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"I want everything to be discussed honestly" – home-dwelling people living with dementia negotiating their psychosocial needs

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Abstract

Dementia presents significant challenges for individuals' well-being, making it crucial for others to understand their psychosocial needs to provide holistic care and support. This qualitative study examined the psychosocial needs of home-dwelling people living with dementia, as described by people with dementia and their partners. The data consist of 20 in-depth interviews with 33 home-dwelling participants, including 14 people with dementia and 19 partners aged 62–88. A data-driven thematic analysis was conducted, followed by a theory-driven analysis in three phases. As a result, seven main themes of psychosocial needs were identified. These themes complemented existing models and highlighted the intertwined nature of psychosocial needs. People with dementia are not only aware of their psychosocial needs, but also assertively express them and advocate

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for their acknowledgement. These findings highlight the importance of addressing psychosocial needs to improve care and enhance the quality of life for people living with dementia.

Keywords: dementia, home-dwelling, psychosocial needs, qualitative study, quality of life.

Introduction

Recognising and addressing psychosocial needs enhance the well-being of people living with dementia and are crucial for high-quality, person-centred care (e.g. Fazio et al. 2018; Kitwood 1997; Mansfield et al. 2022). As the number of people living with dementia continues to grow, understanding and meeting these needs becomes increasingly important. Although psychosocial needs are acknowledged as essential for quality of life (Ballard et al. 2018; Miranda-Castillo et al. 2010; Sabat 2009), research specifically focused on them remains limited.

Psychosocial needs are part of a broader set of human needs. According to Maslow's (1943) hierarchy of needs, basic physiological needs, such as food and shelter, must be largely met before higher psychological needs, such as safety (the need for security, stability and protection from harm), belonging (the need for social connection and acceptance), esteem (the need for respect and self-worth) and self-actualisation (the need to realise one's full potential and personal growth), can be pursued. In contrast, Self-Determination Theory, developed by Ryan and Deci (2017), argues that psychological needs for autonomy, competence and relatedness are essential for motivation and well-being regardless of whether basic needs are fully satisfied (Ryan & Deci 2017). Both theories highlight that well-being extends beyond physical necessities.

In dementia care, psychosocial needs have been conceptualised in multiple ways. We use definitions of psychosocial needs as provided by Tom Kitwood (1997), Naomi Feil (1982; Feil & de Klerk-Rubin, 2012) and Ian Andrew James and Louisa Jackman (2017). While all three models build upon Maslow's (1943) foundational work of needs, they also incorporate insights from other theoretical frameworks. All three models address the psychosocial needs of people living with dementia.

Kitwood's (1997) model is widely recognised as a seminal concept for defining the psychosocial needs of people living with dementia. He identified these needs as comfort, attachment, inclusion, occupation, identity and love (Kitwood 1997). James and Jackman's (2017) model of eight fundamental needs expands Kitwood's model by including autonomy, control over one's life, fun, exploration and intimate touch. Feil's (1982; Feil & de Klerk-Rubin, 2012) definition of psychosocial needs overlaps with the previous models but introduces unique dimensions, such as the need to express emotions, resolve unfinished life experiences, receive sensory stimulation and live in peace.

All three models share a strong focus on the psychosocial well-being of people living with dementia. However, these models have primarily been developed and partly studied in care home settings, with limited attention to people living with dementia at home. Despite Kitwood's significant influence on dementia care, his model has faced criticism. For example, Kontos (2005) argue that Kitwood's approach to psychosocial needs overlooks embodied selfhood and emotional expression. From a different angle, Kaufmann and Engel (2016) suggest expanding Kitwood's model to include agency. Feil's (1982; Feil & de Klerk-Rubin, 2012) definition of psychosocial needs have not been the primary focus of research; rather, the relatively few studies that exist have focused on the validation method she developed, with little critical engagement with the underlying psychosocial needs framework (Neal & Barton Wright 2003). James and Jackman's (2017) model has not been systematically evaluated in peer-reviewed research.

This lack of critical and empirical evaluation indicates that the comprehensiveness and practical utility of these models remain underexplored. Consequently, there is a need for empirical studies to assess the adequacy of these frameworks. Clare et al. (2024) and Hansen et al. (2017) have highlighted the need for further research on the psychosocial needs of people living with dementia, particularly regarding content and conceptual clarity.

Identifying and addressing the psychosocial needs of individuals living with dementia has been hindered by stigma and social exclusion which are influenced by negative public perceptions (Nguyen & Li 2020) and sometimes even by attitudes of healthcare professionals (Gove et al. 2016;

Hansen et al. 2017). Such perceptions often diminish their ability to fully participate in society and to be recognised as capable individuals and experts in their own lives (Hughes 2019; Sabat 2005, 2021).

Structural barriers, such as legal and policy restrictions, impede individuals from actively participating in decisions and actions that affect their lives (Grenier et al. 2024). Even researchers have not always succeeded in listening to and engaging with people living with dementia in ways that respect their agency and lived experience (Halonen et al. 2025). Research governance processes, including ethics committees, may also contribute to the exclusion of people living with dementia by adopting paternalistic approaches that prioritise protection over participation (Fletcher 2023). As a result, these systems often position individuals living with dementia primarily as medical subjects defined by their diagnosis, rather than as active agents in their own lives (Halonen et al. 2025).

Despite these challenges, efforts to promote more positive perceptions of dementia have gained traction (e.g. de Vugt & Dröes 2017; Kitwood & Bredin 1992; Sabat 2005, 2021). Importantly, people living with dementia are increasingly willing to share their experiences (Shakespeare et al. 2019). Through their personal stories, they challenge persistent misconceptions and negative stereotypes and advocate the recognition of their human rights and needs (Zeilig 2014).

Our qualitative study examined the psychosocial needs of home-dwelling people living with dementia as expressed through their own narratives and by their partners. The study aims to produce a more comprehensive model of the psychosocial needs of people living with dementia to promote their well-being in different contexts and interactions.

Methods

Participants

For this study, we used data collected in a previous research project called Full life or survival: the experiences of people living with dementia and their carers on everyday life and the factors that promote and undermine living at home (Aaltonen et al. 2021). Participants were recruited in collaboration with the Alzheimer Society of Finland and Carers Finland organisation. Participants expressed voluntary interest by directly contacting the researchers.

A total of 20 in-depth thematic interviews were conducted between October 2018 and March 2019, including 33 participants living in Finland. Interviews of people living with dementia and their partners were conducted either jointly as couples or separately at a location convenient for the interviewees. The study included 14 people diagnosed with dementia and 19 partners (Table 1). The term "partner" refers to individuals close to people living with dementia, including spouses (husbands or wives) and, in one case, a significant other. Among those living with dementia, eight were men and six were women, aged 62–87 years, with an average age of 77. Twelve interviewees had been diagnosed with Alzheimer's disease, one with vascular dementia and one with mixed dementia. The level of dementia was considered based on the participant's or their spouse's perception and the information they provided to the interviewer. Researchers did not have access to medical records, and no clinical information regarding the severity of dementia was requested.

Among the interviewed partners, six were men and 13 were women, aged 65–88 years, with an average age of 76. All couples were heterosexual and had been in a long-term relationship. All but two couples lived together, and all but one were married. Most participants (*n* = 26) chose joint interviews, while seven preferred individual interviews to facilitate more open communication. In four interviews, only the partner participated, three cases occurring because the partner living with dementia was unable to talk about their experiences. Most interviews took place at the interviewees' homes.

This study was conducted and reported following the COREQ guidelines. COREQ stands for Consolidated criteria for Reporting Qualitative research. It is a 32-item checklist including items related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes and inclusion of supporting quotations (Tong et al. 2007).

Table 1. Participant characteristics

Characteristics	People with dementia	Partners
N	14	19
Sex		
Men	8	6
Women	6	13
Age (mean)	77	76
Interviewed		
Alone	1	6
Together	13	13

Data and Analyses

The thematic interview was guided by the following themes: (1) the impact of dementia on daily life; (2) the need for assistance and support; (3) adequacy of care services; (4) social interactions; (5) living arrangements; and (6) the integration of technology into daily life. The interviewees were not asked directly about "psychosocial needs," as the concept is complex and debated even among researchers. Instead, the focus was on discussing their daily lives and interactions, concentrating on issues that were important to them.

The interviews ranged in duration from one to two hours. The audio-recorded interviews were transcribed verbatim, resulting in 776 pages, with individual transcripts ranging from 59–79 pages. To start the analysis, two authors familiarised themselves with the data by reading it several times and discussing it thoroughly. Next, the first author conducted a data-driven thematic analysis utilising Atlas.ti software. In this phase, all excerpts in the data that referred to the psychosocial needs of people living with dementia were identified and highlighted. All authors discussed this dataset and found that it encompassed a wide variety of psychosocial needs identified in previous models. Consequently, we decided to analyse the new dataset using a theory-driven thematic analysis. We guided our approach using Braun and Clarke's (2006) model for thematic analysis, which acknowledges the potential for analysis to be both inductive and deductive.

Theory-driven analysis consisted of three phases. In each phase, the dataset was examined through the lens of a previously established model of psychosocial needs. We began by applying Kitwood's (1997) model, followed by the framework developed by James and Jackman (2017), and concluded with Feil's (1982; Feil & de Klerk-Rubin, 2012) model. In each phase, we systematically coded the data according to the categories defined by the respective model. The same excerpt could be coded multiple times across different phases if it was relevant to more than one theoretical framework. The data were coded separately for people living with dementia and their partners to see how their narratives differed. When data did not fit any previous models, these instances were noted and informed further refinement and expansion of the models under consideration.

After coding, we examined and interpreted the meaning of each code, grouping them into subthemes that captured key aspects of psychosocial needs. These subthemes were then developed into broader themes describing the psychosocial needs of people living with dementia. We repeatedly returned to the original data to ensure the authenticity and validity of the themes. Themes that were not supported by several data extracts were merged or discarded.

The analysis was not strictly linear; we frequently revisited earlier phases to refine codes and evaluate the significance of themes considering the data and our research questions. We consistently revisited the original extracts and analytic memos to ensure interpretive accuracy and contextual understanding. We continuously reflected on how our preconceptions, theoretical frameworks and evolving insights shaped our interpretations. (Braun & Clarke 2006.)

The Ethics Committee of the Tampere Region (Decision 37/2018) approved the data collection plan. All participants gave written informed consent for the interviews and their recording. In cases where a person living with dementia participated, their partner was also involved in the study. One reason for this was to support the evaluation of the person's capacity to give informed consent. This approach was presented to the Ethics Committee.

The Ethics Committee did not have particular rules for interviewing people living with dementia but instead assessed the study individually. Information about the study was provided both verbally and in writing, and the partner helped to communicate it in a way that was appropriate and understandable for the person living with dementia. The researchers followed all research procedures in accordance with the General Data Protection Regulation. The data collectors, gerontologists with experience in conducting thematic interviews with older adults, understood that interviewing people living with dementia requires emotional sensitivity and respect. The researchers used pseudonymisation to protect the privacy and confidentiality of the interviewees.

Results

As a result of the inductive and theory-driven analysis, we identified seven main themes representing the psychosocial needs of people living with dementia (Figure 1). Table 2 shows themes, subthemes and examples of codes in the analysis. The results section presents the most frequently discussed themes first, followed by those discussed less often. Subthemes are presented in italics. For interviewees living with dementia, we use the term "dementia" or refer to the interviewees by name. If a quote is from a partner, we will specify this. "Q" refers to the interviewer, and "…" denotes omitted parts of the interview.

Figure 1. Psychosocial needs of home-dwelling people with dementia

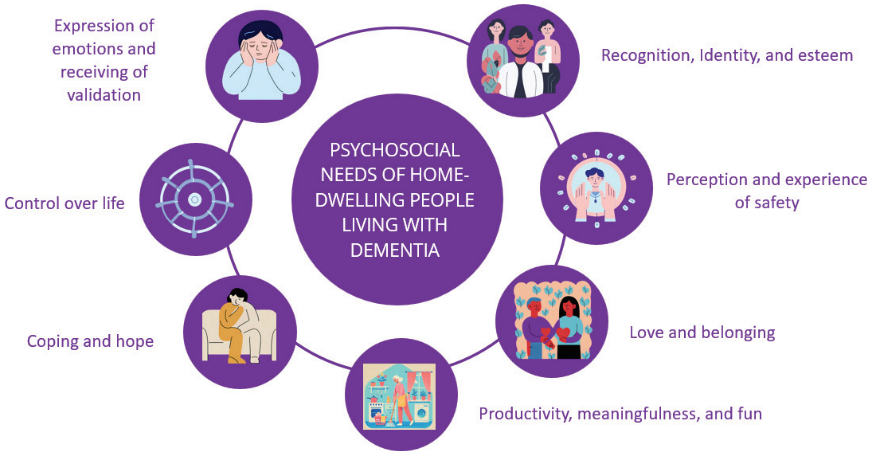

Table 2. Themes, subthemes and examples of codes for psychosocial needs of home-dwelling people living with dementia

Themes describing psychosocial needs	The subthemes describing the need	Examples of codes
Recognition, identity and esteem	1. To be treated with dignity and respect 2. To have self-worth and competence 3. Continuity and stability 4. To be heard	Preserving personal identity ("holding on to selfhood") Maintaining the sense of continuity with the past and consistency across the course of present life Hoping the illness does not define their entire identity Recognition of individual identity despite illness Shame and stigma associated with illness; unwanted labelling as "sick" Need for recognition, status and identity Feeling valued and treated with dignity and respect The need to feel capable and competent Self-affirmation through storytelling, reinforcing personal significance in relationships and life history Maintenance of dignity during interactions

(*Continued*)

Table 2. (*Continued*)

Themes describing psychosocial needs	The subthemes describing the need	Examples of codes
Perception and experience of safety	1. To have a sense of safety in terms of health 2. To have a sense of safety in physical environments 3. To have a sense of safety through social support and care 4. To manage confusing situations and live peacefully	Need for stability in healthcare relationships Fear of being alone Following their partner around for a sense of safety Feeling safety in a familiar environment Sense of safety in the environment (e.g. locks, safe neighbourhood, reliable phone system for emergencies) Reassurance of continued caregiving by a partner Support from a partner A promise of care from a partner Clarity in communication Support in understanding complex situations Adaptation to slower pace of life Things are progressing too fast, hope for peace

(*Continued*)

Table 2. (*Continued*)

Themes describing psychosocial needs	The subthemes describing the need	Examples of codes
Love and belonging	1. General social connections and human contact 2. Inclusion and to feel part of a group 3. Close relationships (human & nonhuman) 4. Affection and intimacy	Visiting cafes or markets to meet people and stay connected
		Enjoys the simple act of smiling and receiving smiles from strangers
		Engaging in social activities to reduce isolation
		The need for relationships with family and friends
		The need to reduce isolation
		Sense of belonging in social settings (e.g. memory groups)
		Valuable peer interactions
		Voluntary support as a lifeline
		Fewer social invitations because of dementia
		Difficulty connecting with people
		Pets providing emotional support
		Romantic and emotional closeness
		Maintaining intimacy as a priority despite the illness

(*Continued*)

Table 2. (*Continued*)

Themes describing psychosocial needs	The subthemes describing the need	Examples of codes
Productivity, meaningfulness and fun	1. To be useful and productive 2. Meaningful activities 3. Sensory stimulation 4. Pleasure, play and laughter	Desire to engage in household chores – continuing to participate in familiar tasks
		Seeking to perform everyday responsibilities
		Travel planning as important habit
		The need to engage in meaningful activities (e.g. dog care, fishing, group participation)
		Adapting past habits; adjusting hobbies or tasks
		Finding stimulation and purpose through computer use, such as reading newspapers online
		Reading as mental stimulation
		Enjoyment of cultural and creative activities
		The need to play and to laugh
		Planning unexpected outings or activities for enjoyment
		Need to exercise curiosity and exploration

(*Continued*)

Table 2. (*Continued*)

Themes describing psychosocial needs	The subthemes describing the need	Examples of codes
Coping and hope	1. To cope with decline and loss 2. To find self-acceptance 3. To resolve unfinished issues 4. To seek hope and support	Coping with cognitive impairments (difficulty watching TV, using computer, driving) Coping when ending long-established ways of life like giving up hunting Sense of loss when abilities fail Hope in shared experiences with others in similar situations The emotional pain of accepting the illness Need to find harmony Feelings of inadequacy when unable to keep up physically or cognitively Coping with existential concerns, including death Recognising that people with dementia have a better position in society Clinging to hope that the illness will progress slowly

(*Continued*)

Table 2. *(Continued)*

Themes describing psychosocial needs	The subthemes describing the need	Examples of codes
Control over life	1. Autonomy and control over one's life direction 2. Independence and choice	Not wanting to hinder the partner's independence or plans
		Desire to maintain own independence
		Control over personal care decisions
		Discusses treatment options with interest and takes an active role in decisions about his care
		Feeling of maintaining independence in daily tasks
		Avoid appearing helpless to their partner
		The need for physical activity to maintain independence
		Transportation options, such as public transport, that support independence and mobility
		The need to clarify an environment that feels chaotic due to a dementia
		Resisting the use of aids (e.g. rollators) to preserve a sense of independence

(Continued)

Table 2. (*Continued*)

Themes describing psychosocial needs	The subthemes describing the need	Examples of codes
Expression of emotions and receiving of validation	1. To express challenging emotions 2. To receive validation and emotional acknowledgment in interactions	Navigating frustration and sadness in previously enjoyable activities like theatre Feelings of jealousy towards a partner Frustration when others do not approach their situation with empathy Frustration when they are not taken seriously or when their mistakes are pointed out Increased anger due to dementia Frustration, sadness or anger when feeling misunderstood The need for encouragement and support instead of criticism for their performance Awareness of the disease's progression creates sorrow and anxiety A desire to speak openly about their lived experiences and emotions

Recognition, Identity and Esteem

The first main theme of recognition, identity and esteem included four subthemes, including *the need to be treated with dignity and respect (subtheme 1).* This need emerged in various situations, both formal and informal. Formal encounters are structured interactions in professional contexts, like appointments with healthcare providers or organised support groups. Informal encounters are casual exchanges in everyday life, such as conversations with family, friends or neighbours. For example, Anja highlighted the importance of dignified treatment during healthcare encounters by expressing her preference for a geriatrician to ensure holistic treatment, highlighting her need to be valued as an individual.

Other interviewees also emphasised the importance of respect in informal encounters, from diagnosis to ongoing care. They stressed the need for people living with dementia to be treated with respect in their care and for care-related discussions to be appropriate and inclusive. For instance, partner Taina shared how her husband Tarmo felt neglected in care after his Alzheimer's diagnosis.

In informal settings, interviewees expressed a desire to be seen and treated as valued friends as before. They wanted to talk openly about their illness without fear of shame or negative reactions. Orvokki described her regret over disclosing her diagnosis due to the subsequent changes in how friends treated her.

Orvokki, woman, 83 years, Alzheimer's disease:

> Q: If we return to the topic of dementia, do you feel that the disease has changed your relationships or, for example, how you meet with friends?
>
> Orvokki: Yes. Unfortunately, yes. I told … as soon as I received the diagnosis, I told them that I have dementia. And for some of them, it immediately changed the way they treated me. They started observing me differently, like "you did this, but that's not how it's done." It was a terrible shock for me that … why on earth did I say that? I would have just gone on and treated my illness there and socialised here.… People don't understand that you can still function normally, even with the disease.… It hurts a lot.

Orvokki shared that after openly disclosing her diagnosis, she received unexpected reactions as her friends began to observe her behaviour more closely and became critical of her actions. Overall, the interviewees desired to engage in meaningful encounters, both formal and informal, without feeling ashamed or diminished by their condition.

The need to have self-worth and competence (subtheme 2) intertwined closely with the previous subtheme. Interviewees stressed the importance of maintaining a positive self-view and self-acceptance, as well as the need to feel good about themselves. For example, Sirpa said during the interview that she is still a smart person. They emphasised the need to be seen as competent despite dementia while also being recognised as a person facing daily challenges due to dementia. When struggling with everyday tasks, they focused on their remaining abilities, highlighting their ongoing capabilities in daily life, such as engaging in hobbies or performing tasks like cooking, shopping, washing clothes, or maintaining the heating system. The desire to be seen as capable was also highlighted through contradictions, with people living with dementia seeing themselves as capable, while their loved ones may have a different perspective, as Pekka's quote shows.

Pekka, man, 78 years, Alzheimer´s disease:

> Q: Do you need any help…. domestic help or something like that?
>
> Pekka: I'm used to it here, I can still do things, like yesterday when my grandson was here, I took care of the food in the kitchen and … … and things like that, and, well, I don't know. It's hard to say how the (social) environment perceives it … me.

Several times during the interview, Pekka stressed that he can still do a lot and wants to see himself as a competent person. He wanted others to see that too, but it was not happening for him as much as he would like, and he had begun to feel that others seem to know his personal matters better than he does.

Interviewees also discussed *the need for continuity and stability (subtheme 3),* focusing on their habits and familiar routines but also their identities. Orvokki wished to live in the moment, holding onto her cherished attitude in life, while Aila-Anna talked about her husband Olli's desire to stay in the familiar environment where he had lived and worked his whole life. Similarly, Eero insisted on reviewing bills, even though his partner Iris managed the payments. Continuity in lifestyle and hobbies, such as sports and cultural activities, was also crucial for many. In addition, narrating one's life was important. During the interview, several people living with dementia began to reminisce about past hobbies like travelling, work life, or, for example, how they fell in love with their partner. The reminiscence was so engaging that people living with dementia, like Erkki, continued to reflect on these memories with pictures, even when their partner in the interview shifted the conversation to the present day and the experience of living with dementia.

Moreover, interviewees discussed *the need to be heard (subtheme 4)*, expressing a desire to discuss their lives and important matters with partners, relatives, friends and professionals. This need arose in contexts such as planning their future, affirming their existence through conversations, and sharing life experiences with attentive listeners. Orvokki, described wanting to reflect on her life experiences more deeply.

Orvokki, woman, 83 years, Alzheimer's disease:

> But, no, I don't have that close relationship with my sister, like, no real, uh, close ties, no, no arguments. We call each other now and then and update each other on how things are, but that's about it. She doesn't invite me over either. … … But it would be nice to have someone to talk to, but there isn't anyone like that, uh. No one does that except for some hired person. They don't have much time.

Orvokki highlighted the importance of communication. She needed to share and reflect deeply on experiences from her own life, to hear herself talk about it, and to talk to someone who really listens. Overall, the main theme of recognition, identity and esteem showed how people living with dementia strive for recognition, respect and a sense of dignity, and how they struggle to maintain these aspects of their personhood despite the challenges posed by dementia.

Perception and Experience of Safety

The second main theme, Perception and experience of safety included four subthemes, one of which was *having a sense of safety in terms of health (subtheme 1).* It described how they need to experience a solid path from diagnosis to care. Tyyne gave an apt example.

Tyyne, woman, 80 years, partner of Toivo (81 years, atypical Alzheimer's disease):

> Q: So, do you feel like you've received enough help from the social and healthcare services, or do you feel you need more support?

> Tyyne: No, we haven’t received anything within the scope of this illness. … … I mean, nothing after the neurologist’s appointments ended. It was nice, it was really nice. … … It was something that felt safe. But after that, no.

Tyyne’s desire for seamless services reflected the need for trust and safety in healthcare for both her and her husband with dementia. Interviewees like Anja and Lasse felt that care often diminished after a dementia diagnosis. Continuity of care, particularly with the GP and nurse, was seen as vital for feeling safe. Concerns about information transfer between providers were raised, especially with frequent changes in the doctor–patient relationship. Proper management of care, like polypharmacy, was crucial, and many mentioned the need for more tailored, supportive services from local health authorities to enhance the sense of safety.

The need to have a sense of safety in physical environments (subtheme 2) emerged as important. Interviewees emphasised the significance of familiarity and safety in their homes. Some highlighted safety technology like stove guards or adding security locks. Sirpa shared how, because of her illness, she felt confused by the abundance of belongings at home, prompting her to reduce her belongings to create a clearer, safer space. Reijo also valued the safety of familiar spaces, like his own courtyard. Additionally, interviewees brought up the need for safety outside their home, such as when shopping, using automated teller machines, or in traffic situations, as Anja explained.

Anja, woman, 62 years, posterior Alzheimer’s disease:

> I realised earlier that I became a nervous driver. I was afraid, thinking, “Oh no, is that car coming at me…” Then, at traffic lights, or when the lights turned on, there were these strange things, like brake lights or taillights. There was this huge red arc. And then if the road was wet, the sun would shine, and the wet road would make this huge yellow ball. After that, a green ball. And then I thought, well, my neighbour was sitting next to me, and I said, “Isn’t that light terrible?”
>
> … “What, what are you talking about?” Then I realised that it was only me *who has it.*

Interviewees also discussed *the need to have a sense of safety through social support and care (subtheme 3)*, which referred to feeling protected, cared for and supported in a reassuring social environment. This was especially important when people living with dementia were left alone at home, even briefly, which often caused anxiety, insecurity and fear. Leena explained how she manages at home, but her partner, Lasse, noted that she panics when he leaves, forgetting the reasons for his absence. In some cases, insecurity leads to constant following of the partner or difficulty settling down to sleep without the partner being in the same bedroom. For many, knowing that their partner or loved one would care for them if needed was crucial. For Leena, her partner Lasse was vital as she could always rely on him.

Interviewees also discussed *the need to manage confusing situations and live peacefully (subtheme 4).* These situations often arose when people living with dementia misinterpreted things or, for example, had difficulty following conversations. Here is Sirpa's example of misinterpretation.

Sirpa, woman, 72 years, Alzheimer's disease; Sauli, man, 72 years, partner:

> Sauli: …there have been these family groups…
>
> Sirpa: Yeah, then I got those brochures, like…
>
> Sauli: Homes or whatever they're called.
>
> Sirpa: Can I interrupt? Then I got those brochures, and I started thinking that Sauli is going to put me in some care home. I was so disappointed, so disappointed…

Sirpa described how receiving brochures about carers' leave made her believe her husband intended to send her to a care home. Sirpa's experience illustrates how misunderstandings can undermine the sense of safety, turning well-meaning actions into sources of fear. The need to live peacefully without feeling rushed or overwhelmed emerged in some of the interviews. While they felt the need to slow down, they also wanted to give time to others, but the fast pace of those around them. Overall, the main theme of Perception and experience of safety clearly demonstrated how people living with dementia stressed the importance of a sense of safety in terms of health, physical environment, relationships, managing confusion and living a peaceful life.

Love and Belonging

The third main theme, Love and belonging, included four subthemes, first being *the need for general social connections and human contact*. Anja expressed how this significant need was often fulfilled by going into the city to see and interact with people:

Anja, woman, 62 years, Posterior Alzheimer's disease:

> Well, I have a huge need to be face-to-face with people… I always want to go to the city and see people, and I smile at them, and they always smile back at me. … … I'd see the hustle and bustle of the city so I wouldn't be … alone. I wouldn't feel lonely, and I'd get that effect from it.

Anja expressed very well what many other interviewees also mentioned: the need to see and meet people in general, even if you don't know them. Anja also said that she is grieving because she doesn't know anybody in their new neighbourhood.

The need for social connections intermingled with *the need for inclusion and to feel part of a group (subtheme 2)*. Interviewees emphasised the importance of being with others in various situations, such as participating in organised group meals with other senior citizens, joining shared activities like women's sauna sessions in their housing community, and attending lifelong hobby groups. Alzheimer's Association groups for people living with dementia were seen as important for fostering belonging and peer support. Interviewees also discussed *the need for close relationships (human & nonhuman) (subtheme 3)*. They described how relationships with family members or friends were very important. Some mentioned that it was the most important thing in their world. For some people living with dementia, like Orvokki, a pet dog fulfilled the need completely.

In addition, *the need for affection and intimacy (subtheme 4)* was important. This need was reflected in the efforts of people living with dementia to express themselves through small words and gestures, such as thanking a partner for dinner each day or showing appreciation, even when their speech had been significantly impaired, as Tuomas explained how his wife Tiina, who usually struggled with speaking, clearly expressed her needs by hugging and saying "Oh, you're so precious." Interviewees also discussed the need for intimacy. Although this need was not widely raised in the interviews, it was brought up by some. Erkki recalled sexually charged memories by looking at pictures of topless women from his photo album. Some spoke openly about the importance of closeness and sex in their everyday lives.

Productivity, Meaningfulness and Fun

The fourth main theme, Productivity, meaningfulness, and fun included four subthemes, such as *the need to be useful and productive (subtheme 1)*. This theme emerged several times in interviews and was related to a wide range of daily activities such as volunteer work in the church or hobbies like amateur theatre, the need to stay physically active, as well as household chores (e.g. cleaning, cooking, ironing, or maintaining the heating system). People living with dementia described having important tasks at home, which were valuable to them, as the following quote shows:

Tiina, woman, 81 years, atypical unspecified dementia; Tuomas, man, 83 years, partner:

> Tuomas: There's a rack for carrying in the firewood, and I can't carry it, so she just goes and grabs it and brings it in.
>
> Q: And you give her instructions on what to do?
>
> Tuomas: No need…
>
> Tiina: I take care of my own chores.

Although Tiina was generally quiet due to her illness during the interview, she became noticeably more engaged when the discussion turned to everyday chores. She clearly expressed that it was important for her to take care of her own share of the household tasks, especially those related to heating the house. In this way, being able to contribute to activities such as bringing in firewood provided her with a sense of usefulness and productivity.

The need to be useful and productive intermingled with *the need for meaningful activities (subtheme 2)*. The need occurred especially through little personally meaningful things in life, such as the possibility to read newspapers and books or online magazines on the computer every day. For some, it was regular outdoor activities with their partner or dog, and for others, like Ilpo, it was going to a café or swimming in the lake at the cottage as he was used to. Occasionally, engagement in meaningful activities was initiated at inappropriate situations or times of the day due to reasons related to dementia, as the following quote illustrates.

Erkki, man, 72 years, Alzheimer’s disease; Elina, woman, 74 years, partner:

> Elina: So, now the situation is that, like last night at eleven, I wanted to go to sleep. But I have to exercise first, and then Erkki starts calling from his office, or not calling, but saying, “Hey, what about this issue and what about that issue?
>
> ”Erkki: You can hear it from the office to the bedroom.
>
> Elina: Right. So, for example, at midnight, Erkki says, “Shall we go to Cyprus?” I didn’t want to deal with it last night because I was completely exhausted and didn’t have the energy to handle it or look into the financial matters.
>
> …
>
> Erkki: I would always be ready to go.

Travel has always played a significant role in Erkki’s life, both professionally and for leisure, and it remained important even after his diagnosis. When this need is activated, it often arises at times that are inconvenient for others.

Interviewees also discussed *the need for sensory stimulation (subtheme 3).* This need was described through everyday activities that engage different senses, such as visual, auditory, olfactory, gustatory and tactile perception. Sensory stimulation was achieved in various and individual ways; creative activities like colouring pictures and assembling puzzles were important to Mari, reading the newspaper from the computer was important to Olli, while social interaction, delicious food and dancing were important to others. Viewing photographs and listening to music was important to Erkki.

In addition, *the need for pleasure, play and laughter (subtheme 4)* was emphasised, reflecting a desire for lightheartedness and joy in everyday moments. This need was reflected in moments of fun, such as going out with a partner, browsing a mobile phone, or taking pictures. Enjoyable activities like walking, going to the gym and swimming also emerged. Helena, a partner, described how she and her husband Heikki, who has dementia, find fun and joy in listening to the weekly radio programme, *Boulevard of Memories* and dancing together.

Coping and Hope

The fifth main theme, Coping and hope, included four subthemes. One subtheme was *the need to cope with decline and loss (subtheme 1)*. Interviewees acknowledged their declining abilities, particularly in daily activities and social interactions, and described how they adapted to these changes. Anja and Ilpo spoke about adjusting to a slower walking pace, while many men struggled with the loss of driving. Toivo mentioned difficulties with shopping, and others faced challenges with cooking or memory loss. Mari highlighted the frustration of struggling to follow conversations, and Toivo felt that with dementia, everything important to him was gone. The discussion also focused on how interviewees coped with giving up meaningful activities, hobbies and social connections that had shaped their lives for years, such as travel, culture, sports and volunteering. Ilpo found it especially hard to stop hunting, a lifelong passion, though letting go of golf was easier.

The need for self-acceptance (subtheme 2) closely intertwined with the first subtheme. Accepting one's own dementia was deeply painful for some of the interviewees. For example, Sirpa shared how difficult and painful it was for her to come to terms with her diagnosis.

Sirpa, woman, 72 years, Alzheimer's disease:

> Now I've been there (in the memory group), when I look at them all…I hate looking at all those people with dementia [crying]. I mean, there are teachers and there are priests and there are, there are these and those. I feel like, I feel totally sick because I belong to this group, even though I know that I really do.

Sirpa expressed emotional pain about her situation, feeling uncomfortable with the idea of being "one of them," even though she logically understood the situation. Her comments illustrate the painful process of accepting her own illness and the need for self-acceptance.

In *subtheme 3, the need to resolve unfinished issues*, Sirpa expressed the need for courage to reflect on her life and its direction as dementia progressed. Kaisa, Tapio's partner, shared how Tapio had sought encouragement in dealing with death. Anja gave an example of this.

Anja, woman, 62 years, posterior Alzheimer's disease:

> If it feels like someone still needs to know about the care plan, I've already written a lot down on paper … I've made a rough draft. I dare to talk about death, so it becomes more

> ordinary, like … it's not something where people say, "Don't talk about it, I can't handle it." I'm sensitive, but I'm happy that I've dared to talk about it.

Anja elaborated on how addressing death in advance can make it feel less daunting and more natural, turning it into part of everyday conversation rather than a taboo topic. This open discussion about death helped people living with dementia approach it calmly rather than fearfully. Interviewees also spoke about *the need to seek hope and support (subtheme 4)*. For some, hope was related to the slow progression of their own dementia, while Ilpo hoped for an increase in dementia care skills among health professionals. People living with dementia were also hopeful about the growth of memory-friendliness in society, as Erkki describes in his extract.

Erkki, man, 72 years, Alzheimer's disease:

> Erkki: Well, there are (treatment) options nowadays, and the care is excellent compared to the past.
>
> Q: Mm, it's constantly improving.
>
> Erkki: In the past, someone with dementia was locked away in a back room … they were seen as senile, a ghost … and nothing more. Now, you can, whenever possible, participate fully in life.

Erkki observed that the perception of people living with dementia has improved over the years, offering hope for life. However, losing skills and facing the impacts of dementia cause emotional suffering. In response, people living with dementia seek support, hope and understanding from their loved ones and healthcare professionals to cope with these challenges.

Control Over Life

The sixth main theme, Control over life, has two subthemes, the first of which was *the need for autonomy and control over one's life direction (subtheme 1)*. Interviewees discussed the importance of knowing how to live after receiving the diagnosis. Anja highlighted the need to learn more about the Alzheimer Society of Finland and get involved in local Alzheimer's Association activities. People living with dementia also wanted to express their care preferences and plan where they wanted to live as the disease progressed. Some expressed a preference to avoid staying at home if their care needs increased, not wanting to burden their partners. In contrast, Olli, whose partner Aila-Anna shared his wish, wanted to stay at home regardless of the dementia stage. Additionally, it was crucial that decisions regarding people living with dementia were and will be made with their knowledge and involvement, as demonstrated by Sirpa's quote.

Sirpa, woman, 72 years, Alzheimer's disease:

> Well, I hope that if we're playing with the open cards, not that I would hear soon from you that Sauli invited you here and so on, so on, so on … secretly from me things like that.… I want everything to be discussed honestly, and it has felt to me that we've spoken honestly here today.

Sirpa emphasised the importance of autonomy and inclusion. She notes that decisions regarding care, living arrangements, and the future must be made collaboratively, with honesty and transparency, while respecting the opinions and perspectives of people living with dementia.

Secondly, interviewees discussed *the need for independence and choice (subtheme 2),* highlighting issues related to living at home or mobility outside the home, such as going shopping, making visits, or using public transportation. For example, Leena emphasised her desire to manage without disability aids such as a rollator. People living with dementia wanted to demonstrate self-sufficiency, such as managing at home without a partner, using a mobile phone independently or, like Mari described, being able to walk home by herself from the Alzheimer's Association memory group meeting. Interviewees also expressed a desire to choose their means of transportation, such as biking, taking the bus, or using an accessible taxi, as well as deciding when they want to be social and when they prefer solitude.

Expression of Emotions and Receiving of Validation

The seventh main theme, Expression of emotions and receiving of validation has two subthemes, the first of which was *the need to express challenging emotions (subtheme 1)*. People living with dementia talked how they experience and express a range of emotions, including anger, frustration, jealousy and shame. Emotions were often due to their dementia, their changing abilities and their interaction with others. Participants expressed different emotions during the interviews as well. Erkki described how anger arises more easily with dementia and how negative atmospheres at home leave a lasting impact, causing distress. Sirpa stated she was not ashamed of her emotions, acknowledging them as natural but still bothersome.

The subtheme 2*, the need to receive validation and emotional acknowledgment in interactions,* emphasises the importance of others recognising and understanding the emotions of people living with dementia and showing them comfort and empathy. When others misunderstood or dismissed their emotions, they often felt irritated and invalidated. In some cases, challenging emotions arose repeatedly during interactions, especially when communication problems occurred. Toivo, a man who had dementia, described his experience by saying that his partner must understand that she cannot speak in a way that provokes, giving rise to frustration. Interviewees living with dementia also described situations where others pointed out their difficulties or failed to understand them, leading to irritation and anger that affected their behaviour. Reijo provided an example of such an experience.

Reijo, man, 76 years, Alzheimer’s disease; Riitta, woman, 75 years, partner:

> Reijo: Especially in the beginning when I got the diagnosis, I guess I … I took it a bit like that, so it was a relief to me that I was diagnosed with something.… And then when she didn’t understand me, I was very, very … uh..ang..
>
> Riitta: Very cranky. [laughing] Very cranky.
>
> Reijo: Cranky and angry, yes.

Reijo expressed a desire to openly share his experiences with the diagnosis and the emotions related to it, highlighting how a lack of understanding from others can lead to emotional struggles. Overall, this theme underscored the importance of creating supportive environments for people living with dementia, where they can express their emotions and feel understood, acknowledged and respected.

Table 3 presents an overview of the psychosocial needs identified in three pre-existing models, their positioning within our main themes, and

Table 3. Comparison of needs in three existing models, their positioning within the main themes, and new dimensions identified through analysis

Need	Kitwood[1]	James & Jackman[2]	Feil[3,4]	Heitto et al. Positioning the needs within the main themes and extensions for the new model	
				Positioning within the main themes	Newly identified aspects
Identity	X	X	X	Recognition, identity and esteem	
Inclusion	X	X	X	Love and belonging	
Love	X	X	X	Love and belonging	Expressing love and feeling loved through interaction with the pet
To reduce emotional pain and discomfort	X	X	X	Coping and hope	
Comfort	X		X	Coping and hope Receiving of validation	
Occupation	X	X		Productivity, meaningfulness and fun	Meaningful role and daily responsibility in walking the pet
Attachment	X			Love and belonging	Nonhuman relationships
Exploration		X		Productivity, meaningfulness and fun	

(*Continued*)

Table 3. (*Continued*)

Need	Kitwood[1]	James & Jackman[2]	Feil[3,4]	Heitto et al. Positioning the needs within the main themes and extensions for the new model	
				Positioning within the main themes	Newly identified aspects
Fun		X		Productivity, meaningfulness and fun	
Independence and autonomy		X		Control over life	Not wanting to hinder the partner's independence or plans
Esteem		X		Recognition, identity and esteem	
Intimate touch		X	X	Love and belonging	
Perception of safety		X	X	Perception and experience of safety	Support in understanding complex situations, Adaptation to slower pace of life, Things are progressing too fast
Resolution of unfinished issues, to die in peace			X	Coping and hope	
Sensory stimulation			X	Productivity, meaningfulness and fun	
Live in peace			X	Perception and experience of safety	

(*Continued*)

Table 3. (*Continued*)

Need	Kitwood[1]	James & Jackman[2]	Feil[3,4]	Heitto et al. Positioning the needs within the main themes and extensions for the new model	
				Positioning within the main themes	Newly identified aspects
Be useful and productive			X	Productivity, meaningfulness and fun	
Express feelings and be heard			X	Expression of emotions and receiving of validation	
Coping and hope				Coping and hope	To cope with decline and loss, to find self-acceptance, active role of people living with dementia, dealing with and adapting to the emotional, practical and social challenges, and to seek hope and support
Receiving of validation				Expression of emotions and receiving of validation	Need to receive validation vs. validation as method

[1] Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

[2] James, I. A. & Jackman, L. (2017). *Understanding Behaviour in Dementia That Challenges, Second Edition: A Guide to Assessment and Treatment*. London: Jessica Kingsley Publishers.

[3] Feil, N. (1982). *V/F Validation: The Feil Method: How to Help Disoriented Old-Old*. Baltimore: Edward Feil Productions.

[4] Feil, N. & de Klerk-Rubin, V. (2012). *The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer's and Other Dementias* (3rd ed.). Baltimore: Health Professions Press.

the additional dimensions revealed through our analysis. There were areas of overlap across the models, as well as aspects that were not fully captured by any of them. Our results deepen and extend the existing models, offering a more comprehensive understanding of psychosocial needs among people living with dementia.

Discussion

This study investigated the psychosocial needs of home-dwelling people living with dementia by interviewing people living with dementia and their partners. We identified seven dimensions of psychosocial needs: (1) Recognition, identity and esteem, (2) Perception and experience of safety, (3) Love and belonging, (4) Productivity, meaningfulness and fun, (5) Coping and hope, (6) Control over life and (7) Expression of emotions and receiving of validation. People living with dementia expressed all seven identified needs more frequently than their partners, except for the need for safety, which was highlighted slightly more often by partners. Our results highlight that the previous models (Feil, 1982; Feil & de Klerk-Rubin, 2012; James & Jackman 2017; Kitwood 1997) have made invaluable contributions by identifying needs such as recognition, safety, meaningfulness and belonging. All of these needs were well-supported in our findings.

In addition, our findings align with previous empirical studies that have emphasised similar psychosocial dimensions. For example, the need for recognition and identity has been highlighted in earlier research (e.g. Hennelly et al. 2018; Sakamoto et al. 2017). Similarly, the vulnerability to reduced emotional safety observed in our data reflects findings by Grobosch et al. (2023). The importance of social connectedness, captured in our model as the need for love and belonging, is consistent with the work of Kotwal et al. (2024).

Our findings showed that pre-existing models did not entirely capture the diversity and complexity of psychosocial needs from the perspective of people living with dementia themselves. Notably, we identified three underrepresented or missing dimensions: (1) the importance of pets and nonhuman companions (2) coping and hope as distinct psychosocial needs and (3) the need to receive validation. These dimensions expand current models and call for a re-thinking of how psychosocial needs are conceptualised in dementia.

We identified pets as an important element of psychosocial needs for people living with dementia, specifically in fulfilling the need for love and belonging and meaningfulness. Although established models (Feil, 1982; Feil & de Klerk-Rubin, 2012; James & Jackman 2017; Kitwood 1997) acknowledge these needs, they have largely overlooked the role of pets and other nonhuman companions. Recent research (Jenkins et al. 2021; Välimäki et al. 2022) shows that animal relationships can promote social connectedness, reduce loneliness and enhance emotional well-being. The importance of nonhuman relationships should be explicitly recognised in conceptualising the psychosocial needs model.

Furthermore, existing models do not recognise coping and hope as independent psychosocial needs. Our findings show that people living with dementia actively seek ways to manage the emotional, practical and social challenges of dementia, and strive to maintain hope for the future despite loss and uncertainty. This supports Moe et al.'s (2021) view that coping is not just a practical skill but is closely tied to psychosocial needs. Recognising coping and hope as distinct needs highlights the ongoing agency of people living with dementia.

Finally, Feil (1982; Feil & de Klerk-Rubin, 2012) acknowledges the importance of emotional expression, and our results support this. However, while Feil presents validation as a method, our findings suggest that it should be regarded as a fundamental psychosocial need. Our results showed that people living with dementia often become frustrated or lose their temper more frequently after disease onset, and that those around them often fail to understand their emotional experiences. This supports Sabat's (2021) observation that emotional responses in dementia are frequently misinterpreted as symptoms to be managed, rather than as genuine reactions to lived experience. By emphasising emotional expression and receiving validation as distinct needs, our findings advocate for a shift from a purely clinical approach to one that values empathy and understanding, areas that have not been adequately addressed in previous research on needs.

Our findings form a comprehensive model of the psychosocial needs of people living with dementia living at home. Although these needs share similarities with those of all people, dementia brings unique characteristics to their recognition. Most of the psychosocial needs identified in our study have been examined separately (Grobosch et al. 2023) or partially (Morrisby et al. 2019). However, our results show that these needs should be considered not only individually, but also as part of a complex, dynamic network, where the fulfilment or lack of one need can influence others.

In line with Kontos et al. (2017) and Tay and Diener (2011), our analysis shows that psychosocial needs are intertwined, context-dependent and often overlapping in daily life, for example, the need for control and emotional safety were closely linked. Our findings challenge hierarchical or categorical models (e.g. Maslow, Kitwood), which may oversimplify the lived experience of dementia by treating needs as static categories. If frameworks such as Ryan and Deci's (2017) Theory are to be applied to people living with dementia, our findings indicate that motivation could be shaped not only by autonomy, competence and relatedness, but also by additional needs including safety, coping and hope, which emerged as fundamental in our study. Recognising this complexity and adopting a broad perspective is essential for both theoretical development and practical service design that truly reflect the lived experiences of people living with dementia.

Although our study focused on people living with dementia living at home, the psychosocial needs identified here are likely also relevant in residential care settings. Cadieux et al. (2013) found similar needs among care home residents, but their findings were narrower in scope, and their definitions partly unclear in terms of what is meant by psychosocial needs. Due to the fundamentally human nature of these psychosocial needs, our model could potentially be applied in care home settings as well, but further research is needed.

In practice, future Support plans for people living with dementia should be co-created to include coping support, hope building and recognition of emotional experiences, ensuring that people living with dementia feel truly acknowledged. Our results support holistic, individualised assessments that go beyond medical or cognitive status. Our findings challenge conventional approaches by emphasising complexity, fluidity and the lived voice of people living with dementia as the foundation for person-centred care.

Strengths and Limitations of the Study

A strength of the study was its direct engagement with people living with dementia, providing valuable and authentic insights into their lived experiences and needs. This approach allowed for nuanced aspects that could not have been fully captured through proxy respondents, as the analysis revealed differing perspectives between people living with dementia and their partners. The study also demonstrated an ethical commitment to inclusivity, recognising the agency and expertise of people living with dementia. It benefited from diverse participant representation across age, gender and stages of dementia, and the analysis was carefully conducted at each stage.

The study also has some limitations. Cognitive decline and difficulties in verbal expression may have limited the depth of responses, particularly for those with advanced stages of dementia, whose needs were often described by partners. This may have biased the findings towards individuals in earlier stages of dementia, potentially excluding the perspectives of those with more advanced conditions. Additionally, participants were not directly asked to define their psychosocial needs, but the researchers analysed those from interviewees' more general descriptions regarding their everyday lives.

Conclusion

This study comprehensively identified the psychosocial needs of people living with dementia, highlighting both well-established needs, such as recognition, safety and meaningfulness, and emerging dimensions of needs, including the importance of nonhuman relationships, coping, hope and the need for validation. By conceptualising these needs as a dynamic, intertwined network rather than a static hierarchy, we provide a framework that better reflects the lived experience of dementia.

Applying this holistic model in care and daily life can help ensure that the diverse needs of people living with dementia are acknowledged and met, thereby supporting their quality of life. Our results invite practitioners and decision-makers to move beyond reductionist approaches and design interventions that truly centre the person. Although perspectives may change at different stages of dementia, the goal – enabling quality of life – remains the same.

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References

Aaltonen, M. S., Martin-Matthews, A., Pulkki, J. M., Eskola, P. & Jolanki, O. H. (2021). Experiences of people with memory disorders and their spouse carers on influencing formal care: "They ask my wife questions that they should ask me." *Dementia* 20(7): 2307–2322. https://doi.org/10.1177/1471301221994300

Ballard, C., Corbett, A., Orrell, M., Williams, G., Moniz-Cook, E., Romeo, R., Woods, B., Garrod, L., Testad, I., Woodward-Carlton, B., Wenborn, J., Knapp, M. & Fossey, J. (2018). Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial. *PLoS Medicine* 15(2): e1002500. https://doi.org/10.1371/journal.pmed.1002500

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2): 77–101. https://doi.org/10.1191/1478088706qp063oa

Cadieux, M.-A., Garcia, L. J. & Patrick, J. (2013). Needs of people with dementia in long-term care. *American Journal of Alzheimer's Disease and Other Dementias* 28(8): 723–733. https://doi.org/10.1177/1533317513500840

Clare, L., Gamble, L. D., Martyr, A., Henderson, C., Knapp, M. & Matthews, F. E. (2024). Living alone with mild-to-moderate dementia over a two-year period: Longitudinal findings from the IDEAL cohort. *The American Journal of Geriatric Psychiatry* 32(11): 1309–1321. https://doi.org/10.1016/j.jagp.2024.05.012

de Vugt, M. & Dröes, R.-M. (2017). Social health in dementia. Towards a positive dementia discourse. *Aging & Mental Health* 21(1): 1–3. https://doi.org/10.1080/13607863.2016.1262822

Fazio, S., Pace, D., Flinner, J. & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist* 58(suppl_1): S10–S19. https://doi.org/10.1093/geront/gnx122

Feil, N. (1982). *V/F Validation: The Feil Method: How to Help Disoriented Old-old*. Cleveland: Edward Feil Productions.

Feil, N. & de Klerk-Rubin, V. (2012). *The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer's and Other Dementias* (3rd ed.). Baltimore: Health Professions Press.

Fletcher, J. R. (2023). Regulating the disenfranchised: Reciprocity & resistance under the Mental Capacity Act. *Journal of Aging Studies* 64: 101099. https://doi.org/10.1016/j.jaging.2022.101099

Gove, D., Downs, M., Vernooij-Dassen, M. & Small, N. (2016). Stigma and GPs' perceptions of dementia. *Aging & Mental Health* 20(4): 391–400. https://doi.org/10.1080/13607863.2015.1015962

Grenier, A., O'Connor, D., James, K., Imahori, D., Minchopoulos, D., Velev, N., Tamblyn-Watts, L. & Mann, J. (2024). Consent and inclusion of people living with dementia (PLWD) in research: Establishing a Canadian agenda for inclusive rights-based practices. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement* 43(4): 621–628. https://doi.org/10.1017/S0714980824000217

Grobosch, S., Wolf, F., Juchems, S. & Kuske, S. (2023). Emotional safety of people living with dementia: A systematic review. *Journal of Mental Health* 32(1): 110–131. https://doi.org/10.1080/09638237.2020.1739241

Halonen, U., Aaltonen, M., Aerschot, L. V. & Pirhonen, J. (2025). Participation of persons living with dementia in research: A means to address epistemic injustice. *Dementia* 24(5): 850–865. https://doi.org/10.1177/14713012241299015

Hansen, A., Hauge, S. & Bergland, Å. (2017). Meeting psychosocial needs for persons with dementia in home care services – A qualitative study of different perceptions and practices among health care providers. *BMC Geriatrics* 17: 211. https://doi.org/10.1186/s12877-017-0612-3

Hennelly, N., Cooney, A., Houghton, C. & O'Shea, E. (2018). The experiences and perceptions of personhood for people living with dementia: A qualitative evidence synthesis protocol. *HRB Open Research* 1: 18. https://doi.org/10.12688/hrbopenres.12845.1

Hughes, J. C. (2019). Citizenship and authenticity in dementia: A scoping review. *Maturitas* 125: 11–16. https://doi.org/10.1016/j.maturitas.2019.04.001

James, I. A. & Jackman, L. (2017). *Understanding Behaviour in Dementia That Challenges, Second Edition: A Guide to Assessment and Treatment*. London: Jessica Kingsley Publishers.

Jenkins, N., Gorman, R., Douglas, C., Ashall, V., Ritchie, L. & Jack-Waugh, A. (2021). Multi-species dementia studies: Contours, contributions and controversies. *Journal of Aging Studies* 59: 100975. https://doi.org/10.1016/j.jaging.2021.100975

Kaufmann, E. G. & Engel, S. A. (2016). Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs. *Dementia* 15(4): 774–788. https://doi.org/10.1177/1471301214539690

Kitwood, T. (1997). Dementia Reconsidered: The Person Comes First. Buckingham: Open University Press.

Kitwood, T. & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing & Society* 12(3): 269–287. https://doi.org/10.1017/S0144686X0000502X

Kontos, P., Miller, K.-L. & Kontos, A. P. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness* 39(2): 182–198. https://doi.org/10.1111/1467-9566.12453

Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease: Rethinking person-centred care. *Dementia* 4(4): 553–570. https://doi.org/10.1177/1471301205058311

Kotwal, A. A., Allison, T. A., Halim, M., Garrett, S. B., Perissinotto, C. M., Ritchie, C. S., Smith, A. K. & Harrison, K. L. (2024). "Relationships, Very Quickly, Turn to Nothing": Loneliness, social isolation, and adaptation to changing social lives among persons living with dementia and care partners. *The Gerontologist* 64(4): gnae014. https://doi.org/10.1093/geront/gnae014

Mansfield, E., Cameron, E., Carey, M., Boyes, A., Nair, B., Hall, A. & Sanson-Fisher, R. (2022). Prevalence and type of unmet needs experienced by people living with dementia. *Journal of Alzheimer's Disease* 87(2): 833–842. https://doi.org/10.3233/JAD-215183

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review* 50(4): 370–396. https://doi.org/10.1037/h0054346

Miranda-Castillo, C., Woods, B., Galboda, K., Oomman, S., Olojugba, C. & Orrell, M. (2010). Unmet needs, quality of life and support networks of people with dementia living at home. *Health and Quality of Life Outcomes* 8: 132. https://doi.org/10.1186/1477-7525-8-132

Moe, A., Alnes, R. E., Nordtug, B., Blindheim, K., Steinsheim, G. & Malmedal, W. (2021). Coping with everyday life for home-dwelling persons with dementia: A qualitative study. *Journal of Multidisciplinary Healthcare* 14: 909–918. https://doi.org/10.2147/JMDH.S300676

Morrisby, C., Joosten, A. & Ciccarelli, M. (2019). Needs of people with dementia and their spousal carers: A study of those living in the community. *Australasian Journal on Ageing* 38(2): e43–e49. https://doi.org/10.1111/ajag.12609

Neal, M. & Barton Wright, P. (2003). Validation therapy for dementia. *Cochrane Database of Systematic Reviews* (3): CD001394. https://doi.org/10.1002/14651858.CD001394

Nguyen, T. & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia* 19(2): 148–181. https://doi.org/10.1177/1471301218800122

Ryan, R. M. & Deci, E. L. (Eds.). (2017). *Self-Determination Theory: Basic Psychological Needs in Motivation, Development, and Wellness*. New York: Guilford Press.

Sabat, S. R. (2005). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian & New Zealand Journal of Psychiatry* 39(11–12): 1030–1035. https://doi.org/10.1080/j.1440-1614.2005.01722.x

Sabat, S. R. (2009). Existential phenomenology and the quality of life of carers and care recipients: A case study. *Dementia* 8(2): 163–166. https://doi.org/10.1177/1471301209103247

Sabat, S. R. (2021). Cognitive and social strengths of people living with dementia: Discoveries through Harré's method. *Journal for the Theory of Social Behaviour* 51(2): 232–248. https://doi.org/10.1111/jtsb.12287

Sakamoto, M. L., Moore, S. L. & Johnson, S. T. (2017). "I'm Still Here": Personhood and the early-onset dementia experience. *Journal of Gerontological Nursing* 43(5): 12–17. https://doi.org/10.3928/00989134-20170309-01

Shakespeare, T., Zeilig, H. & Mittler, P. (2019). Rights in mind: Thinking differently about dementia and disability. *Dementia* 18(3): 1075–1088. https://doi.org/10.1177/1471301217701506

Tay, L. & Diener, E. (2011). Needs and subjective well-being around the world. *Journal of Personality and Social Psychology* 101(2): 354–365. https://doi.org/10.1037/a0023779

Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 19(6): 349–357. https://doi.org/10.1093/intqhc/mzm042

Välimäki, T., Koivisto, A., Kärkkäinen, V., Selander, T., Hongisto, K. & Rusanen, M. (2022). Pet ownership supports quality of life in home-dwelling people with Alzheimer's disease. *International Journal of Geriatric Psychiatry* 37(4): 1–7. https://doi.org/10.1002/gps.5698

Zeilig, H. (2014). Dementia as a cultural metaphor. *The Gerontologist* 54(2): 258–267. https://doi.org/10.1093/geront/gns203