1. BACKGROUND AND AIMS

A participatory approach is becoming increasingly important in health research and dementia studies. The project called "Dementia-friendly Community Pharmacies - community-based health promotion for people with dementia and their caregivers" uses a participatory research approach (Hockley, Froggatt & Heimerl, 2013) to promote dignity and quality of life to people with dementia and their informal caregivers. This poster presents some results of the needs-assessment that was done as a basis for intervention in the participatory project.

2. RESEARCH QUESTION

"What are the daily experiences of caregivers of people with dementia and what role could pharmacies play to support them in their communities?" was the leading research question. Topics covered were experiences and needs in relation to daily caregiving, the use of support systems and strategies to promote their own health.

3. METHODS

Qualitative interviews were conducted and a focus group was used to explore the daily experiences, activities and needs of informal caregivers of people with dementia. A close collaboration with the local self-help group was crucial for this purpose. All participants were strongly motivated to contribute to a better understanding of their perspective.

4. RESULTS

EVERYDAY EXPERIENCES OF CARE

- Positive: Experiencing continuity through shared activity; humour and emotional belonging; "we still are laughing a lot"; "we still have the intensive emotional connection"
- Challenging activities: Problems in assisting in everyday activities; No activities without the person with dementia ("one would think it is psycho-terror if you wouldn’t know better")
- Challenges in care: Experiences of violence; conflicts with sexuality
- Fight against the system: "bureaucratic terror"; ignorance of professionals

IDEAS FOR INTERVENTION IN COMMUNITY PHARMACIES

- Awareness campaigns
- Special training for medication and information about possible reciprocal effects
- Easily accessible Information and proactive talking
- Using the physical space of the pharmacy for information and networking

5. ANALYSIS

A thematic analysis was performed (Braun & Clarke, 2006). The results were discussed with peer-researchers for interpretation and member-checked with representatives of the local self-help group to enhance validity.

6. RESULTS:

IMAGES OF DEMENTIA - “dementia is the new cancer”

- “Harmful information” from professionals and internet/media results in a negative image of predicted “deterioration”
- The negative image contradicts own experiences in daily life
- A more positive image of dementia requires communication

SUPPORT AND NEED OF SUPPORT

- Contradicting the myth of “not getting help”
- Using the community requires communication
- Different in urban and rural settings
- Information about support and health services is missing
- Inadequate services contradict “myth” of “getting help too late”

Funding

The project “Dementia-friendly Community Pharmacy” is funded by “Fonds Getundes Österreich / Gesundheit Österreich GmbH”, “Wiener Gesundheitsförderung WGF” and financially supported by “Österreichische Apothekerkammer ÖAK”.

References


Acknowledgments

We would like to thank the contributing informal care-givers who shared their experiences with us. You thank you also to Alzheimer Austria for their ongoing support of the project, as well as our colleagues at the Institute for Palliative Care and Organisational Ethics, who are contributing to and supporting the project, especially Ilona Wigner. Thank you Petra Plunger for the basic design of the poster.

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