

## Chapter 7

# Stable Self–Concepts and Flexible Coping Strategies of People with Dementia Attending Dementia Self–Help Groups in Germany: Results from the Qualitative Longitudinal SEIN Study

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### ABSTRACT

*In this chapter, results from the qualitative longitudinal Selbstbestimmung und Intervention (SEIN) study conducted at the DZNE site in Witten are presented and discussed against the background of a previously conducted systematic review of the subjective needs, demands, and coping strategies of community-dwelling people with dementia. The objective of the study was to examine how participants of dementia self-help groups in the early and middle stages of the condition cope with their illness. A phenomenological approach with a life-course perspective served as the framework for the study. The findings suggest that a person's self-concept is not changed by dementia but instead adapts over the trajectory of the illness. Struggling between external control (defence against stigmatization) and external protection (being taken seriously), and aiming for "Inner Security" were central concerns for the participants. Biographical background and social network are determining factors in the development and use of coping strategies.*

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## INTRODUCTION

In the context of aging societies worldwide, dementia is often referred to as one of the most important public health priorities. First and foremost, dementia is considered as an epidemic whose existence poses a challenge for health and social security systems (World Health Organization, 2012). The second most urgent concern usually involves addressing the burden that dementia places on the families and significant others who care for individuals with dementia who live in the community (Etters, Goodall, & Harrison, 2008; Hughes et al., 2014; Pinquart & Sorensen, 2003). Only third, the perspective of people living with dementia is focused on in public debates and policy making (Cheston, 2000).

The concept of dementia has undergone a process of “cultural transformation,” such that it has lost its terrifying associations with “raving lunatics in the old-time asylum” and is now perceived as an “understandable and human condition” (Kitwood, 1997, p. 133). Nevertheless, the voices and perspectives of people with dementia have long been ignored. This situation has recently changed, and a growing number of research projects aim to gain insight into the inner experiences of people with dementia. Although a broad range of scientific evidence regarding the perspectives of people with dementia is available, dementia still seems to be perceived as a rather cryptic condition by the general public, policymakers and even health care professionals.

The German Center for Neurodegenerative Diseases (DZNE) at the research site in Witten, Germany, has focused on the perspectives of people with dementia as part of its scientific strategy to consider and meet the subjective needs of affected individuals through health care research and the development of health care strategies for them and their families (Bartholomeyczik, Holle, Riesner, Halek, & Vollmar, 2010). It is assumed that a person-centered approach (Buber, 1983; Rogers, 1983) in health care and research (McCormack, 2004) is the basic foundation to ensure and enhance well-being and quality of life of people with dementia at any stage of their condition (Downs, 2013; Kitwood, 1997; Love & Pinkowitz, 2013). At the DZNE site in Witten we believe that it is essential to consider the needs and subjective demands of people with dementia in coping with their symptoms and promoting self-determination over the illness trajectory to create the (social) conditions that support them in integrating dementia into their daily lives.

In the recent SEIN (Selbstbestimmung und Intervention = Self-Determination and Intervention) study, conducted at the DZNE site in Witten (Panke-Kochinke, 2014), a phenomenological approach (Millet, 2011) is used to study the subjective experiences of participants of dementia self-help groups in Germany. Within the framework of the longitudinal SEIN study, dementia is not approached from a biomedical view but instead from a sociological perspective (Davis, 2004). A life-course perspective is applied to study the meaning of dementia for people who live with the condition and its impact on the self-concept of people who must attempt to integrate dementia into their everyday lives.

In this chapter, the results of the SEIN study are presented and discussed against the background of a previously conducted systematic review on the subjective experiences of community-dwelling people with dementia as well as their needs, subjective demands and coping strategies (von Kutzleben, Schmid, Halek, Holle, & Bartholomeyczik, 2012).

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