Understanding the communication changes experienced by adults with cerebral palsy

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Context

• Change involves:
  - Elements of loss
  - Elements of growth
Context

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

• A ‘lost object’ need not necessarily be a person. It could be a valued object, a job, an identity or status, a dream, a hope or an ideal (Bruce & Schultz, 2001; Engel, 1961)
Context

• Different individuals will attach different meaning and significance to loss events (Bruce & Schultz, 2001; Neimeyer, 1998).

• 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).
Context

• Older age has been identified as a time when multiple, gradual and cumulative losses occur

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

- Adults with CP may experience changes in a range of areas including:

  - Health and Wellness (Turk, 2009)
  - Function, Skill and Independence (Haak, Lenski, Cooley Hidecker, Li and Paneth, 2009)
  - Psychosocial domains (Haak et al., 2009; Horsman, Suto, Dudgeon, & Harris, 2010; Svien et al., 2008)
Study Design

Constructivist Grounded Theory
(Charmaz, 2006)
'MY LIFE IS GETTING SMALLER'

DIMINISHING CONTROL

COMMUNICATION

PHYSICAL CONTROL

EMOTIONAL CONTROL

COGNITIVE CONTROL

SOCIAL CONTROL

ENVIRONMENT

CULTURE

FAMILY

MEANING MAKING

HOPES

SUPPORT STRUCTURES

DREAMS

Past Experiences

Experiences

Expectations

(Dark, 2010)
Communicating through loss

Grieving / mourning is a process that involves the reassessment and reconstruction of meaning associated with a loss. It is a process that occurs invariably within a social and cultural context and requires both communication and interaction.

(Neimeyer, 2001)
Communicating through loss

Managing loss through communication

Finding the words
Choosing how to communicate
Managing communication partners
Managing the communication environment

Interacting with others

Losing communication skills

Communication as a loss

A changing communication identity

(Dark, 2010)
I’m slurring my words. I know what I want to say but people don’t... get my idea (Sarah)
Communication Skills

• Sensory Changes

I can read if it’s a very big font ... VERY big font... I hate reading little font. I’ve had to buy myself a new pair of glasses just for that.

(Sarah)
Communication Skills

• Cognitive Changes

I feel myself going down hill... it’s mentally and a bit of physical combined... I wanted people to write things out for me to help me remember but I know that’s not the way for me now. I find now I need a picture you know, those picture boards...not a spelling one...but one with pictures to help me remember.

(Sarah)
Communication Skills

• The role of communication partners

I always have people who know me and my speech. Because of that I have never have a problem with my communication. I always can say what I need to.

(Bruce)
Communication Skills

• Impact on interaction and relationships

I find it quite curious surprising whatever word you want to use that sometimes.... I can meet some people for the first time and they seem to have no problems understanding me but other people it’s like, “Have you got an interpreter with you?” or something you know... it’s like they really struggle. And then I think “Oh, am I really that bad?” and that just makes it worse because you question yourself! (Henry)
Identity

**Self Concept**
How we understand our self

**Self Image**
How we perceive our self

**Self Esteem**
How we evaluate our self

Personal identity is the distinct personality of an individual and is concerned with the persisting entity particular to a given individual.
Changing Communication Identity

• Changing mode of communication

I would hate to see me go down that track [of using AAC], hate it! But I can feel eventually it would help.

(Sarah)
Changing Communication Identity

• Changing status as a ‘good’ communicator

What is good anyway? What is normal? It’s just an interpretation at the end of the day. Normality is to do what you like to do and do what you want to do, not what everyone else does.

So our communication is normal and it is good.

(Esther)
Reassessment of Communication Changes

• Happens in light of:
  • How a person with CP constructs their identity as a communicator
  • Expectations of changes in communication
  • What previous experience the person has had with AAC and at what point in their life
  • Perception of AAC in later life as a tool to enhance communication or as a sign of lessening communication ability
Understanding Communication Changes

• Coping with loss involves two different processes:

  ➢ *Loss oriented coping* (dealing with, concentrating on and working through some aspect of the loss itself)

  ➢ *Restoration oriented coping* (reorganizing life, developing new identity, mastering new tasks)

• Oscillation between loss oriented and restoration oriented coping occurs

(Stroebe & Schut, 1999)
Implication for AAC Interventions

• For some people with CP, considering use of AAC for the first time later in life can:
  ➢ Be upsetting
  ➢ Be threatening
  ➢ Be inconsistent with personal identity and self concept
  ➢ Be perceived both positively and negatively; and may alternate between the two perspectives
Identity and Communication Participation

• Communication solutions should aim to:
  ➢ Enhance function
  ➢ Enhance participation (in positive and negative life experiences)
  ➢ Sustain positive personal identity and self concept
  ➢ Promote personal wellbeing
  ➢ Include a process of accommodating change and supporting reassessment and reconstruction of meaning


