Supported Decision-Making for people living with dementia

Dr Craig Sinclair, Sue Field, A/Prof. Meredith Blake, Prof. Romola Bucks, Prof. Meera Agar, Prof. Josephine Clayton, A/Prof. Kirsten Auret, Prof. Cameron Stewart, Kathy Williams, Helen Radoslovich, Meredith Gresham, Angelita Martini, Prof. Sue Kurrle
Interviews

• Two-phase qualitative study
  • Phase 1: Lived experiences of decision-making (health and lifestyle)
  • Phase 2: Consultation on Supported Decision-Making

• Individual and dyadic interviews
• 37 people living with dementia, 45 family members
• Process consent approach (Dewing et al 2007)
• Participants were not subject to guardianship
Relational perspectives on decision-making

“...what we are faced with here is a problem that you and I have and you and I have to deal with it. So, it’s not the individual. It’s at least the individual and their carer. To take it further, it’s the family, the friends, the associates ... who have gone through the same process, all those people are somehow affected.” (67 year old man, living with dementia, interviewed alone)
The significance of decision-making involvement

“It’s my life. I don’t mind if the decision doesn’t go my way, none of that matters. It’s to be acknowledged and recognised that you’re still a person and you’ve still got the ability to reflect what it is that I want, that I would like, and I’m quite happy to listen if there is to be another judgment...” (71 year old woman, living with dementia, interviewed with spouse)
Factors associated with decision-making

1. The right to make decisions
2. Support to make decisions
3. Will, preferences and rights
4. Safeguards to prevent undue influence and abuse

**INDIVIDUAL (person with dementia)**
- Stage of dementia
- Daily fluctuations
- Self-efficacy
- Accepting condition
- Accepting help/advice
- Preference to have control or delegate

**INDIVIDUAL (spouse partner)**
- Accepting condition
- Stress and burden
- Beliefs & attitudes about dementia
- Caregiving and communication skills

**EXTERNAL**
- Influence of family members
  - Interactions with professionals
    - Institutional processes
      - Access to services
        - Access to social networks
        - Access to information

**RELATIONAL**
- Relationship quality
- Trust and familiarity
- Relational history of decision-making
- Relational values system

**DECISIONAL**
- Type of decision
- Importance to person with dementia
- Complexity (cognitive & moral)
- Risk
- Time available

Sinclair et al. *Int. Psychoger.* 2018
Emotional processing in decision-making

• Dual-processing theories – rational/deliberative vs emotion/affect driven processes

• Incidental affect
• Integral affect
• Tradeoff aversion
• Stereotype threat

Lockenhoff, C. Gerontology, 2019
A step-by-step approach

- What Decision?
- Preparation
- Communication
- Review and follow-up
- Putting it into practice
- Choosing

- Inclusion
- Knowing and Understanding
- Respect for Rights
- Dignity
- Adapting to Change

Supporters, Family, Friends, Professionals
Implications for maximising participation in Tribunal proceedings

- Decision-making occurs in a social and relational context
- Tribunal decisions often in context of family conflict
- A range of factors impact on involvement
- Preparatory information in advance of hearings
- Emotional processing may play an important role
- Accessibility of key information (multiple domains)
- Attention to setting (cognitive/sensory load, familiarity)
- Awareness and training for all involved (e.g. tribunal members, registry and clerical staff)
References
