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Original Research

Knowledge management in dementia care networks: a qualitative analysis of successful information and support strategies for people with dementia living at home and their family caregivers

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ABSTRACT

Objectives: Stakeholders involved in community dementia support services often work on their own and without coordination with other services. These circumstances can result in a lack of information and support for people with dementia and their family caregivers at home. To increase the coordination between existing support services, so-called 'Dementia Care Networks' (DCNs) have been established. Most of the tasks that are performed in DCNs are based on communication strategies. Therefore, knowledge management (KM) is a key process in these networks. However, few studies have focused on this topic. This study attempted to evaluate KM strategies in DCNs across Germany as part of the DemNet-D study.

Study Design: A qualitative interview study design was used.

Methods: Qualitative data were collected during single and group interviews with key persons associated with thirteen DCNs. Interviews were audiotaped and transcribed, and a structured content analysis was conducted. The framework for the analysis was derived from a KM model.

Results: Information dissemination strategies for people with dementia and their informal caregivers based on actively established contacts appear to be more successful than passive strategies. General practitioners often play a key role as external gatekeepers in initiating contact between a network and a person affected by dementia. In this context, case managers can help integrate external stakeholders, such as general practitioners or pharmacists, into DCNs using different KM strategies. The systematic development of

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common objectives under an agency-neutral leadership seems to be an important aspect of successful KM within DCNs.

Conclusions: The findings reported here can help DCNs optimize their KM strategies for generating tailored information and support services for people with dementia living at home and their family caregivers. In particular, the identified potential knowledge distribution barriers and facilitators will be of practical use to DCN stakeholders.

Introduction

In 2012, approximately 24.3 million people were affected by dementia worldwide. This number is expected to double every 20 years, reaching a total of 80 million people by 2040.[1] Around the world, family caregivers play the most important role in supporting people with dementia (PwD) at home.[1] However, being a caregiver is often a significant burden.[2] There are over 1.5 million people living with dementia in Germany,[1] representing the fifth highest prevalence of PwD worldwide.[3] Germany has one of the most highly developed health care systems in the world;[4] however, most home-based dementia support is provided by general health care service organizations without specialization for PwD.[5] It is the responsibility of these organizations to adapt their services to the needs of PwD and inform caring relatives about available services, but there are no standardized guidelines for these processes.[5] Therefore, existing dementia support services are often not efficiently linked with different stakeholders in the home-care setting.[6] This situation applies to many countries worldwide.[1] As a result, PwD and their family caregivers are often not well informed about the services available in their community and therefore do not use the support structures efficiently.[2]

Some countries have already implemented network-based organizations to enhance cooperation in this area of health care.[1] In Germany, so-called ‘Dementia Care Networks’ (DCNs) have been founded in different regions. DCNs function as diverse structures that improve the connections between dementia support stakeholders, PwD, and their caregivers within the community.[7] Generally, achieving higher degrees of innovation and professionalization are key goals of different types of networks.[8] Furthermore, providing effective points of entry to make support services accessible to PwD and their caregivers is a primary goal of DCNs in particular.[9] The positive effects of a DCN regarding the support of PwD have been only recently demonstrated in a study conducted by Köhler et al.[4] Network goals, such as those referred to here, are based on communication processes and are associated with knowledge management (KM) strategies, including the development, exchange, and use of information,[10] which is why all types of DCNs apply KM structures and processes to achieve their goals.[11]

To our knowledge, no research has been published on applying KM strategies in DCNs until now. Therefore, this study attempts to describe the information-based KM structures and processes of thirteen DCNs in different regions of Germany. Furthermore, it attempts to identify and analyze potential barriers to specific KM processes and suggests how to overcome such barriers. The findings in this article will contribute to the development of a ‘dementia network toolkit’—a compilation of guidelines and materials referring to successful KM strategies in DCNs in Germany.

Methods

Thirteen DCNs in different states of Germany were included in this study. Because the structure and funding of DCNs are very diverse, sufficient data on the total number of DCNs in Germany are not available. The DCNs included in this study were chosen by the German Ministry of Health, which funded this study. The DCNs had the opportunity to apply for funding with the ministry, and based on their application and experience providing support as a successful DCN, the 13 participating networks were chosen. The qualitative data were collected through semi-structured single-person and group interviews using literature-based, pretested interview guidelines. The qualitative analysis was performed using a structured content analysis adapted from Mayring.[12] The first round of interviews was conducted with the coordinators of the included DCNs. The second round of interviews was conducted through group interviews with three to eight key persons in each DCN. These key persons held different positions, and they represented a variety of professional backgrounds, e.g., home care staff, social workers and physical therapists. The number and occupational characteristics of the interviewed DCN stakeholders are listed in Table 1.

The emphasis of these group interviews was to reflect a wide range of perspectives on the topic of KM in DCNs. All interviews were audiotaped and transcribed. To ensure data reliability, the analysis process and code development were supported by feedback from colleagues with qualitative research expertize who were not directly involved in the DemNet-D project.

To facilitate a common understanding of the content in this paper, it is essential to know that there are broad definitions of the terms ‘knowledge’, ‘knowledge management’ and ‘knowledge circulation’.[13,14] In this study, knowledge was defined as the target-oriented and reflective use of information.[10] Furthermore, KM describes strategies for the reflective development, use and evaluation of knowledge.[10] Knowledge circulation is defined as the process of periodic knowledge exchange across different areas of KM and between different