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Seeking the balance between caregiving in dementia, family, and employment: Study protocol for a mixed methods study in Northern Germany

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ABSTRACT

Introduction

The debate on reconciliation between childcare and working has to be expanded on caregiving for the elderly since the importance of informal caregiving will increase in the future due to populations' aging and women's increasing labor force participation. Informal caregivers who are caring for the rising number of people with dementia (PwD) are often female, too, and they are subjected to high caregiving requirements which are added to further demands emerging from their family and work life. How affected caregivers seek for balancing those requirements depends on, inter alia, the characteristics of themselves and the informal caregiving network to whom they relate. Both aspects were not yet considered in previous studies. This study thus aims to explore the reconciliation between caregiving in dementia, family, and employment by including different members of caregiving networks of home-dwelling PwD and considering their personal characteristics.

Methods and analysis

By using a simultaneous qualitatively driven mixed methods-design, this study will combine qualitative and quantitative data collected by interviews and questionnaires of informal caregivers of PwD. The interviews will provide narratives about their way of balancing caregiving in dementia, family tasks, and employment. In this, common topics and types will emerge through interpretation according to the Documentary Method. The questionnaires will objectify caregivers' sociodemo- and psychographic characteristics to describe the sample and to be interpretively connected with the qualitative data. We seek for five caregiving networks comprised of at least three dementia caregivers each living in Northern Germany.

Ethics and dissemination

Ethical approval was obtained from the Ethics Committee of the German Society of Nursing Sciences. Study results will be disseminated through conference presentations and publications in peer-reviewed journals.

Trial registration number

The study is registered in the German Clinical Trial Register (DRKS), DRKS00012929.

Keywords

Statistics and research methods, public health, health services administration and management

Strenghts and limitations of this study

- This German study will provide insights into a complex topic from a network-perspective for the first time.
- Informal caregiving network is composed of familial and non-familial members in this study.
- By merging qualitative and quantitative data, narratives of study participants will be explored considering their sociodemo- and psychographic characteristics, and the caregiving network from whom they arise.
- This study will include only five networks consisting of (at least) 15 informal caregivers of PwD; further research should expand the sample size.
- Results may only apply for the German healthcare system and its providers; we appreciate recreations in other countries.

INTRODUCTION

Family caregivers and other related caregiving persons of people with dementia (PwD) are subjected to a higher load concerning their personal and work life due to their caregiving responsibilities than the general population. Because seniors generally prefer staying at home, many of them are cared for by their relatives at home as long as possible.[1] In Germany, the estimated number of elderly or impaired people living in the community who are cared for by their relatives amounted to more than two million in 2015 which represents 73 % of all people in certified need of care according to the legal regulations fixed in the Social Security Code (*Sozialgesetzbuch*).[2] In many cases of home-dwelling individuals in need of care more than 2 informal caregivers are involved that corresponds to approximately 4 to 5 million informal caregivers (e.g., relatives, neighbors, friends) in Germany.[3] Focusing on dementia, more than 1.5 million PwD lived in Germany in 2012; this is almost 2 % percent of the total population which is higher than the European average of 1.5 %.[4] This number will increase to 3 million by the year 2050 because of the increasing life expectancy and the fact that Alzheimer's Disease and related forms of dementia are age-associated illnesses.[5] Therefore, the importance of informal caregiving in dementia care is bound to increase in the future – not only in Germany but also in a worldwide perspective.[6]

From an economic point of view, the costs of informal care constitute the majority of total societal costs of PwD living in the community and increase with the progression of dementia and patients' impairments in activities of daily living, need for care and supervision.[7 8] Productivity loss (i.e., lost workforce) of informal caregivers of PwD should also be considered if measuring societal costs of dementia. In their review, Lilly et al.[9] concluded that caregivers, in general, are equally as likely to be in the labor market as non-caregivers, but commit fewer work hours to the labor market than non-caregivers; in particular, if the caregiving responsibilities are exceeding ten hours per week the likelihood to withdraw from the labor market also increases.

To take up this evidence but to focus on dementia caregivers, we reviewed the interplay between informal caregiving in dementia and caregiver's employment (Neubert et al. under review[10]). As a result, we can confirm caregiving employees' considerable work impairments on the one hand. Besides objectively measured effects like the reduction of work hours or exit from work, many caregivers perceive work-caregiving conflicts, which stress caregivers' burden in addition to the caregiving requirements. So, working full-time and having difficulties in balancing work and caregiving tasks predicted caregivers' strain, and inflexible work conditions predicted depressive symptoms of dementia caregivers.[11] On the other hand, providing both dementia caregiving and paid work also entails positive work experiences and does not necessarily lead to exacerbated caregivers' burden. Moreover, combining unpaid caregiving with a paid job is associated with more happiness of the informal caregivers.[12]

Society is subject to two inevitable changes, namely women's increasing labor force participation and an expected increase of people in need of care by aging populations.[13] The labor market participation of female employees is indispensable for the maintenance of societal economic productivity. However, as the majority of informal caregivers is female[3 14], the already existing conflict between caregiving and employment might be further exacerbated. For this reason, political and societal stakeholders should be interested in finding a way to reconcile caregiving and working and to support informal caregivers of employment age in maintaining their labor market participation without limiting their role in dementia caregiving.

How informal caregivers of PwD experience balancing care-, family- and employment-related requirements depends on different factors. First, country-specific legal regulations and structural conditions within the respective long-term care-system are relevant. In Germany, for instance, the regulations on Caregiver Leave and Family Caregiver Leave (*Pflegezeitgesetz* und *Familienpflegezeitgesetz*) allow family caregivers to take time off work for a particular time. Employees thus will be given more flexibility and security to temporarily care for their relatives without withdrawing completely from the labor market.[15] Second, personality traits, which means how an individual evaluates her own life and changing circumstances, and coping skills in handling high-load situations considerably influence caregivers' experience. [16 17] Third, professional (paid) services – which form the formal caregiving network – and other supporting persons – who represent the informal caregiving network – contribute to caregivers' perception and can reduce caregivers' burden. However, although the value of a cooperative structure within the family or circle of acquaintances seems to affect caregivers' well-being and quality of life[18 19], their possible relevance to mediate work-caregiving conflicts has rarely been examined. It should be noted that other persons of the social network cannot be mediating but also demanding which we should consider in the reconciliation debate. Therefore, further research might include the perspective of more than one person within the family or circle of acquaintances to gain a more comprehensive picture of the caregiving networks' impact.

Aim and research questions of the study

To the best of our knowledge, no study has investigated the reconciliation between caregiving and other roles from a network-perspective until now since studies only considered the primary caregivers' perceptions and disregarded their psychographic characteristics. Therefore, this mixed methods study aims to explore the reconciliation between caregiving in dementia, family-related, and employment-related requirements of informal caregiving network members of PwD living at home by including at least three familial and non-familial members of each caregiving network. By merging qualitative and quantitative data, narratives of study participants will be explored considering their sociodemo- and psychographic characteristics, and the caregiving network to whom they relate.

Figure 1 outlines the background and aim of this mixed methods study.

Within the prioritized qualitative research strand, in-depth interviews with informal caregivers of PwD living in Northern Germany with written informed consent will provide answers to the following research questions: What motivates the members of informal caregiving networks to care for an individual with dementia? Which tasks (e.g., direct care, supervision, decision making) they are responsible for? Which consequences do they experience in their personal, family, and work life? Which factors influence these consequences positively or negatively?

Measured by validated, self-reported questionnaires of the study participants, the quantitative research strand will provide answers to the following research question: How do the members of informal caregiving networks evaluate their life situation in consideration of reconciliation between caregiving in dementia, family, and employment? To objectify caregivers' evaluation of their life situation the CarerQol-7D, CarerQol-VAS, ZBI (14th+18th item), EQ-5D, and EQ-VAS will be used.

Finally, by merging the qualitative and quantitative data at the level of interpretation, we will explore how the caregivers' perception and evaluation of their life situation are interrelated with their sociodemographic characteristics, personality traits, and coping skills in consideration of the corresponding caregiving network. To measure caregivers' psychographic characteristics we will apply the NEO-FFI-30 (Neo-Five-Factors Inventory), ASKU (short-form of a German self-efficacy scale), and PCI (Proactive Coping Inventory).

METHODS AND ANALYSIS

Overview of the study design

We chose a simultaneous qualitatively driven mixed methods-design to apply both qualitative and quantitative methods complementarily.[20] After separate data collection and analysis, qualitative data and quantitative data will be combined at the level of interpretation. Qualitative (*QUAL*) data collection and analysis will be prioritized. At this, we will interview informal caregivers and interpret their narratives to explore their experience of the reconciliation between caregiving in dementia, family tasks, and employment. Additionally, we will collect quantitative (*quan*) data by using validated questionnaires, which will be filled out by the caregivers themselves, to objectify both caregivers' evaluation of their current life situation and their sociodemographic and psychographic characteristics (i.e., personality traits, coping skills).

The next paragraphs describe the methodical procedure in detail. Figure 2 demonstrates the used *QUAL+quan*-design in this study.

Recruitment of study participants

In the vast majority of cases of informal caregiving, besides the main or primary caregiver (i.e., the individual with the greatest care responsibilities) further persons are involved in a smaller or larger degree. For example, a husband of a caring daughter, who support his spouse in the decision-making procedure regarding the care of his mother-in-law or even if he lends an ear to his wife, is an involved caring person. So, caregiving in general and in dementia mainly affects not only the primary caregiver but further individuals who build the caregiving network.

Koehly et al.[21] used a multi-informant social network approach to investigate caregiving processes within the context of Alzheimer's Disease and related dementia. As a result, they suggest that a sampling approach with at least three informants allows a more comprehensive assessment of a family caregiving network. In our study, we broadened the perspective by including non-familial individuals like neighbors or friends, too.

The first step of recruitment is to personally contact gatekeepers engaged in counseling centers for seniors and family caregivers (*Pflegestützpunkte*) or self-help groups (e.g., affiliated to the *Alzheimer Gesellschaft Hamburg e.V.*) located in Hamburg, Schleswig-Holstein, and Lower Saxony. There, the main researcher (LN) displays the study information covering the aims and procedures of the study, the inclusion criteria to select study participants, data collection, processing, and storage, as well as participants' contribution to this work and the possibilities for opting out. Furthermore, she will visit these service points to inform potential study participants face-to-face. Within this visits, all potential study participants will have time to read and fully understand both the study information and declaration of consent. In case of ambiguities, the main researcher will be present to answer all emerging questions. Because study information contains the researcher's telephone number, mailing address, and e-mail-address, potential study participants can contact her during office hours to ask questions and receive further oral information about the study. Additionally, calls for participation will be published in journals and websites addressing informal caregivers.

In this way, we expect that the first informal caregiver of a caregiving network of home-dwelling PwD will be admitted. This individual is the index-interviewee who also provide access to at least two other informal caregivers of each network who are involved in care, support those involved in care, and could be involved due to their relationships with the cared-for individual with dementia. The index-interviewee has to give written permission before being interviewed and will name at least two other networks members who had agreed to participate. Already then or at their own interviews at the latest, the interviewer (LN) will obtain the declarations of consent of the additional network members. Appointments for the interviews will arranged by the interviewer. She will contact named network members approximately one week after the index-interview. This sampling approach will be continued until the desired number of at least three network members (including the index-interviewee) will be reached.

Sample size and eligibility criteria of study participants

In total, five networks consisting of (at least) 15 informal caregivers of PwD will be included in this study. The sample size is restricted by the feasibility of this study. However, qualitative data analysis requires contrasting cases, whereby further sampling can be necessary until this goal will be achieved (see paragraph "qualitative data analysis"). If potential study participants refuse or withdraw study participation, the research team will replace them. Following Koehly et al.[21], we determined the following inclusion criteria:

- Members of the informal caregiving network are individuals who are important to the affected person with dementia or the first informal caregiver (index-interviewee), i.e., they undertake caring tasks (e.g., personal care, eating), household tasks (e.g., cleaning, cooking), support in the care-related or everyday decision-making, and/or emotional support during caregiving period.
- Members of the informal caregiving network i) are older than 18 years, ii) have appropriate German language skills and no cognitive impairments to conduct the interview, iii) are living in an urban or adjacent region of Hamburg, or an urban or rural region of Schleswig-Holstein or Lower Saxony (within a maximum linear distance of 100 km from our department in Hamburg), and iv) at least one member of each participating caregiving network is employed at the time of investigation.
- The first member of the informal caregiving network verbally confirms the presence of cared-for person's Alzheimer's Disease or related dementia and its functional impairments according to the Social Security Code (*§ 14 Sozialgesetzbuch XI*). The demented individual has to be living at home, informal caregivers of institutionalized individuals will be excluded. Neither the stage of the disease nor whether the diagnosis was medically confirmed are relevant for inclusion. We will not collect any data concerning the care-recipient with dementia.

Recruitment of study participants will start in October 2017, the study (funded by the German Federal Ministry of Education and Research; grant: 01EH1601A) ends in August 2020.

Measuring instruments

Qualitative inquiry refers to the investigation of underlying knowledge and the understanding of social phenomena. Thus, it aims at understanding the meaning of human action.[22] To gain the personal perspectives of human actors in this study, informal caregivers are invited to tell of their experiences regarding the reconciliation between caregiving in dementia, family tasks, and employment. Our research interest also covers the perceived consequences on the wider family or other related persons, on the subjective health status and quality of life since they are informal caregivers and employees. Therefore, we prioritize the qualitative research strand in this mixed methods study, yet, we also appreciate the complementary quantitative approach.

Qualitative data collection

For *QUAL*-data collection we chose *narrative interviews* to elicit stories of experiences in accordance with Schütze 1976[23] and Flick 2011[24]. At the beginning of each interview conducted face-to-face, an asking question will be stated that encourage interviewees' narration. At best, the interviewer (LN) must not intervene at no time besides encouraging phrases like "And then?" or nodding as a non-verbal sign of empathic listening. To standardize interviewing, an *interview guide* was developed and pretested. If the narrative continuity stagnates, maintenance questions and requests were also narratively formulated. The *theoretical framework*, which underlay the development of the interview guide, is based on a topic-specific literature search (Neubert et al. under review[10]) and on both the studies of Koehly et al.[21] and Gröning & Kunstmann[25] who understand (dementia) caregiving as an informal network- or family-task.

Quantitative data collection

To measure *quan*-data, we will use *questionnaires* (ten pages) which will be filled out by the study participants themselves. This questionnaire initially queries sociodemographic characteristics of the study participants including age, gender, relationship to the cared-for person with dementia, employment status, occupation, living situation, and region. These data allow to describe the sample of this study and to hint at the generalizability of the sample. Then, to measure psychographic characteristics of the study participants, the questionnaire comprises the following validated questionnaires: The German version of the CarerQol-7D/-VAS, items no. 14 and 18 of the Zarit Burden Interview (ZBI), the German version of the EuroQol (EQ-5D), the NEO-Five-Factors Inventory (NEO-FFI-30), the German short-form of the perceived self-efficacy scale (ASKU), and the German version of the Proactive Coping Inventory (PCI). After its development, the questionnaire was also pretested.

Figure 3 gives an overview about the schedule of study participation in this study.

To realize interviews and measurements, study participants can choose between a visit at home by the main researcher (LN) or a meeting at the Department of Health Economics and Health Services Research. In the latter case, an insurance covers possible accidents on the way to or from the research department, and travel costs are repaid. In general, it is important that the interviews will be undisturbed, i.e., we will reserve a meeting room and ask colleagues for consideration. We calculate that each narrative interview will last one to two hours followed by answering the questionnaire. To diminish the study participants' burden, it is possible that they will complete the questionnaires later. In this case, the main researcher (LN) will hand a stamped envelope over to them accompanied by reminding to contact her if any questions arise while completing the questionnaire. For this, we originally estimated a duration of 30 to 45 minutes, but we observed shorter periods in some pretests. Each study participant will receive an expense allowance (i.e. a sum of money in €) after completing both measurements.

Data analysis

Qualitative data analysis

The interviews will be recorded and transcribed verbatim. We chose the *Documentary Method of data interpretation* in accordance with Arnd-Michael Nohl[26] to analyze and interpret the textual material of the narrative interviews. This method aims at the reconstruction of the practical experiences of individuals, social groups, milieus, or organizations (referred to as the orientation framework) to obtain access to their orientations of action that are visible in their everyday lives. Narratives are preconditions to reconstruct the orientation framework, the chosen form of interviewing thus is suitable since the provided textual material should consist of impromptu narratives – even if the interviewees' narratives will be, of course, linked with descriptions and argumentations. The researcher's interest refers to the way a narrative text or action is constructed by the interviewee or how the limits within which its topic is dealt with, i.e. the orientation framework within which a topic or problem is handled.[26] In practice, the *Documentary Method* comprises three stages of interpretation: formulating interpretation (to summarize topics), reflecting interpretation (to generate the framework of orientation, in which the topics are elaborated on), and type formation (i.e. the emerged empirical results become visible as types).[27] From the beginning of the three-staged interpretation process to its end, the *Documentary Method* is based on a consistent comparative analysis. So, the orientation framework is generated by comparing one case (interview sequence) with other empirical cases (interview sequences) that deal with the same topic but within contrasting orientation frameworks. For instance, if we only look at one interview sequence, we would interpret it against the background of our own (or common) theories regarding the topic of interest. By comparing this first with other interviews (sequences), both our knowledge and interpretation is methodically relativized. In this way, Nohl declares the comparative analysis as the golden standard of methodically controlled research.[27] In this study, each informal caregiver provides text (sequences) related to the common topic, and by comparing of this (these) with text (sequences) of another informal caregiver the orientation framework emerges. Following the formulating and reflecting interpretation, different approaches of type formation (sensegenetic, sociogenetic, or relational[28]) lead to generalizing the empirical results by identifying similar or overlapping cases based on case comparisons. The steps of interpretation will be supported by *MAXQDA* (version 12).

Quantitative data analysis

Regarding the quantitative data analysis, the questionnaires named above serve to explore the identified care-related strain (CarerQol-7D, ZBI) and the evaluation of the life satisfaction (CarerQol-VAS, EQ-5D) of the study participants with consideration of their personality traits (NEO-FFI-30, ASKU) and coping skills (PCI). The topics or types emanated from the qualitative data analysis will also be interpretively connected with, for example, the value of the care-related strain or the coping skills. Data from completed questionnaires will be transferred into datasets and analyzed by *descriptive and analytic statistical methods* including frequency and contingency analysis to describe study participants' characteristics and bi-/multivariate correlation analysis that examines the association of perceived strain and personality traits or coping skills. These analyses will be supported by the feature "Stats" of MAXQDA (version 12) and IBM SPSS Statistics (version 23). Because of prioritization of the QUAL-approach in this mixed methods study, the *quan*-data are supplemental to validate the *QUAL*-data and to serve – due to the small sample size– at least as a starting point for further research in this field.

ETHICS, DATA PROTECTION, AND DISSEMINATION

Ethical approval for this study was obtained from the German Society of Nursing Sciences (approval no. 17-006). The study is registered in the German Clinical Trial Register (DRKS), DRKS00012929. Furthermore, the study was planned in accordance with the German Federal Data Protection Act (*Bundesdatenschutzgesetz*) and the data protection law of Hamburg (*Hamburger Datenschutzgesetz*), and will be processed under the guidance of the data protection officer of the conducting research department.

Study participants have to give written informed consent before data collection. By using audio records and (paper) questionnaires, data will be collected. All data will be pseudonymised; thus, qualitative (interview) data and quantitative (questionnaire) data will be combined at the level of interpretation. When data collection will be finished, the key list (assignment of study participants' names to pseudonyms) and the mailing addresses of the study participants will be destroyed in according to data protection regulations. Audio records of the interviews will be deleted after transcription. Data of the questionnaires will be transferred into data sets that will only be available to the main researcher (LN) who will store the data sets in her password-protected computer. Written consents and pseudonymized data will be stored separately in locked cabins within secure offices for ten years after the end of the study.

The results of this study will be presented at scientific conferences in Germany and beyond that, and published in peer-reviewed, national and international, journals.

CONCLUSION

By including different familial and non-familial members of caregiving networks, we will be the first who explore the reconciliation between caregiving in dementia, family-related, and employment-related requirements of informal caregiving in dementia at a national level. The network-perspective will provide more detailed insights into this complex topic than an ego-centered perspective. By merging qualitative and quantitative data, the narrated ways of reconciliation will be investigated in consideration of the sociodemographic characteristics, personality traits, and coping skills of each informal caregiver, and in the light of the corresponding caregiving network.

The used methodological approach serve as a starting point for further research in this field; for instance, by including a larger sample of affected informal caregivers of PwD, or applying further methods of network analysis. Our results will help policymakers and stakeholders regarding healthcare, social issues, labor force, and economics to understand better how informal caregivers of PwD are subjected to the requirements of their everyday lives, which ways they are seeking for to balance these requirements, and which interventions can support them to fulfill their major role in dementia caregiving in our society.

AUTHORS' CONTRIBUTION

LN was responsible for the original idea, literature review and study design. HHK and CB advanced the concept. All authors contributed to obtaining the ethical approval. LN drafted this manuscript; HHK and CB critically reviewed it critically. All authors read and approved the final manuscript.

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None declared.

DATA SHARING STATEMENT

Not applicable.

COMPETING INTERESTS

The authors have no conflict of interest to report.

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ETHICS APPROVAL

Ethics Committee of the German Society of Nursing Sciences, Germany (approval no. 17-006).

FIGURES

Figure 1: Background and Aim of this Mixed Methods Study

PwD, people with dementia

Figure 2: Simultaneous Qualitatively Driven Mixed Methods-Design (QUAL+quan-Design)

PwD, people with dementia

CarerQol-7D; CarerQol-VAS (German Version)

ZBI, Zarit Burden Interview (German Version)

EQ-5D, EQ-VAS (German Version)

NEO-FFI-30, Neo-Five-Factors Inventory-30 (German Version)

ASKU, [Allgemeine Selbstwirksamkeitsskala]

PCI, Proactive Coping Inventory (German Version)

Figure 3: Overview of Study Participation

PwD, people with dementia

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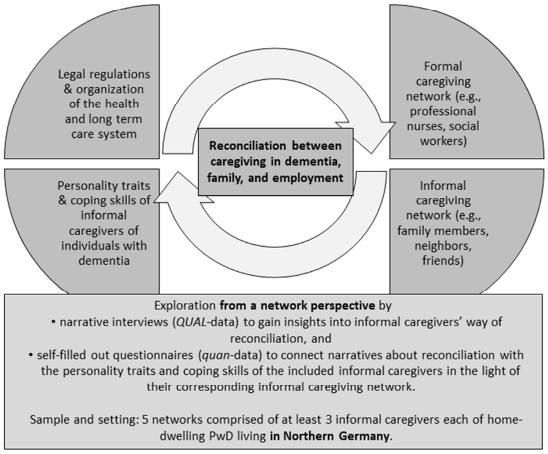

Exploration **from a network perspective** by

- narrative interviews (*QUAL*-data) to gain insights into informal caregivers' way of reconciliation, and
- self-filled out questionnaires (*quan*-data) to connect narratives about reconciliation with the personality traits and coping skills of the included informal caregivers in the light of their corresponding informal caregiving network.

Sample and setting: 5 networks comprised of at least 3 informal caregivers each of home-dwelling PwD living **in Northern Germany**.

Figure 1: Background and Aim of this Mixed Methods Study / PwD, people with dementia

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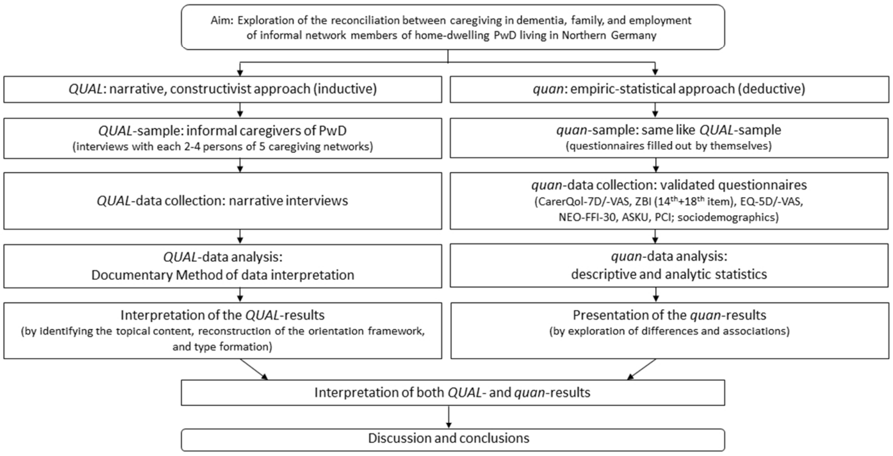

Figure 2: Simultaneous Qualitatively Driven Mixed Methods-Design (QUAL+quan-Design) /
PwD, people with dementia
CarerQol-7D; CarerQol-VAS (German Version)
ZBI, Zarit Burden Interview (German Version)
EQ-5D, EQ-VAS (German Version)
NEO-FFI-30, Neo-Five-Factors Inventory-30 (German Version)
ASKU, [Allgemeine Selbstwirksamkeitsskala]
PCI, Proactive Coping Inventory (German Version)

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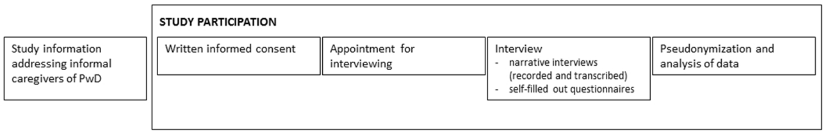

Figure 3: Overview of Study Participation / PwD, people with dementia

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Seeking the balance between caregiving in dementia, family, and employment: Study protocol for a mixed methods study in Northern Germany

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Seeking the balance between caregiving in dementia, family, and employment: Study protocol for a mixed methods study in Northern Germany

submitted by Lydia Neubert, Hans-Helmut König, Christian Brettschneider

– Revised manuscript –

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ABSTRACT (295 WORDS)

Introduction

The debate on reconciliation between childcare and working has to be expanded to caregiving for the elderly, since the importance of informal caregiving will increase in the future due to populations' aging and women's increasing labor force participation. Informal caregivers who are caring for the rising number of persons with dementia (PwD) are often female, too, and they are subjected to high caregiving requirements which are added to further demands emerging from their family and work life. How affected caregivers seek to balance those requirements depends on, inter alia, their own characteristics and the informal caregiving network to whom they relate. Both aspects were not yet considered in previous studies. This mixed methods-study thus aims to explore the reconciliation between caregiving in dementia, family, and employment by including different members of caregiving networks of home-dwelling PwD and by considering their personal characteristics.

Methods and analysis

By purposive sampling, we include at least 5 caregiving networks of home-dwelling PwD, each of them consisting of at least 3 informal caregivers living in Northern Germany. Narrative interviews of participants will be recorded, transcribed verbatim, and interpreted according to the Documentary Method (QUAL). By completing standardized questionnaires, participants will provide sociodemo- and psychographic data concerning theirselves and the networks, from whom they arise (quan). This supplemental, descriptive information will give further background to the themes and types emerging from the interviews. Hence, the quan-data enrich the QUAL-data by exploring the narratives of participants in the light of their personal and network-related characteristics.

Ethics and dissemination

Ethical approval was obtained from the Ethics Committee of the German Society of Nursing Sciences. Study results will be disseminated through conference presentations and publications in peer-reviewed journals.

Trial registration number

The study is registered in the German Clinical Trial Register (DRKS), DRKS00012929.

Keywords

Statistics and research methods, qualitative research, public health, health services administration and management

Strenghts and limitations of this study

- This German study will provide insights into a complex topic from a network-perspective for the first time.
- Informal caregiving network is composed of familial and non-familial members in this study.
- By merging qualitative and quantitative data, narratives of study participants will be explored considering their sociodemo- and psychographic characteristics, and the caregiving network from whom they arise.
- This study will include only five networks consisting of (at least) 15 informal caregivers of PwD; further research should expand the sample size.
- Results may only apply for the German healthcare system and its providers; we appreciate replications in other countries.

INTRODUCTION

Family caregivers and other related caregivers of persons with dementia (PwD) are subjected to a higher load than the general population concerning their personal and work life due to their caregiving responsibilities. Because seniors generally prefer staying at home, many of them are cared for by their relatives at home as long as possible.[1] In Germany, the estimated number of elderly or impaired people living in the community who are cared for by their relatives amounted to more than two million in 2015 which represents 73 % of all people in certified need of care according to the legal regulations fixed in the Social Security Code (*Sozialgesetzbuch*).[2] In many cases of home-dwelling individuals in need of care more than 2 informal caregivers are involved, which corresponds to approximately 4 to 5 million informal caregivers (e.g., relatives, neighbors, friends) in Germany.[3] Focusing on dementia, more than 1.5 million PwD lived in Germany in 2012; this is almost 2 % percent of the total population which is higher than the European average of 1.5 %.[4] This number will increase to 3 million by the year 2050 because of the increasing life expectancy and the fact that Alzheimer's Disease and related forms of dementia are age-associated illnesses.[5] Therefore, the importance of informal caregiving in dementia care is bound to increase in the future – not only in Germany, but also in a worldwide perspective.[6]

From an economic point of view, the costs of informal care constitute the majority of total societal costs of PwD living in the community and increase with the progression of dementia and patients' impairments in activities of daily living, need for care and supervision.[7 8] Productivity loss (i.e., lost workforce) of informal caregivers of PwD should also be considered if measuring societal costs of dementia. In their review, Lilly et al.[9] concluded that caregivers, in general, are equally as likely to be in the labor market as non-caregivers, but commit fewer work hours to the labor market than non-caregivers; in particular, if the caregiving responsibilities are exceeding ten hours per week, the likelihood to withdraw from the labor market also increases.

To take up this evidence and to focus on dementia caregivers, we reviewed the interplay between informal caregiving in dementia and caregiver's employment (Neubert et al. under review[10]). As a result, we can confirm caregiving employees' considerable work impairments on the one hand. Besides objectively measured effects like the reduction of work hours or exit from work, many caregivers perceive work-caregiving conflicts, which stress caregivers' burden in addition to the caregiving requirements. So, working full-time and having difficulties in balancing work and caregiving tasks predicted caregivers' strain, and inflexible work conditions predicted depressive symptoms of dementia caregivers.[11] On the other hand, providing both dementia caregiving and paid work also entails positive work experiences and does not necessarily lead to exacerbated caregivers' burden. Moreover, combining unpaid caregiving with a paid job is associated with more happiness for the informal caregivers.[12]

Society is subject to two “structural mega-trends”, namely women’s increasing labor force participation and an expected increase of people needing care in due to populations’ aging.[13] The labor market participation of female employees is indispensable for the maintenance of societal economic productivity. However, as the majority of informal caregivers is female[3 14], the already existing conflict between caregiving and employment might be further exacerbated. For this reason, political and societal stakeholders should be interested in finding a way to reconcile caregiving and working and to support informal caregivers of an employable age in maintaining their labor market participation without limiting their role in dementia caregiving.

How informal caregivers of PwD experience balancing care-, family- and employment-related requirements depends on different factors (figure1). First, country-specific legal regulations and structural conditions within the respective long-term care-system are relevant. In Germany, for instance, the regulations on Caregiver Leave and Family Caregiver Leave (*Pflegezeitgesetz* und *Familienpflegezeitgesetz*) allow family caregivers to take time off work for a specific time period. Employees thus will be given more flexibility and security to temporarily care for their relatives without completely leaving from the labor market.[15] Second, personality traits, which means how an individual evaluates her own life and changing circumstances, and coping skills in handling high-load situations considerably influence caregivers’ experience.[16 17] In caregiving research, so far, little is understood about how caregivers perform their roles better and why.[18] Third, professional (paid) services which form the formal caregiving network contribute to the caregiving situation at home by providing information, respite and support; for example, offered by day care centers.[19] Fourth, other (usually unpaid) persons who represent the informal caregiving network contribute to caregivers’ perception and can reduce caregivers’ burden. However, although the value of a cooperative structure within the family or circle of acquaintances seems to affect caregivers’ well-being and quality of life[20 21], their possible relevance to mediate work-caregiving conflicts has rarely been examined. It should be noted that other persons in the social network cannot only be mediating but also demanding, which we should also consider in the reconciliation debate. Therefore, further research on reconciliation between caregiving in dementia and other roles might include the perspective of more than one person within the family or circle of acquaintances to gain a more comprehensive picture of the caregiving networks’ impact. Moreover, a short look at the caregiving network might be not sufficient, because caregiving research delves into a very complex and dynamic phenomenon concerning the emotional relationship between a caregiving and cared-for person as well as between different caregivers if caregiving responsibilities are shared.[18] For instance, by comparing caregiving spouses, adult children, and children-in-law, data on outcomes like resources, stressors, and psychological distress differ between the groups; so, each of them has different needs based on her or his subjective burden and personal circumstances (e.g., co-residence with the cared-for person, income, other family responsibilities).[22] Additionally, caregiver relationships are built on a common descent or by marriage, but they are also influenced by social expectations of family and caregiving varying by culture.[23] Furthermore, caregiving research should not ignore personal motives of caregivers if we want to better understand caregiving processes, also, in the light of balancing care-, family- and employment-related requirements.

Aim and research questions of the study

To the best of our knowledge, no study has investigated the reconciliation between caregiving and other roles from a network-perspective until now, since studies only considered the primary caregivers' perceptions. Previous studies on this topic also disregarded psychographic characteristics of informal caregivers. Therefore, this mixed methods study aims to explore the reconciliation between caregiving in dementia, family-related, and employment-related requirements of informal caregiving network members of PwD living at home by including at least 3 familial and non-familial members of each caregiving network. The study focuses on the subjective reconciliation described by the study participants in the qualitative research strand. Thus, the primary question of this study is: how do informal caregivers of PwD experience the reconciliation between caregiving in dementia, family tasks, and employment? By merging qualitative and quantitative data, narratives of study participants will be further explored by combining those with their sociodemo- and psychographic characteristics, and the caregiving network to whom they relate. Figure 1 outlines the background and aim of this mixed methods study.

Figure 1

To gain a broad picture of the experiences of informal caregivers regarding the reconciliation between caregiving in dementia, family, and employment, we formulated the following subordinated research questions.

Within the qualitative research strand, narrative interviews with informal caregivers of PwD living in Northern Germany with written informed consent will provide answers to the following research questions: How do members of informal caregiving networks experience assuming caregiving responsibilities for an individual with dementia? How do they experience the division of caregiving tasks, i.e., who feels responsible for which task and how does she/he experience it? How do they experience possible consequences regarding other commitments and areas of life (e.g., child care, work, leisure time) due to caregiving? How do they experience circumstances which may influence the perceived consequences positively or negatively?

The quantitative research strand will explore the evaluation of the life situation of network members according to a standardized approach by measuring caregivers' care-related strain via CarerQol-7D, CarerQol-VAS, and ZBI (14th+18th item), and life satisfaction via EQ-5D and EQ-VAS.

Finally, by merging the qualitative and quantitative data at the level of interpretation, we will explore how the caregivers' perception –based on the qualitative research strand– and evaluation –based on the quantitative research strand– regarding their current life situation are possibly interrelated with their sociodemographic characteristics, personality traits, and coping skills in consideration of the corresponding caregiving network. To measure caregivers' psychographic characteristics we will apply the NEO-FFI-30 (Neo-Five-Factors Inventory), ASKU (short-form of a German self-efficacy scale), and PCI (Proactive Coping Inventory).

METHODS AND ANALYSIS

Overview of the study design

We chose a simultaneous qualitatively driven mixed methods-design to apply both qualitative and quantitative methods complementarily (*QUAL+quan-design*).[24] After separate data collection and analysis, qualitative data and quantitative data will be combined at the level of interpretation. Qualitative (*QUAL*) data collection and analysis will be prioritized. For this we will interview informal caregivers and interpret their narratives to explore their subjective experience of the reconciliation between caregiving in dementia, family tasks, and employment. Qualitative inquiry refers to the investigation of underlying knowledge and the understanding of social phenomena. Thus, it aims to understand the meaning of human action.[25] To gain the personal perspectives of human actors in this study, informal caregivers are invited to tell of their subjective experiences. Their descriptions regarding the perceived reconciliation between caregiving in dementia, family tasks, and employment is our leading research interest. It also covers the perceived consequences on the wider family or other related persons, on the subjective health status and quality of life, since they have multiple roles as a caregiver, relative, neighbor or friend, and/or an employee. Therefore, we prioritize the qualitative research strand in this mixed methods study; yet we also appreciate the complementary quantitative approach. In this, we will additionally collect quantitative (*quan*) data by using validated questionnaires, which will be filled out by the caregivers themselves, to measure both caregivers' evaluation of their current life situation and their sociodemographic and psychographic characteristics (i.e., personality traits, coping skills). For this, narratives of study participants will be explored considering their personal characteristics, and the caregiving network to whom they relate.

The next paragraphs describe the methodical procedure in detail. Figure 2 demonstrates the used *QUAL+quan*-design in this study.

Figure 2

Recruitment of study participants

In the vast majority of cases of informal caregiving, besides the main or primary caregiver (i.e., the individual with the greatest care responsibilities), further persons are involved in a smaller or larger degree. For example, a husband of a caring daughter, who supports his spouse in the decision-making procedure regarding the care of his mother-in-law or even if he lends an ear to his wife, is an involved caring person. So, caregiving in general and in dementia mainly affects not only the primary caregiver but further individuals who build the caregiving network.

Koehly et al.[26] used a multi-informant social network approach to investigate caregiving processes within the context of Alzheimer's Disease and related dementia. As a result, they suggest that a sampling approach with at least three informants allows a more comprehensive assessment of a family caregiving network. In our study, we broadened the perspective by including non-familial individuals like neighbors or friends, too.

The first step of recruitment was to personally contact gatekeepers engaged in counseling centers for seniors and family caregivers (*Pflegestützpunkte*) or self-help groups (e.g., affiliated with the *Alzheimer Gesellschaft Hamburg e.V.*) located in Hamburg, Schleswig-Holstein, and Lower Saxony. By addressing different gatekeepers in different regions of Northern Germany, we were able to broaden the possibilities to come in contact with eligible study participants and to reduce sampling bias. There, the main researcher (LN) displayed the study information covering the aims and procedures of the study, the inclusion criteria to select study participants, data collection, processing, and storage, as well as participants' contribution to this work and the possibilities for opting out. Furthermore, she visited these service points to inform both gatekeepers and potential study participants face-to-face. Within these visits, the main investigator (LN) informed the gatekeepers comprehensively about the in- and exclusion criteria to avoid unsuitable pre-selection of clients, and all potential study participants had time to read and fully understand both the study information and declaration of consent. In case of ambiguities, the main researcher was present to answer all emerging questions. Because study information contains the researcher's telephone number, mailing address, and e-mail-address, potential study participants can contact her during office hours to ask questions and receive further oral information about the study. Additionally, calls for participation will be published in journals and websites addressing informal caregivers.

In this way, we expect that the first informal caregiver of a caregiving network of home-dwelling PwD will be admitted. This individual is the index-interviewee who also provides access to at least two other informal caregivers of each network who are involved in care, support those involved in care, and could be involved due to their relationships with the cared-for individual with dementia. The index-interviewee has to give written permission before being interviewed and will name at least two other network members who had agreed to participate. Already at that time or at their own interviews at the latest, the interviewer (LN) will obtain the declarations of consent of the additional network members. Appointments for the interviews will be arranged by the interviewer. She will contact named network members approximately one week after the index-interview. This sampling approach will be continued until the desired number of at least three network members (including the index-interviewee) will be reached. The number of persons who refuse to participate and their reasons for opting out will be documented in the study diary.

Sample size and eligibility criteria of study participants

In total, (at least) 5 networks consisting of (at least) 15 informal caregivers of PwD will be included in this study through purposive sampling to reach maximum variation between characteristics of the study participants (e.g., gender, age, relationship to the cared-for person, and living situation). The sample size is restricted by the feasibility of this study; i.e., the target sample size is explained by the explorative character of this study that is a preparatory part of a larger study. However, qualitative data analysis requires contrasting cases, whereby further sampling can be necessary until this goal will be achieved (see paragraph “qualitative data analysis”). If potential study participants refuse or withdraw study participation, the research team will replace them. If participants withdraw or refuse to participate –after they were nominated by the index-interviewee– and cannot be replaced, the index-interviewee’s data are be considered as individual data. This means, their interpreted narrations and analyzed data are relevant for the aggregated results but cannot contribute to the interpretations from the network-perspective. Following Koehly et al.[26], we determined the following inclusion criteria:

- Members of the informal caregiving network are individuals who are important for care delivery to the affected person with dementia or the first informal caregiver (index-interviewee), i.e., they undertake caring tasks (e.g., personal care, eating), household tasks (e.g., cleaning, cooking), support in the care-related or everyday decision-making, and/or emotional support during the caregiving period. The degree of involvement in caregiving and both the relationship to the individual with dementia and the living situation (living together with the cared-for person or not) are not relevant for study inclusion. For instance, an eligible caregiving network can comprise a retired wife caring for her husband with dementia, a daughter of employment age –not living with her parents, with her own family commitments, and supporting her mother in decision-making and visits to medical professionals or authorities–, and a volunteer who supervise the cared-for person once a week for a few hours.

- Members of the informal caregiving network i) are older than 18 years, ii) have appropriate German language skills and no cognitive impairments to conduct the interview, iii) are living in an urban or adjacent region of Hamburg, or an urban or rural region of Schleswig-Holstein or Lower Saxony (within a maximum linear distance of 100 km from our department in Hamburg), and iv) at least one member of each participating caregiving network is employed at the time of investigation. Since many caregivers are old themselves and already retired[22], only employed (younger) caregivers will be asked how they experience the reconciliation between their caregiving and work responsibilities (whether their contributions in caregiving are small or large, i.e., these network members do not need to be the primary caregivers).
- The first member of the informal caregiving network verbally confirms the presence of cared-for person's Alzheimer's Disease or related dementia and its functional impairments according to the Social Security Code (*§ 14 Sozialgesetzbuch XI*). The individual with dementia has to be living at home. Informal caregivers of institutionalized individuals will be excluded. Neither the stage of the disease nor whether the diagnosis was medically confirmed are relevant for inclusion. By ethical reasons we decided to not collect declarations of consent of PwD. Therefore, we cannot directly request any data concerning the care-recipient with dementia while interviewing his/her caregivers. However, it will be essential that the interviewees disclose more or less comprehensive descriptions of the physical and mental constitution of the cared-for person in their own words to illustrate their caregiving situation at home including, for example, their self-perceived burden due to the specific needs of an individual with dementia. Caregivers' perceptions and meanings meet our primary research interest, and additional data like the described functional impairments of the PwD will likely help us to contextualize the findings.

Recruitment of study participants started in October 2017, and first results are expected in 2018. The study is a preparatory part of a larger project (funded by the German Federal Ministry of Education and Research; grant: 01EH1601A) that ends in August 2020; then, results of this study will be published.

Measuring instruments

Qualitative data collection

For *QUAL*-data collection we chose *narrative interviews* to elicit stories of experiences in accordance with Schütze 1976[27] and Flick 2011[28]. At the beginning of each interview conducted face-to-face, an initial question will be stated that encourages interviewees' narration. At best, the interviewer (LN) must not intervene at any time except with encouraging phrases like "And then?" or nodding as a non-verbal sign of empathic listening. To standardize interviewing, an *interview guide* was developed and pretested. For this, each question was first discussed between the main investigator (LN) and professor Nohl from the Helmut Schmidt University in Hamburg, who considerably developed the interpretation of narrative interviews by means of the Documentary Method[29]; then we tested the interview guide in a workgroup of qualitative methods located at the University Medical Center Hamburg-Eppendorf. Participants were asked to provide feedback regarding the comprehensibility of questions; no amendments were necessary after this pretest. If the narrative continuity stagnates, maintenance questions and requests were also narratively formulated. An exemplary, narratively formulated request is "Please tell me about your last week, day after day. I'm interested in every detail that you did for [the person with dementia]. Let's start with last [Monday]". Non-narratively formulated requests at the end of the interview can refer to information that still did not occur in the narratives of the interviewees, e.g., "How many hours are you currently working?". Each interview will close with the invitation to complete a network graph consisting of concentric circles to draw all network members who are important to the interviewee. Used network graphs have an intermediate position between the qualitative and quantitative data (concerning the interpretation of those we refer to the section of quantitative data analysis). The *theoretical framework*, to which the development of the interview guide is subject, is based on a topic-specific literature search (Neubert et al. under review[10]) and on both studies of Koehly et al.[26] and Gröning & Kunstmann[30], who understand (dementia) caregiving as an informal network- or family-task. The main investigator (LN) will conduct all interviews. She is trained in applying qualitative research methods in general and, in particular, in interviewing informal caregivers because of another qualitative study[31]. She is also aware of the specific life situation of caregivers, due to her previous experience as a registered nurse, and she interacts with them empathetically.

Quantitative data collection

To measure *quan*-data, we will use *questionnaires* (ten pages) which will be filled out by the study participants themselves. This questionnaire initially queries sociodemographic characteristics of the study participants including age, gender, relationship to the cared-for person with dementia, employment status, occupation, living situation, and region. These data facilitate descriptions of the sample of this study and hint at the generalizability of the sample. Then, to measure care-related strain, life satisfaction, and psychographic characteristics of the study participants, the questionnaire comprises the following validated questionnaires: The German version of the CarerQol-7D/-VAS, items no. 14 and 18 of the Zarit Burden Interview (ZBI), the German version of the EuroQol (EQ-5D), the NEO-Five-Factors Inventory (NEO-FFI-30), the German short-form of the perceived self-efficacy scale (ASKU), and the German version of the Proactive Coping Inventory (PCI). After its development, the questionnaire was also pretested; previously, we have asked different colleagues to complete the questionnaire while the time needed was measured.

Figure 3 gives an overview about the schedule of study participation in this study.

Figure 3

To realize interviews and measurements, study participants can choose between a visit at home by the main researcher (LN) or a meeting at the Department of Health Economics and Health Services Research. In the latter case, insurance covers possible accidents on the way to or from the research department, and travel costs are repaid. In general, it is important that the interviews will be undisturbed, i.e., a meeting room is reserved and colleagues are askes for consideration. If study participants wished to be interviewed as a couple or a group, we would accept this; however, our intention is that each study participant should have the equal opportunity to respond freely. If study participants did not wish to visit the research department or to be interviewed at home, we would also arrange interviews via telephone or skype. We calculate that each narrative interview will last one to two hours followed by answering the questionnaire. To diminish the study participants' burden, it is possible for them to complete the questionnaires later. In this case, the main researcher (LN) give them a stamped envelope accompanied by a reminder to contact her if any questions arise while completing the questionnaire. For this, we originally estimated a duration of 30 to 45 minutes, but we observed shorter periods in some pretests. Each study participant will receive an expense allowance (i.e., a sum of money in Euros) after completing both measurements.

Data analysis

Qualitative data analysis

The interviews will be recorded and transcribed verbatim. We chose the *Documentary Method of data interpretation* in accordance with Arnd-Michael Nohl[29 32] to analyze and interpret the textual material of the narrative interviews. This method aims to reconstruct the practical experiences of individuals, social groups, milieus, or organizations (referred to as the orientation framework) to obtain access to their orientations of action that are visible in their everyday lives. Narratives are preconditions to reconstruct the orientation framework; the chosen form of interviewing is thus suitable, since the provided textual material should consist of impromptu narratives – even if the interviewees' narratives will be, of course, linked with descriptions and argumentations. The researcher's interest refers to the way a narrative text or action is constructed by the interviewee or how the limits within which its topic are dealt with, i.e., the orientation framework within which a topic or problem is handled.[32] In practice, the *Documentary Method* comprises three stages of interpretation: formulating interpretation (to summarize topics), reflecting interpretation (to generate the framework of orientation, in which the topics are elaborated on), and type formation (i.e. the emerged empirical results become visible as types).[29] From the beginning of the three-staged interpretation process to its end, the *Documentary Method* is based on a consistent comparative analysis. So, the orientation framework is generated by comparing one case (interview sequence) with other empirical cases (interview sequences) that deal with the same topic but within contrasting orientation frameworks. For instance, if we only look at one interview sequence, we would interpret it against the background of our own (or common) theories regarding the topic of interest. By comparing this first with other interviews (sequences), both our knowledge and interpretation is methodically relativized. In this way, Nohl declares the comparative analysis as the golden standard of methodically controlled research.[29] In this study, each informal caregiver provides text (sequences) related to the common topic, and by comparing this (these) with text (sequences) of another informal caregiver, the orientation framework emerges. Following the formulating and reflecting interpretation, different approaches of type formation (sensegenetic, sociogenetic, or relational[33]) lead to generalization of the empirical results by identifying similar or overlapping cases based on case comparisons.

Data analysis will be conducted after each interview from the beginning of the data collection process by the main investigator (LN) and a research assistant on the bachelor level. Because of the comparative analysis within the Documentary Method, further characteristics, i.e. themes, will be used as varying factors during the interpretation and may provoke re-sampling to recruit further study participants who may provide heterologous themes. Thought processes and decision trails during data analysis and subsequent interpretations will be documented, and interpretations will be discussed with the project leader (CB) and another member of the workgroup. Furthermore, attendance of an interpretation group working with the Documentary Method located at the University of Hamburg will also be used to validate the interpretation. Interpretation will be supported by *MAXQDA* (version 12).

Quantitative data analysis

Regarding the quantitative data analysis, the questionnaires named above serve to explore the identified care-related strain (CarerQol-7D, ZBI) and the evaluation of the life satisfaction (CarerQol-VAS, EQ-5D) of the study participants with consideration of their personality traits (NEO-FFI-30, ASKU) and coping skills (PCI). The topics or types emanating from the qualitative data analysis will also be interpretively connected with, for example, the value of the care-related strain or the coping skills. Data from completed questionnaires will be transferred into datasets. With *descriptive statistical methods* including frequency and contingency analysis we will describe the sample of informal caregivers included in this study. The results of *analytic statistical methods* like correlational analysis, which examines the association of perceived strain and personality traits or coping skills, will be interpreted with great caution due to the small sample size. These analyses will be supported by the feature “Stats” of MAXQDA (version 12) and IBM SPSS Statistics (version 23). Because of prioritization of the QUAL-approach in this mixed methods study, the *quan*-data are supplemental to enrich the *QUAL*-data by exploring the narratives of study participants in the light of their personal characteristics named above and the network to whom they relate. Network graphs present the number of network members and their degree of importance from the personal perspective of the respective network member. Additionally, combined with the narratives of those, caregiving tasks of each network member are described. So, the *quan-data* may enhance the profiles of included caregivers in this study and can serve –due to the small sample size– at least as a starting point for further research in this field. This study considers personal and network-related characteristics of informal caregivers of PwD for the first time; in this way, we hope to meet the relevance of these factors in caregivers’ experience of the reconciliation between caregiving in dementia, family, and employment.

ETHICS, DATA PROTECTION, AND DISSEMINATION

Ethical approval for this study was obtained from the German Society of Nursing Sciences (approval no. 17-006). The study is registered in the German Clinical Trial Register (DRKS), DRKS00012929. Furthermore, the study was planned in accordance with the German Federal Data Protection Act (*Bundesdatenschutzgesetz*) and the data protection law of Hamburg (*Hamburger Datenschutzgesetz*), and will be processed under the guidance of the data protection officer of the conducting research department.

Study participants have to give written informed consent before data collection. By using audio records and (paper) questionnaires, data will be collected. All data will be pseudonymised; thus, qualitative (interview) data and quantitative (questionnaire) data will be combined at the level of interpretation. When data collection is finished, the key list (assignment of study participants’ names to pseudonyms) and the mailing addresses of the study participants will be destroyed in according to data protection regulations. Audio records of the interviews will be deleted after transcription. Data of the questionnaires will be transferred into data sets that will only be available to the main researcher (LN) who will store the data sets in her password-protected computer. Declarations of consent and pseudonymized data will be stored separately in locked cabins within secure offices for ten years after the end of the study.

The results of this study will be presented at scientific conferences in Germany and beyond, and published in peer-reviewed, national and international, journals.

EXPECTED IMPACT OF THE STUDY

By including different familial and non-familial members of caregiving networks, we will be the first to explore the reconciliation between caregiving in dementia, family-related, and employment-related requirements of informal caregiving in dementia at a national level. The network-perspective will provide more detailed insights into this complex topic than an ego-centered perspective. By merging qualitative and quantitative data, the narrated ways of reconciliation will be investigated in consideration of the sociodemographic characteristics, personality traits, and coping skills of each informal caregiver, and in the light of the corresponding caregiving network.

The methodological approach used serves as a starting point for further research in this field; for instance, by including a larger sample of affected informal caregivers of PwD, or applying further methods of network analysis. Our results will help policymakers and stakeholders regarding healthcare, social issues, labor force, and economics to understand better how informal caregivers of PwD are subjected to the requirements of their everyday lives, how they are seeking to balance these requirements, and which interventions can support them to fulfill their major role in dementia caregiving in our society.

AUTHORS' CONTRIBUTION

LN was responsible for the original idea, literature review and study design. HHK and CB advanced the concept. All authors contributed to obtaining the ethical approval. LN drafted this manuscript; HHK and CB reviewed it critically. All authors read and approved the final manuscript.

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DATA SHARING STATEMENT

Not applicable.

COMPETING INTERESTS

The authors have no conflict of interest to report.

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ETHICS APPROVAL

Ethics Committee of the German Society of Nursing Sciences, Germany (approval no. 17-006).

FIGURES

Figure 1: Background and Aim of this Mixed Methods Study

PwD, persons with dementia

Figure 2: Simultaneous Qualitatively Driven Mixed Methods-Design (QUAL+quan-Design)

PwD, persons with dementia

CarerQol-7D; CarerQol-VAS (German Version)

ZBI, Zarit Burden Interview (German Version)

EQ-5D, EQ-VAS (German Version)

NEO-FFI-30, Neo-Five-Factors Inventory-30 (German Version)

ASKU, [Allgemeine Selbstwirksamkeitsskala]

PCI, Proactive Coping Inventory (German Version)

Figure 3: Overview of Study Participation

PwD, persons with dementia

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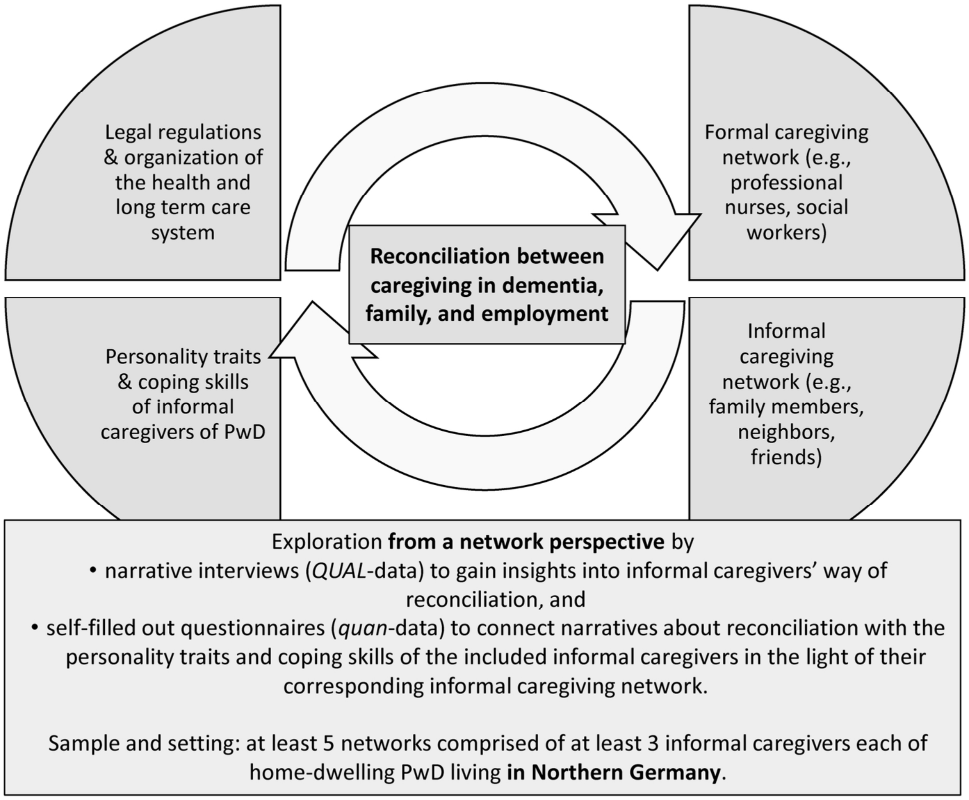

Exploration **from a network perspective** by

- narrative interviews (*QUAL*-data) to gain insights into informal caregivers' way of reconciliation, and
- self-filled out questionnaires (*quan*-data) to connect narratives about reconciliation with the personality traits and coping skills of the included informal caregivers in the light of their corresponding informal caregiving network.

Sample and setting: at least 5 networks comprised of at least 3 informal caregivers each of home-dwelling PwD living **in Northern Germany**.

Background and Aim of this Mixed Methods Study

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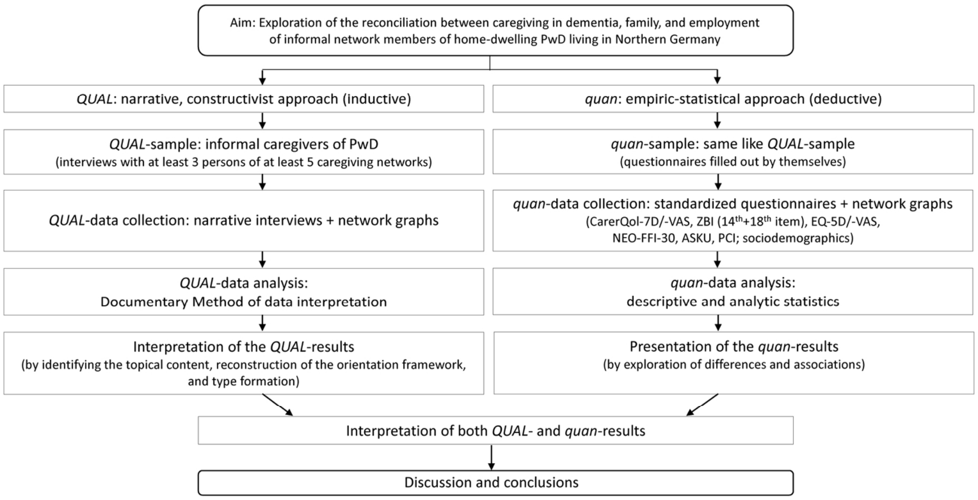

Simultaneous Qualitatively Driven Mixed Methods-Design (QUAL+quan-Design)

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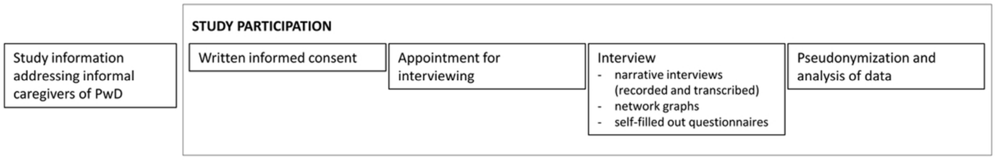

Overview of Study Participation

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Seeking the balance between caregiving in dementia, family, and employment: Study protocol for a mixed methods study in Northern Germany

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Seeking the balance between caregiving in dementia, family, and employment: Study protocol for a mixed methods study in Northern Germany

submitted by Lydia Neubert, Hans-Helmut König, Christian Brettschneider

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ABSTRACT (295 WORDS)

Introduction

The debate on reconciliation between childcare and working has to be expanded to caregiving for the elderly, since the importance of informal caregiving will increase in the future due to populations' aging and women's increasing labor force participation. Informal caregivers who are caring for the rising number of persons with dementia (PwD) are often female and subjected to high caregiving requirements. These are added to further demands emerging from their family and work life. How affected caregivers seek to balance those requirements depends on, inter alia, their own characteristics and the informal caregiving network to whom they relate. Both aspects were not yet considered in previous studies. This mixed methods-study thus aims to explore the reconciliation between caregiving in dementia, family, and employment by including different members of caregiving networks of home-dwelling PwD and by considering their personal characteristics.

Methods and analysis

By purposive sampling, we include at least 5 caregiving networks of home-dwelling PwD; each of them consisting of at least 3 informal caregivers living in Northern Germany. Narrative interviews of participants will be recorded, transcribed verbatim, and interpreted according to the Documentary Method (QUAL). By completing standardized questionnaires, participants will provide sociodemo- and psychographic data concerning theirselves and the networks, from whom they arise (quan). This supplemental, descriptive information will give further background to the themes and types emerging from the interviews. Hence, the quan-data enrich the QUAL-data by exploring the narratives of participants in the light of their personal and network-related characteristics.

Ethics and dissemination

Ethical approval was obtained from the Ethics Committee of the German Society of Nursing Sciences. Study results will be disseminated through conference presentations and publications in peer-reviewed journals.

Trial registration number

The study is registered in the German Clinical Trial Register (DRKS), DRKS00012929.

Keywords

Statistics and research methods, qualitative research, public health, health services administration and management

Strengths and limitations of this study

- This German study will provide insights into a complex topic from a network-perspective for the first time.
- Informal caregiving network is composed of familial and non-familial members in this study.
- By merging qualitative and quantitative data, narratives of study participants will be explored considering their sociodemo- and psychographic characteristics, and the caregiving network from whom they arise.
- This study will include only five networks consisting of (at least) 15 informal caregivers of PwD; further research should expand the sample size.
- Results may only apply for the German healthcare system and its providers; we appreciate replications in other countries.

INTRODUCTION

Family caregivers and other related caregivers of persons with dementia (PwD) are subjected to a higher load than the general population. Because seniors generally prefer living at home, many of them are cared for by their relatives at home as long as possible.[1] Their caregiving commitments affect their personal and work life considerably. In Germany, the estimated number of elderly or impaired people living in the community who are cared for by their relatives amounted to more than two million in 2015. This represents 73 % of all people in certified need of care according to the legal regulations fixed in the Social Security Code XI (*Sozialgesetzbuch XI*).[2] In many cases of home-dwelling individuals in need of care more than 2 informal caregivers are involved, which corresponds to approximately 4 to 5 million informal caregivers (e.g., relatives, neighbors, friends) in Germany.[3] Focusing on dementia, more than 1.5 million PwD lived in Germany in 2012; this is almost 2 % percent of the total population, which is higher than the European average of 1.5 %.[4] This number will increase to 3 million by the year 2050 because of the increasing life expectancy and the fact that Alzheimer's Disease and related forms of dementia are age-associated illnesses.[5] Therefore, the importance of informal caregiving in dementia care is bound to increase in the future – not only in Germany, but also worldwide.[6]

From an economic point of view, the costs of informal care constitute the majority of total societal costs of PwD living in the community.[7] These costs increase with the progression of dementia and patients' impairments in activities of daily living, need for care and supervision.[8] Productivity loss (i.e., lost workforce) of informal caregivers of PwD should also be considered when measuring societal costs of dementia. In their review, Lilly et al.[9] concluded that caregivers, in general, are equally as likely to be in the labor market as non-caregivers, but commit fewer work hours to the labor market than non-caregivers; in particular, if the caregiving responsibilities exceed ten hours per week, the likelihood to withdraw from the labor market also increases.

To take up this evidence and to focus on dementia caregivers, we reviewed the interplay between informal caregiving in dementia and caregiver's employment (Neubert et al. under review[10]). On the one hand, we can confirm considerable work impairments of employees with caregiving commitments at home. Besides objectively measured effects like the reduction of work hours or stop working, many caregivers perceive work-caregiving conflicts that stress caregivers' burden in addition to the caregiving requirements. Hence, working full-time and having difficulties in balancing work and caregiving tasks predicted caregivers' strain; also, inflexible work conditions predicted depressive symptoms of dementia caregivers.[11] On the other hand, to be a caregiver of a PwD and to be employed also involve positive work experiences and does not necessarily lead to exacerbated caregivers' burden. Moreover, combining unpaid caregiving with a paid job is associated with more happiness for the informal caregivers.[12]

Society is subject to two "structural mega-trends", namely women's increasing labor force participation and an expected increase of people needing care due to an aging populations.[13] The labor market participation of female employees is indispensable for the maintenance of societal economic productivity. However, as the majority of informal caregivers is female[3 14], the existing conflict between caregiving and employment might be further exacerbated. For this reason, political and societal stakeholders should be interested in finding a way to reconcile caregiving and working and to support informal caregivers of an employable age in maintaining their labor market participation without limiting their role in dementia caregiving.

How informal caregivers of PwD experience balancing care-, family- and employment-related requirements depends on different factors (figure1). First, country-specific legal regulations and structural conditions within the respective long-term care-system are relevant. In Germany, for instance, the regulations on Caregiver Leave and Family Caregiver Leave (*Pflegezeitgesetz* und *Familienpflegezeitgesetz*) allow family caregivers to take time off work for a specific time period. Employees thus will be given more flexibility and security to temporarily care for their relatives without completely leaving the labor market.[15] Second, personality traits, which means how an individual evaluates her own life and changing circumstances, and coping skills in handling high-load situations considerably influence caregivers' experience.[16 17] In caregiving research, so far, little is understood about how caregivers perform their roles better and why.[18] Third, professional (paid) services which form the formal caregiving network contribute to the caregiving situation at home by providing information, respite and support; such as day care centers.[19] Fourth, other (usually unpaid) persons who represent the informal caregiving network contribute to caregivers' perception and can reduce caregivers' burden. However, although the value of a cooperative structure within the family or circle of acquaintances seems to affect caregivers' well-being and quality of life[20 21], their possible relevance to mediate work-caregiving conflicts has rarely been examined. It should be noted that others in the social network might not only be mediating but rather demanding, which we should also consider in the reconciliation debate. Therefore, further research on reconciliation between caregiving in dementia and other roles might include the perspective of more than one person within the family or circle of acquaintances to gain a more comprehensive picture of the caregiving networks' impact. Moreover, a short look at the caregiving network might be not sufficient, because caregiving research delves into a very complex and dynamic phenomenon. It is based on the emotional relationship between a caregiving and cared-for person as well as between different caregivers if caregiving responsibilities are shared.[18] For instance, by comparing caregiving spouses, adult children, and children-in-law, data on outcomes like resources, stressors, and psychological distress differ between the groups; so, each of them has different needs based on her or his subjective burden and personal circumstances (e.g., co-residence with the cared-for person, income, other family responsibilities).[22] Additionally, caregiver relationships are built on a common descent or by marriage, but they are also influenced by social expectations of family and caregiving varying by culture.[23] Hence, caregiving research should not ignore personal motives of caregivers if we want to better understand caregiving processes, also, in the light of balancing care-, family- and employment-related requirements.

Aim and research questions of the study

To the best of our knowledge, no study has investigated the reconciliation between caregiving and other roles from a network-perspective until now, since studies only considered the primary caregivers' perceptions. Previous studies on this topic also disregarded psychographic characteristics of informal caregivers. Therefore, this mixed methods study aims to explore the reconciliation between caregiving in dementia, family-related, and employment-related requirements of informal caregiving network members of PwD living at home by including at least 3 familial and non-familial members of each caregiving network. The study focuses on the subjective reconciliation described by the study participants in the qualitative research strand. Thus, the primary question of this study is: how do informal caregivers of PwD experience the reconciliation between caregiving in dementia, family tasks, and employment? By merging qualitative and quantitative data, narratives of study participants will be further explored by combining those with their sociodemo- and psychographic characteristics, and the caregiving network to whom they relate. Figure 1 outlines the background and aim of this mixed methods study.

Figure 1

To gain a broad picture of the experiences of informal caregivers regarding the reconciliation between caregiving in dementia, family, and employment, we formulated the following subordinated research questions.

Within the qualitative research strand, narrative interviews with informal caregivers of PwD living in Northern Germany with written informed consent will provide answers to the following research questions: How do members of informal caregiving networks experience assuming caregiving responsibilities for an individual with dementia? How do they experience the division of caregiving tasks, i.e., who feels responsible for which task and how does she/he experience it? How do they experience possible consequences regarding other commitments and areas of life (e.g., child care, work, leisure time) due to caregiving? How do they experience circumstances which may influence the perceived consequences positively or negatively?

The quantitative research strand will explore the evaluation of the life situation of network members according to a standardized approach by measuring caregivers' care-related strain via CarerQol-7D, CarerQol-VAS, and ZBI (14th+18th item), and life satisfaction via EQ-5D and EQ-VAS.

Finally, by merging the qualitative and quantitative data at the level of interpretation, we will explore how the caregivers' perception –based on the qualitative research strand– and evaluation –based on the quantitative research strand– regarding their current life situation are possibly interrelated with their sociodemographic characteristics, personality traits, and coping skills in consideration of the corresponding caregiving network. To measure caregivers' psychographic characteristics we will apply the NEO-FFI-30 (Neo-Five-Factors Inventory), ASKU (short-form of a German self-efficacy scale), and PCI (Proactive Coping Inventory).

METHODS AND ANALYSIS

Overview of the study design

We chose a simultaneous qualitatively driven mixed methods-design to apply both qualitative and quantitative methods complementarily (*QUAL+quan-design*).[24] After separate data collection and analysis, qualitative data and quantitative data will be combined at the level of interpretation. Qualitative (*QUAL*) data collection and analysis will be prioritized. For this we will interview informal caregivers and interpret their narratives to explore their subjective experience of the reconciliation between caregiving in dementia, family tasks, and employment. Qualitative inquiry refers to the investigation of underlying knowledge and the understanding of social phenomena. Thus, it aims to understand the meaning of human action.[25] To gain the personal perspectives of human actors in this study, informal caregivers are invited to tell of their subjective experiences. Their descriptions regarding the perceived reconciliation between caregiving in dementia, family tasks, and employment is our leading research interest. It also covers the perceived consequences on the wider family or other related persons, on the subjective health status and quality of life, since they have multiple roles as a caregiver, relative, neighbor or friend, and/or an employee. Therefore, we prioritize the qualitative research strand in this mixed methods study; yet we also appreciate the complementary quantitative approach. In this, we will additionally collect quantitative (*quan*) data by using validated questionnaires. These will measure caregivers' evaluation of their current life situation, their sociodemographic and psychographic characteristics (i.e., personality traits, coping skills). Based on this, narratives of study participants will be explored considering their personal characteristics, and the caregiving network to whom they relate.

The next paragraphs describe the methodical procedure in detail. Figure 2 demonstrates the used *QUAL+quan*-design in this study.

Figure 2

Recruitment of study participants

In the vast majority of cases of informal caregiving, besides the main or primary caregiver (i.e., the individual with the greatest care responsibilities), further persons are involved in a smaller or larger degree. For example, a husband of a caring daughter, who supports his spouse in the decision-making procedure regarding the care of his mother-in-law or even if he lends an ear to his wife, is an involved caring person. So, caregiving in general and in dementia mainly affects not only the primary caregiver but further individuals who build the caregiving network.

Koehly et al.[26] used a multi-informant social network approach to investigate caregiving processes within the context of Alzheimer's Disease and related dementia. As a result, they suggest that a sampling approach with at least three informants allows a more comprehensive assessment of a family caregiving network. In our study, we broadened the perspective by including non-familial individuals like neighbors or friends, too.

The first step of recruitment was to personally contact gatekeepers engaged in counseling centers for seniors and family caregivers (*Pflegestützpunkte*) or self-help groups (e.g., affiliated with the *Alzheimer Gesellschaft Hamburg e.V.*) located in Hamburg, Schleswig-Holstein, and Lower Saxony. By addressing different gatekeepers in different regions of Northern Germany, we were able to broaden the possibilities to come in contact with eligible study participants and to reduce sampling bias. There, the main researcher (LN) displayed the study information covering the aims and procedures of the study, the inclusion criteria to select study participants, data collection, processing, and storage, as well as participants' contribution to this work and the possibilities for opting out. Furthermore, she visited these service points to inform both gatekeepers and potential study participants face-to-face. Within these visits, the main investigator (LN) informed the gatekeepers comprehensively about the in- and exclusion criteria to avoid unsuitable pre-selection of clients.All potential study participants had time to read and fully understand both the study information and declaration of consent. In case of ambiguities, the main researcher was present to answer all emerging questions. Because study information contains the researcher's telephone number, mailing address, and e-mail-address, potential study participants can contact her during office hours to ask questions and receive further oral information about the study.

In this way, we expect that the first informal caregiver of a caregiving network of a home-dwelling PwD will be admitted. This individual is the index-interviewee who also provides access to at least two other informal caregivers of each network. Each of them has to be involved in care, support those involved in care, or could be involved due to their relationships with the cared-for individual with dementia. The index-interviewee has to give written permission before being interviewed and will name at least two other network members who had agreed to participate. Already at that time or at their own interviews at the latest, the interviewer (LN) will obtain the declarations of consent of the additional network members. Appointments for the interviews will be arranged by the interviewer. She will contact named network members approximately one week after the index-interview. This sampling approach will be continued until the desired number of at least three network members (including the index-interviewee) will be reached. The number of persons who refuse to participate and their reasons for opting out will be documented in the study diary.

Sample size and eligibility criteria of study participants

In total, (at least) 5 networks consisting of (at least) 15 informal caregivers of PwD will be included in this study through purposive sampling to reach maximum variation between characteristics of the study participants (e.g., gender, age, relationship to the cared-for person, and living situation). The sample size is restricted by the feasibility of this study; i.e., the target sample size is explained by the explorative character of this study that is a preparatory part of a larger study. However, qualitative data analysis requires contrasting cases, whereby further sampling can be necessary until this goal will be achieved (see paragraph “qualitative data analysis”). If potential study participants refuse or withdraw study participation, the research team will replace them. If participants withdraw or refuse to participate –after they were nominated by the index-interviewee– and cannot be replaced, the index-interviewee’s data are be considered as individual data. This means, their interpreted narrations and analyzed data are relevant for the aggregated results but cannot contribute to the interpretations from the network-perspective. Following Koehly et al.[26], we determined the following inclusion criteria:

- Members of the informal caregiving network are individuals who are important for care delivery to the affected person with dementia or the first informal caregiver (index-interviewee); i.e., they undertake caring tasks (e.g., personal care, eating), household tasks (e.g., cleaning, cooking), support in the care-related or everyday decision-making, and/or emotional support during the caregiving period. The degree of involvement in caregiving and both the relationship to the individual with dementia and the living situation (living together with the cared-for person or not) are not relevant for study inclusion. For instance, an eligible caregiving network can comprise a retired wife caring for her husband with dementia, a daughter of employment age –not living with her parents, with her own family commitments, and supporting her mother in decision-making and visits to medical professionals or authorities–, and a volunteer who supervise the cared-for person once a week for a few hours.

- Members of the informal caregiving network i) are older than 18 years, ii) have appropriate German language skills and no cognitive impairments to conduct the interview, iii) are living in an urban or adjacent region of Hamburg, or an urban or rural region of Schleswig-Holstein or Lower Saxony (within a maximum linear distance of 100 km from our department in Hamburg), and iv) at least one member of each participating caregiving network is employed at the time of investigation. Since many caregivers are old themselves and already retired[22], only employed (younger) caregivers will be asked how they experience the reconciliation between their caregiving and work responsibilities (whether their contributions in caregiving are small or large; i.e., these network members do not need to be the primary caregivers).
- The first member of the informal caregiving network verbally confirms the presence of the Alzheimer's Disease or related dementia of the cared-for person and its functional impairments according to the Social Security Code XI (*Sozialgesetzbuch XI*). The individual with dementia has to be living at home. Informal caregivers of institutionalized individuals will be excluded. Neither the stage of the disease nor whether the diagnosis was medically confirmed are relevant for inclusion. By ethical reasons we decided to not collect declarations of consent of PwD. Therefore, we cannot directly request any data concerning the care-recipient with dementia while interviewing his/her caregivers. However, it will be essential that the interviewees disclose more or less comprehensive descriptions of the physical and mental constitution of the cared-for person in their own words to illustrate their caregiving situation at home including, for example, their self-perceived burden due to the specific needs of an individual with dementia. Caregivers' perceptions and meanings meet our primary research interest, and additional data like the described functional impairments of the PwD will likely help us to contextualize the findings.

Recruitment of study participants started in October 2017, and first results are expected in 2018. The study is a preparatory part of a larger project (funded by the German Federal Ministry of Education and Research; grant: 01EH1601A) that ends in August 2020; then, results of this study will be published.

Measuring instruments

Qualitative data collection

For *QUAL*-data collection we chose *narrative interviews* to elicit stories of experiences in accordance with Schütze 1976[27] and Flick 2011[28]. At the beginning of each interview conducted face-to-face, an initial question will be stated that encourages interviewees' narration. At best, the interviewer (LN) must not intervene at any time except with encouraging phrases like "And then?" or nodding as a non-verbal sign of empathic listening. To standardize interviewing, an *interview guide* was developed and pretested. For this, each question was first discussed between the main investigator (LN) and professor Nohl from the Helmut Schmidt University in Hamburg, who considerably developed the interpretation of narrative interviews by means of the Documentary Method[29]; then we tested the interview guide in a workgroup of qualitative methods located at the University Medical Center Hamburg-Eppendorf. Participants were asked to provide feedback regarding the comprehensibility of questions; no amendments were necessary after this pretest. If the narrative continuity stagnates, maintenance questions and requests were also narratively formulated. An exemplary, narratively formulated request is "Please tell me about your last week, day after day. I'm interested in every detail that you did for [the person with dementia]. Let's start with last [Monday]". Non-narratively formulated requests at the end of the interview can refer to information that still did not occur in the narratives of the interviewees; e.g., "How many hours are you currently working?". Each interview will close with the invitation to complete a network graph consisting of concentric circles to draw all network members who are important to the interviewee. Used network graphs have an intermediate position between the qualitative and quantitative data (concerning the interpretation of those we refer to the section of quantitative data analysis). The *theoretical framework*, to which the development of the interview guide is subject, is based on a topic-specific literature search (Neubert et al. under review[10]) and on both studies of Koehly et al.[26] and Gröning & Kunstmann[30], who understand (dementia) caregiving as an informal network- or family-task. The main investigator (LN) will conduct all interviews. She is trained in applying qualitative research methods in general and, in particular, in interviewing informal caregivers because of another qualitative study[31]. She is also aware of the specific life situation of caregivers due to her previous experience as a registered nurse, and she interacts with them empathetically.

Quantitative data collection

To measure *quan*-data, we will use *questionnaires* (ten pages) which will be filled out by the study participants themselves. Each questionnaire initially queries sociodemographic characteristics of the study participants including age, gender, relationship to the cared-for person with dementia, employment status, occupation, living situation, and region. These data facilitate descriptions of the sample of this study and hint at the generalizability of the sample. Then, to measure care-related strain, life satisfaction, and psychographic characteristics of the study participants, the questionnaire comprises the following validated questionnaires: The German version of the CarerQol-7D/-VAS, items no. 14 and 18 of the Zarit Burden Interview (ZBI) of its German version, the German version of the EuroQol (EQ-5D), the NEO-Five-Factors Inventory (NEO-FFI-30), the short-form of the perceived self-efficacy scale (ASKU), and the German version of the Proactive Coping Inventory (PCI). After its development, the questionnaire was also pretested; for this, we have asked different colleagues to complete the questionnaire while the time needed was measured.

Figure 3 gives an overview about the schedule of study participation in this study.

Figure 3

To realize interviews and measurements, study participants can choose between a visit at home by the main researcher (LN) or a meeting at the Department of Health Economics and Health Services Research. In the latter case, insurance covers possible accidents on the way to or from the research department, and travel costs are repaid. In general, it is important that the interviews will be undisturbed; i.e., a meeting room is reserved and colleagues are askes for consideration. If study participants wished to be interviewed as a couple or a group, we would accept this; however, our intention is that each study participant should have the equal opportunity to respond freely. If study participants did not wish to visit the research department or to be interviewed at home, we would also arrange interviews via telephone or skype. We calculate that each narrative interview will last one to two hours followed by answering the questionnaire. To diminish the study participants' burden, it is possible for them to complete the questionnaires later. In this case, the main researcher (LN) give them a stamped envelope accompanied by a reminder to contact her if any questions arise while completing the questionnaire. For this, we originally estimated a duration of 30 to 45 minutes, but we observed shorter periods in some pretests. Each study participant will receive an expense allowance (i.e., a sum of money in Euros) after completing both measurements.

Data analysis

Qualitative data analysis

The interviews will be recorded and transcribed verbatim. We chose the *Documentary Method of data interpretation* in accordance with Arnd-Michael Nohl[29 32] to analyze and interpret the textual material of the narrative interviews. This method aims to reconstruct the practical experiences of individuals, social groups, milieus, or organizations (referred to as the orientation framework) to obtain access to their orientations of action that are visible in their everyday lives. Narratives are preconditions to reconstruct the orientation framework; the chosen form of interviewing is thus suitable, since the provided textual material should consist of impromptu narratives –even if the interviewees' narratives will be, of course, linked with descriptions and argumentations. The researcher's interest refers to the way a narrative text or action is constructed by the interviewee or how the limits within which its topic are dealt with; i.e., the orientation framework within which a topic or problem is handled.[32] In practice, the *Documentary Method* comprises three stages of interpretation: formulating interpretation (to summarize topics), reflecting interpretation (to generate the framework of orientation, in which the topics are elaborated on), and type formation (i.e., the emerged empirical results become visible as types).[29] From the beginning of the three-staged interpretation process to its end, the *Documentary Method* is based on a consistent comparative analysis. For this, the orientation framework is generated by comparing one case (interview sequence) with other empirical cases (interview sequences) that deal with the same topic but within contrasting orientation frameworks. For instance, if we only look at one interview sequence, we would interpret it against the background of our own (or common) theories regarding the topic of interest. By comparing this first with other interviews (sequences), both our knowledge and interpretation is methodically relativized. In this way, Nohl declares the comparative analysis as the golden standard of methodically controlled research.[29] In this study, each informal caregiver provides text (sequences) related to the common topic, and by comparing this (these) with text (sequences) of another informal caregiver, the orientation framework emerges. Following the formulating and reflecting interpretation, different approaches of type formation (sensegenetic, sociogenetic, or relational[33]) lead to generalization of the empirical results by identifying similar or overlapping cases based on case comparisons.

Data analysis will be conducted after each interview from the beginning of the data collection process by the main investigator (LN) and a research assistant on the bachelor level. Because of the comparative analysis within the Documentary Method, further characteristics, i.e. themes, will be used as varying factors during the interpretation and may provoke re-sampling to recruit further study participants who may provide heterologous themes. Thought processes and decision trails during data analysis and subsequent interpretations will be documented, and interpretations will be discussed with the project leader (CB) and another member of the workgroup. Furthermore, attendance of an interpretation group working with the Documentary Method located at the University of Hamburg will also be used to validate the interpretation. Interpretation will be supported by *MAXQDA* (version 12).

Quantitative data analysis

Regarding the quantitative data analysis, the questionnaires named above serve to explore the identified care-related strain (CarerQol-7D, ZBI) and the evaluation of the life satisfaction (CarerQol-VAS, EQ-5D) of the study participants with consideration of their personality traits (NEO-FFI-30, ASKU) and coping skills (PCI). Data from completed questionnaires will be transferred into datasets. With *descriptive statistical methods* including frequency and contingency analysis we will describe the sample of informal caregivers included in this study. Using *analytic statistical methods* (i.e., correlational analysis by calculating Pearson's correlation coefficient r or Spearman's rank correlation coefficient ρ), we will explore possible associations of care-related strain and personality traits or coping skills variables. We will also examine if topics or types emanating from the qualitative data analysis could be used as variables that may also be associated with the personality traits variables, for example. Furthermore, using a regression model by applying care-related strain (measured by the CarerQol-7D) as outcome variable, we will generate an equation to describe the statistical relationship between this outcome and predictor variables based on the *quan*-data. These results will be interpreted with great caution due to the small sample size. All analyses will be supported by the feature “Stats” of MAXQDA (version 12) and IBM SPSS Statistics (version 23). Because of prioritization of the QUAL-approach in this mixed methods study, the *quan*-data are supplemental to enrich the *QUAL*-data by exploring the narratives of study participants in the light of their personal characteristics named above and the network to whom they relate. Network graphs present the number of network members and their degree of importance from the personal perspective of the respective network member. Additionally, combined with the narratives of those, caregiving tasks of each network member are described. So, the *quan-data* may enhance the profiles of included caregivers in this study and can serve –due to the small sample size– at least as a starting point for further research in this field. This study considers personal and network-related characteristics of informal caregivers of PwD for the first time; in this way, we hope to meet the relevance of these factors in caregivers’ experience of the reconciliation between caregiving in dementia, family, and employment.

ETHICS, DATA PROTECTION, AND DISSEMINATION

Ethical approval for this study was obtained from the German Society of Nursing Sciences (approval no. 17-006). The study is registered in the German Clinical Trial Register (DRKS), DRKS00012929. Furthermore, the study was planned in accordance with the German Federal Data Protection Act (*Bundesdatenschutzgesetz*) and the Data Protection Law of Hamburg (*Hamburger Datenschutzgesetz*), and will be processed under the guidance of the data protection officer of the conducting research department.

Study participants have to give written informed consent before data collection. By using audio records and (paper) questionnaires, data will be collected. All data will be pseudonymized; thus, qualitative (interview) data and quantitative (questionnaire) data will be combined at the level of interpretation. When data collection is finished, the key list (assignment of study participants' names to pseudonyms) and the mailing addresses of the study participants will be destroyed in according to data protection regulations. Audio records of the interviews will be deleted after transcription. Data of the questionnaires will be transferred into data sets that will only be available to the main researcher (LN) who will store the data sets in her password-protected computer. Declarations of consent and pseudonymized data will be stored separately in locked cabins within secure offices for ten years after the end of the study.

The results of this study will be presented at scientific conferences in Germany and beyond, and published in peer-reviewed, national and international, journals.

EXPECTED IMPACT OF THE STUDY

By including different familial and non-familial members of caregiving networks, we will be the first to explore the reconciliation between caregiving in dementia, family-related, and employment-related requirements of informal caregiving in dementia at a national level. The network-perspective will provide more detailed insights into this complex topic than an ego-centered perspective. By merging qualitative and quantitative data, the narrated ways of reconciliation will be investigated in consideration of the sociodemographic characteristics, personality traits, and coping skills of each informal caregiver, and in the light of the corresponding caregiving network.

The methodological approach used serves as a starting point for further research in this field; for instance, by including a larger sample of affected informal caregivers of PwD, or applying further methods of network analysis. Our results will help policymakers and stakeholders regarding healthcare, social issues, labor force, and economics to understand better how informal caregivers of PwD are subjected to the requirements of their everyday lives, how they are seeking to balance these requirements, and which interventions can support them to fulfill their major role in dementia caregiving in our society.

AUTHORS' CONTRIBUTION

LN was responsible for the original idea, literature review and study design. HHK and CB advanced the concept. All authors contributed to obtaining the ethical approval. LN drafted this manuscript; HHK and CB reviewed it critically. All authors read and approved the final manuscript.

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None declared.

DATA SHARING STATEMENT

Not applicable.

COMPETING INTERESTS

The authors have no conflict of interest to report.

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ETHICS APPROVAL

Ethics Committee of the German Society of Nursing Sciences, Germany (approval no. 17-006).

FIGURES

Figure 1: Background and Aim of this Mixed Methods Study

PwD, persons with dementia

Figure 2: Simultaneous Qualitatively Driven Mixed Methods-Design (QUAL+quan-Design)

PwD, persons with dementia

CarerQol-7D; CarerQol-VAS (German Version)

ZBI, Zarit Burden Interview (German Version)

EQ-5D, EQ-VAS (German Version)

NEO-FFI-30, Neo-Five-Factors Inventory-30 (German Version)

ASKU, [Allgemeine Selbstwirksamkeitsskala]

PCI, Proactive Coping Inventory (German Version)

Figure 3: Overview of Study Participation

PwD, persons with dementia

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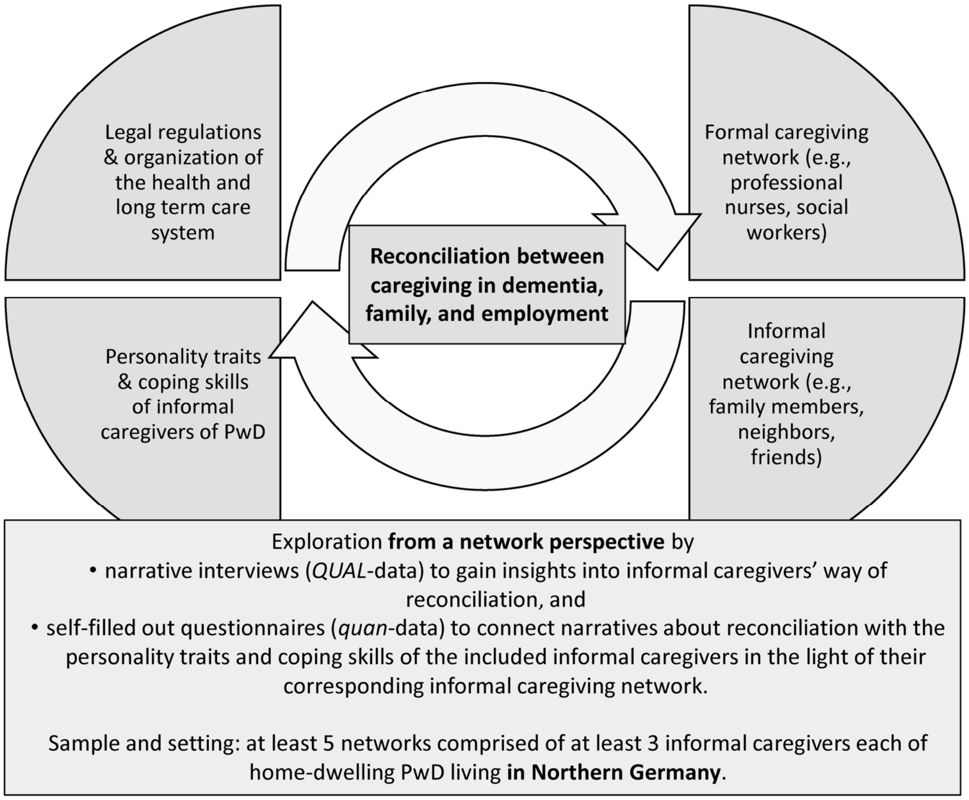

Exploration **from a network perspective** by

- narrative interviews (*QUAL*-data) to gain insights into informal caregivers' way of reconciliation, and
- self-filled out questionnaires (*quan*-data) to connect narratives about reconciliation with the personality traits and coping skills of the included informal caregivers in the light of their corresponding informal caregiving network.

Sample and setting: at least 5 networks comprised of at least 3 informal caregivers each of home-dwelling PwD living **in Northern Germany**.

Background and Aim of this Mixed Methods Study

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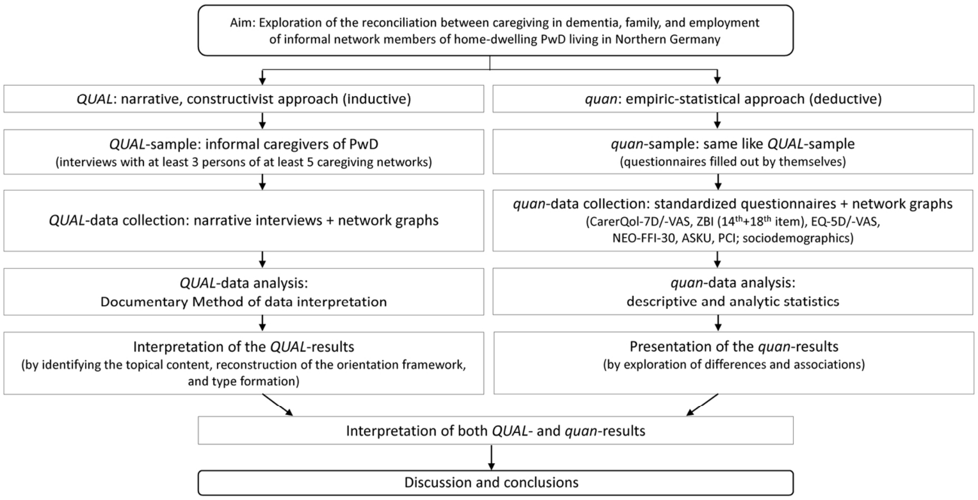

Simultaneous Qualitatively Driven Mixed Methods-Design (QUAL+quan-Design)

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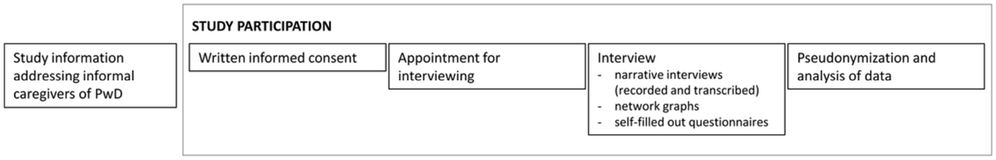

Overview of Study Participation

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