Review

Royal College of Occupational Therapists

British Journal of Occupational Therapy
1–16

DOI: 10.1177/03080226241253699
journals.sagepub.com/home/bjot
Sage

A meta-ethnography of identity formation among people with early-onset dementia

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Abstract

Introduction: Living with dementia can be challenging, even more so for people diagnosed before age 65. Loss of identity is one of the main subjective consequences dementia poses at this stage in life due to the loss of social relations and daily activities. While a growing body of research is reporting the experienced impact of early-onset dementia on identity for this group, studies synthesizing this knowledge are very limited. Therefore, we have conducted a meta-ethnographic review to explain how people with early-onset dementia form their sense of identity.

Method: A systematic review of literature from five databases was conducted. Ten original studies published between 2004 and 2020 were included and analyzed using an interpretive approach.

Findings: A conceptual interpretation emerged from the analysis, showing that social arenas and activities of daily life, as well as assumptions about dementia and natural aging made by the participants and society, influenced the participants' sense of identity.

Conclusion: Being in nonjudgmental environments can support people with early-onset dementia in creating continuity and positive connections in their personal history. Providing such environments can be a viable venue for healthcare professionals to support people with early-onset dementia in maintaining a positive sense of identity.

Keywords

Alzheimer's dementia, everyday life, self, occupation, stigmatization

Received: 10 January 2024; accepted: 23 April 2024

Introduction

Dementia is sometimes conceived as "an old person's disease" and is associated with retirement and a sedentary, withdrawn lifestyle (Low and Purwaningrum, 2020). However, a growing number of people under 65 face immense challenges in daily life due to the loss of memory, language, and social skills that follow early-onset dementia.

Globally, early-onset dementia accounts for up to 9% of all dementia cases (WHO, 2017). In Denmark, where this meta-ethnographical study was conducted, about 3000 people under 65 have dementia (Nationalt videncenter for Demens (Danish Dementia Research Centre), 2019). The number may be higher because the symptoms are misinterpreted as stress or depression (Spreadbury and Kipps, 2019).

Studies have shown that the experience of living with early-onset dementia is fraught with challenges that may differ in complexity from those related to late-onset dementia (Greenwood and Smith, 2016). To people with early-onset dementia, the illness enters their lives at a significant personal cost when they are perhaps married with children living at home, at the height of their careers, and financially and socially obligated. Research exploring people's experiences of living with early-onset dementia reports that the changing and eroding fabric of daily life are, in particular, encroaching on their sense of identity (Busted et al., 2020; Clemerson et al., 2014). According to Vignoles et al. (2011), regardless of how identity is conceptualized, at its core, it involves the answer to the seemingly simple but indeed complex question "Who am I?." A person's identity is formed throughout life by their engagement in social relations and places, through the use of objects, and in response to critical and life-changing

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events as these experiences are interpreted and infused with personal meaning (Jørgensen, 2009). In particular, the activities people engage in daily are prolific sources of self-continuity and normality and self-experiences related to, for example, feeling competent and being connected with other people (Hansson et al., 2022; Maersk, 2021). To people with early-onset dementia, their sense of identity and being the same person is compromised by deteriorating and fluctuating cognitive and emotional capacities. Their inability to live up to expectations and navigate social situations causes them to voluntarily or involuntarily retract from meaningful relations and activities related and work or personal life (Busted et al., 2020; Spreadbury and Kipps, 2019; Thorsen et al., 2020).

In Denmark, national strategies and approaches to dementia rehabilitation align with WHO's global action plan on dementia, which states that people with dementia should receive care and support to empower them to live meaningful lives and avoid marginalization (Danish Health Authority, 2017; WHO, 2017). However, the services provided by the municipalities in Denmark consist primarily of counseling and leisure activities (Thuesen et al., 2018). These services may be appropriate for people with dementia above 65 who are no longer working. However, they are not designed for the complex issues people with early-onset dementia face. Consequently, there is a need for healthcare services that enable them to handle the practical problems related to symptom management while maintaining a sense of being the same person for as long as possible. Such services must built on knowledge that allows for a profound understanding of the complexity of their situation and points to areas and issues these services must address (Nilou et al., 2022).

Identity among people with early-onset dementia has not been researched as extensively as among people with dementia in general (Caddell and Clare, 2010). However, the body of research on the topic is growing (Busted et al., 2020; Greenwood and Smith, 2016). Only a few reviews have been made to synthesize the knowledge in this area. One scoping review regarding early-onset dementia and identity was identified when conducting the literature search for this study (Andrew et al., 2019). However, this review included studies with carers, employers, and people above 65. A meta-ethnographic review (Greenwood and Smith, 2016) was also identified, which did not specifically address the identity of people with early-onset dementia but the experiences of this group, though more broadly. Therefore, a meta-ethnography was conducted to accumulate and synthesize available research. Accordingly, this meta-ethnography aimed to explain how people with early-onset dementia form their sense of identity.

Method

Our study followed the seven phases of meta-ethnography described by Noblit and Hare (1988) and clarified by Cahill et al. (2018). Phases one to six are reported in the method section. Phase 7 is the presentation of the findings. The eMERGe meta-ethnography reporting guidance was followed rigorously to ensure transparency of the research process (France et al., 2019). A reflective journal was kept to document thoughts and insights throughout the research process (Cahill et al., 2018).

Phase 1: Rational for doing a meta-ethnography

Compared to other types of qualitative reviews, the strength of meta-ethnography is that it allows the researcher to take an interpretive stance, move beyond a descriptive level, and reach a higher-order interpretation of the included accounts (Noblit and Hare, 1988). Here, it was the relevant choice because it could help identify and understand issues, conditions, actions, and interactions of importance to the identity formation of people with early-onset dementia.

Phase 2: Deciding what is relevant to the initial interest

A search strategy was developed to identify qualitative studies reporting subjective data on the identity of people with early-onset dementia. Five databases (Embase, Cinahl, PsychINFO, Scopus, and Web of Science) were searched using Boolean operators with the following limitations:

- Aged 65 or younger
- Studies from 2000 to 2021
- Peer-reviewed journals
- Published in English
- Qualitative studies

The search was done in October 2022 and guided by an experienced health science librarian. Table 1 provides an overview of the keywords used in the database search.

In all, 3745 articles were found. After the removal of duplicates, 3609 remained. Two researchers independently screened titles and abstracts using these criteria:

Inclusion criteria

- Qualitative studies
- Participant group 65 or younger
- Experiences of people with early-onset dementia
- Studies from 2000 to 2021
- Peer-reviewed journals
- Published in English
- Western countries/Europe
- The title, keywords, or abstract should include the following words or variations thereof:
  - Identity and self

Table 1. List of keywords.

"early onset" or "early-onset" or "young-onset" or "young onset" or "younger onset" or "younger-onset" or "young" or "early" or "younger" or "early stage" or "early-stage" or "younger people" or "young people" or "working age" or "working-age"	and
"dementia" or "alzheimer" or "alzheimers"	and
"identity" or "identities" or "sense of self" or "self" or "self-continuity" or "self-identity" or "personhood" or "sense of identity" or "selfhood"	and

Exclusion criteria

- Mixed method studies
- Gray literature, book chapters, non-peer-reviewed journals, books, opinion papers, theoretical papers, conference presentations, dissertations, poster presentations, discussion papers, reviews (relevant in introduction and discussion)
- Caregiver/spouse/family/partners' perspectives

Some studies did not specify the age of the participants in the title, keywords, or abstract. These studies included people representing a wide age range, so they were not included. In all, seventeen studies were identified for full-text reading.

Following an independent assessment using the Critical Appraisal Skills Programme (CASP), the first and last authors discussed the scientific quality of the seventeen studies. Four studies were excluded based on the quality assessment and discussions between the two authors. These studies did not include direct verbal accounts from people with early-onset dementia but had Twitter blogs, Facebook posts, and other types of postings on social media. Three studies were excluded because they did not specify the participants' ages or included mixed accounts from family members, which left ten remaining studies. Tables 2 and 3 provide overviews of the included studies and critical assessments. Figure 1 illustrates the literature search.

Phase 3: Reading the studies

The studies were read independently by the first and last authors. Some studies yielded richer and more detailed information, whereas others were more superficial and lacked analytical depth in the findings. Based on the reading, it was decided to include all 10 studies in the analysis because, as a whole, they represented different aspects and issues of relevance when grasping the complexities of identity formation for people with early-onset dementia. This study's conclusions represent all the included studies.

At first, the studies were read to get an overview of the different contexts, participant groups, and verbal accounts (first-order constructs). Subsequent readings had an interpretive purpose by noting metaphors and themes (second-order constructs) that captured essential aspects, experiences, and conditions that shaped the identity formation of the participants (Cahill et al., 2018; Noblit and Hare, 1988). The readings were guided by questions like "Which physical, social, and emotional conditions influence the participant's sense of identity?", "How and why does their sense of identity change?" Table 4 provides examples of first-order constructs and corresponding second-order constructs.

Phases 4 and 5: Determining how the studies are related and translating the studies into one another

In praxis, phases 4 and 5 unfolded simultaneously as an interactive process of looking across studies and comparing emerging theoretical ideas and metaphors (second-order constructs). The analysis resembled a hermeneutical interpretation, in which understandings emerging from reading one study became the background for understanding and interpreting the following study.

Specifically, the second-order constructs were compared and juxtaposed across the studies to identify patterns, relationships, and differences and ensure emerging interpretations' groundedness. Particular attention was given to how the participants' everyday life contexts, such as homes, workplaces, or nursing homes, influenced their possibilities for forming and expressing their identities. For example, there were clear indications in all studies that how the participants interpreted the social responses toward their challenges significantly impacted their sense of identity. Attention was also given to disconfirming cases, that is, how individual accounts or themes from studies contradicted or refuted each other and the emerging understanding of the studies as a whole (Cahill et al., 2018). However, there was a surprising homogeneity and agreement between studies. Therefore, the final synthesis of the studies is what Noblit and Hare refer to as reciprocal (Noblit and Hare, 1988).

Table 2. Overview of included studies.

Number	Study	The research question/ aim/purpose	The method/ methodology	Participants	Ethical procedures	Research context	Key findings	Conclusions and implications for practice
1	Laila M Busted, Dorthe S Nielsen, and Regner Birkelund. "Sometimes it feels like thinking in syrup"—the experience of losing sense of self in those with young onset dementia	". . .this qualitative study aimed to explore and describe the experience of people having young-onset dementia"	Qualitative study using semi-structured interviews and reflexive thematic analysis	Men = 5 Women = 4 Age range at the time of diagnosis: 47–65	Interviewer with experience with people with dementia The participants received oral and written information about the study and gave written consent Ethical clearance was obtained. The study was approved by the Danish Data Protection Agency The study was conducted according to the Declaration of Helsinki	People with early-onset dementia living alone or with a partner at home in Denmark The primary context was daily life at home and activities associated with upholding daily life and social relations and obligations	Shifting between good days and bad days Loss of memory leads to loss of self Avoid being identified as a person with dementia Understanding oneself anew Strategies to support memory, form continuity in self, and create a favorable future Feeling embarrassed by the loss of control and repetitive behavior Dreading a humiliating future	The experience of having and living with young-onset dementia caused a loss of personality and sense of self Thoughts about the future were associated with fear regarding changing personalities and humiliation Listening to people with young-onset dementia can help maintain autonomy Advanced care planning should take place before critical cognitive decrease Family health conversations are recommended
2	Aud Johannessen, Knut Engedala, Per K Haugena, Marcia C N Douradoc, and Kirsten Thorsen. "To be, or not to be": experiencing deterioration among people with young-onset dementia living alone	". . .we have performed this longitudinal study aiming to explore the existential experiences and coping of people with YOD (young-onset dementia), as they narrate the deterioration due to dementia that they go through over time"	A longitudinal, explorative, descriptive study over two years with five sequential interviews with each participant	Men: 3 Women: 7 Age range 49–67 (For the 67-year-old person, the symptoms started many years before 65)	The study was approved by a regional ethics committee and a national data protection authority The participants received oral and written information about the study and gave written consent The study was conducted according to the Declaration of Helsinki	People with young-onset dementia living alone or with a partner at home in Norway The primary context was daily life at home, nursing home, and at work and activities associated with upholding daily life and social relations and obligations	Loss of identity over time Employ strategies to counter the loss of memory Fear of the future	Preserving and protecting a positive identity is a massive challenge for YOD The voices of people with early-onset dementia should be listened to in the planning of personalized care
3	Mariko L Sakamoto, Sharon L Moore, and Steven T Johnson. "I'm Still Here": Personhood and the Early-Onset Dementia Experience	"The current study examined the lived experiences from the point of view of four adults younger than 65 with dementia, particularly how they perceive their personhood"	Interpretive phenomenological approach Data collection was augmented by asking participants to provide art-based data	Men: 4 Age range: 46–62	Ethical approval was obtained Participants gave informed consent	The primary context was daily life at home and activities associated with upholding daily life and social relations and obligations in Canada	A strong need to be recognized as the person they are and not as demented Not being recognized leads to a loss of self Engagement in daily activities is a way to preserve hope and connection to the world	People with early-onset dementia have a strong sense of personhood, which deserves recognition Healthcare professionals should support people with early-onset dementia by letting their voices be heard

(Continued)

Table 2. (Continued)

Number	Study	The research question/ aim/purpose	The method/ methodology	Participants	Ethical procedures	Research context	Key findings	Conclusions and implications for practice
4	Kirsten Thorsen, Marcia C N Dourado, and Aud Johannessen. Developing dementia: The existential experience of the quality of life with young-onset dementia – A longitudinal study	". . . we conducted a longitudinal study aiming to examine the experience of the quality of life with YOD (young-onset dementia) as a single person"	Longitudinal case study of one person using a narrative methodology and in-depth interviews Interviews were conducted every 6 months for 3 years. Seven interviews in all	Women: 1 The participant was among the youngest person in a larger study of people ranging from 49 to 67 years	The study was conducted following the Helsinki Declaration Permission from the regional ethical committee and data protection authority was obtained The participant received oral and written information about the study and gave written consent	The daily life of one woman living in Norway Narratives revolved around her life at home and later in a nursing home	Expectations of family and friends undermined the participant's sense of identity to be her "old self" She employed strategies by belittling herself and saying she had a brain injury to make her behavior more understandable to others Living in a nursing home with fewer expectations revitalized her life, and she took up activities that she found meaningful	The voices of people with dementia need to be heard to avoid stigma and undermining of their identity The needs of people with YOD during the progression of dementia must be heard, and should provide the foundation of individualized support Services to people with YOD need to be individualized to support their sense of identity Institutional settings should be transformed in order to support individual identities and mastering capacities
5	Fiona E Pipon-Young, Kristina M Lee, Fergal Jones, and Guss Reinhard. I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study	"The main aims of the study were to: (1) develop a broader understanding of the experiences of younger people with dementia, including what it was like to receive their diagnosis and what particular concerns or difficulties they encountered (including work, finances, social relationships); (2) to develop an understanding of the support that has been beneficial, including support from services, family and friends; (3) to identify areas in need of change (e.g., lack of appropriate services, information about dementia); (4) to draw out the key problem areas with the aim of developing an action based on a problem or problems identified"	Action research design using semi-structured interviews followed by discussion groups Data were analyzed using inductive, thematic analysis, focused coding (grounded theory), and concept mapping	Men: 1 Women: 7 Age range at interview: 60–67 Age range at diagnosis: 58–62	Informed consent was obtained using "the process consent method"	The participants spoke of their life as retirees at home and in different contexts with friends and family	The participants tried to maintain their self and sense of identity, preserving their autonomy and independence by continuing to engage in daily activities and life as they used to The participants employed several strategies to save face and remain positive The participants did not feel the need for age-appropriate services	Support groups can help people with YOD to develop shared identities and adjust their identities to their current situation Professionals can support the use of compensatory strategies to train memory functions and maintain meaningful activities in daily life Recovery may serve as a relevant framework in the development and provision of services to people with YOD

(Continued)

Table 2. (Continued)

Number	Study	The research question/ aim/purpose	The method/ methodology	Participants	Ethical procedures	Research context	Key findings	Conclusions and implications for practice
6	Dag Rostad, Ove Hellzen, and Ingela Enmarker. The meaning of being young with dementia and living at home	". . . the aim of this study was to gain an understanding of the lived experiences of younger persons (<65 years) who lived at home and suffered from early-onset dementia, and the meanings that could be found in their experiences"	An inductive, phenomenological, hermeneutical approach Narrative interviews with open-ended questions	Men: 2 Women: 2 Age range 55–62	The study was approved by a regional ethics committee Participants were informed orally and in writing Participants gave written consent	The daily life of people living at home in rural Norway The participants were still working	Loss of self-identity, loss of self-esteem, self-determination, and social relationships led to a sense of loss of humanity The participants did not experience the onset and progression of their illness Their homes was associated with feelings of security, independence, and quality of life Having meaningful activities in their life provided a sense of hope that they could preserve their identity The participants coped with their changing situation by adapting and staying positive	People with young-onset dementia should remain independent for as long as possible Healthcare professionals should be aware of the potential loss of humanity that comes with the progression of memory loss and other functions and the reactions from the surroundings
7	Gemma Clemerson, Sue Walsh, and Claire Isaac. Toward living well with young onset dementia: An exploration of coping from the perspective of those diagnosed	"The aim of this study was to provide an exploration of the individual's subjective experiences of young-onset AD (Alzheimer's disease). More specifically, it aimed to explore in depth the personal, social and psychological impact of living with the disease in younger life and the processes individuals go through in adjusting to and coping with these experiences"	Semi-structured interviews Interpretive Phenomenological Analysis	Men: 7 Women: 1 Age range: 35–63	The study was given ethical approval Participants gave informed consent Participants were given the option of having a carer present during the interview to limit distress Participants were allowed to disclose emotional stress related to their participation in the study	The daily life of people living at home in the UK None of the participants were working	The experience of living with AD was situated in the participants' social contexts and life-cycle as middle-aged people The participants used several coping strategies, such as re-establishing self, reconnecting with others, regaining control, and reviewing life	Services specific to younger people with dementia need to be provided to counteract isolation and feelings of being different Group-based interventions and self-help groups could enable younger people with dementia to contribute to society, support individual coping strategies, regain control and a sense of agency Society as a whole needs to develop an understanding of the condition to avoid the stigma
8	Phyllis B Harris. The perspective of younger people with dementia: Still an overlooked population	"The purpose of this study is to explore the lived experiences of younger persons who have received a diagnosis of dementia and to give voice to their experiences. Specifically, the study focuses on the social dimension of the disease, examining how such a diagnosis impacts the daily life of a younger person"	A qualitative approach using grounded theory Focus groups, face-2-face interviews, and online interviews	Men: 10 Women: 13 Age range at interview: 43–68 Age range at diagnosis: 41–63	The study was approved. No further details are presented The participants were given written and verbal information about the study The participants gave written consent	The daily life of people living at home in the US Some participants had children living at home	The participants experienced that their identity, self-esteem, and self-hood were affected by the illness and its effect on skills and social relations Rolls, relationships, and the family structure changed significantly Early retirement caused financial problems Diminishing skills reduced the repertoire of activities possible	Young people with dementia should be offered various peer-support groups and financial counseling Attention should be given to their young age and the age-related challenges they face, and they should not be stereotyped as people with dementia older than them

(Continued)

Table 2. (Continued)

Number	Study	The research question/ aim/purpose	The method/ methodology	Participants	Ethical procedures	Research context	Key findings	Conclusions and implications for practice
9	Kirstin Broders and Elaine C Wiersma. Creating change: The experience of women living with young onset dementia	"The aim of this paper is to fill this gap through investigation of the lived experiences of women living with young onset dementia who have moved into advocacy roles, generating new insights and enriching our understanding of these experiences by giving voice to an overlooked subset of the dementia population"	A qualitative constructivist approach Semi-structured interviews with open-ended questions Thematic content analysis using open and focused coding and memoing	Women: 5 All participants had been diagnosed before turning 65. One participant was diagnosed in her forties, one in her late forties, two in their early fifties, and one in her early sixties	The participants were recruited from various communities with the help of contact persons with personal knowledge of the women The participants received written and verbal information about the study The participants gave written, audiotaped oral consent The participants were given the opportunity to review the manuscript if they had concerns A university research ethics board approved the study	Women who identified themselves as active advocates for people with dementia Four participants lived with family or partners, and one lived alone Experiences centered around getting the diagnosis, leaving work, and engaging in advocacy work	Getting a diagnosis of dementia early in life posed several challenges related to insurance, healthcare services, and changing relationships with friends Accepting the diagnosis was essential to moving on in life and finding a new purpose Engaging in advocacy work provided opportunities to regain and find new roles in life	Opportunities to engage in advocacy work can help people with young-onset dementia retain or develop new roles in life and challenge dementia sigma
10	Linda Clare, Julia M Rowlands, and Rebecca Quin. Collective strength: The impact of developing a shared social identity in early-stage dementia	"In this study, we explore the experience of belonging to DASNI and the impact this has on self-concept and adjustment in the early stages of dementia, from the perspectives of DASNI members. We aim to understand more about the factors that promote self-help, and the effects of engaging in self-help, mutual support and advocacy in this context, in order to consider the possibilities for genuine empowerment of people experiencing early-stage dementia"	An exploratory, qualitative, longitudinal, internet-based study Participants participated in two interviews. After each round of interviews, participants provided written answers to follow-up questions posed by the researchers Interpretive Phenomenological analysis was used to analyze the transcripts	Men: 2 Women: 5 Age range at interview: 48–66 Estimated length of time since diagnosis: 4–9 years	The research project this study was a part of was reviewed by a university ethics committee Participants gave informed consent	Experiences related to getting diagnosed, losing the job, and participating in support groups under DANSI (Non-profit organization to promote respect, dignity, and awareness about people with dementia)	Dementia led to the loss of self-esteem and personal worth The participants experienced loneliness and isolation due to the lack of recognition and understanding from other people Participating in support groups under DASNI engendered a sense of pride and belonging through a sense of collective strength	Support groups like those in DASNI can help people with dementia grow and remedy the loss of identity through pride, collective strength, bonding, and a sense of belonging Developing supportive environments in which people with dementia can have a "voice" and reject the passive patient role can have an impact at the social and policy level

Table 3. Critical assessment of included studies using CASP.

Study number	CASP question 1	CASP question 2	CASP question 3	CASP question 4	CASP question 5	CASP question 6	CASP question 7	CASP question 8	CASP question 9	CASP question 10
1	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
2	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
3	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes
4	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No
5	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Yes
6	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
7	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
8	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
9	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
10	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

CASP: Critical Appraisal Skills Programme.

Phase 6: Synthesizing the translations

This phase aimed to place the included studies into a new interpretive context (Cahill et al., 2018; Noblit and Hare, 1988). The third-order constructs were organized in clusters and ordered according to their seeming position in each cluster. Third-order constructs emerged by taking an interpretive stance toward each cluster to find overarching themes and reach a higher level of abstraction that could explain their content and relationships. For instance, the third-order construct of "Identity composure in everyday life" emerged as a composition based on several second-order constructs, such as "Losing memory means losing your sense of self" and "inability to locate relations and activities in time and place". Discussions between the authors, reflective writing, and drawing of graphical models supported the development of third-order constructs and understandings of their relationships. The emerging third-order constructs were continuously compared with the first-order constructs and original studies to ensure their groundedness (See Table 5).

Findings

The following third-order constructs represent the findings:

1. Identity composure in everyday life
2. Identity domain: The self in social arenas and activities
3. Identity domain: The self in time and life trajectory
4. Societal discourses and shared assumptions about dementia, natural aging, and life progression

Figure 2 is a graphical model that illustrates the interrelationship between these four constructs.

Central to the findings and overarching the other constructs is the process by which people with early-onset dementia compose their identity amid the challenges of the progressive decline of cognitive, physical, and emotional functions (construct I). The composure of identity revolves around two identity domains. The first identity domain encompasses their experiences while engaging in activities and social relationships in different arenas, such as workplaces, institutions, and homes (construct II). The second identity domain compiles their thoughts and expectations about their life trajectory as it changes (construct III). Societal discourses and assumptions about dementia and natural aging intruded upon their identity composure and influenced how the participants and others perceived them (construct IV). The circle surrounding the two-person figures in Figure 2 illustrates the impact of challenges experienced in everyday life on the participants' sense of identity. "Disruption," "loss of control," "loneliness," and "discontinuity" are words used directly or implied in the included studies.

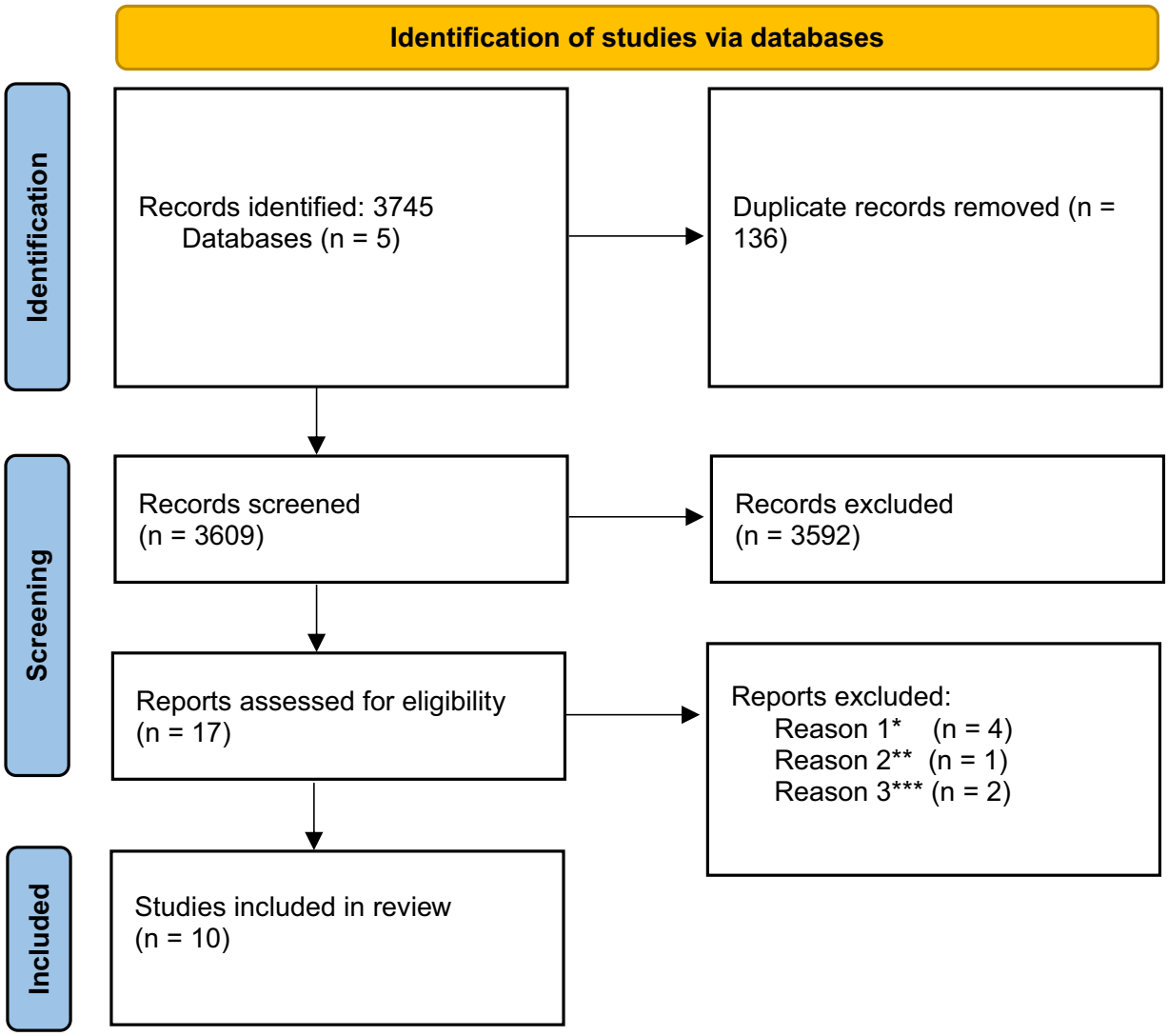

Figure 1. PRISMA Flow diagram.
*Excluded because they did not include direct verbal accounts from people with early-onset dementia.
**Excluded because they entailed accounts from family members.
***Excluded because the authors did not specify the age of the participants.

Identity composure in everyday life (construct I)

The construct of identity composure interprets how identity is viewed across the studies. Notably, none of the studies presents definitions or frameworks of identity from which this construct could be deduced. It is a process of composing an inner cohesive sense of being the same person over time and connected with people and places. The participants did this by continuously striving for continuity, coherence, or positive connections between past experiences, as they fragment, wither, and disappear, experiences in the present of engaging in activities and relations and shifting expectations about the time to come. Importantly, to some participants, it was not only a matter of holding on to the past and who they used to be. It was also about accepting the illness and letting go of the past by living in the present (Clemerson et al., 2014; Johannessen et al., 2018). Thus, it was not a question of preserving or letting go but rather two concurrent processes (Clemerson et al., 2014).

Identity composure includes but is not limited to a social and self-reflective process of creating an identity through language and self-representation in social arenas. It was also a "doing process" related to how the participants managed practicalities and orchestrated the entirety of their everyday life in liveable ways (Broders and Wiersma, 2022; Johannessen et al., 2018; Pipon-Young et al., 2012; Rostad et al., 2013).

Although not strongly represented in all studies, the analysis revealed several strategies the participants developed and applied to preserve coherence and self-continuity inwards and outwards. The participants used these strategies to handle practicalities in their everyday lives (construct II) but also to avoid being confronted with negative perceptions of dementia and prejudices emanating from societal discourses about dementia and normal aging (construct IV; Thorsen et al., 2020).

Table 4. Examples of first- and second-order constructs.

First-order constructs	Second-order constructs
The loss expressed through *Dementia Land* appeared to be mitigated by the impact of DASNI. Participants' reciprocal relationship with DASNI enabled them to help others with dementia, both within and outside of DASNI. This process then facilitated the development of their sense of pride, purpose and value and hence their contributions were able to flourish to the point where they had the confidence to work to improve both DASNI and the situation of people with dementia as a whole. In this way, DASNI allowed them to use their skills in a new context. (Clare et al., 2008: 21). It seemed that as people began to reconnect with others, their focus shifted from concern with how they cope to concern with how their loved ones cope: "My wife. She's had so much to deal with. I just want to protect her and make sure she's alright" (George). Others focused their attentions on contributing to the community and helping other people with dementia: " . . . if I could help somebody else then I will do it because that will make me feel like I have had some part of things" (Emma). (Clemerson et al., 2014: 460). At the fourth visit, when she has returned to the nursing home, she tells about the transformation to the social person she was earlier. She now prefers to sit in the living room with the other residents. Her feeling of security has restored her sense of connectedness to other people. "All [the] people here are nice. There is always someone to talk with." She enjoys being with other persons. (Thorsen et al., 2020: 884).	Redefining self and reconnecting in new social arenas
In addition to the difficulties of navigating the system, each participant experienced stigma. They all encountered lack of understanding and misperception, in which their diagnosis of EOD became the "stigmata," or mark that distinguished them from others, making them feel different and affecting their self-worth. Mitch illustrated these feelings in his poem, STIGMA: *My greatest challenge is to reduce the amount of stigma and put it in the past.* (Sakamoto et al., 2017: 15). Typically described were the negative perceptions of the word "dementia," resulting in a lack of understanding about dementia and a loss as to how to be with people with dementia: *"Some people are absolutely don't understand any of it [dementia] (sic). They, it's just like they don't know what to do with it, or you with it (sic)."* (Julie, Phase One). Penny described the loss of how to be around people with dementia as a fear of the unknown: "*My grandmother obviously had it and it was laughed about in the family. You know it was kind of she's gone pooey, that was the word that was used, she's gone pooey . . . . Sad, sad isn't it. People don't like anybody who's outside of their perception of life that's it somehow; I don't know what it is because they're scared of it I suppose.'* (Penny, Phase 1). (Pipon-Young et al., 2012: 605).	Lack of understanding and negative perceptions of dementia
Loss of adult competency represents another sub-theme in the disruption to the life-cycle. This emerged through people's experience of either feeling more "childlike" due to a loss of skills or being treated this way by others: You know when I am trying to get my coat on and then my wife is trying to get it on for me and I feel like a baby (Don). [. . .] there is a couple a couple of doors away who seem to treat me, I don't know, maybe a little bit childlike perhaps (Malcolm). (Clemerson et al., 2014: 457). The change from close connection to disconnection is felt as dramatic and sad. Her son has been offered information about dementia but avoids talking about it. She thinks that he is not able to accept that his mother got dementia in her fifties. "The talk is much about what I was and I what did". She has withdrawn from family gatherings, as her weakened memory makes them too demanding and difficult: *I was fond of the family, but I was not able to participate in the conversations. I did not remember who had a birthday, when we met the last time, and which old grandmother had undergone an operation – all the things you normally remember. I made awkward situations, sad situations – and I withdrew*. (Thorsen et al., 2020: 883).	Not acting according to their age

Social and practical strategies. With the progression of dementia, "inner" autonomy regarding thinking and memorizing was lost, and habitual ways of engaging in daily activities eroded (Thorsen et al., 2020). Practical strategies were used to maintain a desirable everyday life and independence, such as using the same parking space, writing Post-It notes, and using a calculator instead of doing the math in the head (Broders and Wiersma, 2022; Busted et al., 2020; Johannessen et al., 2018; Thorsen et al., 2020). However, these strategies also had the social purpose of hiding their difficulties from family and co-workers, thus preserving their social status and living up to expectations (Broders and Wiersma, 2022). Some strategies had the purpose of appearing normal and age-appropriate and of hiding or minimize the difficulties they might experience in social situations, like forgetting names, emotional outbursts, or repetitive behavior (Busted et al., 2020; Johannessen et al., 2018; Pipon-Young et al., 2012; Thorsen et al., 2020). It also entailed apologizing for incomprehensible or inappropriate behavior, using self-irony, and providing plausible excuses by saying that they

Table 5. Overview of studies supporting third-order constructs.

Study number	Identity composure in everyday life (Construct I)	Social and practical strategies	Preserving the past self and forming a desirable future	Identity domain: The self in social arenas and activities (Construct II)	Identity domain: The self in time and life trajectory (Construct III)	Societal discourses and shared assumptions about dementia, natural aging, and life progression (Construct IV)
1	X	X	X	X		X
2	X	X	X	X	X	X
3	X	X		X	X	X
4	X	X	X	X	X	X
5	X	X	X	X	X	X
6	X		X	X	X	X
7	X	X	X	X	X	X
8	X		X	X	X	X
9	X	X		X	X	X
10	X	X		X		X

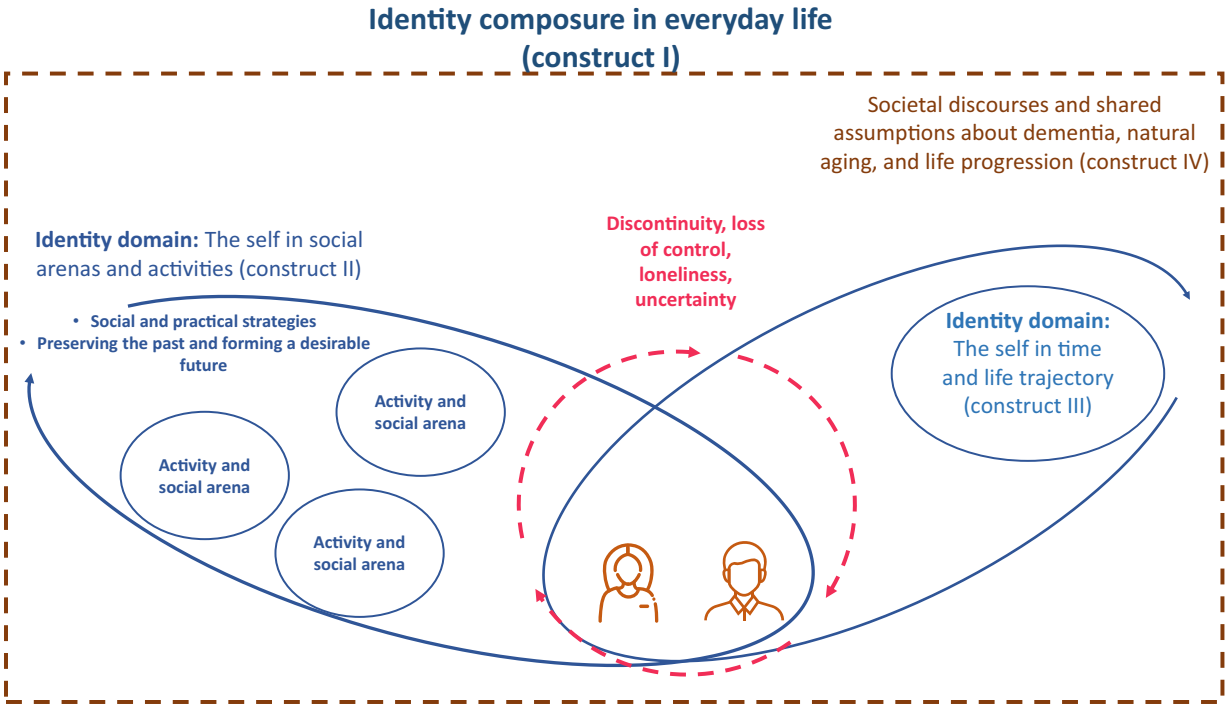

Figure 2. Illustration of the findings.

had suffered a brain injury, thus managing other people's perceptions of them (Busted et al., 2020; Thorsen et al., 2020). Appearing normal for as long as possible was stated to be greatly important in several studies (Busted et al., 2020; Johannessen et al., 2018; Pipon-Young et al., 2012). However, when using these strategies, a mismatch arose between how the participant felt inside and their outer appearance.

Moreover, although these strategies could avert the awkwardness of social encounters, they might leave the person feeling shameful and undermine their self-esteem and sense of self (Thorsen et al., 2020). Some authors believe that there is a temporal perspective in using these strategies. The attempt to hide dementia may be a preferred approach in the early stages of the disease (Johannessen et al., 2018). As the illness progressed, it became difficult, and the need to redefine oneself inwards and outwards might arise.

Preserving the past and forming a desirable future. Other strategies were focused on the time that had passed and possible future trajectories. Loss of memory and increasing difficulties doing what they used to and how they did it left the participants feeling that their personal history and past self were fading and disappearing (Clemerson et al., 2014). Memory loss seemed to threaten the participants' identity in two ways. First, forgetfulness could evoke negative social responses and cause feelings of low self-esteem and embarrassment (Broders and Wiersma, 2022; Busted et al., 2020; Clemerson et al., 2014; Harris, 2004;

Johannessen et al., 2018; Pipon-Young et al., 2012; Sakamoto et al., 2017). Second, as their memory deteriorated, the participants forgot the past and who they were. For fear of forgetting or being forgotten by others, some participants wrote down their personal history or memorable moments from their marriage or looked through old photo albums to preserve their past and who they were (Busted et al., 2020; Thorsen et al., 2020). Yet another participant had divorced her husband before her challenges would disrupt their life together and the good memories from their joint past (Thorsen et al., 2020).

The fear of a humiliating future was a strong theme in the participants' narratives, like becoming dependent on relatives or being a wheelchair user (Busted et al., 2020; Clemerson et al., 2014; Johannessen et al., 2018; Pipon-Young et al., 2012). The participants describe that losing a predictable future brought death closer (Clemerson et al., 2014). Some developed and implemented strategies to form desirable, liveable future trajectories and preserve control of their future selves. One participant had set money aside for euthanasia in the Netherlands or moved to more accommodating housing (Rostad et al., 2013). Another had signed a divorce decree for the partner to effectuate when her condition had deteriorated beyond her control (Busted et al., 2020).

Composing a sense of identity revolved around and was driven by two identity domains. The first identity domain was experiential and related to daily activities and social encounters. The other identity domain was self-reflective and connected to the participants' thoughts and expectations about their life trajectories and aging.

Identity domain: The self in social arenas and activities (construct II)

The participants' daily lives unfolded in different arenas connected to work, home, and places where various activities related to their spare time took place. Across the studies, it was clear that dementia caused ripples and changes in social relations and activities. The experiences of dementia at this stage in life seemed closely related to the participants' abilities to meet the expectations and demands of activities and the responses they got from their social surroundings (Broders and Wiersma, 2022; Busted et al., 2020; Clemerson et al., 2014; Harris, 2004; Johannessen et al., 2018; Pipon-Young et al., 2012; Sakamoto et al., 2017; Thorsen et al., 2020). Dementia could come to the fore in certain activities, particularly in social activities like parties and activities entailing complex tasks such as those that were work-related. Dementia could seep out of awareness in other activities with less cognitive demands and social expectations. Thus, it seems that the experience of dementia was, to some degree, contextual, particularly in the early stages (Clemerson et al., 2014; Thorsen et al., 2020).

It could be deduced that expectations and acceptable behavior in social activities were bound up with the social relations they revolved around and the activities preceding them (Busted et al., 2020; Johannessen et al., 2018). For instance, conversations at family gatherings could build on shared experiences, like past outings or birthdays, and shared references in time and place, like who died or got married when? (Thorsen et al., 2020). The inability to remember or locate these experiences in time and place or behave according to family members' prior experiences with the participant provoked a negative social response and made them feel shameful (Johannessen et al., 2018; Thorsen et al., 2020). In this way, being with family and friends could be challenging, degrading, and humiliating (Busted et al., 2020; Harris, 2004; Johannessen et al., 2018). The connections between this construct and constructs III and IV become evident in these social activities. That is, the participants' deteriorating abilities collided with what they and their social surroundings expected they should be able to do at this stage in life. They described being perceived as childlike because they could not act in ways adequate to their age (Clemerson et al., 2014; Harris, 2004).

Activities performed alone could pose other challenges, such as sudden confusion about using the vacuum cleaner or a doorbell ringing (Johannessen et al., 2018). Here, it was not the social expectations but the inherent cognitive demands of the activity that caused anxiety and feelings of not being the same person as before (Thorsen et al., 2020). Loss of meaningful activities led to isolation, frustration, and loneliness (Harris, 2004).

The importance of upholding daily activities was clearly expressed in several studies (Broders and Wiersma, 2022; Johannessen et al., 2018; Pipon-Young et al., 2012; Sakamoto et al., 2017). The participants explained that doing something meaningful and maintaining familiar activities was one way to maintain continuity, hope, and connection to the world and was linked to a positive sense of identity and normalcy (Busted et al., 2020; Pipon-Young et al., 2012; Sakamoto et al., 2017). Fortunately, some social arenas and activities provided an opposing force to the impact of dementia, offering support and understanding that augmented a positive sense of identity. These arenas and activities counteracted loneliness and were characterized by reciprocity, providing the participants with a sense of purpose in life and being valued and contributing. Interestingly, some participants described engaging vicariously through other people by watching them do things brought joyful feelings (Thorsen et al., 2020). In social arenas such as nursing homes or dementia-friendly settings and organizations, the participants' inability to remember and locate themselves in time and place did not matter (Clare et al., 2008; Johannessen et al., 2018; Thorsen et al., 2020). In these social arenas, there was an understanding of how aging, illness, and abilities entwine and unfold over time, which differed from the

rest of society (Thorsen et al., 2020). They did not have to act normally or age appropriately, nor did they use strategies to hide their difficulties, freeing mental energy to resume and engage in meaningful activities and (re-)connect with others (Johannessen et al., 2018). For instance, advocating for people with dementia or being part of a dementia self-help network provided participants with a sense of collective strength that might even remedy the loss of identity following job loss (Broders and Wiersma, 2022; Clare et al., 2008). In these arenas and activities, self-continuity was preserved, and their old self could re-emerge, albeit in a reduced and manageable version (Thorsen et al., 2020).

Identity domain: The self in time and life trajectory (construct III)

This identity domain concerns the self-reflections and ongoing internal dialogue that the participants experienced regarding their illness, related to their age and stage in life. These self-reflections were evident in their thoughts about being diagnosed with dementia. They were sometimes prompted or reinforced by the often negative responses of other people to their diagnoses and problems. Experiences in daily life were also a source of these reflections (construct II) when confronted with their inability to live up to expectations about what they could or should be able to do. For instance, statements like "I am not *that* old" or "I am *too* young" (Clemerson et al., 2014; Pipon-Young et al., 2012; Rostad et al., 2013) are testimonies to the mental conflicts and disruption that dementia at this stage in life caused the participants. Consequently, some participants revised their sense of age and life trajectory to fit the reality of their situation, making some feel older than their actual age (Clemerson et al., 2014).

Societal discourses and shared assumptions about dementia, natural aging, and life progression (construct IV)

The experience of living with dementia early in life and composing an identity amid these challenges was heavily influenced by societal discourses, views about dementia, and ideas about natural aging (Broders and Wiersma, 2022; Johannessen et al., 2018; Pipon-Young et al., 2012). As such, construct IV is related to and provides a background for understanding the three other constructs. These discourses depicted dementia and memory problems as connected with old age and retirement. It also seemed to be an underlying assumption that dementia was more socially acceptable if the person was retired or past 65 (Broders and Wiersma, 2022). Moreover, to the participants and the people around them, they also served as a frame of reference for age-appropriate behavior (Johannessen et al., 2018). In some studies, the participants described how these discourses influenced their experiences in daily life or were communicated to them by others (Broders and Wiersma, 2022; Clemerson et al., 2014; Harris, 2004; Johannessen et al., 2017, 2018). In other studies, they were indirectly present in their experiences when interacting with family, friends, and work colleagues (Busted et al., 2020; Pipon-Young et al., 2012; Rostad et al., 2013; Sakamoto et al., 2017). These discourses also materialized in participants' difficulties in getting the correct diagnosis. Some participants received various incorrect diagnoses, including menopause and even mental illness, showing that doctors sought explanations for their symptoms in their age rather than dementia (Broders and Wiersma, 2022; Clare et al., 2008; Harris, 2004; Sakamoto et al., 2017). They also described similar challenges in claiming pension and healthcare benefits from their insurance companies (Broders and Wiersma, 2022; Clemerson et al., 2014; Sakamoto et al., 2017).

Discussion

The aim of this meta-ethnography was to explain how people with early-onset dementia form their sense of identity. Some scholars maintain that dementia at an early stage in life is more disruptive to people than in the post-retirement period of their lives (Johannessen et al., 2018; Steeman et al., 2006). The findings from this study do not offer clarity on this question. However, the construct of identity composure in everyday life captured and explained the immense social, psychological, and practical complexities that this identity process entails. As the findings from this study show, the participants' possibilities of composing a positive sense of identity with dementia were mitigated by their lives no longer being synchronized with what they and others seem to expect to constitute normal aging and by a progressive decline over time. Added to this are the challenges of obligations related to stages of life, such as those associated with a job, family, childrearing, and finances (Busted et al., 2020; Johannessen and Möller, 2013; Spreadbury and Kipps, 2019). Arguably, people with dementia during retirement may not face the same complex challenges.

An essential finding in this study relates to the contextuality of the participants' experiences of engaging in different activities. In none of the studies did the researchers specifically focus on how the experience of dementia could differ across contexts of daily life. However, there are clear indications in many studies that engaging in activities and social relations was experienced as disruptive in several arenas of everyday life. Activities performed alone, such as vacuum cleaning, could disrupt the participants' sense of identity because of the difficulties it posed. Moreover, arenas entailing social interaction were associated with embarrassment and low self-esteem due to problems connected with remembering and deciphering body language, but also being met by prejudice and a lack of understanding of dementia. These

findings support the argument that dementia is more than a neurodegenerative disease but also a psycho- and sociodegenerative illness (Dzwiza-Ohlsen, 2021). In contrast, the participants experienced other arenas as supportive and accommodating in maintaining and augmenting a positive sense of self. Other studies point to the same conclusion (Greenwood and Smith, 2016; Roach and Drummond, 2014; Van Vliet et al., 2017). For instance, studies have found that engaging in valued activities related to work can reduce the personal consequences of dementia early in life by making the person feel useful and that they have a purpose, increasing the quality of life, and providing enjoyment, self-esteem, and self-confidence (Richardson et al., 2016; Robertson et al., 2013).

Implications for practice

This study points to areas that healthcare professionals, such as occupational therapists, need to pay attention to in developing and providing healthcare services to enable people with early-onset dementia to preserve a positive sense of identity. Healthcare services, whether related to employment or supporting daily life outside work, should be based on a contextual and activity-based approach to understanding and supporting these people (Kielsgaard et al., 2022). In terms of contextuality, emphasis might be placed on providing nonjudgmental and nonstigmatizing environments. This may entail ongoing updates of the knowledge and competencies of health professionals, facilitating awareness about dementia-friendly environments and how biomedical and age-related understandings of dementia may stigmatize people in unintended ways (Chaston, 2010). Considerations should be given to the neurodegenerative nature of dementia, meaning that, unfortunately, the person's abilities in many areas of daily life will fluctuate and eventually diminish. Having an activity-based focus means focusing on what the person can do and seizing the here-and-now possibilities for engagement in activities (Kielsgaard et al., 2022). Such approaches could be inspired by the Place-Then-Train rehabilitation paradigm, which emphasizes shifting the focus from the person and their impairment to the interaction between the person, the environment, and activities (Corrigan and McCracken, 2005).

Study limitations

As with any review, there is a slight possibility that studies relevant to the focus were missed during the screening of titles, abstracts, and keywords despite our rigorous approach. Arguably, the homogeneity characterizing the included studies diminishes the likelihood that a study not identified during the literature search would report negative cases contradicting the findings in this study. However, the purpose of meta-ethnography is not representativeness and generalizability but interpretive and conceptual depth in understanding the topic. As Noblit and Hare (1988) state, generalizing from all studies may lead to trait conclusions. Therefore, the quality of this meta-ethnography should be assessed based on the new interpretive understandings of the phenomenon it provides.

It was decided that the words "identity," "self," and possible variations should be included in the title, abstract, or keywords. In addition, studies that reported accounts from relatives were excluded because extracting information about individual identity from the shared accounts would have been challenging.

Only studies from Europe and other Western countries were included based on the assumption that these countries are, to some degree, comparable to the Danish context regarding societal values and healthcare systems. One study was from Denmark, and three were from Norway, the neighboring country. Accordingly, readers of this study should be critical about transferring findings from this study to non-Western countries.

The keyword "early-stage" was included even though the word refers to the progressive stage of the illness and not the age of the person with dementia. This was done to ensure the identification of studies in which dementia under the age of 65 was categorized as early-stage. This proved to be a sound decision since, during the screening of the title, abstract, and keywords, two studies were identified that included participants with early-stage dementia under the age of 65. However, these studies were later excluded for other reasons.

Conclusion

The construct of identity composure captures how participants in the included studies strove for continuity and positive connections between past, present, and possible future life trajectories. Social arenas and activities of everyday life and assumptions about dementia and natural aging were key factors influencing the participants' identities positively and negatively. Engaging in meaningful activities in nonstigmatizing environments can provide venues for reducing the personal and social consequences of early-onset dementia. Healthcare services should adopt a contextual and activity-based approach by adapting to the physical, social, and cultural environment.

Key findings

- Assumptions about natural aging and dementia influenced the participants' identity.
- Healthcare professionals should facilitate activities and environments that enable people with early-onset dementia to preserve their sense of identity.

What the study has added

This study shows the complex interplay between factors affecting the identity of people with early-onset dementia and how activities in nonjudgmental environments can support purpose in life and a sense of being a valued and contributing member of society.

Acknowledgements

We thank research librarian and information specialist Heidi Maria Holm Jørgensen for supporting protocol development and literature search. We would also like to thank the Danish Occupational Therapist Association, which funded this study.

Research ethics

Not applicable.

Consent

Not applicable.

Patient and public involvement data

During the development, progress, and reporting of the submitted research, Patient and Public Involvement in the research was not included at any stage of the research.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research received funding from the Danish Occupational Therapists Association. Reference number: FF1/21-R169-A3926.

Contributorship

JLM and JP conceived the study and searched and analyzed the literature. All authors were involved in protocol development. JLM wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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