# Exploring experiences of times without care and encounters in persons with dementia: A three-year multi-method exploration in the Swiss and German nursing home and domiciliary care setting

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## *Abstract*

**Background:** Persons with dementia spend a large part of the day without care and encounters, often without activity. This has been confirmed by numerous studies. However, no scientific analysis has yet examined how persons with dementia experience these periods. Such knowledge would be highly relevant for health care professionals and relatives to develop adequate strategies for dealing with times without care.

**Objective:** Starting from the fundamental Goffmanian question "What is going on here?", our study aims at reconstructing times without care and encounters in persons with dementia.
We examine this phenomenon from the perspective of persons with dementia themselves and from the point of view of formal or informal caregivers in the institutional and domiciliary care setting. In these contexts, we compare the situation in Switzerland and Germany. Our intention is to present a descriptive account of the effects and to develop a typology. This typology addresses dementia-affected persons' lifeworld understandings of time and ways of arranging time.

**Methods:** Our study is designed as an explorative, sequential multi-method investigation.
We systematically reconstruct times without care and encounters during 35 months with ethnographic methods. Afterwards, we examine the resulting typology by means of a survey.
To describe different social and caring cultures, practices and arrangements, we analyze
time periods across all phases of dementia. This takes place a) in institutions exclusively caring for persons with dementia, b) in institutions where persons with and without dementia live together, and c) in domiciliary care. For each type of care (a-c), our target is ten intensive case observations. These observations occur in participatory and non-participatory ways.
We videotape selected situations and perform situational conversations as well as interviews with persons with dementia and nurses. We analyze data according to grounded theory methodology. Furthermore, we perform a hermeneutic sequence analysis of selected text passages. To interpret videographic material, we conduct a video interaction analysis.
In order to obtain complementary information about the newly developed typology, we perform a written survey of around 400 formal and 150 informal caregivers. We summarize the findings of the ethnography and the survey in an overall concept of times without care and encounters in persons with dementia.
To fulfil the research interest, our cross-disciplinary and cross-country team comprises researchers with expertise in nursing sciences, gerontology, sociology, psychology, and ethnography.

**Results:** This approach allows us to formulate statements about the nature, frequency and prevalence of times without care and encounters across countries and types of care. In this way, we contribute to making visible the lifeworld of persons with dementia.

**Conclusions:** Our research offers points of departure for the representative investigation of times without care and encounters, for the development of diagnostic instruments and for dealing critically with possibilities of interruption, e.g., by developing action-guiding and goal-oriented interventions.

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# Exploring experiences of times without care and encounters in persons with dementia: A three-year multi-method exploration in the Swiss and German nursing home and domiciliary care setting

## ABSTRACT

**Background:** Persons with dementia spend a large part of the day without care and encounters, often without activity. This has been confirmed by numerous studies. However, no scientific analysis has yet examined how persons with dementia experience these periods. Such knowledge would be highly relevant for health care professionals and relatives to develop adequate strategies for dealing with times without care.

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**Methods:** Our study is designed as an explorative, sequential multi-method investigation. We systematically reconstruct times without care and encounters during 35 months with ethnographic methods. Afterwards, we examine the resulting typology by means of a survey. To describe different social and caring cultures, practices and arrangements, we analyze time periods across all phases of dementia. This takes place a) in institutions exclusively caring for persons with dementia, b) in institutions where persons with and without dementia live together, and c) in domiciliary care. For each type of care (a-c), our target is ten intensive case observations. These observations occur in *participatory* and *non-participatory* ways. We videotape selected situations and perform situational conversations as well as interviews with persons with dementia and nurses. We analyze data according to grounded theory methodology. Furthermore, we perform a hermeneutic sequence analysis of selected text passages. To interpret videographic material, we conduct a video interaction analysis. In order to obtain complementary information about the newly developed typology, we perform a written survey of around 400 formal and 150 informal caregivers. We summarize the findings of the ethnography and the survey in an overall concept of times without care and encounters in persons with dementia.

To fulfil the research interest, our cross-disciplinary and cross-country team comprises researchers with expertise in nursing sciences, gerontology, sociology, psychology, and ethnography.

**Results:** This approach allows us to formulate statements about the nature, frequency and prevalence of times without care and encounters across countries and types of care. In this way, we contribute to making visible the lifeworld of persons with dementia.

**Conclusions:** Our research offers points of departure for the representative investigation of times without care and encounters, for the development of diagnostic instruments and for dealing critically with possibilities of interruption, e.g., by developing action-guiding and goal-oriented interventions.

**Keywords**

Dementia [MeSH]; Nursing Homes [MeSH]; Home Nursing [MeSH]; Home Care Services [MeSH]; Review [MeSH]

## INTRODUCTION

### Background

The diagnosis and progression of dementia are associated with lifeworld crises. Such crises arise and persist in working and care worlds located in domestic-familial and institutional settings. For the most part, these crises receive political and social acceptance. Isolation, loneliness, helplessness, excessive demands, despair (and the associated severe restrictions on basic rights and liberty) are characteristic of the life-world contexts experienced by persons with dementia and their caregivers. Persons with dementia and their caregivers *navigate* a marginalized world characterized by the collapse of structures of help, care, support and relationships. The associated (care-)ethical conflicts and dilemmas are politicized and discussed in society. However, this does not change the affected persons' experience of crisis [1–6].

The issue of dementia has played an enormous role in the political, social and scientific debate for several years. This is now reflected in the population. As the Dementia Barometer 2018 shows, the majority of the population feels well informed about dementia and believes that there are good opportunities for supporting persons with dementia [7].

At the same time, however, a marginalization of the dementia phenomenon is evident at various levels. The review by Lara et al. [8] indicates the interrelation between subjectively experienced loneliness and the risk of developing dementia. According to the findings, people with a subjective feeling of marginalization are particularly affected by dementia. They feel socially excluded even before they are diagnosed. On the other hand, the pathologization or stigmatization of persons with dementia as "dementia sufferers" increases their marginalization. Due to and because of their varying degrees of loss of cognitive and communicative abilities, they are less and less involved in social life in the sense of social participation. Caring for them increasingly takes place in a "social protective sphere" [9], for example in a familial, dyadic care dependency or in a care facility. The social, restrictive area of protection results predominantly from a caring motivation or a "benevolent compulsion" [10]. Country-specific differences could play a role here: In Switzerland, caring for and supporting persons with dementia in the institutional setting predominantly occurs in so-called *"protected/secured living areas"*.

In comparison with Germany, these areas are mostly secluded. As a result, persons with dementia become even more fixed in place, immobile and therefore isolated agents at the margin [11–13]. They enter a downward spiral due to inadequate cognitive, emotional and sensory stimulation. This has a negative impact – on the course of dementia, the development of challenging behavior, the way of shaping relationships with their environment and, above all, on their physical, cognitive and emotional state [14]. Almost on the basis of a conceptual justification and thus in a socially legitimized way, persons with dementia are isolated and immobilized [13,15]. This imposed solitude seems to support the *production* and *potentiation* of care dependency in persons with dementia [16,17]. The scientific and social discourse on this "Closed Door Policy" takes place internationally [18–22].

There are numerous empirical indications that persons with dementia in institutional care settings experience long periods of boredom, inactivity and associated phases of loneliness [13,23–29]. Observational studies document the lack of activation and involvement of persons with dementia. Accordingly, in 40 to 80% of the periods observed, persons with dementia were found sitting alone, being inactive, resting, dozing, sleeping or sitting/lying in front of the television set [28,30–32]. They spend an average of five hours a day asleep [33].

It should be noted that activity programs in inpatient care settings only take place to a limited extent [34]. Theurer et al. [35] confirm institutionalized inactivity in their study on physical activity in institutional long-term care. Two observational studies [36,37] addressed activities of persons with dementia during the day in different long-term care settings. Both studies found significantly more activity and social interaction in specialized institutions. However, also in these settings, persons with dementia seem to spend a relatively large amount of time in non-purposeful activity or inactivity. These quantitative studies took an external perspective. Therefore, it was not possible to draw conclusions about how persons with dementia evaluate the times and activities.

In a Swedish ethnographic study addressing the situation in nursing homes, Harnett [38] described these periods of time as "respite spaces". A large part of the life of persons with dementia seems to consist of "respite spaces". During these periods of time, persons with dementia neither communicate nor interact with nurses. They are not involved in interventions or routine processes. Harnett [38] advocated intensive investigation of these "respite spaces". She observed that persons with dementia do not just passively submit to institutional events, but actively shape them – by using communicative strategies and entering into contact with each other. In "respite spaces", persons with dementia seem to construct an intersubjectively shared reality of life. However, they usually do not organize their own daily routines – they see nurses as responsible for the social organization of a living unit [38]. In community rooms, they try to fulfill the shared expectation of sitting still and taking care of their own things [39]. On the other hand, nurses' practices seem to be directed at *prompting* persons with dementia to sit as still as possible and "mind their own business" [39,40]. Other reasons for the low level of activity and involvement may be physical impairments, obstructive architecture (e.g., large, noisy community rooms) and unfavorable design of the living environment. Limited time resources or a shortage of (nursing) staff might also play a role [41,42]. All these reasons limit opportunities and choices to participate in activities and social relationships that persons with dementia consider important [43-45].

According to a study based on qualitative interviews with persons with dementia and nurses, the former wish to be more involved in activities and relationships. This is important for them to lead a dignified life [46]. In contrast, nurses often consider persons with dementia as inactive and unmotivated [44]. For their part, persons with dementia seek to engage in individual and group activities. These activities are important to them [46] and help them to live a meaningful and fulfilling life [47]. In addition, persons with dementia can experience and co-construct their identity in activities that are meaningful to them [48]. Relationships characterized by respect and goodwill, in which they feel heard, understood and accepted, are important for them [49,50]. In the domiciliary care setting, family caregivers also emphasize the importance of routines and sense-giving activities to maintain the continuity and stability of the care situation [51].

In times without care and encounters, persons with dementia strive for activities that are similar in their requirements to those generally described as leisure activities. Studies on the importance of leisure for persons with dementia are congruent with the socio-psychological concept of leisure [52]. According to Prahl [53], leisure has become a dominant area of modern societies. It refers to people's *free* time. Leisure varies across social groups in terms of quantity and quality. For persons with dementia, access to leisure activities understood in this way is often difficult. They experience leisure time in increasing dependence on family members or other people. As a result, the leisure time of persons with dementia (as well as that of their informal caregivers) is condensed in terms of time and space.

However, engaging in or participating in activities considered as leisure activities can have a positive impact on the well-being of persons with dementia and their families [52]. Leisure activities can be an opportunity for self-fulfillment. They allow persons with dementia to "be me, be with, make a difference, seek freedom, find balance, grow and develop and have fun" [54]. In relation to persons with advanced dementia, the literature does not generally refer to leisure activities but to "meaningful activities". For the most part, however, "meaningful activities" coincide with leisure activities, as a synthesis of qualitative studies on the perspective of persons with dementia regarding meaningful activities shows [55].

In a qualitative study, family caregivers emphasize the need to constantly reassess and adapt the goals, content and types of activities that are meaningful for persons with dementia [51].

The authors of a meta-ethnography on meaningful activities of persons with dementia underline the relevance of meaningful activities for a fulfilling life of persons with dementia. They point out that these activities "evolve and change" with a person's identity [47]. Supporting meaningful activities for persons with dementia seems to be challenging for nurses. They consider those activities as essential that reflect the interests of the person with dementia. Activities should be personalized and fit into the social or physical environment. However, they perceive structural, personal and interprofessional barriers preventing the introduction and implementation. They also identify a low awareness of meaningful activities [56,57].

Times without care and encounters can also have a negative impact. Low levels of physical or cognitive activity may have a long-term influence on the progression of cognitive impairment and mortality in persons with dementia [58,59]. During periods of low social involvement, Cohen-Mansfield et al. found an increase in challenging behaviors, e.g., agitation [15] and hallucinations [60].

It can be assumed that behind challenging behaviors are unmet needs – expressed in the form of behaviors [61]. In their findings, Cohen-Mansfield et al. [27] showed three main unmet needs of persons with dementia exhibiting challenging behaviors: (1) boredom or sensory deprivation, (2) loneliness or lack of social interaction, and (3) the need for meaningful activities.

To obtain an idea of times without care in persons with dementia, it seems necessary to examine the structures of these periods of time. According to the (pseudo)phenomenological findings of Honer [62], the lifeworld understanding of time in persons with dementia is characterized by confusions of the subjective and intersubjective perception of temporal structures. Persons without dementia switch in their thoughts between worldtime-related present, past and future. In contrast, persons with dementia confuse the worldtime-related past with the present – also in their perception of here-and-now-reality. Honer’s comments indicate that the temporal structures of the lifeworld of persons with dementia differ from those of persons without dementia. In addition, persons with dementia experience time subjectively differently.

Dealing with times without care and encounters requires an exploration of their origins, their subjective experience, and the subjective attribution of meaning. This applies particularly to those times that are intersubjectively described as long periods of boredom and as supposedly destructive. These are conditional social categories of time, whose effects are described from a rather objective perspective. Little is known about their genesis, temporal perception and meaning for persons with dementia and for formal or informal caregivers – also in relation to the past and the future.

There is a need to investigate these times and to examine how persons with dementia perceive them. It is not known how to interpret times without care and encounters from the perspective of persons with dementia. Knowledge is particularly relevant against the background of different logics for assessing care and support conditions in different countries and settings. These logics result in different care services. One can assume that these logics influence the existence and experience of times without care and encounters. It would be premature to assume that these periods are generally undesirable, empty times that are frequently associated with a certain amount of suffering. They could also be considered as relaxing "off-time" allowing for *healing* contemplation in a condensed time – in the sense of "time for oneself". Based on the literature, however, it is possible to suppose that there are also times without care and encounters that are experienced negatively. However, an a priori negative interpretation of these times should be avoided.

Times without care and encounters in persons with dementia are in the focus of our explorative and sequentially designed multi-method ethnographic study [63-66]. We examine these periods of time across dementia phases in different institutional as well as domiciliary care arrangements in German-speaking Switzerland and in Germany. Our aim is to describe social, cultural and country-specific practices and arrangements in a contrasting manner.

### Aim and Research Questions

The research objective of the study is to reconstruct times without care and encounters from the perspective of persons with dementia themselves and from the point of view of formal or informal caregivers. For this purpose, we apply ethnographic methods. We also explore the respective forms of perception as well as the strategies for dealing with these times. Furthermore, we perform a supplementary survey in order to validate the interpretative typology developed from the ethnographic material. Specifically, we examine the provisions, regulations and associated dimensions of the phenomenon of times without care and encounters in persons with dementia. With the survey, we also want to create a complementary information base. We hope to obtain additional information on the frequency, duration and effects of times without care and encounters. This occurs particularly against the background of different national care systems, institutional and domiciliary arrangements, types of organization, grade-mix specifications and staffing principles for nursing homes [41,67,68].
With regard to the so far scarcely researched times without care and encounters, the fundamental Goffmanian question arises: "What is going on here?" [69]. Do persons with dementia address these time periods? If so, *how* do they talk about them? *How* do they experience and interpret these times? *How* do formal or informal caregivers experience and interpret these periods?

Exploring these times and the lifeworld time perspectives also requires identifying the situational frameworks and the associated behaviors and actions. This occurs in relation to persons with dementia themselves as well as to the formal and informal caregivers.
We want to clarify *how* they perceive and experience these times. To what extent do these times represent for them meaningfully delimitable periods of time – in the sense of periods of action? *How* do they act in these (social) periods of time? How do they act by not acting?
The aim of clarifying these questions is to develop and verify a typology of lifeworld understandings of time and of the ways of shaping time.
We also intend to provide a descriptive presentation of the effects: How do times without care and encounters affect persons with dementia in the respective (care)cultural system?
This also includes the question of *how* persons with dementia and their caregivers interpret their perception of these times and how they communicate this perception verbally and non-verbally, e.g., to relatives or colleagues. In which way is this expressed perception and attitude associated with behavior and actions? In this context, we also clarify *how* formal or informal caregivers interpret verbal and non-verbal expressions of persons with dementia. *Which* consequences do they draw from these interpretations in terms of dealing with times without care and encounters?

In addition, we examine *whether* and *which* person-related (biographical) aspects evoke and support or interrupt and inhibit times without care and encounters. It is also of interest which external conditions (e.g., organizational framework conditions and cultural frameworks) have an influence.

In addition, there may be further, so far (still) unknown, possibly country-specific aspects not covered by our preliminary typology. Therefore, we will be sensitive to uncovering aspects with the aim to explain and describe the periods, their construction, their awareness and the resulting behavior and actions. Consequently, we first explore *where, when, how, how often* and *by what means* times without care and encounters occur and how the respective situations are socially situated. In addition, it is important to explore across disciplines how these periods are described (i) from the perspective of persons with dementia, (ii) from the point of view of their formal or informal caregivers and from the researchers' perspective. We are also interested in (iii) *whether* and *how* persons with dementia "appresent" (in the phenomenological sense) of these periods of time and how these times affect persons with dementia.

With regard to the individual perspectives, we explore the following aspects:

ad i)

- *whether* and *how* persons with dementia individually and subjectively perceive and describe times as periods without care and encounters,
- *which* verbal and *non-verbal* techniques and expressions they use to communicate about these times
- *which* interpretations, wishes, intentions and interests they express.

This also includes describing *what* persons with dementia do *in which way* during times without care and encounters, *how* they use these times and *whether* or *how* they prioritize their activities.

ad ii)

- *whether* and, if so, *how* formal and informal caregivers perceive and describe times without care and encounters,
- *which* verbal and non-verbal techniques and expressions they use to communicate about these times,
- *which* interpretations, wishes, intentions and interests they express and
- *how* they respond to perceived times without care and encounters and to actions of persons with dementia.

ad iii)

- *how* times without care and encounters affect the physical, cognitive and emotional status as well as the social interaction of persons with dementia and
- how this effect manifests itself.

## METHODS

### Overview

The project is scheduled for 36 months. The work packages proceed partly in parallel, although mostly at different times and always in interdisciplinary dialogue. We interrelate the results of this work in an ongoing, reciprocal process and then gradually integrate them.

To do justice to the research interest, we organize the project on an interdisciplinary and multi-professional basis. Of particular interest is the transnational use of the respective competence profiles, which are closely linked to the research questions. Expertise in the fields of nursing science, gerontology, sociology and ethnography is located at the Eastern Switzerland University of Applied Sciences (CH), the University of Applied Sciences Fulda (D) and the University of Applied Sciences Furtwangen (D). Expertise in cognitive psychology is located at the University of Geneva (CH).

The cooperation between different sites and professions seems extremely useful and synergetic. It allows us to combine methodological competences for sociological, psychological, and practical nursing issues with expert knowledge concerning interactive and communicative action. In addition, the transnational research consortium can address (inter)national realities, relevancies, differences and similarities with regard to the questions posed.

The research locations Eastern Switzerland University of Applied Sciences (CH), University of Applied Sciences Fulda (D) and University of Applied Sciences Furtwangen (D) are focusing on the ethnographic exploration of times without care and encounters on site. The University of Geneva is focusing on the cognitive psychological parameters and is involved in the interdisciplinary and transnational fieldwork as well as in the survey. The respective analyses take place across locations and countries.

A combination of ethnographic observation and standardized survey procedures forms an adequate methodological approach to answer the research questions [72]. After the project installation, we explore the structures and dimensions of the lifeworld texture of time to appropriately reconstruct times without care and encounters in persons with dementia (Figure 1).

### Methodological positioning

These explorations deal with "*foreign world*" experiences, but also with *familiar* everyday phenomena. We therefore orientate ourselves to the methodological considerations of Honer [62] on lifeworld-analytical ethnography. Hitzler and Eisewicht [73] have developed these considerations further. In addition, focused ethnography according to Knoblauch [74] serves as guidance. Both ethnographic strands are methodologically pluralistic and presuppose reflexivity in the research process [75].

Lifeworld-analytical ethnography refers "decidedly" [73] to mundane-phenomenological approaches of lifeworld analysis [76]. Therefore, we relate ourselves, among others, to the reflexive attempt of pseudo-phenomenology realized by Honer for describing "demential world experiences" [62]. Due to the cognitive limitations of persons with dementia, "dementia-related world experience" as research

subject is associated with considerable validity problems.
Thus, we try to adopt a naïve point of view in the analysis. We attribute a pseudo-natural status to the respective situation [77].

### Exploration

The ethnographic exploration and identification of times without care and encounters involves a close observation of these times. We also observe periods immediately preceding and following times without care and encounters. To capture the behaviors and strategies in these periods of time in a methodologically sound way, it is necessary (1) to observe them in a *participatory* and *non-participatory* manner, (2) to videotape them and (3) to talk to persons with dementia or to their caregivers. This involves situational conversations and subsequent qualitative interviews.

To verify the developed typology and to obtain complementary information on times without care and encounters, we conduct a subsequent standardized survey using a self-developed instrument. Formal and informal caregivers take part in this survey. We analyze their written statements using statistical methods. Afterwards, we synthesize the knowledge generated and the associated combination of qualitative and quantitative research results in an overall model of times without care and encounters in persons with dementia.

### Research field and sample

We intend to collect data in

- German and Swiss institutions in which persons *with* dementia live *separately* from persons *without* dementia. "Segregation" is explicitly envisaged as a concept,
- German and Swiss facilities in which persons *with* dementia and people *without* dementia live *together*. The concepts of "integration" and "inclusion" are explicitly envisaged, and
- in German and Swiss private households.

In this study, we involve persons assigned to dementia levels 3-7 according to the "Global Deterioration Scale" (GDS) by Reisberg et al. [78]. This means that we include persons with mild to severe loss of cognitive abilities.
As part of the observation procedures, we perform an initial screening by means of the GDS [79]. We sample according to theoretical criteria and the principle of maximum and minimum contrast [80,81].
It is inherent to the strategy of theoretical sampling and mini-max contrasting that the number of participants is determined during the research process. However, due to time constraints and the scope of the planned study, we plan ten case observations per type of care. This corresponds to thirty case studies.

The population of the planned survey (work package 3) are formal and informal caregivers of persons with dementia in inpatient long-term care or domiciliary care in German-speaking Switzerland or in

Germany. In view of time constraints and the confirmatory nature of the survey, we plan an opportunity sample comprising around 400 formal (D: 250, CH 150) and circa 150 (D: 100, CH 50) informal caregivers.

**Detailed methodological outline**

Work package 1: "Pre-field"

The first work package "Pre-field" (two months) serves to prepare, organize and install project structures. It also serves allows to compare the content of the working methods between the interdisciplinary, multi-professional and transnational research team. This work package also includes targeted sampling for the domiciliary care setting.

Work package 2: "Explorative fieldwork"

In the second work package (24 months in total, eight steps [a-h]), we collect data in the research field. We process and analyze data in parallel.

a. Participant observations (four months) in the respective institutions and households serve to identify times without care and encounters and to determine the institutional sampling [82]. In terms of research practice, we familiarize ourselves with the field and with the persons living and working there. In return, persons in the field can become familiar with our research assistants. To this end, research assistants take on care and support tasks, depending on their own expertise. In some cases, they take part in the everyday lives of persons with dementia. In doing so, we develop preliminary hypotheses about the interpretation and effects of times without care and encounters, and about strategies for dealing with them.
b. By means of non-participant observations (structured and unstructured, four months) in the institutional setting and by further participant observations in the domiciliary care setting, we continue to identify times without care. We explore strategies for dealing with these periods on site or in situ, with the aim of formulating statements that are appropriate to the subject matter. For example, we document the time, the duration, the frequency, the physical and verbal "appresentation" (in the phenomenological sense) as well as the behavior and actions of persons with dementia during these periods. In addition, we capture upstream and downstream "social times" and worldtime-related events. These should reveal communicative regularities and remarkable irregularities in interactions between formal and informal caregivers or among fellow residents. In doing so, we further test and specify the assumptions we made so far.
c. There is a plan to perform structured non-participant observations using Dementia Care Mapping (DCM) [83, 84]. In this way, we intend to uncover worldtime-related processes and social-worldly predefined limits of the time budget [62] and the forms/types of interaction. We also identify the impact of times without care on individual well-being. Based on DCM analysis data, we narrow down the subsequent unstructured non-participant observations to the identified periods of time.

By means of focused and multi-day observations, we further explore the periods of interest in greater depth. We also talk to persons with dementia *during* and *after* an observation. In situational conversations [62], we find out *if, how* and *to which degree* of awareness persons with dementia frame and describe the situation in the sense of Goffman. Of note, Dementia Care Mapping only takes place in an institutional context, not in the domiciliary care setting.

d. The time periods of interest and the associated communication processes/interaction processes are both highly complex and ephemeral. We assume that the researchers influence the experience of time merely by *being present* whereas the exploring person as such represents an intervention. Based on this assumption, it is necessary to consider how the researcher influences the field. It is essential to clarify whether questions can be derived from the observations: What if the person had not been there? How do persons with dementia co-construct the situation? How would they have dealt with the situation? How do persons with dementia comment on the situation? What is the result of the situation? Is it possible to anticipate how persons with dementia would have spent the time if the researcher was absent? What if the person had not been there? How do persons with dementia co-construct the situation? How would they have shaped the situation? How do persons with dementia comment the situation? What results from the situation? Is it possible to anticipate how persons with dementia would have spent the time if the researcher was absent? Inevitably, the person exploring the field becomes the subject (or object?) of the analysis. Therefore, we videotape times without care and encounters (four months). Using videography [85], we record the range of expressive variants appearing on a micro and nano level (language, facial expressions, gestures, body orientation, voice pitch and melody, as well as their interplay in interaction). Videography takes place in a targeted manner – after careful consideration within a framework that appears acceptable to the participants involved. Despite its clear benefits, videography is an invasion of privacy – it interferes with the "leisure time" of persons with dementia and with the private spheres of formal or informal caregivers. For this reason, we use the camera sparingly, in a focused way, and only to the extent strictly necessary to answer our research questions. We conduct at least two videographies for each person recruited (60 in total). Findings from our previous observations guide and determine the selection of interactions to be videotaped [86, 87].

In the context of domiciliary care, we involve informal caregivers in a participatory way as co-researchers in the videography process – with the aim of reducing possible reactance to the camera [88].

e. To reconstruct the respective subjective views and explicable background knowledge of formal or informal caregivers, we conduct exploratory interviews [62] over a period of four months. We want to find out about caregivers' awareness of times without care and encounters. How do they understand these periods of time? Do they consciously use "strategies" to promote or reduce these periods? If so, which strategies do they use?

We also seek to find out the extent to which organizational framework conditions are beneficial or obstructive. Which conditions are favorable or problematic according to caregivers? Which options do they consider as desirable for solving difficulties in dealing with times without care and encounters? We orient ourselves towards the ideal of an interview that is minimally standardized, but structured by means of a guideline. This is intended to ensure that respondents are as open as possible in their responses, while at the same time maintaining the thematic focus of the interview [89,90]. We plan interviews with at least two formal or informal caregivers per recruited person (60 interviews in total). Afterwards, transcription, coding according to grounded theory methodology and sequence analysis follow.

f. In a further assessment step (parallel to steps b and c), we additionally use cognitive-psychological methods to determine the effect of times without care and encounters on the cognitive and emotional status. Whenever possible, we use self-assessment tools for persons in the early stages of dementia. If self-assessment is impossible, data collection is based on proxies or an external assessment instrument. Repeated use of compact assessment tools (at least four assessments at three-month intervals) allows us to document and examine changes. We focus on assessing the general cognitive state, emotional stat activities in daily living and perceived loneliness. The assessment instruments should be applicable for different stages of dementia and the exact combination of instruments will be developed at the beginning of the project. We will use instruments such as COGTEL [91] for cognitive stat and the emotional state in a global perspective using the "Geriatric Depression Scale" (GDS) for the global perspective on emotional state [92], the "Short Depression-Happiness Scale" (SDHS) [93] and the "Self-Assessment Manikin-Scale" (SAM) [94] for a momentary perspective. In addition, we will assses functional independence in everyday life (ADL) [95] and perceived loneliness for example using the "De Jong Gierveld Short Scales for Emotional and Social Loneliness" [96]. Furthermore, we aim to evaluate mediators such as cognitive reserve (CRIq) [97] and desires/goals by means of the "Sense of Coherence Questionnaire" (SOC) [98]. We also consider the social network of persons with dementia and their contact with this network [99]. Furthermore, we measure stress using the abbreviated "Perceived Stress Scale" (PSS) [100].

g. In the second phase of data collection (four months), we conduct observations and video recordings. We also apply the knowledge gained from previous observations and interviews to situations now observed. In this way, we clarify questions that remain unanswered. This relates, for example, to our more precise understanding of persons with dementia and their formal or informal caregivers. During this phase, we also perform observations at different times of the day. Whether it will be necessary at this point to focus specifically on certain times without care and encounters, will depend on the findings obtained up to that point. We process and analyze the data collected in this stage and relate it to the analyses carried out so far.

h. After the phase of direct fieldwork (four months), we interrelate, compare and contrast the findings and assumptions from the analyses of observations and interviews as well as video data and neuropsychological assessment data collected at different points of time.

*Qualitative data analysis*

To combine sampling, data collection, interpretation and theory formation, we use grounded theory [81] as a "corresponding" [101] research approach in the sense of a "hermeneutic grounded theory" [102]. We write down all observations in protocols and transcribe the audio data. After each step of data collection, we first perform a (successive) overall review of the initially open coded, then axially coded and finally selectively coded data material takes place. In addition, we deliberately select certain passages and subject them to additional hermeneutic sequence analysis [103-108]. In doing so, we relate the different observation situations and the interview statements to each other and compare them. Supplementary video data provide the necessary access to the complexity of the events of interest. They allow an in-depth, repeated evaluation by means of video interaction analysis [85,109]. This is of central importance for clarifying the questions raised in this context.

Our experience in analyzing videotaped care interaction situations revealed that this method indeed allows to capture important subtleties of communication and interaction that would otherwise have remained hidden. During the joint cross-site and cross-national interpretations [110], it is necessary to implicitly and explicitly "triangulate" different types of qualitative data with regard to their meaningful referential context [111]. We clarify, *whether* and *how* they correspond, complement or contradict each other. Furthermore, we retrace the referential contexts of events and actions thematized in the interviews and conversations. We also backtrack to events and actions that emerged in the participant or non-participant observations and in the video documentation.

Working package 3: "Survey of times without care and encounters"

In this work package (14 months in total, five steps [a-d]), we collect, edit and analyze quantitative data. The design we chose is a standardized mixed-mode survey (e.g., SosciSurvey and paper-pencil version) directed at formal or informal caregivers. The questionnaire is based on the results of the ethnographic observations and the interviews. To test the questionnaire, we use a qualitative pre-test procedure with expert validation [112]. The analysis involves multivariate statistical methods. The methodological approach is as follows:

a. First, we develop the item batteries and case vignettes for the survey (over a total of six months) – based on the elaborated typology and the associated phenomenal dimensions. This takes place in parallel and in coordination with work package 2.
b. We test the instrument with 15 participants in a qualitative pre-test procedure (interviews) (three months) and adapt it accordingly.
c. Sample recruitment (three months) occurs as part of an ad hoc procedure. To this end, we

develop and implement a gatekeeper system for recruiting in the institutional sector (nursing homes) and in the outpatient sectors (domiciliary care and self-help organizations, for example, Alzheimer Switzerland and German Alzheimer Society).

d. The survey (five months) is designed as a mixed-mode survey (online, written-postal, telephone).

*Quantitative data analysis*

The analysis (*two months*) is based on descriptive and interferential statistical methods. We determine the specific analysis procedures when developing the instrument.

Work package 4: "Overall concept and dissemination"

A triangulation focusing on convergence and complementarity takes place in the fourth work package (*six months* in total). For this purpose, we integrate the results of the ethnographic research and the survey. We analyze the results in cross-site, virtual group interpretations to determine whether and how they correspond, complement or contradict each other. This occurs with the aim of contextualizing, plausibilizing and, if necessary, generalizing the elaborated typology. The triangulation strategy paves the way to the concentrated final phase aimed at developing the overall theoretical concept for times without care and encounter in persons with dementia.

Work package 5: "Living literature review"

A living literature review accompanies the project. The specific aim of this review is to provide a continuously updated overview of times without care and encounters from the perspective of persons with dementia and formal or informal caregivers. This can have a guiding function for data synthesis and interpretation. During the entire project, we conduct comprehensive systematic literature searches in MEDLINE/PubMed, CINAHL, PsycInfo/Ovid and Web of Science Core Collection (citation-based searches and web searches). We include observational studies performed in the institutional or domiciliary care setting and published in English, French, or German without restrictions on the year of publication. Studies have to address times without care and encounters from the perspective of persons with dementia and formal or informal caregivers. One reviewer screens titles, abstracts, full texts and extracts data. We present the key characteristics and results of the included studies in tabular form. Searches take place during the entire study (every six months for two years from 2023 to 2025) [113].

## Ethics Approval

Ethical clearing was performed by the responsible ethics committees (Switzerland: Ethics Committee of Eastern Switzerland [BASEC 2021-02150, EKOS 21/179]; Germany: Ethics Committee of the German Society of Nursing Science [21-009, BL 1787/1-1, KO 5965/2-1]).

Participation in the survey is voluntary for all participants (persons with dementia, informal or formal caregivers). For all participants, we ensured comprehensive and target group-specific information. The project team is aware that persons with dementia are potentially (highly) vulnerable individuals [114]. Since the research project invades privacy, we ensure that persons with dementia or their relatives receive detailed information in a target-group-specific manner. If participating persons with dementia have only limited capacity to give informed consent due to reduced cognitive and communicative abilities, we also inform them about the research project in an appropriate manner. Inclusion in the sample only occurs if it is possible to obtain a declaration of consent from authorized representatives/legal representatives. However, if it is obvious that a person with dementia refuses to participate in the research project, we respect this in any case – regardless of legal representatives' possible consent [115]. The design of the entire study and the proceedings ensure that no exceptional risks are to be expected for participants. Participation takes place on the basis of "ongoing consent" [116,117]. All persons involved can withdraw from the project at any time. They can interrupt or cancel an observation. The designated research assistants have proven expertise in nursing and nursing science. They also have several years of research experience with persons affected by dementia. Therefore, they are able to pay sensitive attention to (non-)verbal signs of refusal and/or vegetative signs evoking an immediate interruption or cancellation of the observation, interview or video recording.

After the video recording, we review the video material with the videographed persons with dementia and/or with their authorized representatives in order to confirm or revoke the previously granted release. However, our experience in previous projects shows that persons with dementia and/or their relatives accept this option only occasionally – for various reasons.

In our view, it would be ethically unacceptable to pressurize people to participate (and thus not respect their autonomy) or to withhold recordings from them.

It is crucial to ensure that the persons in question are aware of their option to co-decide, to participate and to access their data at any time – even later if they have refused to do so at an earlier stage. Being aware of the problems associated with videography in (highly) vulnerable persons, we conduct prospective and retrospective ethical case discussions on the targeted video recordings. This occurs with the aim of ascertaining the presumed and situational will of the person with dementia and of complying with this will.

Against the background of (potential) vulnerability, we pay equal attention to providing comprehensive information to relatives about the voluntary nature of participation, about data collection methods, data protection, data analysis, data utilization, data backup/archiving, and about the possibility of withdrawing consent and release.

The persons responsible for the project and the research assistants have many years of experience in qualitative/interpretative and quantitative research. They are also experienced in the care and support of persons with dementia. To achieve the necessary intersubjectivity, we discuss and analyze all data in the interdisciplinary and cross-location team. For this purpose, we perform continuous interpretation meetings and workshops. We document all interpretation sessions and workshops, transcribe them in extracts and prepare a protocol of them.

Two nursing scientists advise and support the research team: Prof. Dr. Gabriele Meyer (Martin-Luther University Halle-Wittenberg, Medical Faculty, Institute for Health and Nursing Science, Germany) and Prof. Dr. Hanna Mayer (Karl Landsteiner University, Austria). Both have proven expertise in the field of dementia care research.

## RESULTS

The study started in March 2022 and ends in February 2025. It is underway as part of a lead agency process and has been approved by the Swiss National Fonds (SNF project number 200919) and by the German Research Foundation (DFG project number 458561353).

The exploratory investigations associated with work package 2, the within-case analyses as well as location-related and cross-country cross-case analyses terminate in September 2024. The cross-national survey results are available in September 2024. Work package 4 "Overall concept and dissemination" and 5 "Living literature review" finish in February 2025.

## DISCUSSION

Our approach enables us to obtain information about the nature, frequency and prevalence of the phenomenon of times without care and encounters. The basis created for assessing these periods by means of a survey instrument lends itself to validating the instrument in a follow-up project – with two intentions: 1) to assess times without care and encounters in a representative and reliable way with this instrument and 2) to develop a diagnostic instrument for nursing practice.

Furthermore, with this project we would like to make a fundamental methodological contribution allowing to further develop research *on* and *with* dementia-affected persons.

In the context of dementia care research, procedures for field research, intervention planning/implementation and data collection require an extended framework of care ethics and research ethics. At the same time, however, there are almost insurmountable problems of validity and generalization. The proposed research strategy envisages not only methodological and methodical triangulation but also data triangulation and researcher triangulation. In this way, we would like to contribute to the existing cross-disciplinary discourse on these problems.

### Conclusions

With our research, we intend to pave the way for a qualitative assessment of lived times without care and encounters and for scrutinizing organizational and professional practices. In doing so, we also ask about the need for change. However, expecting a priori a need for change with regard to all times without care and encounter seems to be inappropriate and paternalistic – despite initial scientific findings pointing in this direction. Therefore, it is our intention to present examples that have been described and proven as "good practice".

In this research project, we shed light on the concepts of autonomy, well-being, independence, self-determination and meaningful activities of persons with dementia in relation to the need for security and continuous attachment to formal and informal caregivers in times without care and encounters. The everyday field of tensions in the care of persons with dementia will continue to increase as social and human care resources become increasingly scarce. Against the background of the current political and social understanding of care, it is unlikely that times considered as worthy of change will be compensated for in a humane way. In a survey of nursing and care staff in Swiss care institutions, caregivers reported times when they had to keep residents waiting or were unable to offer them emotional support or activating care [118]. Therefore, it seems indispensable to consider alternative interventions and possibly technical alternatives.

## DECLARATIONS

### Funding

Swiss National Science Foundation (Weave/Lead Agency; project number: 200919) and German Research Foundation (Lead Agency; project number: 458561353). The funders had no influence on the design, conduct, and reporting of this study protocol.

### Competing interests

None to declare.

### Ethics approval and consent to participate

Ethical clearing was performed by the relevant ethics committees in Switzerland and Germany. Switzerland: Ethics Committee of Eastern Switzerland (BASEC 2021-02150, EKOS 21/179). Germany: Ethics Committee of the German Society for Nursing Science (21-009, BL 1787/1-1, KO 5965/2-1).

### Consent for publication

Not applicable.

### Availability of data and material

Not applicable.

### Authors' contributions

Substantial contributions to the conception or design of the work: All authors.

Drafting the work: TB, JH, LA, UL, MD, HB.

Revising it critically for important intellectual content: All authors.

Final approval of the version to be published: All authors.

Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy and integrity of any part of the work are appropriately investigated and resolved: All authors.

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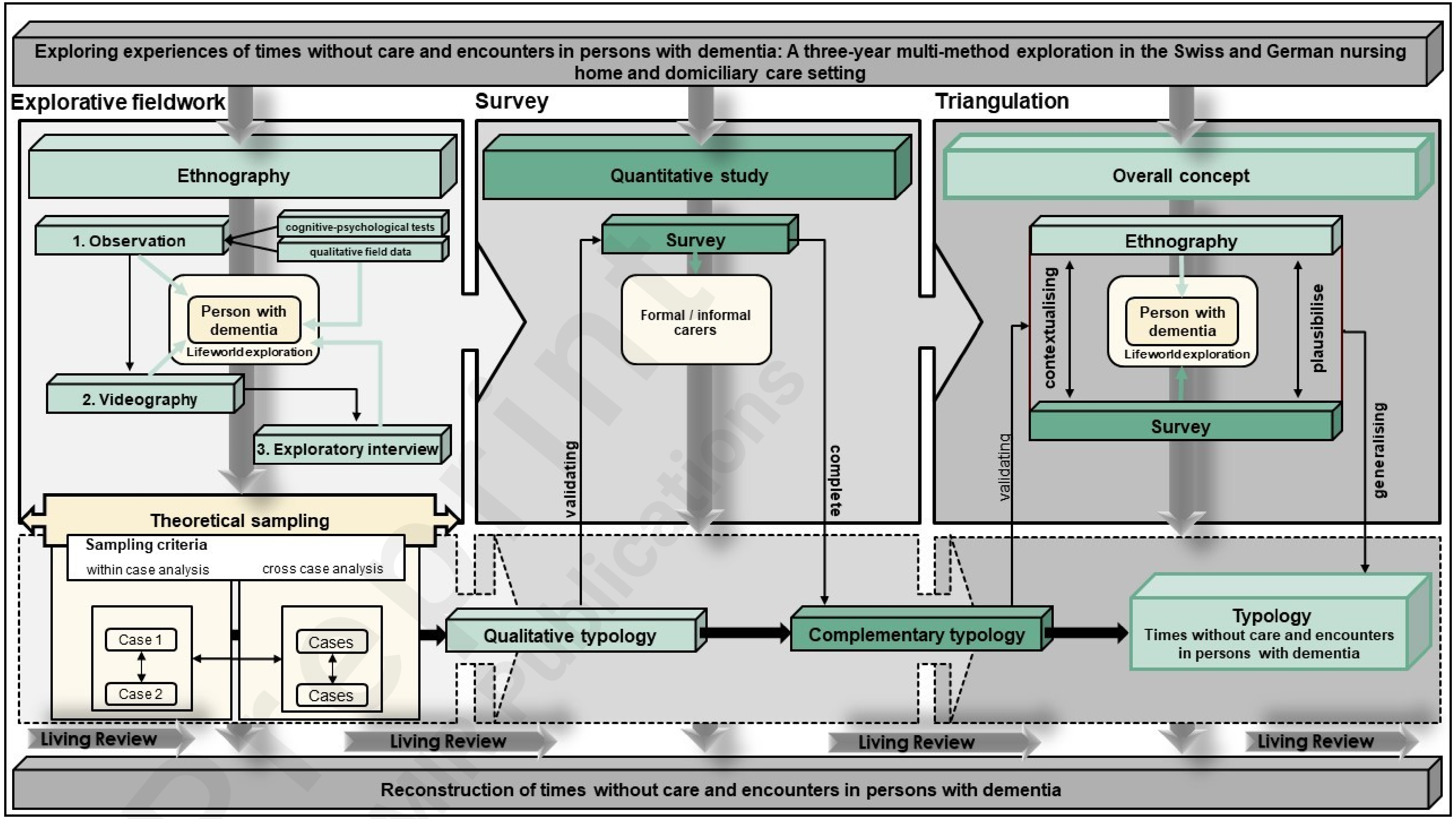
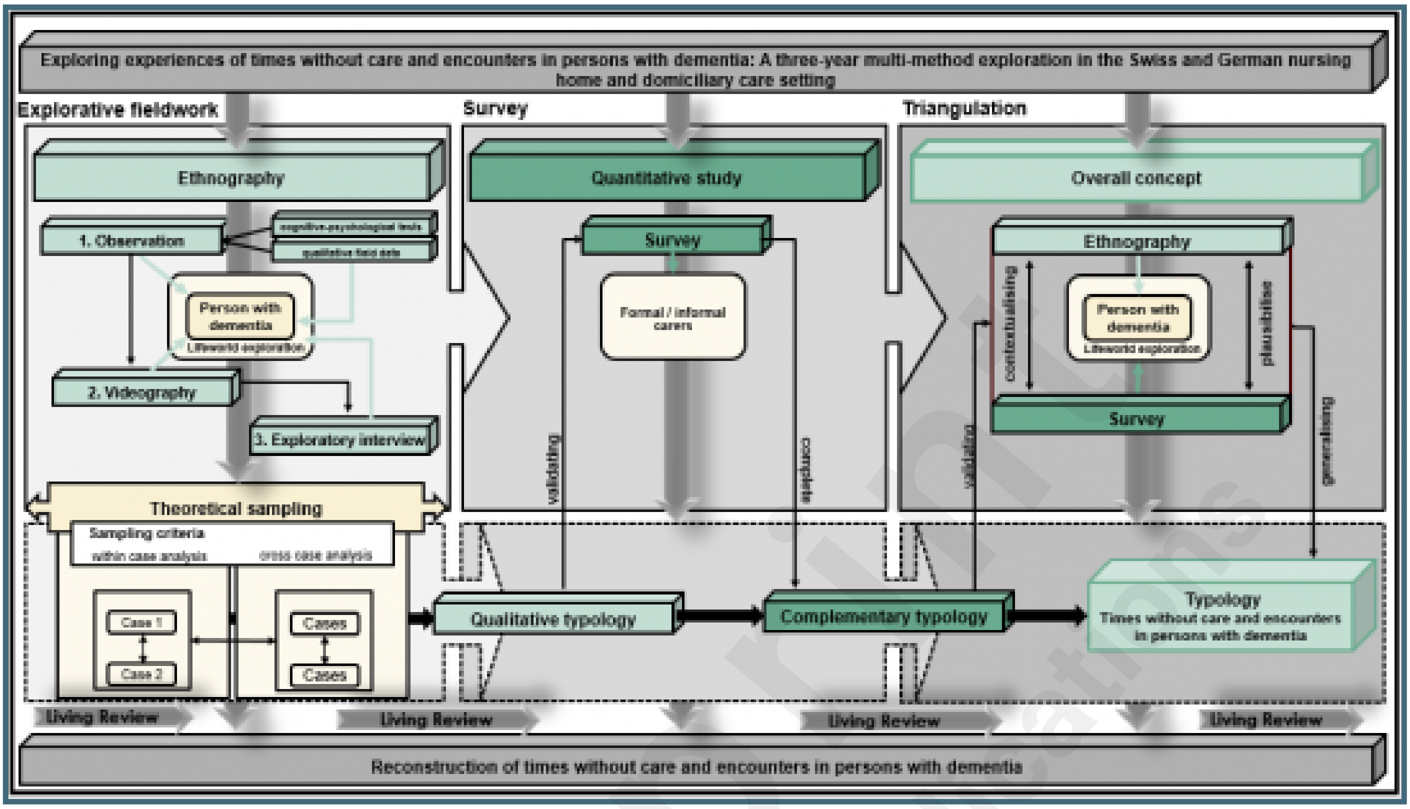


Figure 1. Project overview

# Supplementary Files

# Figures

Project overview.



# Multimedia Appendixes

Grant agency peer-review report.
URL: http://asset.jmir.pub/assets/3c8e494a5cb4adfecfd4fac612fd4fda.pdf