

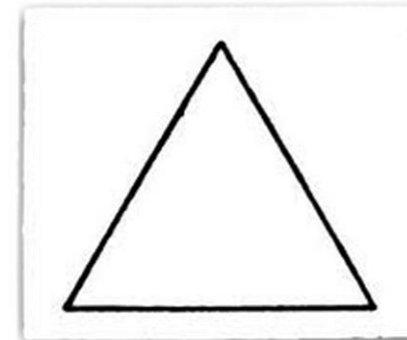
# Understanding the communication changes experienced by adults with cerebral palsy

Dr Leigha Dark  
Australian Catholic University

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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

Twenty  
Participants

Theory

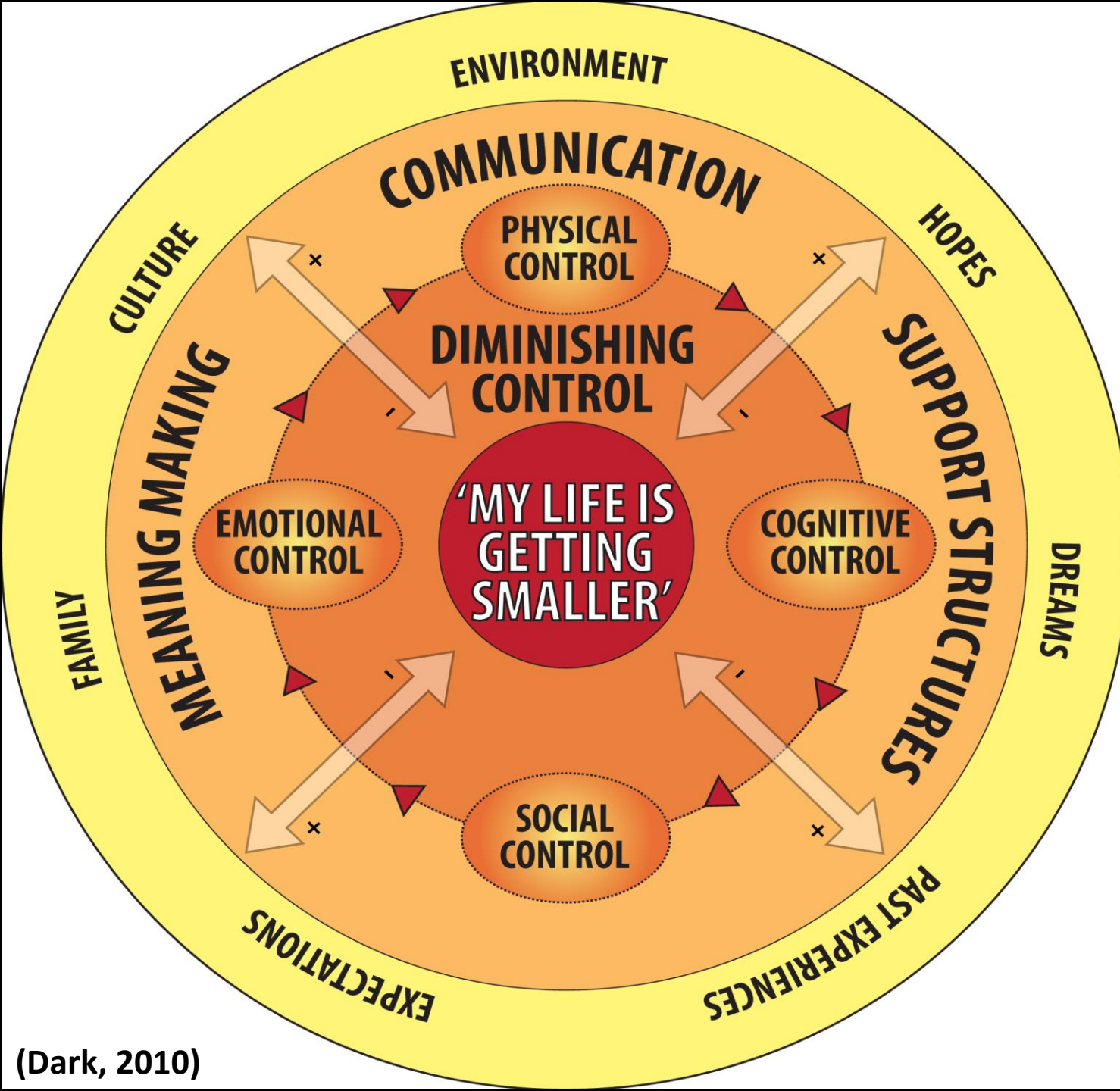
Multiple  
Interviews



Constructivist Grounded Theory  
(Charmaz, 2006)

Constant  
Comparison





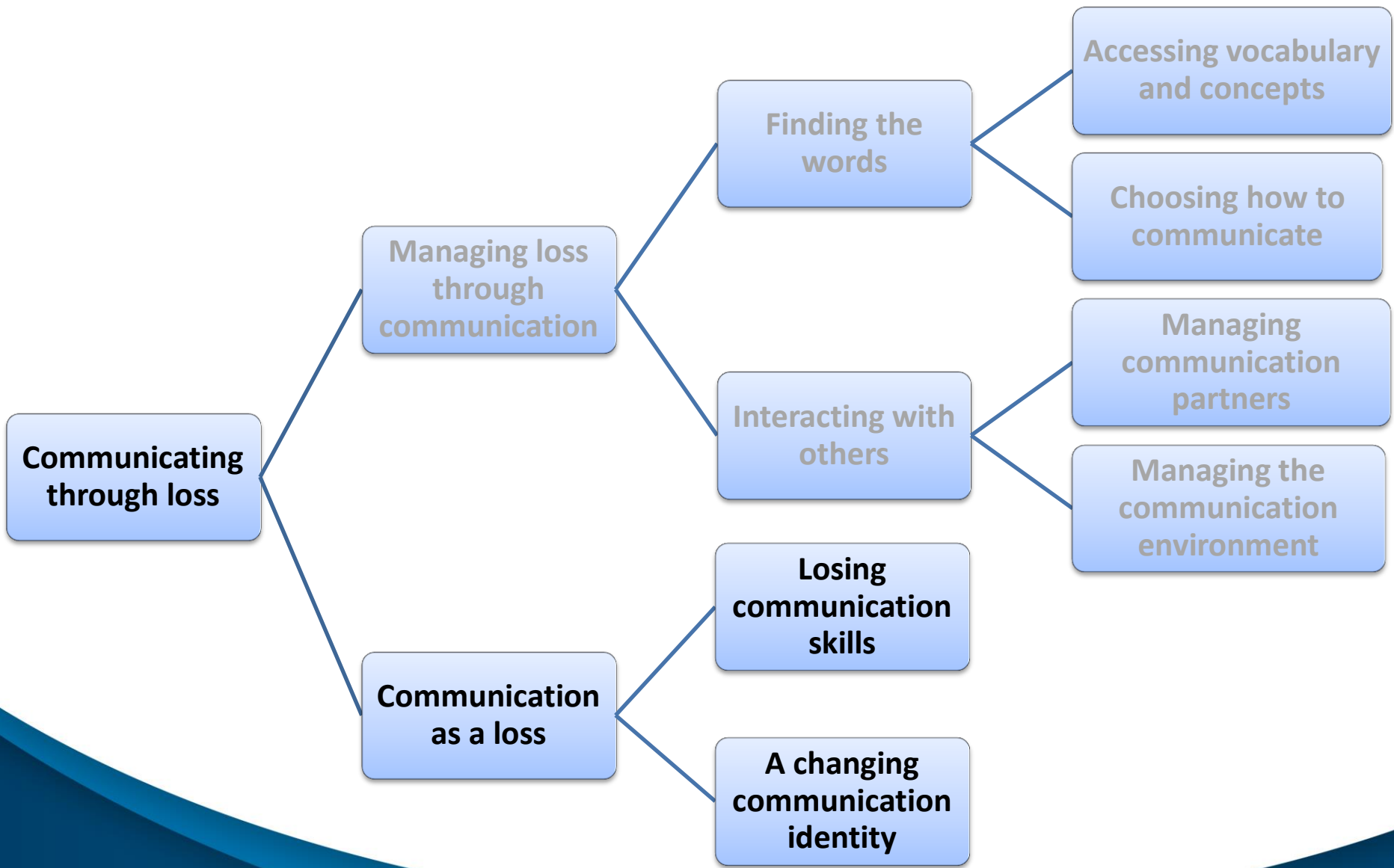


# Communicating through loss

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)



# Communication Skills

- Intelligibility

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)



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

# Identity

## Self Concept

How we understand our self

## Self Image

How we perceive our self

## Self Esteem

How we evaluate our self

# 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

# 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



# References

- Ambler Walter, C., & McCoyd, J.L.M. (2009). *Grief and Loss Across the Lifespan: A biopsychosocial perspective*. New York: Springer Publishing Company.
- Bruce, E.J., & Schultz, C.L. (2001). *Non-finite loss and grief: A psychoeducational approach*. Baltimore, Maryland: Paul.H. Brookes Publishing Co.
- Charmaz, K. (2006) *Constructing Grounded Theory: A practical guide through qualitative analysis*. Sage Publications, London.
- Dark, Leigha & University of Sydney. Faculty of Health Sciences (2010). *My life is getting smaller: the experiences of loss and grief of older adults with cerebral palsy and complex communication needs*. Unpublished doctoral thesis.  
<http://trove.nla.gov.au/work/156544235?versionId=170674028>
- Engel, G. L. (1961). Is grief a disease? A challenge for medical research. *Psychosomatic Medicine*, 23, 18-22.

Haak, P., Lenski, M., Cooley Hidecker, M.J., Li, M., & Paneth, N. (2009). Cerebral palsy and aging. *Developmental Medicine and Child Neurology*, 51(Supp.4), 16 - 23.

Hagman, G. (2001). Beyond decathexis: Towards a new psychoanalytic understanding and treatment of mourning. In R.A. Neimeyer (Ed.) *Meaning reconstruction and the experience of loss* (pp. 13 – 32). Washington, DC: American Psychological Association.

Neimeyer, R. (Ed). (2001). *Meaning reconstruction and the experience of loss*. Washington, DC: American Psychological Association.

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, 23, 197-224.

Svien, L., Berg, P., & Stephenson, C. (2008). Issues in aging with cerebral palsy. *Topics in Geriatric Rehabilitation*, 25, 26-40.