Palliative Care for People with Dementia: Gender-Narratives

Elisabeth Reitinger, Erich Lehner, Doris Lindner
Elisabeth Wappelshammer, Katharina Heimerl

IFF-Institute of Palliative Care and Organisational Ethics
University of Klagenfurt, Vienna

BACKGROUND and AIMS

Person-centered care as well as palliative care for people with dementia are gaining importance. Dying trajectories are characterised by lingering ways of moving away and coming back to life again. These particular circumstances in living with men and women with dementia as well as their special needs have to be taken into account in accompanying them during their journey with dementia (Kojer, Schmidl 2011; Small, Froggatt, Downs 2007, Arcand et al 2013).

Gender-identity as a central dimension of being a person as well as gender as a social category influence all relationships and have to be acknowledged as relevant aspects in care situations. Therefore the aims of the study presented are 1) to reveal gender-narratives within care situations of people with dementia in different care settings, 2) to contribute to reflection among professionals for gender-sensitive care as well as 3) to find out „rules of the gender-games“ that support gender-equity in organisational cultures.

METHODS

Based on a qualitative participatory approach (Hockley, Froggatt, Heimerl 2013) the study design encompassed collaboration with three different types of organisations: a long term care setting, three home care teams and an acute care unit. Four provinces in Austria were included. As an interdisciplinary research team we conducted seven focus groups with multiprofessional care teams. Leading questions were „In which stories did gender become obvious?“ and „What are your reflections about the meaning of gender-sensitive care relations?“.

Expert interviews with ten professionals in management positions completed the inquiry. Leading themes in the interviews were „gender-relations within the team“ and „relevant aspects for gender-equity within organisations“. A qualitative content analysis of data was undertaken within the research team. Committed to the participatory approach these results were validated with practitioners and gender-experts and gender-narratives were identified.

RESULTS

Results show the diversity of gender as a personal, relational and social category. The intersection of gender with other social categories like generation, ethnicity, sexual orientation or social class becomes evident in various situations.

Gender in Care Situations: Gender-Sensitivity

Themes that emerge within dominant narratives are dignity and appreciation, family dynamics, doing gender while doing care, sexual attraction and intercultural communication. Gendered life stories - e.g. being a young woman or man during the war - have to be listened to and taken serious. Relational aspects of doing gender while doing care reveal the importance of reflecting one’s own gender-biographies, attitudes and values. Gender sensitive reactions to family dynamics question traditional female care burden and include men into care networks.

Gender in Organisations: Gender-Equity

Within professional teams gender-mix seems to be most welcome. Different perspectives to care-work enrich common learning. Some duties as emotion work or bodywork are viewed more as “female” and others like technical or organisational tasks more as “male”. To support gender equity in organisations qualitative and quantitative indicators were formulated.

Booklet on Gender-Sensitive Care for Professionals

Based on these insights a booklet with narratives, theoretical background and questions for reflection for professionals, especially managers and teachers was composed. Gender reflection is presented as a collective learning opportunity and is always interconnected with „doing gender“ and gender structures in society (West and Zimmermann 1987).

CONCLUSIONS

- Talking about gender-relevant issues in care situations with people with dementia supports reflection of professionals and researchers. Gender narratives include different issues and show how doing gender takes place by involving all those who participate in a care situation. Interestingly, themes interconnected with gender show the full range of dimensions of diversity and give professionals a chance to talk about taboos.
- Power dynamics interact with doing care and doing gender. Living with dementia means that needs for care grow with time. Emotional work, communication, touch and bodywork – most often still interpreted as „female domains“ – gain more impact in palliative care but are at the same time devaluated by society (Twigg 2006).
- Gender-equity in care organisations always requires a change of cultures within an institution and also recognition that the organisation is embedded in gender-structures of society. Balance of emancipatory innovation and appreciation for traditional values seems to be central especially in palliative care for people with dementia, where continuing communication and relations are most important for a dignified life until the end.

References


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Contact of Presenting Author

Assoc. Prof. Dr. Elisabeth Reitinger
Institute of Palliative Care and Organisational Ethics
IFF-Institute of Palliative Care and Organisational Ethics
Schottenfeldgasse 29/1,
1070 Vienna, Austria
elisabeth.reitinger@aau.at