, but just talking… just being able to talk to you I’m starting to relax. It’s really good just letting the thoughts and the ideas flow out”

“I know that some people find my speech very hard to understand and that is frustrating. That is why I am waiting to get a communication device to help make things easier. I don’t really want to use it all the time but one day when my speech really does go, I will have something as a backup. One part of me doesn’t want to become a person who uses AAC”

“Your life is like an open book and you pour out your personal details, you talk to them [staff] openly and then they leave… So where does the person with the disability find their place? I mean they expect you to open up to them but it never
3. Support Structures

- Participants identified that when managing loss and grief it is important to:
  - Receive support from others
  - Have the opportunity to be self supporting
    - Cultivating Strength
    - Cultivating knowledge
    - Cultivating Influence
  - Support others
    - Needing to be needed
    - Reciprocity
“It’s about being big enough and strong enough to see you need support and admit that there are some things that you can’t do and need help in”

“I worry about what happen to me when my mum pass away”

“You have to be really really strong.”

“I know the staff try to do a good job and they do their best, but they change so often and now they don’t know me and the way I like to work”

“They can use my knowledge… cos I want to give something back”

(Dark, 2010)
4. Making Meaning

- Participants described the need to “make sense” or make meaning of their experiences of loss and grief.

- This involved moments of “holding on” to what is important e.g. ideas, beliefs, activities, hopes and dreams.

- Making sense of loss and grief also involved moments of “letting go” of what was not important. Often participants had to review their life, reorganise what was important to them and relearn new strategies or ways of being in the world.
“You have to fight for everything!”

“I am a bottler. I keep it all inside. But one day it will let go. And it will be a small thing, not a big thing that makes it happen.”

“I hope one day people will listen to me.”

“You do have to be realistic about things. It’s all about attitude”

“It was all going to plan for a little while and then everything changed overnight”

“Facing the wall of reality”

(Dark, 2010)
In summary

• All people with cerebral palsy and complex communication needs experience loss and grief

• Some types of loss and grief are the same as for people without a disability and some are unique

• One of the biggest causes of loss for participants in this study was feeling out of control of their life and not involved in choices and decisions
• The ability to communicate, having access to support and being able to make meaning of a situation all influenced the experience of loss and grief in either positive or negative ways.

• It is helpful to have realistic expectations about life because when reality is different from what is expected, this can lead to a feeling of loss.

• For people with cerebral palsy and complex communication needs, some losses do not have a start or finish. They are continuous or ‘non-finite’. How these types of loss are experienced depends on the environment, individual hopes, dreams, beliefs, expectations and past experiences.
• Participants felt it was important for people in the community to learn about the experiences of people with cerebral palsy and communication difficulties as they get older.

• This will help change attitudes, promote partnerships and encourage people to work together in a positive way.
Implications

• Collaboration between aged care and disability services
• Person centred practice & person centred planning
• Access to information about cerebral palsy and ageing to facilitate planning
• Maintenance of functional skills, autonomy and independence
• Opportunities for meaningful social interaction
• Reciprocal relationships
• Means and opportunity for formal and informal communication about loss and grief
References


Appendix

Definition of Cerebral Palsy:

• Is an umbrella term for a group of disorders
• Is a condition that is permanent but not changing
• Involves a disorder of movement and posture causing activity limitation
• Is due to a non progressive interference, lesion or abnormality in the immature (developing) brain
• Often accompanied by disturbances of:
  ▪ Sensation
  ▪ Communication
  ▪ Perception
  ▪ And/or behaviour
  ▪ And/or seizure disorder

(Rosenbaum et al., 2007)
Appendix

Definition of Complex Communication Needs (CCN):

• Communication problems associated with a wide range of:
  - physical,
  - sensory and
  - environmental causes
  which restrict/limit an individual’s ability to participate independently in society.

• People with CCN and their communication partners may benefit from using: Augmentative or Alternative Communication (AAC) methods either temporarily or permanently.

(Balandin, 2002)