

Home care services for people with dementia in Sweden: challenges for care-recipients and caregivers with diverse linguistic and cultural backgrounds

Over 160.000 people are living with dementia in Sweden. Due to greater longevity of people, age-related diseases such as dementia are also estimated to rise to 250.000 in 2050¹. Moreover, health care provisions and early medical diagnosis of dementia allow people to live longer with their disease in their own homes (Hydén & Antelius, 2017). There is therefore currently a growing demand for home care services for people with dementia (Socialstyrelsen, 2014). This is true for the native Swedish majority population, as well as for minority ethnic groups living in Sweden.

With the growth of an elderly population and care workers with culturally and linguistically diverse backgrounds in Sweden, new challenges for the provision of care for people with dementia is arising. Dementia is an irreversible degenerative brain disease, which diminishes cognitive and communicative abilities of people (Hellström & Hydén, 2016). People with dementia who speak Swedish as a second language may also have other particular challenges as they may mix languages, or revert to speaking only their native tongue as the disease progresses (see e.g. McMurtray et al., 2009).

This project proposal is based on three important issues – First, the study of dementia care in the context of multilingual home care services is scarce. This is also true for the whole issue of immigration and eldercare (e.g. Torres, 2010), and particularly Swedish dementia care for various ethnic groups (but see Antelius & Kiwi, 2016; Heikkilä & Ekman, 2003; Jansson, 2014). Second, apart from individual differences, there are distinctive challenges in care practices due, not only to family-specific relations, but also to traditional filial piety or cultural, normative care-seeking and caregiving behaviors (Schrauf & Iris, 2011). Third, although there are many studies recognizing the impact of ethnocultural differences on the perception of dementia (e.g. Connell et al., 1997; Yeo & Gallagher-Thompson, 1996), there are no studies of how these perceptions relates to behaviors in real practices. Research on actual interaction in dementia care that involves ethnocultural and language differences is lacking. This leads to the fact that not knowing enough about the challenges and the needs for the particularities of communication with people with dementia with non-Swedish backgrounds may negatively impact the caregiving processes for them.

Research focusing on social encounters in residential care facilities shows the significance of common understanding in communication between the residents and the staff which may otherwise lead to interactional conflicts and misunderstandings (e.g. Jansson & Plejert, 2014). Mutual understanding facilitates the establishment of trust and rapport between participants and affect people with dementia positively (Emami & Ekman, 1998; Runci et al., 2012). However, there are not many studies on communication in home care services (but see Lindström, 2005; Heinemann, 2009), and research on multilingual encounters in that setting is particularly lacking.

Purpose/Aim of the project

By applying an interactional perspective and focusing on two sets of data; one where the participants share a (relatively) common language and culture (e.g. Swedish), and one where they do not (e.g. Swedish-Arabic), the project aims to investigate challenges in communication that may occur in these settings, and what methods and strategies that caregivers and people with dementia (and their family members) employ to overcome such challenges. Thus, the project will provide both knowledge about problems and prospects of various communicative practices, and recommendations about participants' well-functioning methods regarding how they understand and manage difficulties that may arise in social encounters.

Through a systematic investigation of the organization of communicative practices in real social encounters in home care service for people of diverse ethnic backgrounds with dementia, the project intends to answer the following questions:

¹ <http://www.demenscentrum.se/Fakta-om-demens/Demens-i-siffror/> retrieved 20181112

- 1) When receiving home care services, what types of communicative challenges are people with dementia and their family caregivers faced with when they and the home care staff do not share the same language and culture?
- 2) What types of communicative strategies and practices do people with dementia (and their family caregivers) and home care staff use to overcome arising challenges in their interaction?
- 3) What are the differences and/or similarities in the communicative practices of people with dementia and home care staff when they share language and culture from when they do not?

By answering these questions, this project will 1) uncover challenges in communication in two types of social encounters where participants either share or do not share a common language and culture and 2) provide knowledge about actual care practices in relation to both data sets, with a particular focus on the strategies used by participants to overcome emerging difficulties in their communication, and 3) provide empirically based recommendations related to common strategies to overcome communicative challenges in the setting of home care services, relevant for people with dementia and their relatives, as well as for care-giving staff.

Theory and Method

The project draws on a dialogical theory of communication (Linell, 2019) in which communication is considered a social activity which is performed through contextualized interaction. That is, people including people with dementia, are considered to have abilities to interact directly or indirectly with others and can make sense/meaning of the interaction they are engaged in. Interaction, nonetheless, requires a common ground (Clark, 1996) by which people co-construct an interpersonal and mutual understanding. Social interaction is thus “a primordial site of sociality and social life” (Schegloff, 1987: 101), something that is considered crucial as the basis for the quality of life for people with dementia (Hydén & Antelius, 2017).

To focus on communication with people with dementia, this project adopts a qualitative empirical approach by combining ethnographic observations, semi structured interviews together with video recordings (e.g. Silverman, 2014), and also by conducting interaction analysis (Goodwin, 2018; Sidnell & Stivers, 2013). By video recordings of naturally occurring data, the project intends to document the designs of concrete courses of actions in real time. Attending the details of human conduct and to investigate the ways that people with various linguistic competences interactionally engage with each other would not be possible using mere observation. Video recordings and their analysis will certainly be part of the triangulation in the research method which will give more thorough picture of the complexity and the richness of human conduct (Cohen & Manion, 2000: 254). Moreover, the unique possibility of audio-visual recordings to capture both vocal and embodied conduct constitutes an important resource for studies focusing on the interactive organization of caregiving activities as “video data enable the analyst to consider how the local ecology of objects, artefacts, texts, tools and technologies feature in and impact on the action and activity under scrutiny” (Heath et al., 2010: 7). The analysis of videos, therefore, adds to the knowledge regarding communicative practices and experiences of the participants that the project also aims to collect through interviews and ethnographic observations. On the whole, the analysis of video recordings augmented with direct observation and interviews will uncover not only common practices used in the settings but also demonstrates the challenges in communications and also the ways that participants in those communications use to overcome the challenges.

The project is designed to be conducted in the span of 4 years. The participants will include 20 families/couples living with dementia, or people with dementia living alone, divided evenly on Swedish persons and immigrants. The setting for the implementation of the project will be private residential environments of people with dementia. Two sub-projects are designed to answer the research questions proposed in this project and will generate at least 4 studies:

- (1) The first sub-project will be based on interviews of main participants in home care service providing. These participants often include care staff, people with dementia and their caregiving relatives. The semi structured interviews will provide information to explore participants'

understanding and experience as regards communication between home care staff and the persons with dementia and also their caregiving relatives.

- (2) The second sub-project aims to mainly use video recordings – also corroborated by direct observations and interviews – to show (a) the challenges in care practices provided by home care staff regarding people with dementia and how people involved in care practices overcome those challenges themselves by exercising particular social practices. The project will also show (b) what communicative challenges may arise in care providing situations for people with dementia when they do not share the same language with home care staff and how participants overcome those challenges. At the end the project will uncover (c) similarities and difference which stem from communicative issues between people with dementia and home care staff when they share language and culture and also when they do not.

The project's implementation and its analytic procedure heavily depend on constant contact with already existing research networks in the field of dementia research. The project will make use of the contacts and competences both within the department of Education in Stockholm university and also outside, such as the Center for Dementia Research (CEDER) at Linköping university and the Nordic network of Dementia Language Interaction, and Cognition (DELIC). Contact with the networks of scholars not only facilitates recruiting human subjects in the project, but it also provides an intellectual environment for the current project. The analytic procedure in the project relies on data sessions with constant discussions and consultations with the researchers both in the field of discourse and conversation analysis, particularly those in the field of studying dementia. To prepare the data for the analysis, the gathered data from direct observations and interviews will carefully be reviewed to reveal the meanings and significance of different recorded practices and activities. The different empirical materials including direct ethnographic observations, interviews and video recordings will inform each other in an iterative process and contribute to the collection of relevant data to answer the project's research questions. The relevant data will then be transcribed verbatim. The data will be presented in a form of data sessions for a number of scholars for comments on the analysis of the data. The results of the research will be disseminated chiefly in the form of a doctoral dissertation, but also in the form presentations in national and international conferences and written scientific articles published in international journals. For the benefit of social actors involved in the project, the results of the project will also be published in popular scientific journals and will be conveyed back to the practitioners in home care service providing in a form of commentaries or recommendations.

Ethical considerations

The project will strictly follow the Swedish Research Council's ethical principles for research in the humanities and social sciences (VR, 2002; 2006) as well as the responsible committee of human experimentation and with the Helsinki Declaration of 1975, as revised in 1983. The project will practice with utmost care the current European GDPR law to protect the individual's personal information and integration. An application for ethical vetting will be submitted. The project will be based on the awareness that ethical considerations, such as obtaining informed consent, is a complex issue in research involving people with dementia. Participants might not at all points fully understand information provided to them, nor remember previous agreements. So, having the permission to gather data from the close caregiving relatives and possible guardians are necessary. However, the data gathering will also be very sensitive and responsive to any signs of hesitation or discomfort from people with dementia. It should also be pointed out that even though getting consent to study people with dementia may be ethically considered challenging, excluding a group of people from research that could lead to the betterment of their situations should also equally be considered unethical. It is also worth mentioning that despite the challenges in studying people with dementia, there are current projects on dementia which have proven the possibility of overcoming those challenges with careful consideration of ethics to study human subjects with communicative and cognitive difficulties (see e.g. the project "Life with Dementia" at Linköping university led by Lars-Christer Hydén).

Social Relevance

According to the National Board of Health and Welfare, there are 160.000 people with dementia in Sweden of whom over 23.000 are of immigrant background. With the new flux of immigration, there will be a steady growth of elderly immigrants (1.9 million people in Sweden are over the age of 65; 230.000 were born outside of Sweden). As growing numbers of people with dementia will live for a lengthy period of time in their own home instead of moving to residential care, the demand for home care services is also rising. There is, however, hardly any studies that deal particularly with home care services for people with dementia, especially when it comes to people with immigrant backgrounds. In providing care for people with dementia, the National Guidelines for Care in Cases of Dementia (2010) recommends “to be cared for by staff who can speak the same mother tongue and have cultural competence may give the person with dementia with other ethnic background security, well-being and a sense of familiarity” (p. 21; translation from Swedish). This proves that due to a dearth in empirical research about possible communicative challenges regarding cross-cultural and multilingual encounters in care services, recommendations regarding communications with people with dementia of various ethnic backgrounds are provincial and based on general experiences rather than detailed studies of actual data. Despite a growing number of studies on dementia from an interactional perspective, very little is known about communicative challenges in home care services for people with dementia among different ethnic groups.

An immediate need for studying home care services that provide care for native Swedes as well as for people with immigrant backgrounds is evident and the proposed project will be a significant contribution to an important social demand. By studying actual care practices and cross-cultural encounters in home care services, the project will supply empirically based recommendations for care providers, and support for the persons with dementia as well as their families. Uncovering common communicative practices in family care in minority communities also helps developing guidelines for home care services to be complementary to family caregiving under auspices of cultural values and family ties of the patients. Thus, the results of this project may be used, as a long-term achievement, to improve the quality of the current care system and social policies.

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