Qualitative nursing research in dementia

Abstract (taken from the Abstract Booklet):

Qualitative research, an umbrella term for different methods and methodologies, has received increased attention in health care research, also in the domain of the care for persons suffering from dementia. Qualitative research is often used to study the lived experience of health care “clients”, their perception of their situation and the meaning they give to the situation they are in. It allows uncovering processes at play in dealing with (taxing) situations and demands arising from health problems. Qualitative studies can be used to study the process and the effects of health care. Action research studies allow improving practice directly.

In the field of dementia care qualitative research has been used extensively to study the lived experience of family members and more particular family caregivers. In particular burden and coping have been paid attention to. More recently, family members have been seen and studied as such: persons close to someone suffering from debilitating and alienating disease. What it means for professionals to give care to patients suffering from dementia has also been a topic repeatedly investigated. The lived experience of the persons suffering from dementia has been less frequently studied, and almost exclusively in the early stage of dementia. Qualitative studies rely mostly on interviews and the interviews with patients suffering from (serious) dementia are not easy to conduct and/or interpret.

Care giving and ward atmosphere can and have been fruitfully studied using ethnographic methods. Observation studies, nowadays often using video-registration, can help to understand care processes in dementia care, and evaluate the care from an ethical perspective. Especially the combination of observation and interviewing is fruitful to uncover what goes on in the care of demented patients. In the seventies Norberg et al. conducted a series of observation studies focusing on actions of daily care for demented patients. Nurses and patients were meticulously observed during care giving, and the reactions of the demented patients were carefully analyzed, thus allowing
defining what could be considered best practice in the (daily) care of patients suffering from dementia. It seems that the tradition of such studies has disappeared and we would applaud its coming back. The use of a qualitative design to experimentally study the effects of deliberate change in care arrangements or organization is rather exceptional. The study of de Lange shows that it can be very interesting. Action research has been conducted in the field of dementia care with the aim of directly improving care.

Qualitative research in patients suffering from dementia presents particular challenges. As communication with the patient is not easy, interpretation of what is said often difficult, and family members not always able to speak for the patient, it is not easy to evaluate findings as to the meaning for dementia care. Really understanding patients suffering from dementia remains difficult, as the interpretation does not easily allow crossing the border of what is “foreign”. It often remains difficult to judge whether what seems right is indeed right. Nonetheless, even if the research does not allow going further than best guesses, our contention is that it should be used abundantly, as best guesses are certainly to be preferred above uninformed guesses. Qualitative researchers need to be real and realistic as to their pretences, but not so humble that the potential contribution they could make to improve the care and the quality of life of persons suffering form dementia and their family members, would remain unrealized.

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Maria Grypdonck, Prof. Dr., Els Steeman, Sofie Verhaeghe, Dr., Dep. of Nursing Science, Ghent University, 9000 Ghent, Belgium
E-mail: maria.grypdonck@ugent.be
Qualitative Research in Dementia and Dementia Care

M. Grypdonck
E. Steeman
S. Verhaeghe
Ghent University
Qualitative Research

• Generic term
• For disparate methodologies
• With a number of common characteristics
• Fast growing body of research in health care
• In spite of the Evidence Based Practice hype
Common characteristics

• Data based; empirical
• Analysis through interpretation: assigning meaning to data; saying more than is in the data
• Investigates “subjective world”
• Controlled researcher subjectivity
• Disciplined, systematic procedures
The world of qualitative researchers

- Reality as lived by the subjects
- Phenomenological world
- Focus or attention to meaning and existential themes
- Symbolic interactionism
- Or at least perceptions
- Research reconstructs co-created reality (Charmaz)
- Several reconstructions can be valid
- Objectivity: doing justice to the object of study (Smaling)
Some important types of qualitative research

• Phenomenological descriptions
  – Often using “common themes”
  – Or identifying “essence” of experiences

• Studies explaining existential themes and behaviour
  – By reconstructing the internal logic of the behaviour
  – Identifying meaning
  – Laying bare the processes at play

• Grounded theory
  – Inductive theory (grounded in the data)
  – Identifying “basic social/psychological process”
Major types of qualitative research

- Phenomenological descriptions
- Qualitative studies explaining behaviour
- Grounded theory
- Ethnographic studies
  - Studying communities
  - “culturally mediated meaning and behaviour
- Case studies/multiple case studies
  - N=1; N=nx1
  - In depth studies of individuals
Qualitative research in dementia

• The lived experience of persons suffering from dementia (PSD)
  – Several studies
  – In spite of difficulties qualitative research poses
  – Limited to early stage
The lived experience of patients in early stage (Steeman et al.)

PSD relate positive stories

- Problems due to memory loss are limited or have limited consequences
- They have many competencies resulting in past and present accomplishments
- They are being valued by others, in the past and in the present.
The lived experience of patients in early stage (Steeman et al.)

• PSD relate positive stories:
  – Problems due to memory loss are limited or have limited consequences
  – They have many competencies resulting in past and present accomplishments
  – They are being valued by others

• Positive story does not correspond with observations and reports/stories of family members? What does it mean?
The lived experience of patients in early stage (Steeman et al.)

- PSD relate positive stories
- Positive story does not correspond with observations and reports/stories of family members? What does it mean?
- Do we elicit positive stories by asking about problems?
- Struggling to remain of value
  - By balancing being valued and being worthless
  - Using strategies such as minimizing, rationalizing, normalizing, somatizing problems, affirming competencies, humour, avoiding confrontation....
Qualitative research in dementia in later stages

- Problems:
  - Communication
  - Interpretation

- Adapted strategies to collect data

- Ethnographic and (video-)observation studies to overcome problems
  - Provide rich context to help interpretation
  - Disease precludes validation with “members”
Lived experience and burden in family members

• Approached mainly as caregivers
• Study of burden
• Study of lived experience as a family member
Constructing Alzheimer's: narratives of lost identities, confusion and loneliness in old age.

W. L. Hinton, & S. Levkoff

- Analysis of narratives
- Reconstructing the story line
- In multicultural context
- Three story types

*Cult. Med Psychiatry, 23, 453-475, 1999*
The story of AD
as recounted by Irish-Americans, Afro-Americans and Chinese-Americans

• Stories of lost identities and deteriorating brains
• AD is an insidious inner process of deterioration of the brain and loss of self
• “Difficult” behaviour is a consequence of the disease and out of the person’s control
• “let go” and disappearance of the person
• Social death with grief and sadness in family members
Other stories of AD

- **Chinese stories:**
  - Confusion and dependency coming with old age
  - The machine breaks down over time
  - Stories about helping and ethics in family

- **Puerto Rican stories**
  - Extreme loneliness both as cause and as consequence of AD
  - AD is consequence of family tragedies
  - Destigmatization of AD
Studies of care and communication

- Studies of professional care givers
  - To bring problems to light
  - To identify excellent practices
  - Descriptions intended as either the former or the latter

- Studies of care arrangements
  - Evaluation through interviews with family members, practitioners and (much less frequently) patients
  - Observation
  - Problem of criteria: what is good care?
  - Experimental research: de Lange et al.
Daily care for patients suffering from severe dementia

- Observational studies
- Uncovering patterns in reactions
- Through meticulous observation
  - Of nurses' behaviour in practical care giving
  - Of patient's reactions to these actions at the detailed level
- Leading to advice for care
- Video-observation increases possibilities
- Could be used by very patient researchers for study of communication
Action research

- Participation of researched and researchers in designing, executing and interpreting the study
- Directed toward changing practice in a specific setting
- Bringing about and understanding change is more important than the generation of generalizable knowledge
Using qualitative research diligently

• Qualitative research brings to light subjective reactions to illness, care, loss, life
• It can foster understanding
• Being understood is a crucial factor in good, fine-tuned care
  – The experience of being understood is essential in humanizing care
  – Understanding the lived experience of the client helps in choosing well tuned measures, interventions, in designing settings and arrangements
Using qualitative research diligently

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- It can foster understanding
- Being understood is a crucial factor in good, well-tuned care
- Knowledge from qualitative research should not function as prejudices
- It can help to understand the situation but should not take the place of careful and open connection and investigation in every particular situation
Qualitative research and Evidence based practice

• Qualitative research does provide “evidence” of a different nature than quantitative studies
• It is not to be used as “external” evidence
• But as an aid in the exploration of the meaning of the situation for the client and of what can be helpful given the situation and its meaning
• Is is of great value in interpreting how to apply “evidence” in particular cases
Conclusions

• Qualitative research has much to offer to health care
• Despite the limitations in reflective competencies of the PSD and the difficulty to understand the world of the patients, qualitative research can enlighten practice
• Even though in many cases the researchers cannot offer the degree of certainty that we like to find in research
• It is better to make well informed guesses than uninformed guesses.