

## **Summary**

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Title of the dissertation: Experiences of family carers of people with Alzheimer's disease providing care in the home environment.

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## **Introduction**

Care is one of the most primal human activities and has always been an inseparable and fundamental element of human existence. One of its areas is the care of a person with Alzheimer's disease, which is the daily routine of millions of people around the world. People aged 75 and over currently account for over 10% of the Polish population, and it is estimated that the aging of the said population will accelerate from 2030. This change means that both the economy and society face a serious, real challenge of preparing to meet the consequences of this process. This change is particularly important in regards to providing appropriate care for people with Alzheimer's disease in the local community, including ensuring that it is exercised by family members.

## **Methodology**

The subject of interest of this work is the experience of family carers of people affected by dementia in the course of Alzheimer's disease.

The starting point for the conducted research was the question: How do informal caregivers of people with Alzheimer's disease providing care in the home environment describe the experience of the care they provide?

Research interest was aroused by such aspects as: becoming a caregiver, daily problems and joys of caregivers, giving meaning to events that take place in the course of providing care, as well as designing the future after its completion. Recognizing the pressing social and demographic problem of the increased demand for care among the elderly and wanting to create a reality that supports people suffering from dementia, their carers and families, it is necessary to know and understand what mechanisms occur in the course of caring for a dependent person

in the home environment. By principal, Dementia syndromes concern the area of medical sciences, but these are issues whose civil and social consequences affect caregivers, local communities and the society as a whole. The research issues discussed relate to the subject of interest that is social pedagogy, which examines the mechanisms affecting an individual's development as well as their social environment.

The research is of an exploratory and diagnostic nature and allows for exploration and possibly full description of the social phenomenon that is caring for a person with Alzheimer's disease in the home environment by a family carer. The subject of the research are the experiences of informal carers of people with Alzheimer's disease who provide care in the home environment, and the aim is to learn about their individual experiences.

This dissertation uses qualitative methodology due to the complexity of the issues raised in it and the need for a holistic approach to the social problem. The research tool was an in-depth interview questionnaire. 12 informal carers from 10 families took part in the study.

No research hypothesis has been formulated in this work, due to the lack of empirical data that could support the hypothesis in a legitimate way. An interpretive paradigm was adopted, referring to the phenomenological perspective and hermeneutics, the aim of which is to understand, describe and interpret human behavior.

### **Conclusions and recommendations**

The main postulate in the field of care for the elderly and chronically ill in Poland is to strive to establish a separate, comprehensive support system covering care for people suffering from dementia, including Alzheimer's disease. The most appropriate action is the integration of the assistance system through mutual cooperation of social assistance institutions, the patient's family and local environment, health care institutions, as well as third sector organizations, including those providing volunteer work.

For practical reasons, recommendations have been made within the concept of deinstitutionalization, which is crucial for social policy, and have been indicated for social pedagogy, health pedagogy, andragogy, as well as medicine and broadly understood social policy.

This dissertation is a contribution to research on informal care in the context of dementia diseases.

Providing adequate, holistic long-term care for the elderly, interdependent and dependent is a demographic and social challenge faced by many countries in the world, including Poland. Systemic changes in the field of long-term care are necessary, from increasing the financing and creating a coherent system of financing benefits, to the development of community social services.

The recipient of the service should be treated as a co-producer of the service (empowerment), whose needs and possibilities in terms of independent existence are met by the system. Design and coordination of services must be of an environmental and local nature, which translates into accessibility regardless of the geographical location of the recipient's place of residence. The scientific community and practitioners in the field of social policy and welfare should jointly face the new challenges posed to society, giving rise to dilemmas and questions in the face of moving away from the intervention model of social policy in favor of deinstitutionalization, coordination and process-based action rooted in social prevention.