

Understanding the client's experience of Personal Care: A phenomenological study

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(consumer)



Origins of the study

- Originated from MDC Client Reference Group.
- Joint initiative between MDC and Flinders University (Masters of Primary Health Care)
- Study to contribute toward staff education and training



Hearing the client's voice.....

- Literature review- Elding (2005), MDC Client Reference Group (2005)
- No studies identified in literature.
- Existing studies focussed on professional perspective re equipment, OH&S and paid carers.



Theoretical Framework



- Phenomenological Inquiry
- A methodology for discovering subjective meanings and interpretations given to experiences.
- “What is the lived experience of being a personal care recipient?”

Broad questions



- How is the personal care service actually experienced?
- What is it like to lose your independence and rely on others for your basic needs?
- How do carers of people with disabilities experience personal care services?



When things go askew.....

- Impact of power on decision making in regards to care.
- Flexibility and approach to personal care assessment.
- Vulnerability to perceived change in care arrangements.



Sample



- 3 participants who had a negative personal care experience and had made formal complaints.

(Convenience sample)

Participant Characteristics



- “Jan”
66 year old woman with multiple sclerosis.
- “Louise”
Woman in 70’s with a progressive spinal cord condition.
- “Kim”
Primary Carer of elderly mother with brain injury.



Setting

- own homes



Information collection

- Informal semi-structured interview
- Interviews taped and transcribed verbatim
- Analysis followed by second interview
- Participant comment on transcriptions



Data analysis

- Exploration of assumptions/prejudices
- Bracketting process
- Themes formulated and interview coded
- Derived personal narrative of person's story
- Participant comment on narratives

Identified themes



- Personal care as a reflection of perception of chronic illness or disability.
- Personal care as a social experience.
- Personal care as a means of improving quality of life.

- The context of seeking help.
“Jan”
- An emotional journey through change.
“Kim”



Personal care as perception of chronic illness or disability

- Asking for help is difficult.
“Jan”
- Ongoing loss and frustration.
“Louise”



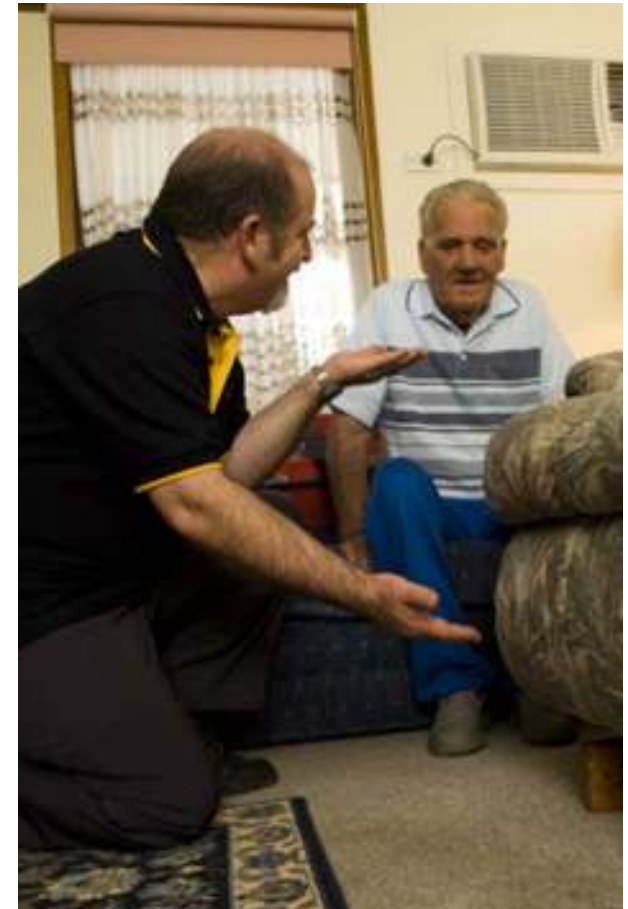
Tension between ongoing losses and fighting to maintain wellness

- Chronic illness shapes our response to our life situation and relationships.

“Jan”

- The need to fight to maintain a sense of wellness and normality.

“Louise”



Personal Care as a social experience



- The formation of valued relationships.
“Jan”
- Blurring of worker-friend relationships.
“Kim”
- Social contact as a coping mechanism
“Jan”

- The need to have trust.

“Kim”

- Denial of help in the absence of trust.

“Jan”

- Overcome feelings of social isolation.

“Kim”

“Jan”



Personal Care as a means for improving quality of life



- Link between perceived control, use of health services and wellbeing.
- Having respect.
“Jan”
- Valuing the client as an individual.
“Kim”
- Willingness to do tasks outside of the written care plan.
- An understanding of physical, psychological and emotional wellbeing.



- Control through doing things yourself.
“Jan”



- Control through directing workers.
“Louise”



- Control through self selecting workers and a valued role.
“Kim”

The benefits

- Personal care generally a positive experience.
- Promotes physical and psychological wellbeing.
“Jan”
- Improved quality of life.
“Louise”
- Opportunity to exert control.
- Meet personal needs as a carer
“Kim”



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