

# BMJ Open CaRegiving frOm A Distance (ROAD): home care in the future – flexible and nearby – multimethod qualitative study protocol

Andrea Budnick , Farina Bünning, Adelheid Kuhlmeiy

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Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität Berlin, and Institute of Medical Sociology and Rehabilitation Sciences, Virchowweg 22, 10117 Berlin, Germany, Charité Universitätsmedizin Berlin Campus Charite Mitte, Berlin, Germany

## Correspondence to

Dr Andrea Budnick;  
[andrea.budnick@charite.de](mailto:andrea.budnick@charite.de)

## ABSTRACT

**Introduction** Demographic change in Germany is accompanied by a birth rate deficit and increasing life expectancy. One effect of the ageing population is an increase in people needing care, most of whom want to grow old in their homes and to be cared for there. At the same time, informal caregivers are a core resource in the German care system, but due to social changes, this resource is not endless. Processes of social change in German society will cause further erosion in the potential number of informal local caregivers. Therefore, it will be increasingly important to provide conditions so that individuals at a distance who support people needing care are actually able to do so. *Distance caregiving* is a broad field, posing questions of intergenerational and intragenerational solidarity and the balance between work, family and caring responsibilities. Systematic research is required into opportunities and limitations, including innovative technology, in the whole field of care arrangements over a distance. The demands of the different actors in the distance caregiving arrangement are not yet known and are the subject of our study.

**Methods and analysis** This study will develop a model for distance caregiving. A qualitative multimethod research design (non-interventional study) will be adopted. The study will take place between September 2021 and August 2024. Participants will be selected by a purposeful sampling process. Phenomenological analysis will guide our data analysis. Data collected in this study will allow for triangulation, thereby increasing the trustworthiness of findings.

**Ethics and dissemination** Ethical approval for this study has been granted by the ethics committee of the Faculty of Medicine of the Charité, Universitätsmedizin Berlin (ID: EA1/371/21). Dissemination of the results will take place among the scientific community. Results will also be disseminated among the public and actors involved in healthcare and nursing care.

## INTRODUCTION

Demographic change in Germany is accompanied by a birth rate deficit and increasing life expectancy. Forecasts predict an average life expectancy in 2060 of 88.1 years for women and 84.4 years for men.<sup>1 2</sup> One effect of the ageing population will be an increase in people needing care. Currently, approximately

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A qualitative multimethod research study (non-interventional) will ensure comprehensive model development.
- ⇒ A purposeful sampling process will ensure data saturation.
- ⇒ Participants are recruited nationwide including both urban and rural areas.
- ⇒ Due to the interpersonal approach, perspectives of *all* actors in the distance caregiving arrangement are included using phenomenological analysis.
- ⇒ The study only includes people in need of care who live in Germany, so a one-to-one transfer of the findings relating to the distance caregiving arrangement to other countries is not possible.

4.1 million people in Germany are in need of care, of whom approximately 3.3 million (80%) are cared for at home by relatives and/or care providers. Of these, 2.1 million are cared for at home by informal caregivers—mostly women.<sup>2 3</sup> In most cases, caregivers are motivated to care for their relatives by an emotional relationship.<sup>4</sup> In Western culture, this development is driven by the fact that most people in need of care want to grow old and be cared for in their home.<sup>5</sup> In addition to the main caregivers, other individuals often take on care tasks as well. Overall, 9% of the German population from the age of 17 take on help or care work.<sup>6</sup>

The proportion of informal caregivers in the working age population increases in the 55–64 age group (11% women and 8% men, age group 45–54: 10% women and 6% men). In most cases, these working informal caregivers mostly support children needing care (39%), their own parents (27%) or partners (25%), while 8% care for someone outside their immediate family circle. Taking on informal care of people in their homes often leads to reduced earnings.<sup>7 8</sup>

In total, informal caregivers are a core resource in the German care system, but



due to social change, this resource is not endless.<sup>9</sup> For example, professional and private mobility has risen in recent decades in Western societies. Changing family and household structures also tend to erode the family support potential described previously. For instance, numbers of partnerships with children have declined markedly: while in 1996, half of all subjects aged 25–39 years old lived in a partnership with at least one child; by 2016, this figure was only 37%.<sup>10</sup> Additionally, the rising employment rate for women (1960=47%, 2020=77%)<sup>11</sup> also reduces the objective number of women available for caring tasks.<sup>12</sup>

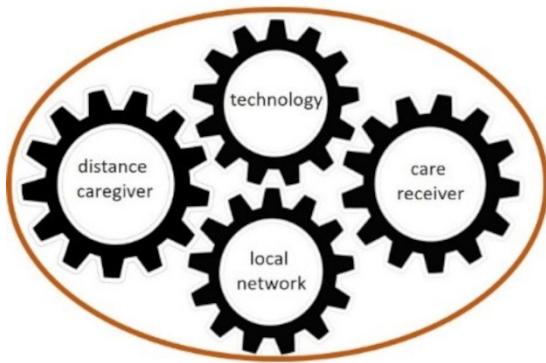
All these changes make it essential for these families and acquaintances to find alternatives to informal care on the spot by relatives in order to sustain the home care arrangement. The adaptation of such an alternative to the current regulations of the German healthcare system, for example, the individual level of care, is an aspect that must be given special attention. Despite the fact that families show great willingness to take responsibility for one another (solidarity principle), the impact on German society of the processes described earlier will cause erosion in the potential number of informal local caregivers.<sup>12</sup> Thus, in future, it will be increasingly important to provide conditions that enable individuals at a distance to support people needing care if they wish to do so.

### Distance caregiving

The *distance caregiving* arrangement is a common term in gerontological research in English,<sup>13 14</sup> although there is no clear definition of what it entails.<sup>15 16</sup> Most studies focus on well-situated English-speaking distance caregivers, excluding diverse populations.<sup>13</sup> In other words, research on this topic and its actors (distance caregivers, care receivers, and the informal and professional local network) in Germany is still in its infancy. One German study (DiCa) uses the following definition of distance caregivers: ‘The term [distance caregiver] includes relatives and people close to the care receiver, such as marriage partners and life partners, parents, adult children and siblings, friends and neighbors. The care-providing person lives at a distance from the person they care for. Some are still working; others do not work, while others are retired. [...] Distance caregivers support [...] regularly and in a range of areas’.<sup>17</sup> This definition shows that distance caregiving is a broad field, posing questions of intergenerational and intragenerational solidarity, social support, quality of life, mental and physical health,<sup>18 19</sup> and the balance between work, family and caring responsibilities. This balance is particularly important to enable caregivers to avoid periods of absence from work, reduced working time, loss of income, etc.<sup>7</sup> Informal care at a distance is therefore significant on both the individual and family levels and for the economy.<sup>8</sup> Nevertheless, in Germany, there is a general lack of knowledge on the subject of distance caregiving. There are no findings on how distance in the care process influences well-being or quality of life nor on the barriers experienced in the care arrangement or what they consist of, on conflicts

in the family or with the local support network, or on solution strategies.<sup>17 20</sup> More contextualised research is needed, especially involving perspectives of both distance caregivers and care receivers, as well as the local support network.<sup>14</sup> Moreover, there is no information about the prevalence of distance caregivers in Germany. A European study gives some indications: it shows that approximately 10% of those who provide care for their parents live between 25 km and 100 km away, while about 15% live over 100 km away.<sup>17</sup> Initial studies in English-speaking countries reveal the fields of support that distance caregivers provide (eg, emotional and organisational support and financial support) and reflect the challenges (eg, distance, unequal distribution of responsibilities and family conflicts). The question arises, however, whether these aspects are applicable in Germany. There is also a lack of information about how distance caregivers and care receivers or the wider supporter networks define ‘functioning of a distance caregiving arrangement’. Two initial qualitative studies in German-speaking regions highlight a reliable local network and transparent communication as decisive aspects for distance caregivers.<sup>20 21</sup> This local network includes both informal social contacts like the care receiver’s friends, partners and neighbours, and professional care services.<sup>20</sup>

Clearly, many open questions remain, revealing the need for further research. It would be interesting to discover how all concerned evaluate the distance involved, since this may contain resources as well as risks in situations such as the SARS-CoV-2 pandemic.<sup>22</sup> Solution strategies for distance caregivers and their care receivers hardly exist. First indications for German regions show that cross-sector efforts are necessary in order to effectively support distance caregiving.<sup>20</sup> As well as developing professional service provision and case management, measures within companies to improve the balance between work and care provision are required.<sup>17 21</sup> Potentials in information technology, ambient assisted living and service robotics have not yet been researched for this field, either in the area of digitalisation of the workplace or in relation to telehealth and digital networking of caregivers and others.<sup>23 24</sup> Otto *et al.*<sup>25</sup> highlight cognition, communication, control and coordination as different aspects where help could be provided by technological support for and between actors of the distance caregiving arrangement.<sup>25</sup> A coordinated effort is required, not to replace informal and professional caregivers but to provide assistive technological support systems (eg, cognitive support by electronic reminders for medication, communication aids such as telemedical consultations instead of driving to the doctor, home emergency calls, electronic patient files, intelligent refrigerators and visual doorbells).<sup>24</sup> The opportunities and risks entailed in the use of technological support systems are generally the subject of controversial discussion.<sup>26 27</sup> Technological support systems may offer opportunities for distance caregivers within the overall care arrangement, but this needs further research. Systematic research is therefore required into opportunities and limitations,



**Figure 1** Actors in the *distance caregiving* arrangement.

including innovative technology, in the whole field of care arrangements over a distance (see [figure 1](#)), where distance caregivers and the local network both play a key part and make a decisive contribution to maintaining a care receiver's autonomy at home. The demands of the different actors in the distance caregiving arrangement in relation to innovative technologies are not yet known and are a subject of our study. Accordingly, we follow up on Bei *et al's* proposal to examine technologies in *dyads*<sup>16</sup>; in this study, we focus on the triad of distance caregiving (see [figure 1](#)).

Overall, the objective of this study is to highlight aspects of a reliable and functioning care arrangement over a distance in one best practice model. Accordingly, our research will address the following main and subquestions:

- ▶ What are the actors' demands (including attitudes, preferences and needs) on the distance caregiving arrangement (see [figure 1](#))?
  - What are the actors' attitudes or preferences in relation to the distance caregiving arrangement?
  - What is necessary in order for the distance caregiving arrangement to meet existing needs?
  - What interdependencies exist between the actors (distance caregiver, care receiver, local network and technology) in the care arrangement?
  - What demands does the care arrangement place on technological support systems?
  - What are the potentials and risks of existing technological support systems?
- ▶ What enables the distance caregiving arrangement to function reliably to ensure autonomy and safety for all actors?
  - What scenarios can be imagined for the distance caregiving arrangement?
  - How are these scenarios evaluated by the actors in the care arrangement (see [figure 1](#))?
- ▶ What recommendations can be made for sustainable translation of the research findings on distance caregiving:
  - For distance caregivers?
  - For care receivers?
  - For application-oriented research organisations that design technological products?

- For the local network?

Novel aspects include the development of a best practice model that will take into account all components of the distance caregiving arrangement (see [figure 1](#)) and will give recommendations derived from the interviews in this study. This will be the first examination of this forward-looking model using social science methodology for the benefit of geriatric care studies in Germany. It will also give recommendations that take into account the needs of *all* actors in the caregiving arrangement as well as provide guidance for application-oriented research organisations by defining the demands that the distance caregiving arrangement makes on technological support systems. We anticipate that the study will generate increased safety in distance caregiving arrangements and open up new methods of communication and mobility for the future. In detail, we will carry out the following steps:

- ▶ Definition of the term distance caregiving by means of a scoping review.
- ▶ Description of the demands made by and on actors in the distance caregiving arrangement (see [figure 1](#)).
- ▶ Development of explanatory films based on the actors' demands that will show how distance caregiving arrangements can function reliably for all actors, ensuring autonomy and safety; explanatory films will enable technological support systems to be included without having to buy expensive equipment (a complex, cost-saving approach that enables the development of a forward-looking model in geriatric care science) and generating knowledge of how to describe ways in which life in their own homes can still be possible for care recipients, even if relatives or others cannot visit the person's home daily.
- ▶ Development of a model with recommendations for research and practice that will be tailored to the actors' needs.
- ▶ Preparation of guidelines for application-oriented research organisations describing what is required of technological support systems in distance caregiving arrangements, to enable technology to contribute to increased safety in the care arrangement.

## METHODS AND ANALYSIS

### Objective

In this study, we will develop a best practice model for distance caregiving regarding the perspectives of *all* actors in the distance caregiving arrangement and their interactions. This model will include recommendations for all actors to ensure that the care arrangement functions in a reliable and satisfactory way.

### Aims

- ▶ To clarify the actors' demands (including attitudes, preferences and needs) on the distance caregiving arrangement.





- ▶ To reveal what enables the distance caregiving arrangement to function reliably, ensuring autonomy and safety for all actors.
- ▶ To define recommendations that can be made for sustainable translation of the research findings on distance caregiving.

## Study design

### Study phase I

To filter out the essence of the distance caregiving phenomenon, we will use a qualitative multimethod design (non-interventional study) to describe the ‘[...] everyday life<<from the inside>>from the point of view of the actors’.<sup>28</sup> This procedure aims to enable researchers to develop an understanding of the social reality of the distance caregiving arrangement and to reconstruct the ‘[...] processes, patterns of meaning and structural features [...]’<sup>28</sup> of everyday life in this context, elements that non-members of the team cannot access and that those involved in the widest sense are not consciously aware of. Therefore,

- ▶ We will conduct guided interviews with (1) distance caregivers, (2) care receivers and (3) representatives of care receivers’ local networks, separately, to collect data on the demands of all actors.
- ▶ Additionally structured observation will take place in the care receiver’s home setting to gain a more detailed insight into the current care situation of every participating care receiver.
- ▶ Finally expert interviews with representatives from application-oriented research organisations that design technological products will cover opportunities and limitations of technical support systems for distance caregiving arrangements.

The guided interviews will be carried out in compliance with ethical principles such as respecting needs, individual boundaries and inhibitions, and interviews will of course be held separately with individual research subjects in order to protect their privacy. This procedure promotes authentic statements by all study participants and reduces the bias that can occur due to the presence of a third person. Since we want to avoid participants needing to travel for the purposes of our research, we will travel to them.

### Study phase II

This field phase described previously will be supplemented by a scoping review to determine a definition of distance caregiving. We will use the results of our scoping review and compare it to the self-defined distances given by our study participants. This study phase will also comprise data transcription, phenomenological analysis of the interviews and participant observations, and triangulation of the qualitative results in order to develop the first draft of a model for distance caregiving. This first draft will be the basis for the development of three explanatory films (three video-based scenarios lasting

1–2 min, developed by an external company) that will present variations of the distance caregiving arrangement concerning different levels of care and involving technological support systems. In addition, these films will show best practice examples of how the distance caregiving arrangement can function reliably for all actors, enabling care receivers to remain in their own homes with the aim of ensuring autonomy and safety for everyone involved. Each of the three explanatory films will include all actors seen in [figure 1](#), but the scenarios will differ according to the level of care the care receiver requires (explanatory film 1: care level 1=slight impairment; explanatory film 2: care levels 2 and 3=medium impairment; explanatory film 3: care levels 4 and 5=severe impairment) and the degree to which the distance caregivers are available.

### Study phase III

Following a participatory approach, study participants (see [figure 1](#)) will evaluate the three explanatory films on distance caregiving arrangements. Evaluation of the explanatory films will be part of the social science-based phenomenological analysis that will take the environment of the research subject as its starting point. To analyse the essence of distance caregiving as a phenomenon, the participants’ subjective attributions of meaning must be reconstructed.<sup>29</sup> This participatory approach has the advantage of following up the demands determined by the interviews in study phase I. A team member will introduce the three explanatory films one after the other to each study participant. Evaluation of the explanatory films will thus be carried out separately in the form of a brief guided interview with each of the participants of study phase I (n=20 distance caregivers, n=20 care receivers and n=20 local network). Additionally, actors in the distance caregiving arrangement who did not participate in phase I will also be included in the evaluation to give an external perspective. The findings in this study phase will also feed into further development of the model.

### Study phase IV

The demands on the functioning of the distance caregiving arrangement that were determined in phase I and described in the first version of the model (phase II) will be expanded, optimised and finalised through the evaluation of the explanatory films in phase III. Based on the triangulation of these findings, a final model for the functioning of distance caregiving arrangements will then be developed, which will include recommendations for all actors to ensure that the care arrangement is planned to function in a reliable and satisfactory way for all parties (see [figure 1](#)). *Functioning* refers to the mutual reliance of distance caregiver, care receiver and the local network, that technology components are equally reliable, and communication is continuous and transparent. In this way, it could be established over time that the distance caregiving arrangement as described in [figure 1](#) functions satisfactorily to guarantee autonomy and safety for all actors.

We define our expected outcomes as follows: on the one hand, this research will determine the actors' understanding of the term 'functioning arrangement' in the distance caregiving arrangement. On the other hand, we will examine whether the actors are currently satisfied with how the distance caregiving arrangement is working. For the benefit of application-oriented research organisations that design and create technological products, the model will formulate what demands the distance caregiving arrangement places on technological support systems, so that innovative technology can make a contribution to increased safety in the care arrangement, opening up new, forward-looking paths for home care in relation to safety, communication and mobility. Finally, the model to be developed will make a contribution to enabling care receivers to live autonomously and safely in their own homes for as long as possible even if concerned caregivers live at a distance. Sustainable translation of the research findings on the distance caregiving arrangement will be another objective of this study. The findings will be presented in a final explanatory film that is to be published.

### Patient and public involvement

In the context of patient and public involvement the word *public* refers to patients, potential patients, caregivers and people who use health and social care services. People from organisations that represent people who use services as well as members of the public will also be included (invo.org.uk). Interest groups (eg, the German National Association of Senior Citizens' Organisations) will support the recruitment of study participants. Engaging in this way encourages researchers to listen and interact with the public. Actors in the distance caregiving arrangement will be involved as contributors to the project, on the one hand as interview partners and on the other hand as evaluators of the first draft of the model for the distance caregiving arrangement. Including interest groups in the field in the progress of the study will provide the opportunity to connect with the public, discussing science on a more general level or addressing topics relevant to the distance caregiving arrangement. Moreover, study results can feed directly into practical care. For instance, managers of outpatient care providers can work according to the new model and can use the guidelines formulated in order to offer a care concept for care receivers supported by distance caregivers. Voluntary services can also make use of the research findings.

### Setting and sample

Recruitment will primarily take place in the Berlin and Brandenburg regions in order to include both urban and rural areas, although all regions of Germany can be included in our study. In addition to working distance caregivers, non-working groups such as retired people, pensioners, students, etc, will be also considered as study participants.

### Inclusion criteria

A *distance caregiver* can be anyone who cares for a care receiver from a self-defined distance (a family relationship

is not required), implying that the distance caregiver cannot be at the care receiver's home quickly in case of an emergency, is older than 18 years (ie, of legal age in Germany), a German native speaker, employed or unemployed, capable of self-report, not themselves dependent on care in accordance with the German Social Security Code (SGB) XI and lives with or without dependent children. The distance to the care receiver will be individually defined by the distance caregiver in an open question before inclusion in the study. In this way, the inclusion criteria will be tested, and the subjective definition of distance will be documented. *Care receiving participants* may include anyone who is cared for by a distance caregiver, dependent on care according to the SGB XI (recipients of a care allowance or non-cash or combined benefits) and capable of providing information (Mini-Mental-Status-Test (MMST) score  $\geq 18$ <sup>30</sup>). As described in the Introduction section, the proportion of older citizens in German society is increasing, while the number of care recipients increases from the age of 50. For that reason, we will focus on care receivers who are 50 or older. The *local network* and its key members will be defined by the distance caregiver and/or care receiver; it may include informal supporters like neighbours or friends as well as professional healthcare staff. In addition to these direct actors in the distance caregiving arrangement, we will recruit *representatives of application-oriented research institutions* who will describe the potential and limitations of technology applications in home care. Different institutions will be involved to avoid bias in favour of products from one company. To avoid conflicts of interest, we will not collaborate with these companies, and we will collect information on technical support systems from independent consulting institutions.

### Exclusion criteria

Exclusion criteria include people living in the same household or in the immediate vicinity of a care receiver or who can just drop in to visit the care receiver. Care receivers must live in their own home (neither in a nursing home nor in a shared housing arrangement). Cognitive restrictions are a general exclusion criterion (MMST score  $\leq 17$ ) as is being a minor (<18 years). Distance caregivers who are interested in the study will be asked if the care receiver is capable of self-report. The first contact to the care recipient by the research team will take place via telephone. MMST will be conducted in order to scientifically confirm the subject's ability to give information.

### Sample

We aim to conduct

1. At least 60 guided interviews (study phase I) with (1) distance caregivers (n=20), (2) care receivers (n=20) and (3) representatives of care receivers' local networks (n=20).
2. A structured observation of the home setting (n=20) that will take place after every interview with a care receiver.

3. Expert interviews with representatives from application-oriented research organisations (n=3). The final number of cases examined will depend on the research subject; thus, data saturation will determine this final sample. In research practice, this means that if the planned number of interviews is insufficient, additional guided interviews, expert interviews and observations will be carried out until theoretical data saturation is reached.<sup>31</sup> In study phase III, three explanatory films will be shown to participants in the distance caregiving arrangement who participated in study phase I and will be involved in later stages. The distance caregiver and the care-dependent person will evaluate the films separately. Additionally, application-oriented research organisations that design technological products will also evaluate these films.

### Recruitment procedure

#### Distance caregivers, care receivers and representatives of the local network

Public contact points include, for example, care support centres and care services that exist in both urban and rural settings. Umbrella organisations and regional associations for informal caregivers will also be included in the recruitment procedure to round off the sampling process. The Charité Office of Family Affairs will support the recruitment of research subjects. Participants will be selected by a purposeful sampling process, a technique widely used in qualitative research with the aim of identifying and selecting cases that are rich in information to make the most effective use of limited resources.<sup>32</sup> When preparing a qualitative study sample, the decisive factor is not the recruitment source but the sample constellation. In the present study, the selection of distance caregivers will take place according to age, gender, family status, education, working (yes/no) and place of residence (urban/rural). Data collection started in March 2022 and is expected to last until December 2022. These criteria will be similar for the care receivers while also including the official level of care allocated to them according to the SGB XI. Qualitative methods will emphasise data saturation, described as achieving a deep and comprehensive understanding by continuing to sample until data offer no new direction: the account satisfies.<sup>31</sup>

### Technology

Partners for expert interviews with representatives from application-oriented research organisations that design technological products are approached by direct request.

### Data collection

As stated, there is a general lack of knowledge in Germany about distance caregiving, which is why we have selected a multimethod qualitative research approach.

- ▶ Guided interviews with (1) the distance caregiver and (2) the care receiver will be conducted at home by trained interviewers, separately. This also will apply to the interviews with representatives of care receivers'

local networks (3). The interviews will be conducted face-to-face, a method which promotes the trust of the interviewees and might allow deeper insight into the topic of interest.

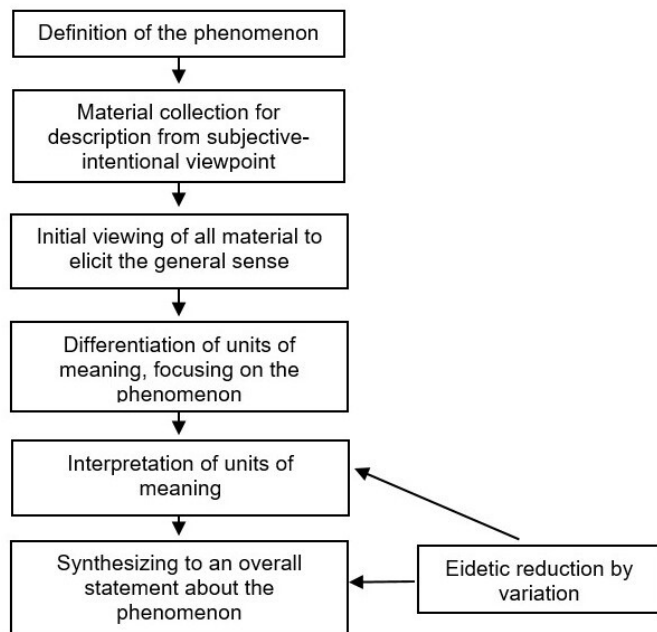
- ▶ Structured observation of the care receiver's home setting will take place on-site. The participant observation will be open, that is, the researcher's role will be transparent for the care receiver in the household. An observation protocol will be developed and will be evaluated immediately after the observation.<sup>29</sup>
- ▶ The expert interviews with representatives from application-oriented research organisations that design technological products (n=3) will be conducted at their offices. Guided interviews and expert interviews will be conducted according to the Standards for Reporting Qualitative Research (SRQR),<sup>33</sup> recorded on tape and transcribed line by line. The content of the guidelines and of the observation protocol will be determined in a 2-day workshop on carrying out qualitative interviews, both generally and specifically for this study. In addition, the doctoral candidate and study nurse who conduct the interviews will be regularly supervised by the principal investigator to guarantee high-quality interviews. Interviewers will also receive refresher courses. The interview guidelines, the tape recordings and immediate transcription of interview content, and supervision by the principal investigator, will guarantee a high standard of the qualitative material.

Data collection until saturation occurs is a strategy to reduce the influence of implicit bias, non-response or missing data. Complying with SRQR,<sup>33</sup> the interdisciplinary research team consisting of a social scientist, an international comparative sociologist, a gerontologist, a study nurse (nurse and bachelor student of nursing education) and a medical student will constantly supervise and elaborate the process of achieving data saturation. Thus, reviewers and readers will understand how this process influenced data collection and interpretation.

### Data analysis

The model for phenomenological analysis procedure according to Mayring<sup>34</sup> will guide our qualitative data analysis. Since little is known about distance caregiving arrangements (see figure 1), the planned *junior research project* will take the form of an explorative phenomenological analysis as used in the social sciences. The phenomenological approach is preferred to grounded theory (that aims to generate theory) or ethnography (looking at people in their cultural setting) because the proposed project aims neither to generate a new theory nor to investigate a new cultural setting. Phenomenological analysis begins in the world of daily life, the ordinary everyday aspects of life of the research subject. To penetrate the essence of a phenomenon, the subjective attributions of meaning by participants in the phenomenon (in this case, the distance caregiving arrangement) must be reconstructed.<sup>29</sup> Interviews will be transcribed verbatim





**Figure 2** Model for the phenomenological analysis procedure by Mayring.<sup>34</sup>

and will be coded and categorised accordingly. MAXQDA software will be used to support data analysis. The data analysis stages will follow the steps shown in figure 2 and will be carried out by an interdisciplinary research team. Triangulation of the data material takes place on the findings level.

### Data monitoring

An advisory board will audit conduct of the trial twice during the study period.

### Data sharing

To protect confidentiality of participants, anonymised transcripts will only be made available on request.

## ETHICS APPROVAL AND DISSEMINATION

### Ethics

This study will involve recruitment of distance caregivers, care receivers, representatives of the local network and representatives of application-oriented research organisations that design technological products. Written informed consent will be obtained from all study participants, and they will receive written information about the study and contact details. Ethical approval for this study has been granted by the ethics committee of the Faculty of Medicine of the Charité, Universitätsmedizin Berlin (ID: EA1/371/21).

### Data storage and retention

Study materials will be deidentified. All team members work with password-protected computers belonging to the main university site. All data will be stored via these password-protected computers. Access to all data will only be provided for members of the research team.

### Dissemination

Dissemination of the results will take place among the scientific community via publication of all results in peer-reviewed, high-ranked, open-access gerontological, nursing, and sociological journals. Findings will also be presented at scientific conferences globally. Planned strategies to disseminate the results among the public and actors involved in health service research will include presenting the final model to actors in healthcare and nursing care (eg, local networks and self-help groups). The study findings will be published in a final report and in an explanatory film for the distance caregiving arrangement, giving visual recommendations for practical implementation. In addition, care support centres and representatives of the German healthcare system (eg, the German College of General Practitioners and Family Physicians) will receive the distance caregiving arrangement information, the final explanatory film and a summary of the final model via email. This will ensure that those involved will have their attention drawn to the model at an early stage of care need, as well as at later stages.

### RESEARCH SIGNIFICANCE, INNOVATION AND IMPACT

This multimethod qualitative study will provide the first model as a framework for the functioning of distance caregiving arrangements. This model will include recommendations for all actors to ensure that the care arrangement is planned to function reliably for all actors in the arrangement, as seen in figure 1. Functioning means that the distance caregiver and care receiver know that they can rely on each other, that the local network and technology components are equally reliable, and that communication is continuous and transparent. Additionally, this study will fill a desideratum by adding conceptual understanding about the term distance caregiving, of which several definitions currently exist, predominantly in the literature from English-speaking countries. The study will be significant in investigating different scenarios of distance caregiving, depending on the level of care required by the care receiver. It also will have the potential to present a new way of arranging home care that lasts as long as possible, aiming to avoid the transition into nursing home care. The findings of this project may lead to follow-up research investigating different scenarios of distance caregiving, depending on the living and professional situations of the distance caregiver, the needs of the care receiver, the availability of a local network and appropriate technological support systems. The planned use for the final model is to make it available for the German public (see the Dissemination section). Moreover, we plan to test the model in an intervention study, which is beyond the scope of this proposal.

**Contributors** AB and AK designed the trial. AB drafted the manuscript. AK and FB edited the manuscript. All authors provided final approval of the version submitted and accepted its accuracy and integrity.

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**Competing interests** None declared.

**Patient and public involvement** Patients and the public were involved in the conduct, reporting or dissemination plans of this research. Refer to the Methods and analysis section for further details.

**Patient consent for publication** Not applicable.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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#### ORCID iD

Andrea Budnick <http://orcid.org/0000-0002-0036-4790>

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