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About our presenter...



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- *Decision-making, personhood and dementia: Exploring the Interface (2009)*
- *Broadening the Dementia Debate: Toward Social Citizenship (2010)*

“Assessing Capacity Within a Context of Abuse or Neglect”

Deborah O'Connor, Margaret Isabel Hall, Martha Donnelly

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Assessing (In)Capacity in Situations of Abuse: Toward a Contextual Practice Model

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Purpose

- Begin to tease out some of the complexities associated with understanding decisional capacity within a context of abuse;
- Address the importance of two critical elements:
 - Power
 - Relationship
- Develop a framework for considering a more contextualized assessment process

Data

- Retrospective analysis of professional experiences conducting assessments of incapacity under BC's Part 3, Adult Guardianship Act;
- Evaluation study of two pilot programs providing support to older adults who were victims of abuse

Case I: MARY WILSON

- Mary Wilson is an 82-year-old woman suffering from emphysema and severe arthritis. She also demonstrates signs of early dementia including poor short-term memory, disorientation to time and location, and impaired insight.
- Prior to her recent hospitalization, she lived with her husband of over fifty years and was dependent upon him for assistance with all of her daily care needs.
- His ability to provide this care is questionable – he is unable to establish reasonable routines for her care, prevents Mrs. Wilson from having contact with others, is routinely overheard by neighbours verbally berating Mrs. Wilson, and is physically rough with her.
- Several months ago, Mrs. Wilson was admitted to the hospital in very poor physical condition – she was confused, emaciated and dehydrated. She improved dramatically and, against the advice of the health care team, she returned to her apartment under the care of her husband. Both refused all home supports but did co-operate with periodic visits from the family physician.
- Recently, during one of these visits, Mrs. Wilson was found once again to be dehydrated, malnourished and very weak; she requested that she be taken to the hospital.
- Her condition is now stabilized and her husband is insistent that she return home. Mrs. Wilson indicates that she is quite frightened by her husband and does not believe he can take care of her. However, she is not agreeing to remain in care nor will she agree to a restraining order against Mr. Wilson even though he is becoming belligerent and threatening.
- **Is she capable of making this decision to turn down support?**

Case 2: LIZZIE DOBBS

- Lizzie Dobbs is a 77 year old widow living in a small basement apartment with her son, Victor. She is a tiny, frail woman who is legally blind.
- Victor, 47 years old and unmarried, moved in three years ago after he lost his job. He has not worked since related to increasing paranoia that others are out to get him. He refuses to seek help and is no longer bathing.
- About six months ago, the police were called by Mrs. Dobb's neighbor when she saw Victor slamming Mrs. Dobb's repeatedly onto the concrete floor. This was not the first incident of physical aggression that the neighbor had observed.
- When the police arrived Mrs. Dobbs was disoriented and taken by ambulance to the hospital. She was diagnosed with a shattered ankle, several broken ribs and severe bruising over her body.
- Victor was jailed overnight, given a restraining order against his mother and charged by the police.
- This was not the first incidence of violence but it was the first time that charges were filed. Mrs. Dobbs denies that she is at risk and is reluctant to testify against her son.
- **How can Mrs. Dobb's refusal to charge her son be understood? Does she understand and appreciate her situation? Is she capable of testifying in court?**

Understanding the Context of Assessments of (In)capacity

- Clarifying terms: competence, capacity, ...
- Capacity to do what?
- Standards for assessing: what will establish capacity?
- What will be assessed?

Use of Language

- Health/Legal Distinction
 - Competence – legal status as judged by legal professional
 - Capacity: ability to perform a certain task or make a specific decision
- Social status vs. function

“capacity can be thought of as a functional ability intrinsic to the individual whereas competency is a social status conveyed upon them” (Royall, 2002p.1885).

What is being measured?

- Domain-specific
 - Personal care
 - Health care
 - Finances (property)
 - Testamentary capacity
 - Ability to provide informed consent or give advanced directives
- Different levels of cognitive and procedural skills required for different domains
- Legislation specific

What are the standards for determining incapability?

- Four common standards:
 - Evidencing a choice;
 - Understanding relevant information;
 - Appreciating information in relation to one's own experiences;
 - Ability to reason;
- Standards invoke different levels of functioning
- Decisional assessment tools apply different standards
- Important to determine congruence between standards being used and legislation

What gets measured?

- Components of capacity
 - Cognition: information handling system and includes thought processing, perception, orientation, memory, judgment, and intelligence
 - Emotionality: includes feelings, motivations and values
 - Control (Intentionality): expression of behaviors (performance)
- Issues related to undue emphasis on cognitive component
 - Prioritizes rational thought as only relevant factor in making a decision
 - Link between cognitive reasoning and concept of autonomy is culturally-biased
 - Reliance on measures that have not necessarily been developed to assess capacity
- Need for a more contextualized, holistic assessment

Contextualizing the Assessment

- Feminist understanding of abuse dynamics
 - Power analysis
 - Violence represents coercive control by one person over another;
 - Reinforced by societal subordination of some groups over others
 - Prioritizing Relationships and connection
- Personhood or relational dementia lens
 - Conventional biomedical lens presumes a trajectory of decline related to neurodegenerative changes;
 - Personhood or relational lens recognizes that how a person is treated and perceived by others contributes to how they perform and behave
 - Focus shifts to personhood which is defined as a 'standing or status bestowed on one human being by others within the context of social relations and social being: it conveys respect, recognition and trust' (Kitwood, 1997)

Implications

- Strength perspective;
- Congruent with legislation that presumes competence;
- More holistic, person-centered and culturally sensitive
 - Provides a broader lens for interpreting responses
- Relationship building is an important part of of assessment process;
- Participation of person being assessed is a goal

Context: Addressing Safety Issues

- General literature on assessing incapacity does not usually address this component
- Safety considerations must be considered in relation to:
 - Process of conducting assessment
 - Actual decision-making of person being assessed (intimidation, undue influence)

Addressing Power Issues

- What is being assessed:
 - Importance of understanding emotional context:
How is disempowerment contributing to decision-making capacity?
- How is assessment carried out?
 - Presence of significant others
 - Relationship with assessor
 - Structure of data gathering
- Gendering (and culturing) meaning making

Meaning Making: Reinterpreting Consequences

- DO: *[Attempting to summarize and clarify] So then, what is more important [than getting help for yourself] is...your contact with your son and that you are able to continue in your role of taking care of him?*
- MB: *Absolutely. 100%*
- DO: *So having somebody step in, even if they were to step in and try to protect you, that's not really what you want?*
- MB: *No. I don't need that... NO (adamant voice) I don't need that*
- DO: *So, is it that you want to still to be able to*
- MB: *[Interrupting] to be Victor's mother! I want to be there for him.*
- DO: *So to be there for him?*
- MD: *Absolutely*
- DO: *[Clarifying an earlier message] Doing things like being able to help him take care of things...you want to be able to help him?*
- MD: *Yeah. Absolutely. Absolutely [Forceful tone]*
- DO: *And your contact with him, and having him involved in your life is more important to you than...?*
- MD: *Than Anything.*
- INT: *Than even your own physical safety?*
- MD: *Absolutely.*

Moving beyond 'capacity': Undue Influence

- Concept of capacity is *individualist*
- Undue influence considers the *situation* including interpersonal power dynamics
 - Focus is the nexus between power relationships and individual decision-making;
 - Does not consider intentionality of abuser

Conclusion

- Assessments of incapacity must incorporate the dynamics of abuse
- Assessments must move beyond a focus on intellect to consider the entire person;
- People are relational beings and must be understood as such;