Capacity & rights in older people – what is the role of the health professional ?

Carmelle Peisah

Capacity Australia

UNSW

University Sydney

THE FRAME ….

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (THE "CORPD")

- United Nations
- Entered into force May 2008; entered into force for China, including the HKSAR, in 2008
- 50 articles, including :-
  - Article 14: Liberty and security of the person
  - Article 16: Freedom from exploitation, violence and abuse
  - Article 19: Living independently and being included in the community
  - Article 22: Respect for privacy
  - Article 23: effective appropriate measures to eliminate discrimination against PWD in all matters relating to marriage, family, parenthood & relships, on an equal basis with others
  - Article 25: Health

ARTICLE 1

- defines persons with disabilities to include those who have "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others
- promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".

ARTICLE 12- EQUAL RECOGNITION BEFORE THE LAW

- 12.2 - recognize that persons with disabilities (PWD) enjoy legal capacity on an equal basis with others in all aspects of life
- 12.3 – to take appropriate measures to **provide access of PWD to support they may require in exercising their legal capacity**
- 12.4 - ensure all measures that relate to the exercise of legal capacity:
  - provide for appropriate & effective safeguards to **prevent abuse**;
  - respect the **rights, will & preferences** of the person;
  - are **free of conflict of influence and undue influence;**
  - are proportional and tailored to the person's circumstances;
  - apply for shortest time possible & subject to regular r/v by competent, independent impartial authority or judicial body;
  - are proportional to the degree to which such measures affect the person's rights & interests.

REMEMBER WHAT IS CAPACITY..

- 1. understand the information relevant to the decision;
- 2. “use” or “weigh up”, that information as part of the process of making the decision;
- 3. communicate the decision.

- (Roth, 1977; Appelbaum and Grisso, 1988; Grisso and Applebaum, 1995)

THE ROLE TO PROMOTE AUTONOMY

- The **presumption of capacity**
- Maximise informal decision making
- **Advance planning** – health, POA
- If conflict: Use mediation family therapy where possible
- If impaired capacity use **SUPPORTED DM**
- Minimise formal substituted DM; minimise applications (you do!)
- When you do apply, do so for the minimal decisions/powers
- Only if there is a NEED

WHERE ARE WE WITH PREFERECNE OF SUPPORTED >SUBSTITUTE DM?..

- **Internationally, there has been broad brush catch up approach with people with ID, often driven by coarse & clumsy guardianship and administrative legislation, that is plenary, not last resort**
- **Eg supported DM is "a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the "need" for a guardian" (Blanck & Martinis, 2015);**

- Paradigm > process – based; self determination and agency

GUARDIANSHIP AND THE POTENTIAL OF SUPPORTED DECISION MAKING WITH INDIVIDUALS WITH DISABILITIES; JAMESON ET AL, 2015 RESEARCH AND PRACTICE FOR PERSONS WITH SEVERE DISABILITIES 1-16

Guardianship is a complicated legal concept, which is further complicated by differences from state to state in the framing and implementation of distinctly different forms. Few professionals explain the long-term consequences of obtaining guardianship or provide the range of alternatives available to support an adult with disabilities. This study reports descriptive data from a national survey on guardianship and people with disabilities. The results indicate that regardless of who provides information about guardianship, and regardless of disability classification, full guardianship is consistently discussed most frequently while other options are rarely discussed. We describe implications for practice and provide recommendations.

Specifically, supported decision making is described as one potential alternative to legal guardianship that, according to these data, is the least frequently discussed with parents, but which has the potential to avoid many of the legal and social pitfalls that guardianship presents.

HOW TO DO SUPPORTED DECISION-MAKING

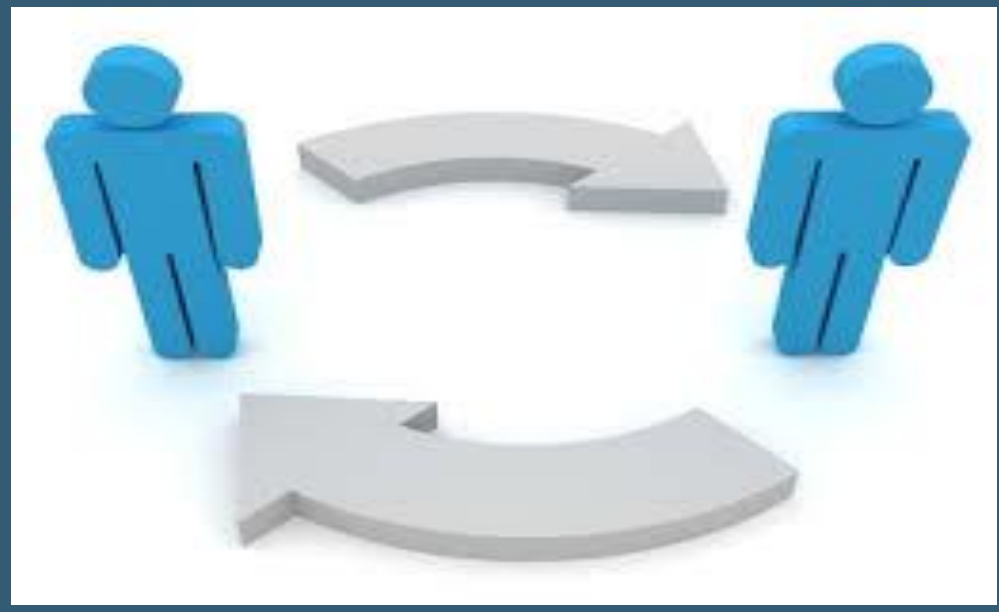
COLLABORATIVE MODEL SUPPORTED DM

- A collaborative process involving exchange of information & knowledge building
- Useful for people with decision-making disability
- Focuses more on the *how* + *why* of the decision making
- the health, legal or financial professional "informs" the person about the options, while the person, and/or carers "informs" the professional about wishes, needs, values
- A decision is made

- Peisah C., Sorinmadeayo D. Mitchell L., Hertogh C., (2013) Decisional capacity: towards an inclusionary approach The International Psychogeriatric Association Task Force on Capacity International Psychogeriatrics 25 (10): 1571-9

THE INFORMING IS CRUCIAL

- How do we MAXIMALLY inform : "the information step" (Darzins et al, 2000)
- The right to "learn about death"(Wiese et al, 2015)
- How can we BE informed by people with communication difficulties associated with mental disorder & dementia?



MAKING THE DECISION TOGETHER

"ASK ME" MODEL

Stepwise approach to assessment & support:

(i) **A**ssessing strengths and deficits;
(ii) **S**implifying the task;
(iii) **K**nowing the person;
(iv) **M**aximizing understanding; and
(v) **E**nabling participation in DM (use threshold or hierarchy approach).

Peisah C., Sorinmadeayo D. Mitchell L., Hertogh C., (2013) Decisional capacity: towards an inclusionary approach The International Psychogeriatric Association Task Force on Capacity International Psychogeriatrics 25 (10): 1571-9.

POSITIVE RISK MANAGEMENT, OR RISK ENABLEMENT

- based on balancing the positive benefits of taking risks against the negative effects of avoiding risk altogether.

- Risk enablement uses 4 step approach:
  1. **understanding the person's needs;**
  2. **understanding the impact of risks;**
  3. **enabling & managing risk, &**
  4. **risk planning** (Lightbody, 2014)

COMPLEXITIES OF SUPPORTED DM ..

A critical assessment of supported decision-making for persons aging with intellectual disabilities.Kohn NA[1], Blumenthal JA[2]. Disabil Health J. 2014 7(1 Suppl):S40-3.

Abstract

Supported decision-making is increasingly being promoted as an alternative to guardianship for persons aging with intellectual disabilities. Proponents argue that supported decision-making, unlike guardianship, empowers persons with disabilities by providing them with help in making their own decisions, rather than simply providing someone else to make decisions for them. To evaluate the empirical support for these claims, we reviewed the evidence base on supported decision-making. Our review found little such empirical research, suggesting that significant further research is warranted to determine whether--and under what conditions--supported decision-making can benefit persons with intellectual disabilities. Indeed, without more empirical evidence as to how supported decision-making functions in practice, it is too early to rule out the possibility it may actually disempower individuals with disabilities by facilitating undue influence by their alleged supporters

BIGBY, C., WHITESIDE, M., & DOUGLAS, M. (2015). *SUPPORTING PEOPLE WITH COGNITIVE DISABILITIES IN DECISION MAKING – PROCESSES AND DILEMMAS.* MELBOURNE: LIVING WITH DISABILITY RESEARCH CENTRE, LA TROBE UNIVERSITY

- Fundamental to the process were relationships & tailoring support to individual.
- skills & knowledge required included communication skills, self-awareness, the capacity for reflective discussion, conflict resolution skills, and knowledge of strategies for tailoring the decision making process to the individual.
- multiple dilemmas, tensions a/w supporting someone with cognitive disability to make a decision:
  - remaining neutral,
  - managing conflicting perspectives amongst differing supporters,
  - balancing rights with risk & best interests,
  - resource constraints,
  - managing power differentials,
  - the risk of undue influence,
- **Conclude: Collaboration between the different supporters involved in the life of a person with cognitive disability, and strategies to identify others who might potentially become involved in supporting decision making, is essential. Practitioners require understanding of the differing roles, contexts and challenges confronting different types of supporters. All supporters, whether they are family members, support workers or lawyers need ongoing opportunities for training and supportive**

WHAT ABOUT OUR ROLE RE ABUSE…

RISK FACTORS UNDUE INFLUENCE

- Relationship risk factors
  - anyone in position of trust or upon whom p is dependent for emotional or physical needs
- Social or environmental risk factors
  - Isolation and sequestration of the person,
  - Change in family relationships/dynamics
  - Recent bereavement.
  - Family conflict
- Psychological and physical risk factors
  - Physical disability
  - Non-specific psychological factors e.g. deathbed wills, sexual bargaining, serious medical illness with dependency/regression
  - Personality disorders
  - Substance abuse
  - Mental disorders including dementia, delirium, mood and paranoid disorders
- Legal risk factors
  - Beneficiary instigates or procures the will
  - Contents of the will has unnatural provisions
  - Contents favour the beneficiary
  - Contents not in keeping with previous wishes;
  - Other documents have changed at the same time

RISKS

Autonomous DM

- Abandonment, abuse

Supported

- Getting it wrong; undue influence

Substituted

- Getting it wrong; disempowerment; abuse

Proxy/surrogate

- Getting it wrong; disempowerment; abuse

APPROACHES TO SDM IN PEOPLE WITH COGNITIVE DISABILITY OR MENTAL ILLNESS.

1. Presume capacity
2. Start talking
3. Watch for *beneficence vs non-maleficence*
4. Elicit rights, will & preferences
5. Do they have capacity?

Yes → Autonomous DM

maybe ? → assess strengths & weaknesses → SDM

No → substitute/proxy DM

OPPORTUNITIES FOR AND DIFFERENCES IN NEURODEGENERATIVE DISORDERS

- In neurodegenerative disorders, there is a reference point of the precedent self in determining choice
- Arguments regarding the rule/autonomy of the precedent self
- Stepwise or fragmented loss of capacity, leads to nuances and opportunities that cross-sectional stable disease does not

ARRIGHI ET AL, 2013

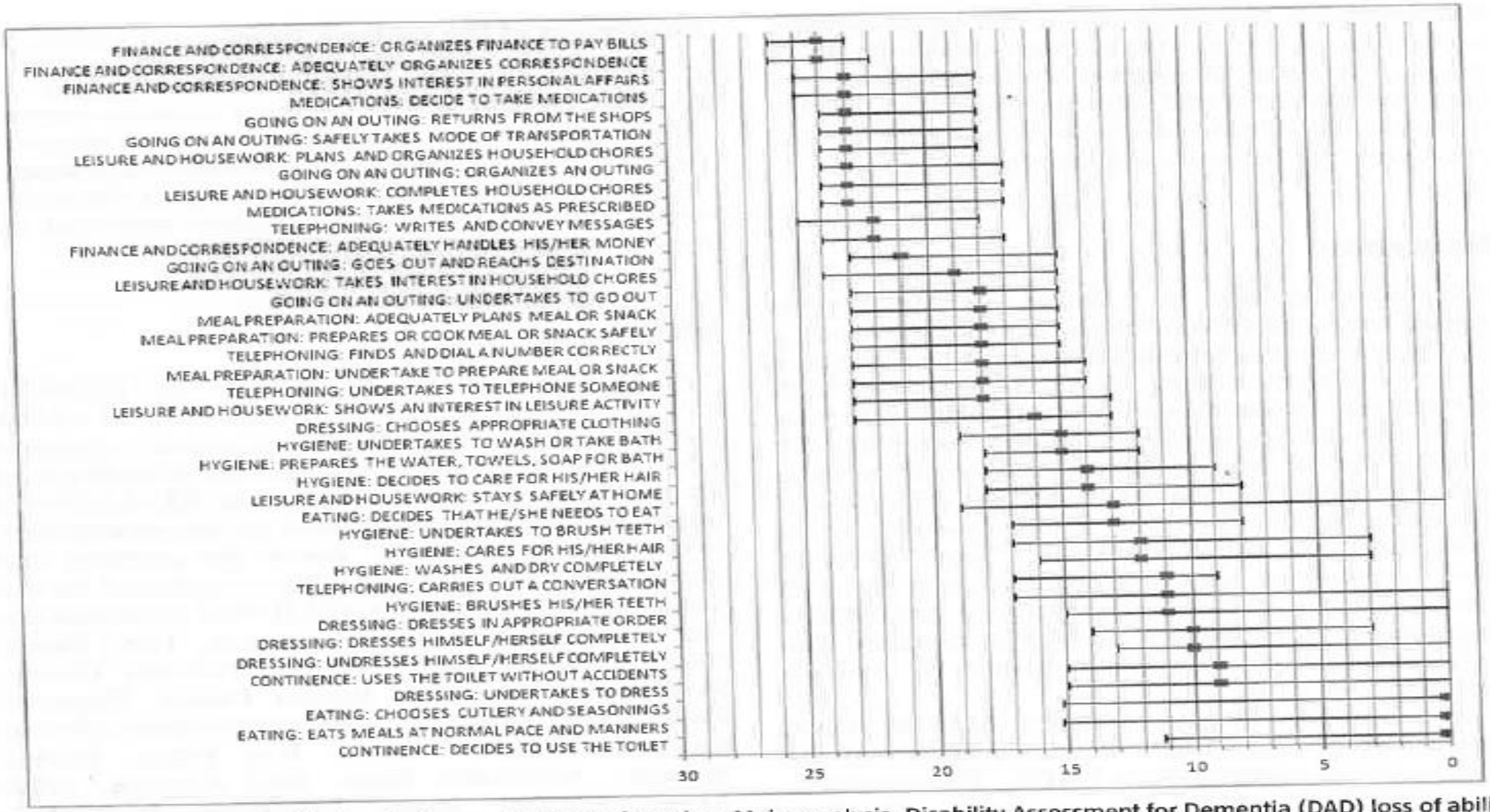


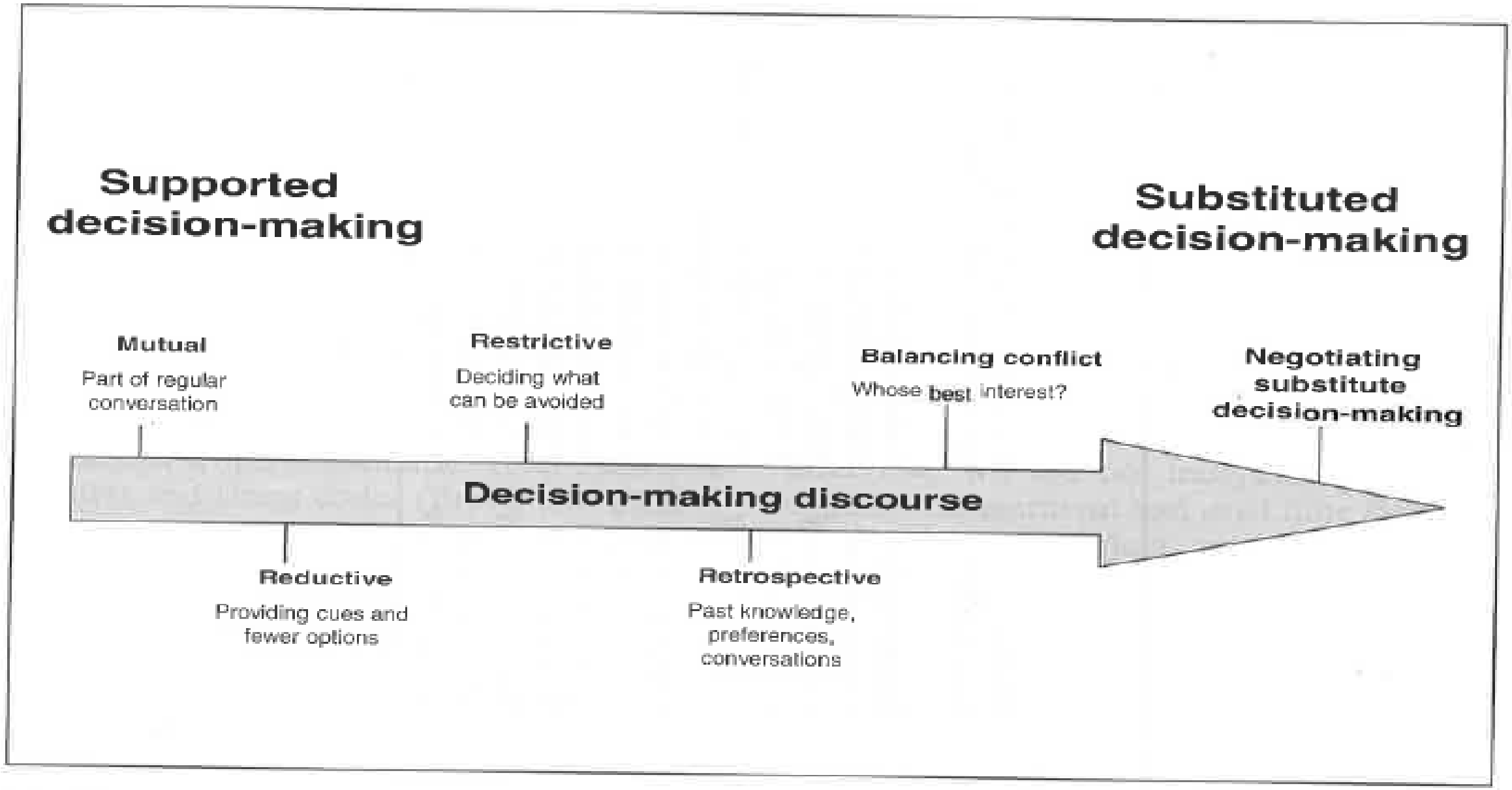
Figure 4. (Colour online) Alzheimer's disease participant's Kaplan–Meier analysis. Disability Assessment for Dementia (DAD) loss of ability

VARIABLE COGNITIVE LOSS

- Complex decisions (Okonkwo et al 2006; Griffith et al, 2003)
- Appraisal others (Peisah et al, 2006)
- Memory
- Word finding (Bayles et al, 1992; Frank, 1994)
- Expressive & receptive language
- Reading (Bayles et al, 1992)
- Signalling (Schiatratura, 2008)

Samsi & Manthorpe, 2013 **Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers.** Int Psychogeriatr. 25(6):949-61

BACKGROUND:
Exercising choice and control over decisions is central to quality of life. The Mental Capacity Act 2005 (England and Wales) provides a legal framework to safeguard the rights of people with dementia to make their own decisions for as long as possible. The impact of this on long-term planning has been investigated; everyday decision-making in people's own homes remains unexplored.
METHODS:
Using a phenomenological approach, interviewed 12 dyads (one person with dementia + one carer) 4 x over a year to ascertain experience of decision-making, how decisions were negotiated, and how dynamics changed. Qualitative interviews were conducted in people's own homes, thematic analysis applied.
RESULTS:
Respecting autonomy, decision-specificity and best interests underlay most everyday decisions in this sample. **Over time, dyads transitioned from supported decision-making, where person with dementia and carer made decisions together, to substituted decision-making, where carers took over much decision-making. Points along this continuum represented carers' active involvement in retaining their relative's engagement through providing cues, reducing options, using retrospective information, and using the best interests principle. Long-term spouse carers seemed most equipped to make substitute decisions for their spouses; adult children and friend carers struggled.**
CONCLUSIONS:
Carers may gradually take on decision-making for people with dementia. This can bring with it added stresses, such as determining their relative's decision-making capacity and weighing up what is in their best interests. Practitioners and support services should provide timely advice to carers and people with dementia around everyday decision-making, and be mindful



e 1. Decision-making discourse.

AWARECARE: A PILOT RANDOMIZED CONTROLLED TRIAL OF AN AWARENESS-BASED STAFF TRAINING INTERVENTION TO IMPROVE QUALITY OF LIFE FOR RESIDENTS WITH SEVERE DEMENTIA IN LONG-TERM CARE SETTINGS. CLARE ET AL, INT PSYCHOGERIATR. 2013 (25):128-39

BACKGROUND: **The extent to which care home residents with severe dementia show awareness is influenced by the extent to which the environment provides opportunities for engagement and by the way in which care staff interact with them**. We aimed to establish whether training care staff to observe and identify signs of awareness in residents with severe dementia resulted in improved quality of life for residents.

METHODS: In this pilot cluster randomized trial, care staff in four homes (n = 32) received training and supervision and carried out structured observations of residents using the AwareCare measure (n = 32) over an eight-week period, while staff in four control homes (n = 33) had no training with regard to their residents (n = 33) and no contact with the research team. The primary outcome was resident quality of life. Secondary outcomes were resident well-being, behavior and cognition, staff attitudes and well-being, and care practices in the home.

RESULTS: Following intervention, **residents in the intervention group (FAST STAGE 6-7) had significantly better quality of life as rated by family members than those in the control group**, but care staff ratings of quality of life did not differ. There were no other significant between-group differences. Staff participating in the intervention identified benefits in terms of their understanding of residents' needs.

CONCLUSIONS:

Staff were able to use the observational measure effectively and relatives of residents in the intervention homes perceived an improvement in their quality of life

SDM & END OF LIFE (HERTOGH, 2015)

- What do we when there is discrepancy in current choice with past choice in someone who has now lost capacity?
- authenticity and the need to update one's self concept in the face of memory loss and failure to recall precedent choices
- The right to change your mind when your mind has changed
- How do we use SDM (Hertogh, 2015).

ARTICLE 25
ALL IN SECTION MHO 59ZB

The Court when considering whether or not to give consent to the carrying out of treatment or special treatment, or the guardian when considering whether or not to give consent to the carrying out of treatment, under this Part,

shall observe and apply the following principles, namely to-

(a) ensure that the mentally incapacitated person is not deprived of the treatment or special treatment, as the case may be, merely because he lacks the capacity to consent to the carrying out of that treatment or that special treatment; and

(b) ensure that any treatment or special treatment that is proposed to be carried out in respect of the mentally incapacitated person is carried out in the best interests of that person.