

Experience of Younger-Onset Dementia Stigma: Protocol for a Constructivist Grounded Theory Study Based on Qualitative Episodic Interviews With People Living With Dementia and Their Significant Others

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Abstract

Stigma based on younger-onset dementia (YOD) is a significant challenge for individuals living with the condition and their significant others (i.e., family and/or friends) as well as for a society that aspires to be inclusive, ensure social participation, and enable all people to exercise their civil and human rights. The STELDA study aims to develop a theoretical framework of YOD stigma and stigmatization that is empirically grounded in the lived experience of people living with younger-onset dementia (PlwYOD) and their significant others and to identify ways of counteracting YOD stigmatization processes in the sociocultural context of Germany on a lifeworld level. The research question is as follows: How do PlwYOD and their adult significant others experience stigma and stigmatization based on YOD in their lifeworlds, and what implications do these experiences have for their actions in their lifeworlds? The study is designed as a constructivist grounded theory (CGT) study. Qualitative episodic interviews with community-dwelling PlwYOD and their adult significant others will be conducted to give participants the opportunity to share their individual narratives and express their subjective views. As an outcome, recommendations for action will be developed for the public and for professionals in diverse settings. On a methodological level, novel insights will be gained regarding specific issues related to qualitative research with PlwYOD and their significant others.

Keywords

stigma, stigmatization, younger-onset dementia, lived experience, lifeworld, narrative inquiry, episodic interview, constructivist grounded theory, study protocol

Background

In Germany, there are currently approximately 1.7 million people living with dementia (PlwD) (Deutsche Alzheimer Gesellschaft, 2020). This number is predicted to increase to 2.7 million by 2050 (Alzheimer Europe, 2019). Among the estimated 1.7 million PlwD in Germany, approximately 25,000 to 60,000 people are younger than 65 (Deutsche Alzheimer Gesellschaft, 2020). This number may also be indicative of the number of people living with younger-onset dementia (PlwYOD). The term younger-onset dementia (YOD) refers to the onset of dementia symptoms before the

age of 65 (Loi et al., 2023), although PlwYOD may be older than 65 during the course of the disease. Precise data on the number of PlwYOD in Germany are not available. However,

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due to demographic changes and diagnostic possibilities (Hendriks et al., 2021), the number of PlwYOD will continue to grow.

Dementia poses great challenges to individuals and societies. There are direct and indirect economic costs for societies resulting from dementia in general (Meijer et al., 2022; Michalowsky et al., 2019) and from YOD in particular (Ruiz-Adame, 2022). In addition, dementia imposes a challenge for those societies that aspire to be inclusive – dementia is still a stumbling block in this endeavor (Cahill, 2018; World Health Organization, 2021). Fear of developing dementia is present in the general population (Hajek & König, 2020), and depictions of dementia in popular culture are associated with negative images and feelings (Low & Purwaningrum, 2020). Having dementia and caring for or living with someone with dementia are often perceived as threats to personal well-being, self-identity, and social inclusion (e.g., Egilstrod et al., 2019; Spreadbury & Kipps, 2019).

According to symbolic interactionism following Mead (1934), people's views of themselves are significantly shaped by how they are perceived by other people and how other people react to them; the self-identity of a person is formed in social exchange with others, and people can only experience themselves through the lens of others' perspectives. Interactions based on negative attributions can harm a person's self-identity and subsequently have a detrimental effect on their participation in society.

One type of identity-threatening interaction is stigmatization. "Stigma represents a social construction that is an expression of social power, it involves identifying a socially conferred mark that distinguishes individuals who bear this mark from others and portrays them as deviating from normality and meriting devaluation" (Major et al., 2018, p. 4). Culture and society provide the overall grounds and context for stigma and stigmatization. In addition, a specific stigma is related to characteristics of the attribute in question (e.g., whether the attribute is immediately visible and whether it is perceived as congenital or acquired; Jones et al., 1984), to characteristics of the social situation (e.g., the relationship between the interacting people; Goffman, 1963), and to the individual (social-)psychological characteristics of the person with the attribute (e.g., how strongly a person self-identifies with a domain in which they are negatively stereotyped, such as cognitive performance; Major & O'Brien, 2005). Stigmatization leads to people being denied full social acceptance and equal participation in social life (Goffman, 1963); it is associated with shame (Scheff, 2014), and it can lead to negative self-esteem and reduce psychological performance (Corrigan & Watson, 2002; Major & O'Brien, 2005). Consequently, stigmatized people might become excluded from social life either by the actions of others or because they withdraw themselves (Goffman, 1963; Major & Eccleston, 2004).

Dementia is associated with a high risk of being stigmatized (Alzheimer's Disease International, 2012, 2019). Dementia stigma may be associated with misconceptions (e.g., ignorance of causes of dementia other than

Alzheimer's disease) and negative emotions (e.g., fear of developing dementia), as well as stereotypical attributions (e.g., unpredictability), negative evaluations (e.g., unproductivity), and subsequent actions (e.g., avoiding a work colleague with dementia) (Nguyen & Li, 2020). Dementia stigma can affect both people living with dementia and their significant others, such as relatives (Herrmann et al., 2018; Nguyen & Li, 2020). Dementia stigma encompasses multiple dimensions:

- Public stigma: Stigmatizing perspectives on dementia and PlwD in society (e.g., Werner & Kim, 2021). One part of this is courtesy stigma (Goffman, 1963), also labeled stigma by association, which means that public stigma is extended to significant others of the primary stigmatized person because of their relationship to each other (Pryor et al., 2012).
- Stigma experience: Stigma experienced by PlwD based on their dementia (e.g., Gajardo et al., 2021) or stigma by association experienced by significant others (e.g., Werner et al., 2020).
- Self-stigma: Internalization of public stigma based on dementia when the person self-identifies as part of the stigmatized group and simultaneously shares the stigmatizing norm (Nguyen & Li, 2020); affiliate stigma as internalized stigma by association (Mak & Cheung, 2008).
- Structural stigma: "Societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized" (Hatzenbuehler & Link, 2014, p. 2; e.g., Werner & Doron, 2017).

Dementia stigma not only impacts mental and social health but also contributes to people ignoring symptoms in themselves or hiding these symptoms from others because of shame (Lopez et al., 2020). For relatives, dementia stigma can also have negative psychological and social consequences (e.g., Greenwood et al., 2018) and lead to them not using support services directed at them (Lopez et al., 2020). In addition, however, the stigmatization of relatives can have an impact on the person with dementia if, for example, relatives avoid going out in public together with the person with dementia, hesitate to initiate care services, or reduce their own contact with the person with dementia (e.g., Müller, 2019).

PlwYOD are affected differently (e.g., in terms of finances or ageism) and in part more strongly by stigmatization than people living with dementia at an older age (e.g., Ashworth, 2020; Tang et al., 2023). In YOD, symptoms appear before the age of 65. The forms and causes of YOD are varied and include Alzheimer's disease, frontotemporal dementia, cerebrovascular disease, Lewy body dementia, and secondary forms (RHAPSODY, 2017). YOD is much less common than dementia at older ages (Hendriks et al., 2021), and there is less knowledge about it in the general public. The diagnosis is

often made years after the first signs, either because people who observe changes in themselves delay the process or because physicians do not interpret symptoms in the context of dementia (O'Malley et al., 2021). Changes in behavior are more common in YOD than in older-onset dementia, while changes in memory are less common (Ducharme & Dickerson, 2015). In this context, YOD can pose specific challenges for the person with the disease and those around them – on the one hand, because of the forms of dementia in younger age groups and, on the other hand, because of the circumstances in which people of this age find themselves compared with older people. In this phase of life, people tend to be strongly involved in social tasks (e.g., family, employment, volunteer work). Societal expectations include the assumption that employment and/or family work will be performed. In addition, there are specific role expectations associated with being in a partnership and a family. The possible discrepancy between social expectations and the person's changed potential is correspondingly large, which lays the ground for stigmatization to occur (Goffman, 1963). Support services are regularly aimed at the vast majority of PlwD of an older age and often do not fit the needs of younger people (Bannon et al., 2022; Mayrhofer et al., 2018). As a result, PlwYOD and their significant others are at risk of experiencing social exclusion, negative attitudes in society, stigmatization and shame in specific ways (e.g., Hutchinson et al., 2018; Thorsen et al., 2020; Werner et al., 2020).

Research on stigma due to dementia has been undertaken for well over twenty years, and for the last decade, this research has been showing a growing momentum. Most of the existing research has focused on public stigma but has not examined the experience of stigma or self-stigma (Nguyen & Li, 2020). In addition, most research has used quantitative scale-based instruments to assess stigma, while detailed insights into individual experience are lacking (Fletcher, 2021). Furthermore, most research has been limited to countries other than Germany and, at the same time, to a small number of countries, but research in the sociocultural context of Germany is lacking (Herrmann et al., 2018; Nguyen & Li, 2020). Lived experience, i.e., the subjectivity of persons in a historical context (Ellis & Flaherty, 1992), differs from person to person. It can be assumed that persons with different forms of dementia might show specific differences in their lived experience, e.g., regarding stigma. However, lived experience is always grounded in the social and cultural context that the individual person shares with others; thus, common patterns can be found in persons from similar social and cultural backgrounds (Leichtman et al., 2003). For this reason, it is difficult to generalize research findings related to lived experience across contexts; rather, context-specific research is necessary.

Against this background, the STELDA study focuses on the experience of stigmatization and self-stigmatization of PlwYOD and of adult significant others of PlwYOD, including implications of this experience in their lifeworlds in

the sociocultural context of Germany. It is assumed that the lifeworld domains, in which the potential stigma of dementia is interactively negotiated, simultaneously provide opportunities for action to counteract stigmatization.

Study Aim

The aim of the STELDA study is to develop a theoretical framework of YOD stigma and stigmatization that is empirically grounded in the lived experience of PlwYOD and their significant others and to identify ways of counteracting processes of YOD stigmatization in the sociocultural context of Germany on a lifeworld level. Dimensions of intersectionality, especially gender and socioeconomic status (education, occupation, income), will be considered. Recommendations for action will be developed and discussed with stakeholders, including study participants from both groups, and subsequently made available to professionals and the public.

Research Questions

The primary research question is as follows: How do PlwYOD and their adult significant others experience stigma and stigmatization based on YOD in their lifeworlds, and what implications do these experiences have for their actions in their lifeworlds? The following subquestions are relevant:

- In which lifeworld domains do people experience stigmatization based on YOD?
- What forms of stigmatization are experienced?
- Which consequences of stigmatization are experienced?
- Which intraindividual differences between persons (e.g., regarding intersectional dimensions) can be observed?

Methods

The STELDA study follows an open and flexible qualitative approach within the framework of constructivist grounded theory (CGT) (Charmaz, 2014). CGT builds on pragmatism and symbolic interactionism and can be subsumed under the constructivist research paradigm (Guba & Lincoln, 1994; Lincoln et al., 2018). This approach places subjectivity and reflexivity at the core and takes the researcher's preliminary knowledge into consideration. According to CGT, research findings are constructions of reality that are possible through interpretive analysis of rich qualitative data (Charmaz, 2014).

Participants

The study will include two groups of participants:

1. Community-dwelling PlwYOD. Their subjective perspectives will be included in terms of their lived experience of living with YOD. In addition, they will be

considered as observers of the experiences of their significant others.

2. Adult significant others (family members or friends) of PlwYOD. Their subjective perspectives will be included in terms of their lived experience of being a significant other to a PlwYOD. In addition, they will be considered as observers of the experiences of their significant others with YOD.

The inclusion criteria are listed in [Table 1](#). Compliance with the criteria will be clarified during the recruitment process. Individual PlwYOD will be able to be included without their significant others and vice versa; however, the aim is to include persons who form a dyad.

Recruitment

Potential participants will be approached with a written invitation (flyers, web/social media postings, blog articles, newsletters, mailing lists) including initial information about the study. Relevant organizations, such as the National Dementia Strategy office, the German Alzheimer Association, regional dementia networks, and self-help groups, will be asked to disseminate the information and to serve as gatekeepers. Individuals who are interested in participating in the study will be able to contact the research team either by phone or email. Potential participants will receive an information letter providing information about the objective, research question, relevance, possible risks of the study and the voluntary nature of participation. In addition, oral information (in person or by phone) will be provided. Questions about potential participation will be clarified. To be able to participate in the study, potential participants (or, if applicable, a legal guardian) will need to sign an informed consent form. In addition to the one-time written informed consent, ongoing consent/assent of the participants will be needed ([Dewing, 2008](#); [Slaughter et al., 2007](#)). To ensure ongoing consent/assent, the researcher will ask for consent again at the beginning of data collection and continue to pay attention to verbal and nonverbal signs of refusal to participate further. In this case, an interruption and adjournment or termination of the interview will be agreed upon with the participant, and an appreciative conclusion of the encounter will be arranged.

Sampling

Fifteen participants from each of the two groups will be included. Following the CGT approach, we will use a purposive sampling strategy that allows for minimal and maximal contrasting ([Charmaz, 2014](#)). We will use initial sampling to obtain access to the field and to obtain a first convenience sample. For this, we aim to include PlwYOD with different forms of dementia (e.g., young-onset Alzheimer's disease, frontotemporal dementia, Lewy body dementia), different types of significant others (e.g., spouses, adult children, siblings, close friends) and participants living in different life circumstances (e.g., those living in rural and urban environments; married, widowed and single persons; and those with higher and lower socioeconomic status). After the first preliminary analytic categories are drafted, we will use theoretical sampling to develop the properties of the categories, to explore gaps and to elaborate and refine the emerging theory. Theoretical saturation of the categories is our goal in this process.

Data Collection

Data will be collected between summer 2023 and spring 2024. To accommodate different life situations and needs, the participants will be able to choose between a face-to-face interview, an interview by phone or video conference (with only the audio recorded), or an asynchronous written interview via the messenger app Nextcloud Talk. Our aim is to conduct individual interviews with PlwYOD and individual interviews with their significant others. Joint interviews with two or more participants can be arranged if that format best satisfies the preferences of the participants. The interviews (approximate duration 45–150 min) will be conducted as qualitative episodic interviews ([Flick, 2000](#)) based on an interview guide that covers certain topics (see [Table 2](#)) but can be modified and restructured as the interview progresses according to the situation.

Different types of questions will be used according to the different topics, the individual abilities of participants and the situational requirements. Questions that target narrative-structured responses are preferred whenever possible because they provide the strongest foundation for analyzing lived experience ([Ricoeur, 1991, 1994](#)). A particular focus will be placed on the narration of situations as episodes because it

Table 1. Criteria for the Inclusion of Study Participants.

PlwYOD	Significant Others
Self-reported dementia with onset before the age of 65	Family member or friend of a person with self-reported dementia with onset before the age of 65
18 years old or older	
Community-dwelling	
Sufficient command of the German language	
Sufficient capacity of verbal articulation	

Note. PlwYOD = people living with younger-onset dementia.

Table 2. Topics of the Interview Guide.

Overarching topic	Subtopics
Life before dementia-related changes	- Biographical aspects - Story of illness
Dementia in different lifeworld domains	- Dementia in everyday life and in various lifeworld domains; positive/negative changes
Diagnostic process	- First signs of dementia - Time until diagnosis - Personal meaning of diagnosis
Situation after diagnosis	- Time after diagnosis - Reactions of others
Social interactions in light of dementia	- Significant others in one's life - Contact with other PlwD - Disclosure/concealment - Feelings in social interaction
Negative/positive experiences related to dementia	- Interpretations of negative/positive situations - Experience of degradation/exclusion
Closing question	PlwYOD: Significant other: - A pleasant experience the participant has had - An important message the participant wants to convey to others

Note. PlwD = people living with dementia; PlwYOD = people living with younger-onset dementia.

is assumed that experiences of stigma and stigmatization can be approached through narratives in which participants provide self-constructed accounts of social interactions (Flick, 2000). During the interviews, any lifeworld domains addressed by the participants will be recorded on index cards and used as visual stimuli later during the interview to further explore experiences regarding each domain. Relevant contextual information, e.g., sociodemographic data and information on the care arrangement, will be collected with a context questionnaire that will be completed together with the participants. A postscript will be prepared for each interview to document the situational context and subjective views of the interviewer. The interviews will be audiotaped (merged and saved as text documents in the case of written interviews).

Data Handling

Data collection and analysis will be subject to strict confidentiality, which will be guaranteed to potential participants prior to their participation. The use of data, in particular health data, will be carried out in accordance with the applicable legal provisions, in particular the provisions of the GDPR, especially Articles 6 (1) (a), 7 and 9 (2) (a), and will require that the participants voluntarily declare consent prior to participation in the study. The data will be processed in pseudonymized form in the protected server environment of the DZNE according to the internal regulations of the DZNE Witten in compliance with data protection regulations. Only staff involved in the project will have access to the data. Identifying data and research data will be processed separately. The research data will be archived after the end of the project and kept for ten years following the recommendations of the Deutsche Forschungsgemeinschaft (DFG). After completion of the project, the audio recordings will be completely deleted.

The audio data will be transcribed verbatim, and all transcripts will be pseudonymized. The transcribed data will be organized using MAXQDA 2022 software (VERBI Software, 2021) for qualitative analysis.

Analysis

The analysis will be conducted within the framework of CGT (Charmaz, 2014). This approach involves an interactive comparative method based on a minimum of two stages of interacting with the data through coding. First, initial coding is performed with the aim of obtaining first analytical access to the data and identifying directions to explore further. Second, focused coding is carried out with the aim of determining the adequacy and conceptual strength of the initial codes and identifying central codes and possible categories. Axial coding and theoretical codes can be used in addition to further consolidating the categories and their dimensions and developing a theory that explains the phenomenon under study.

Our interests, sensitizing concepts and disciplinary perspectives on the research topic of stigma and stigmatization, will be used to initially guide the focus of analysis before more specific concepts are developed in interaction with the data. Inductive categories will be formed based on the empirical material; these categories will be thematically guided by the research questions and the deductive categories of the interview guide. The emerging theoretical framework will be related to existing research, e.g., on dementia stigma, coping strategies of stigmatized people, and anti-stigma communication. Conducting the analysis collaboratively in an interdisciplinary research team will help us develop the best possible explanations while at the same time staying reflexive regarding potential bias. In the event of disagreement, we will engage in a focused discussion to try to identify the best possible explanation. If necessary, we will

involve other colleagues to broaden the possible perspectives on the data in question and to resolve the bias in the research team. Writing memos (informal analytic notes) throughout the research process will support the successive construction of theoretical categories.

Ethics

Ethical approval for this study was obtained from the Ethics Committee of the German Society of Nursing Science (DGP) (reference number 23–003).

It is considered ethically beneficial for PlwD to be able to express themselves about their concerns (Alzheimer Europe, 2011). At the same time, it is necessary to reflect on vulnerability, which, on the one hand, is generally regarded as a human characteristic and which, on the other hand, is particularly rooted in the living situation and social stigmatization of PlwD (Reitinger et al., 2018). Generally, data collection on the experience of stigma is associated with the risk of emotional and cognitive distress. This risk must be minimized, but without denying participants the right to grieve, suffer, and experience other distressing emotions. The attentive preservation of ongoing consent is considered central to managing this risk. In addition, the chosen interview approach also offers the opportunity for a positive or relieving experience for the participants, since they are shown appreciation, time is devoted to them, and a personal encounter is created with them.

Guided by the facilitative practices identified by Novek and Wilkinson (2019) for safe and inclusive qualitative research with PlwD, specific preventive precautions will include avoiding stigmatizing language; communicating sensitively with participants who may be (temporarily) unaware of their dementia diagnosis; allowing a trusted third person to be involved; planning the time, place, and duration of the research encounter according to participant preferences; building rapport with participants and actively managing withdrawal from the research relationship; establishing and monitoring role clarity; adapting communication style and interview questions to participant abilities; planning how to deal with stressful moments and following the ‘ending on a high’ approach of the CORTE criteria (Murphy et al., 2015); supporting the researcher through peer reflecting; and communicating the overall results to the participants.

Rigor

We understand rigor as a quality of reasoning, which includes coherence of the argumentation and inference to the best explanation (Harley & Cornelissen, 2022). In Table 3, we list the related criteria and the steps we intend to take to maintain rigor in our study.

Particular criteria for CGT studies that ensure the needed coherence of the argumentation and inference to the best explanation are credibility, originality, resonance, and usefulness (Charmaz, 2014, pp. 337–338).

Discussion

The STELDA study aims to explore the lived experience of YOD stigma and stigmatization. It was motivated by a theoretical interest in filling gaps in the research on dementia stigma pertaining to the particular situation of PlwYOD and their significant others in the sociocultural context of Germany. Additionally, it was inspired by the German National Dementia Strategy, which was launched in 2020, and its focus on research into the lifeworlds of PlwD. One goal of the strategy is to ensure the social participation of PlwD and their relatives (BMFSFJ & BMG, 2020). Stigmatization poses a barrier to the system of care for PlwD and their families. From a societal perspective, it is a challenge when certain groups have fewer opportunities to participate and are threatened by processes of exclusion. Other challenge include the misjudgment of the potential of PlwD and a focus on deficits rather than abilities (Alzheimer’s Disease International, 2012). Destigmatization and participation for PlwD are therefore not only important for the individual person but are also linked to the overarching goal of an inclusive society (Heimerl et al., 2019).

The results of this study will form the basis for the development of recommendations for action that will inform professionals in diverse settings, such as counseling, health care, and politics. In addition, they will inform recommendations for PlwYOD, their families and friends, and the general public as potential interaction partners of PlwYOD and their significant others. The findings will provide these groups with an empirically grounded, in-depth understanding of the processes of YOD stigma and stigmatization and with initial ideas for overcoming these processes. In addition to dissemination through scientific publications and congresses, the findings of the study will be disseminated through press releases and the media.

From a methodological perspective, the study will first provide important insights and knowledge regarding the practice of qualitative episodic interviews with PlwYOD, e.g., regarding the phrasing of questions, the pace of the interview, and the necessary relational work. Second, it will allow conclusions to be drawn about how to avoid ascribing greater validity to either perspective when PlwYOD and their significant others are interviewed about a topic in their shared lifeworld. Finally, third, the study will contribute practical and methodologically reflective experiences to the debate on how to analyze qualitative data from PlwYOD and how to overcome related challenges. Thus, the project touches on fundamental and not yet conclusively clarified questions in qualitative dementia research (Teupen et al., 2023a, 2023b).

Limitations could be related to access to relevant groups of participants, as it is known that PlwD in general, but especially certain subgroups such as people with a migration history or low socioeconomic status, are hard to reach for research. This could ultimately limit the scope of the findings. The scope is

Table 3. Criteria of Rigor and Steps to Maintain Rigor (Adapted From Harley & Cornelissen, 2022).

Criteria of rigor		Steps to Maintain Rigor
Coherence of the argumentation		
Methodological coherence	The ontology, epistemology, methodology, method/data, and theoretical claims in a study are consistent with each other.	We will explicate our ontological, epistemological, and methodological assumptions and how they relate to each other and to the methods used for data collection and analysis. We will make sure that our claims made about reality are consistent with this underlying framework.
Logical consistency	There are explicitly articulated and logical links between each part of the explanation of why theoretical claims are inferred from empirical data.	We will precisely specify the data basis, focus, and theoretical resources of our analysis. We will explain and demonstrate the steps of the analytical and inferential processes.
Inference to the best explanation		
Consideration of competing explanations	In inferring an explanation for findings, several possible explanations are considered.	We will justify why we have chosen a preferred explanation ahead of rival ones.
Contrastive reasoning	In reaching theoretical explanations based on empirical findings, the question, “why this finding and not a different one?” is asked.	We will explicate which elements of a finding seem salient and important and what is the crucial difference between the preferred and alternative explanations.
Explication of the virtues of explanations	In choosing a theoretical explanation, the researchers do not immediately accept the “likeliest” but seek the one with the most explanatory power (the “loveliest”).	We will explicate how we balance the virtues of simplicity and richness in our choice of a preferred explanation.

also limited by the situatedness of the studied phenomenon in the German context.

Author Contributions

ST, NB, and AH conceptualized the study. NB and ST prepared the initial draft of the manuscript equally. AH provided parts of the methods section. BY supported the writing process. ST supervises all steps of the project. All authors read and approved the final manuscript.

Declaration of Conflicting Interests

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