

ORIGINAL REPORT

FUNCTIONING AND DISABILITY IN COMMUNITY-LIVING PEOPLE WITH PERCEIVED COGNITIVE IMPAIRMENT OR DEMENTIA: A MIXED METHODS STUDY USING THE WORLD HEALTH ORGANIZATION DISABILITY ASSESSMENT SCHEDULE

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Objective: To explore how community-living people with perceived cognitive impairment or dementia and their next-of-kin perceive functioning and disability in major life domains.

Methods: Individual interviews guided by the World Health Organization Disability Assessment Schedule (WHODAS 2.0) were conducted with 26 people with perceived cognitive impairment or dementia (age range 38–87 years) and 26 next-of-kin. Qualitative content analysis- and International Classification of Functioning, Disability, and Health (ICF) linking methods were used to analyse the transcripts. The perceived degree of disability in daily functioning was calculated and compared between people with perceived cognitive impairment or dementia and next-of-kin, using a Mann–Whitney *U* test.

Results: A total of 38 of 47 (81%) established ICF categories corresponding to WHODAS items and 38 additional International Classification of Functioning, Disability, and Health (ICF) categories describing participants perceived cognitive and physical impairments, activity limitations and participation restrictions in interaction with the environmental factors were confirmed from the transcripts. The perceived disability of people with perceived cognitive impairment or dementia was scored higher by next-of-kin (48%) than by people with perceived cognitive impairment or dementia (16%, $p < 0.0001$).

Conclusion: Interviews provided a comprehensive picture of participants' perceived activity limitations and participation restrictions in the life domains cognition, mobility, self-care, getting along, life activities, and participation. For a better understanding of the impact of cognitive impairment on people's daily lives, inclusion of the perspective of the next-of-kin and the factors that hinder or facilitate daily living in the community setting is necessary.

Key words: community living; dementia; functioning and disability; ICF linking rules; individual interviews; perceived cognitive impairment; WHODAS 2.0.

LAY ABSTRACT

Dementia is one of the leading causes of disability in Sweden, and most of the people with dementia and those with perceived cognitive impairment, i.e. persons not diagnosed with dementia, live at home. A comprehensive understanding of their needs is required in order to develop dementia care in the community. The aim of this study was to explore what kind of difficulties community-living people with perceived cognitive impairment or dementia and their next-of-kin perceive in their daily lives. Twenty-six people with perceived cognitive impairment or dementia and their next-of-kin were interviewed in their homes, and the perceived degree of difficulties was compared between the 2 groups. The interviews provided a broad picture of how people with perceived cognitive impairment or dementia and next-of-kin perceive difficulties in their daily lives. The next-of-kin perceived the difficulties as greater than did the persons with dementia. For a better understanding of the impact of dementia on people's daily lives, inclusion of the perspective of the next-of-kin and the factors that hinder or facilitate daily living in the community setting are necessary.

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Dementia is one of the leading causes of disability and mortality among people older than 65 years (1, 2). Dementia is an umbrella term for diseases and conditions affecting cognitive functions, such as memory, language, problem-solving, behaviour, and functioning in daily life (3–6). Dementia not only places psychological, social, and financial burdens on a person and their close family, but also places an economic burden on society (7–10). In Sweden, the

prevalence of dementia is estimated at 200,000 persons, when people with a mild cognitive impairment are included (10–12). The total costs of dementia in Sweden in 2012 were estimated at approximately 60–124 billion Swedish kronor (SEK), and almost 80% of these costs occurred in the social care sector at the municipality level (10).

The Swedish National Guidelines for Care in cases of dementia (11) endorse the development of evaluation methods and a multidisciplinary team approach to support person-centred dementia care (13–15). However, there is no consensus or specific guidelines on how this should be done. Furthermore, there is a lack of comprehensive information on how community-living people with mild cognitive impairment or dementia in Sweden perceive their functioning and disability in major life domains. For a more comprehensive understanding of the needs of persons with mild cognitive impairment or dementia, the inclusion of their family member's perspective is advocated in the research (5, 15, 16).

The objective of this study was to explore how people with dementia or people with perceived cognitive impairment, i.e. persons not diagnosed with dementia (PwCI), as well as their next-of-kin (NOK) perceive functioning and disability in their daily lives. The specific aims were to explore to what degree perceived disability provided by the PwCI and NOK were covered by the World Health Organization Disability Assessment Schedule (WHODAS 2.0) according to the International Classification of Functioning, Disability, and Health (ICF), and to investigate whether there are differences between the perception of PwCI and that of NOK of disability in daily functioning.

METHODS

Instruments

In Sweden, since 2019, the National Board of Health and Welfare has recommended the use of the ICF (17) for structured and standardized documentation of health information in the municipalities (18). The second version of the WHODAS 2.0 is a standardized, generic measure developed following ICF consistent language for describing different aspects of functioning and disability and the impact of a health condition on people's lives (19–21). WHODAS 2.0 includes 6 life domains: cognition, mobility, self-care, getting along, life activities, and participation, corresponding directly with the ICF activity and participation component (20, 21). In the WHODAS 2.0, having difficulty is defined as increased effort, discomfort or pain, slowness, or changes in the way the person performs the activity due to their health condition (21). The WHODAS has been used for assessing functioning and disability and

estimating mental and physical burdens across different populations (3, 4, 22, 23).

Participants

Information about the study was communicated to dementia associations during their meetings. Municipalities' healthcare and homecare units were contacted, and information about the study was provided to them in 2 municipalities in the north of Sweden in 2017 to 2018. Through these channels the first author encountered the participants and their NOK.

Written information about the study and a guarantee of confidentiality was given to participants. They were also informed that participation in the research was voluntary and that they had the right to withdraw at any time, without explanation. The authors were aware of the difficulty of knowing when the interviewed PwCI is no longer capable of deciding whether they want to participate in research (24). Therefore, the first author verified that both the PwCI and NOK had received information about the study before they signed the informed consent. Informed consent was obtained both from the PwCI and NOK before participating in the study.

Ethics approval was received from the Ethical Board at the University of Umeå (2017/81-31).

A purposeful sample of 26 PwCI and their 26 NOK were included in the study. Twenty-one PwCI were native Swedes, and 5 had immigrated to Sweden in the 1960s. Inclusion criteria for the PwCI were: diagnosed dementia disease or self-perceived cognitive impairment; ability to give informed consent, a score of ≤ 27 in the Mini-Mental State Examination (MMSE) (25); and/or ≤ 4 in the Clock Drawing test (26); together with living at home; and Swedish or Finnish speaking.

Four people who were contacted declined to participate in the study. Six persons who had heard of the study made contact with the first author and asked if they could perform the memory tests because they perceived that they had memory problems. These people did not fulfil the inclusion criteria and were excluded and advised to consult a doctor.

Methodology and procedures

The first author conducted the assessments and the interviews. The PwCI completed the MMSE and the Clock Drawing test before the interview. Twenty of the PwCI and NOK were interviewed individually and 6 chose to be interviewed as a group.

Semi-structured interviews (27) guided by the WHODAS 2.0 interviewer and proxy administered forms (21) were conducted with each PwCI and NOK, respectively. The researcher conducting the interviews had prior experience in individual interviews

Table I. Structure of different levels of the International Classification of Functioning, Disability and Health (ICF)

ICF component	Chapter level	Level 2 ICF category	Level 3 ICF category	Level 4 ICF category
b	b2	b280	b2801	b28010
				Body function Sensory functions and pain Sensation of pain Pain in a body part Pain in head and neck

with community-living people. The interviews lasted approximately 40–60 min, and were conducted in participants’ homes and tape-recorded. The interview began with an open conversation about how the PwCI perceived their life concerning the cognitive impairment (24), followed by how it had been affecting their daily lives in each WHODAS life domain: cognition (understanding and communicating), mobility (moving and getting around), self-care (attending to one’s hygiene, dressing, eating and staying alone), getting along (interacting with other people), life activities (domestic responsibilities), and participation (joining in community activities, participating in society) (20, 21). Each NOK reported how they perceived functioning and disabilities of the PwCI who was close to them. Participants were encouraged to speak freely, comment, and give further information they considered important during the interview (21, 24). Follow-up questions, such as: Can you tell me what you mean by that?; Can you be more specific?; or Can you tell me more about that? were used to explore meanings and areas of interest that emerged during the interview. The PwCI also rated the perceived degree of disability when performing activities in each life domain, using a 5-point Likert scale (0=no difficulty, 1=mild difficulty, 2=moderate difficulty, 3=severe difficulty, 4=extreme difficulty/cannot) and the NOK also rated the degree of disability on the same scale as they perceived the PwCI had in each life domain (21).

The time constraint of the previous 30 days and averaging of good and bad days, as defined by the WHODAS 2.0 (21), was considered too demanding for PwCI and was not used in the study. Since all the PwCI were retired, the WHODAS 36-item questions concerning work and school were not included (21). Thus, the scores from 32-items were used in the analysis. The 32- and 36-items are considered comparable (21).

Data analysis

The interviews were transcribed verbatim and read several times to obtain a general understanding and overview of the content. Each interview was considered as a separate unit of analysis. Subsequently, deductive content analysis (28) was used to identify the manifest concepts of functioning (29), i.e. words or sentences that contained the interviewed person’s perspective of perceived functioning and disability in their daily lives.

The identified concepts of functioning were then linked according to rules for linking existing health information to the ICF (30) to the most relevant categories describing PwCI perceived functioning and disability in the ICF framework (17). The NOK perspective on perceived difficulties in daily functioning were linked to the ICF categories in the same way. Subsequently, the identified ICF categories were compared with the ICF categories corresponding to the WHODAS 32-items (20). The identified ICF categories not included in the ICF categories corresponding to the WHODAS 32-items were labelled as additional. One concept of functioning could be linked to 1 or more ICF categories, depending on the number of topics contained in it. Concepts of functioning that did not provide sufficient information about precise ICF categories were assigned according to the linking method (30). Since the ICF categories are arranged in a hierarchical category system, as shown in Table I, the ICF categories corresponding to WHODAS 32-items (20) and additional ICF categories were considered confirmed when the corresponding 2nd-, 3rd-, or 4th-level ICF category was identified from the transcripts. An example of the scheme of the content analyses and how the concepts of functioning were linked to the ICF categories is shown in Table II.

Table II. Content analysis scheme, linking the identified concepts of functioning to the ICF categories.

World Health Organization Disability Assessment Schedule (WHODAS) 2.0 Item 1.1: <i>How much difficulty do you have in concentrating on doing something for 10 minutes?</i>
<ul style="list-style-type: none"> • Main concept in the Item 1.1; Concentrating on doing something. • PwCIs answer to the Item 1.1 question: I am going to get some things from the garage, and at the door I do not find the keys that I am sure I took with me a couple of minutes earlier. Later I find the keys on the table in the vestibule. • Concept of functioning: Going to get some things/taking the keys with me, not finding the keys/ I am sure I took with me.
Linked to the most relevant ICF categories describing PwCI problem in concentrating on doing something:
<ul style="list-style-type: none"> • d160 problem in focusing attention on doing something (Intentionally focusing on specific stimuli) • d1402 problem in diving attention in doing something (Mental functions that permit focusin on two or more stimuli at the same time).

The perceived degree of disability in performing activities in WHODAS 2.0 items was calculated for each participant using the WHODAS 2.0 32-items scoring sheet (31). The scoring is based on item response theory (20, 21), which converts the WHODAS 2.0 item scores into a metric ranging from 0 to 100 (where 0=no disability; 100=full disability). The perception between PwCI and NOK regarding perceived difficulties was determined using the Mann–Whitney *U* test.

The first author, a physiotherapist and ICF expert, performed the linking of concepts of functioning to the ICF categories in all transcripts independently. Then the second author, also a physiotherapist and ICF expert, analysed the results of the process from above in 20% of the transcripts. The second author did not meet the participants. Both investigators subsequently discussed and agreed on the concepts of functioning identified from the 20% of the transcribed text. The agreement on linking to the 2nd-level ICF categories in 20% of the transcripts ranged from 80% to 100%.

RESULTS

In total, 26 community-living PwCI (12 women and 14 men, mean age 71.1 years, age range 38–87 years) and 26 of their NOK (12 wives, 2 husbands, 9 adult children, and 3 homecare employees (assistant nurses)) were interviewed. Sixteen of the PwCI were diagnosed with dementia, 8 of them lived with a spouse and 8 lived alone. All PwCI were retired, 3 of them due to dementia. Eight PwCI with diagnosed dementia had

daily homecare services and 1 twice a week. Three PwCI not diagnosed with dementia had daily homecare services and 1 once a week.

None of the interviewed adult children lived with the PwCI, but all had regular contact with them. The interviewed homecare employees were the primary contact for 3 PwCI who lived alone, and they had had regular contact with the PwCI for over 1 year. During the time of the study, all PwCI with diagnosed dementia had access to a day centre for people with dementia once or twice a week. None of the PwCI participated in an intervention or programme to prevent physical decline. Characteristics of the PwCI are shown in Table III.

Data saturation

The data saturation (32, 33) was considered to have been reached when the interviews did not reveal any new concepts of functioning of the participants’ perceived functioning and disability. The 19th and 20th interviews with the PwCI and NOK, respectively, were the last interviews in which new concepts of functioning were identified. To confirm that this assumption was correct, 6 more interviews with the PwCI and NOK were conducted. No new concepts of functioning emerged from the interviews.

Qualitative data analysis

The transcripts included 1,308 perceived functioning and disability concepts. Of these, 693 were linked to 38 out of 47 (81%) previously established ICF

Table III. Characteristics of persons with cognitive impairment (PwCI)

Sex	Living situation NOK		Diagnosed with dementia	MMSE score	Clock Drawing test score	Type of comorbidity	Assistive devices	Homecare
F	Spouse	Spouse	No	23	3	Arthritis	Cane	None
F	Alone	Daughter	No	24	4	Arthritis	Cane	Twice a week
M	Spouse	Spouse	No	24	2	HD	None	None
M	Spouse	Spouse	Yes	20	1	Cancer	None	Twice a week
F	Alone	Daughter	No	26	2	Diabetes	Walker	None
M	Spouse	Spouse	No	27	2	None	None	None
F	Alone	Spouse	No	27	3	None	Cane	None
F	Alone	Daughter	Yes	13	1	None	None	Daily
M	Spouse	Spouse	Yes	18	2	HD	GPS	None
M	Spouse	Spouse	No	26	3	HD	Walker	Daily
M	Alone	Assistant nurse	No	25	3	Stroke	None	Daily
M	Alone	Spouse	Yes	17	1	HBP	None	Daily
M	Alone	Assistant nurse	Yes	15	3	None	None	Daily
F	Alone	Daughter	No	22	3	HBP	None	Daily
F	Alone	Daughter	Yes	22	4	HPB	None	Daily
F	Alone	Assistant nurse	No	26	4	Post-cancer	Cane	Once a week
M	Spouse	Spouse	Yes	15	1	None	None	None
F	Alone	Daughter	Yes	17	2	Asthma	Walker	Daily
F	Alone	Daughter	Yes	25	3	HBP	Walker	Daily
F	Alone	Daughter	Yes	18	2	HBP	Walker	Daily
F	Alone	Daughter	Yes	13	2	HD	Walker	Daily
M	Spouse	Spouse	Yes	27	3	None	None	None
M	Spouse	Spouse	Yes	20	2	None	None	None
M	Spouse	Spouse	Yes	20	4	None	None	None
M	Spouse	Spouse	Yes	24	4	None	None	None
M	Spouse	Spouse	Yes	18	2	None	Cane	None

NOK: next-of-kin; MMSE: Mini-Mental State Examination; HBP: high blood pressure; HD: heart disease; GPS: global positioning system; M: male; F: female.

categories corresponding to the WHODAS 32-items (Appendix S1). The following ICF categories corresponding to WHODAS 2.0 items; d115–d129 (Purposeful sensing), d130–d150 (Basic learning), d610 (Acquiring a place to live), and d950 (Political life and citizenship) were not confirmed from the transcripts.

In addition, 201 concepts were linked to 14 additional Body Functions categories describing cognitive, and physical impairments affecting PwCI in their daily lives, 17 concepts were linked to 8 additional Activities and Participation categories, 382 concepts were linked to 16 Environmental Factors categories describing perceived facilitators or barriers. Complete lists of identified additional ICF categories and examples of concepts of functioning linked to the ICF categories are shown in Appendices S2 and S3.

The remaining 15 concepts were linked as not covered health condition (nc-hc), not covered quality of life (nc-qol), not definable functioning (nd-func), not definable disability (nd-dis), not definable general health (nd-gh) and personal factor (Pf) according to the ICF linking rules. These concepts of functioning are shown in Appendix S4.

Differences between PwCI’s and NOK’s perceptions of disability in daily functioning

The overall median reported perceived disability in performing daily activities was 48% for NOK and 16% for PwCI ($p < 0.0001$, Table IV). Difficulties in all life domains, except mobility, were rated as greater ($p < 0.05$) by NOK than by PwCI. Among PwCI self-care was perceived as the least problematic, and in all other life domains, the difficulties were rated between 13% and 20%. The mobility domain was perceived as least problematic by NOK, while difficulties in life domains were rated as most problematic.

Perceived functioning and disability in major life domains

Cognition. The majority of PwCI ($n = 22$) perceived disability related to cognition. Cognitive impairment was considered as a factor influencing them emotionally and that they missed being involved in their former hobbies, which was difficult when they mostly stayed

at home. The 4 PwCI who did not perceive problems related to cognition had a MMSE score of 13–20. Eight PwCI reported that they used assistive tools, such as a calendar, clock, stove timer, or medicine carousel, to cope with the cognitive disability.

One PwCI described how she dealt with the cognitive impairment: *“I have always been like that. I can make mistakes, but I try again until I get it right”* (PwCI).

Remembering to do important things, learning a new task, concentrating on doing something, and analysing and finding solutions to problems in day-to-day life was perceived as problematic by the majority of PwCI. Other common difficulties, as described by PwCI, were finding the right contact on a mobile phone, learning how to use a new mobile phone or TV remote control, planning and preparing a meal, taking medication at the right time, using a new bus route, or finding the way back home from the city. One PwCI reported that he no longer knew how to write letters, and, because of that writing had become impossible/unmanageable. One PwCI and 1 NOK described the difficulties in the following way: *“While I am cooking potatoes, I can go to the living room and forget all about the potatoes. I feel embarrassed about it”* (PwCI). *“She starts to make coffee, forgets it, and then she starts all over again”* (NOK).

One PwCI used a global positioning system (GPS) device because of the risk of getting lost. With the help of the GPS device, the NOK could locate him if he did not come home at an agreed time. The NOK described the benefits of the GPS in the following way: *“It is fantastic. The quality of life has improved for all of us. Now we do not need to fear that he gets lost, and he can continue with the walks that are so important for him”* (NOK).

To understand what people say and to start and maintain a conversation were perceived as problematic by a few PwCI. The majority of NOK ($n = 20$) described, however, that they perceived problems in conversation with the PwCI, or that the PwCI had displayed problems in understanding what other people say to them ($n = 18$).

Mobility. Eighteen PwCI and 18 NOKs perceived disability in the domain Mobility. Nearly half ($n = 12$) of the PwCI perceived that pain and stiffness in different body parts, as well as “balance problems” were

Table IV. Comparison of perceived disability in performing activities between persons with cognitive impairment (PwCI) and next-of-kin (NOK) in World Health Organization Disability Assessment Schedule (WHODAS) 2.0 domains

Domains	PwCI Median	PwCI Mean rank	NOK Median	NOK Mean rank	Stand test statistics	p-value
Cognition	0.17	17.85	0.54	35.15	4.129	<0.0001
Mobility	0.20	24.71	0.11	28.29	0.865	0.387
Self-care	0	20.42	0.34	32.58	2.998	0.003
Getting along	0.20	19.52	0.48	33.48	3.339	0.001
Life activities	0.16	18.96	0.63	34.04	3.607	<0.0001
Participation	0.13	19.8	0.42	33.92	3.538	<0.0001
Overall score	0.16	18.88	0.48	34.12	3.624	<0.0001

common causes of the mobility problems. Some PwCI and NOK acknowledged that difficulties in mobility, such as insecurity regarding leaving the house because of the fear of getting lost, were caused by cognitive impairment. One NOK described the problem in the following way: *“He does not dare take a bus anymore. He does not know where to hop off, and that is why he walks the whole way”* (NOK).

Standing for long periods (30 min) and walking a long distance (1 km) were described as a problem by many PwCI ($n=15$). Approximately half perceived problems, such as boarding a bus or climbing stairs, that hindered them from getting out of the house. A few found standing up and moving around the home as a problem, however, and maintaining a standing position while taking a shower or preparing a meal were described as difficult. PwCI ($n=11$) who used a walking device when moving around rated the difficulties as slight.

Self-care. Approximately half of the PwCI ($n=14$) and almost all NOKs ($n=25$) perceived disabilities in the domain of self-care. Eight PwCI perceived that they could not manage to be at home by themselves, while 18 NOK perceived that the PwCI could not stay alone due to cognitive impairment. One PwCI and 1 NOK described this dependency in the following way: *“Homecare staff come every day. That is good. I am not afraid (of being alone), but I feel safe. They check that I am alive, wake me up, and see that I get up”* (PwCI). *“Homecare staff help him. Otherwise, he would not wash or change his clothes”* (NOK).

Similarly, to the mobility domain, the PwCI perceived those difficulties in self-care were mostly caused by problems in physical functioning. Five PwCI perceived problems in washing and getting dressed, but, from the NOK perspective, the majority of the PwCI needed help with washing themselves. No longer changing clothes, washing oneself, and not remembering to eat without support were described as the most common problems by the NOK. One PwCI who perceived difficulties in controlling his weight reported that he had gained too much weight lately, but he felt unsure why. The PwCI and the NOK described the same problem: *“I know that I have gained weight and I weigh too much. My daughter and I have talked about it; maybe I get too much food”* (PwCI). *“He is gaining more and more weight. He already has food distribution, and now he has started to order food at home too. The homecare staff should control this because he cannot”* (NOK).

Getting along. The majority of PwCI ($n=18$) and all but 2 NOKs perceived disabilities in getting along with other people. Many of the PwCI perceived that the main problem was that they mostly stayed at home and did not meet other people. The majority of NOK ($n=19$) reported that the PwCI no longer had contact

with, or had lost contact with, their friends. Making new friends and maintaining friendships were perceived as a problem by 11 PwCI and 10 NOK. One PwCI stated that: *“I could meet my friends, but I do not do it. When my head started to function worse, I chose not to do it”* (PwCI). Those who had access to the daycentre reported that they enjoyed being there and that, in this way, they made new friends.

Most of the NOK perceived that the problems were due to cognitive impairment, and 12 of them said that the problems often led to arguments with their spouse, children, or friends. Five PwCI perceived problems in the interaction with family members or friends. Not having a partner was perceived by the PwCI ($n=16$) as the main reason for not engaging in sexual activity. Seven NOK living with PwCI perceived problems in engaging in sexual activity.

The 5 PwCI who had immigrated to Sweden perceived increasing difficulties in interacting with other people because of the language problems. One of them described the problem in the following way: *“I understand that I have started to mix languages and my Swedish has become so bad; because of that, I do not have any friends”* (PwCI).

Life activities. Eighteen PwCI and all but 2 NOK perceived functioning problems in different life activities. Thirteen PwCI perceived that, despite the cognitive impairment, they still managed their daily life at home with the support of NOK and/or homecare staff.

Three PwCI and 14 NOK perceived that the problems in life activities were due to cognitive impairment. One NOK described the problem in the following way: *“He has stopped using the dishwasher and started washing dishes by hand. Cleaning, in general, has become like a mania (for him)”* (NOK).

Taking care of the household responsibilities and doing the most important household tasks well, were perceived as a problem by many (10 PwCI and 14 NOK). Getting the necessary household work done in time was also perceived as a problem by many (11 PwCI and 14 NOK). Five PwCI living alone had Food delivery because they no longer could manage to buy groceries or prepare meals for themselves. Eight PwCI perceived that they could still manage to take care of the household, even though it took more time than previously.

Participation. The majority of PwCI ($n=22$) and all but 1 NOK perceived disabilities in participation. Joining in community activities and doing things by themselves were perceived as a problem by approximately half of PwCI. Few PwCI perceived problems with finances or with living with dignity. The NOK and the homecare staff were considered the most important facilitators for functioning. One PwCI described how cognitive impairment had affected him emotionally:

“I am afraid, that I become a person who does not remember anything. I have pushed away from my thoughts. I cannot do anything about it” (PwCI).

One PwCI reported that she had tried to talk about her memory problems during a normal check-up with her diabetes nurse, but the nurse had dismissed her concerns by saying: *“It is just a normal part of ageing (Nurse)”*. One PwCI perceived that the attitudes of others concerning his cognitive impairment hindered him from joining in community activities. He described it in the following way: *“I cannot blame others, but I feel that I am hindered from taking part in the activities because of this thing (dementia)” (PwCI).*

Sixteen PwCI who attended to the daycentre as well as their NOK, perceived the daycentre as an essential facilitator for them. One PwCI stated that; *“At the daycentre, I meet people who have about the same (dementia) that I have. It is fantastic to meet the guys. Otherwise, you lose contact with people, and I have nobody to talk to in this apartment” (PwCI).*

The majority of NOK ($n=21$) felt uncertainty and confusion about how to deal with a family member with cognitive impairment, who, for example, unexpectedly could not open an envelope, or was repeatedly in conflict with their friends, or that the fridge was empty when they visited. Many of the NOK also felt left alone. They lacked information about what was going to happen next and who was in charge. Many of them reported that it had been important to have the dementia diagnosis in order to understand what this was all about. One NOK described her situation in the following way: *“I have become her lifeline. So much energy goes to solve problems caused by poor communication (between the healthcare, and social care and the NOK. I never know who is in charge” (NOK).*

DISCUSSION

The objective of this study was to explore how PwCI and their NOK perceived functioning and disability in their daily lives in the community setting. The individual interviews confirmed that the cognitive impairment was perceived to have a major impact on perceived disability in daily lives in PwCI.

The interviews, guided by the WHODAS 2.0, provided a comprehensive picture of cognitive and physical impairments affecting PwCI's daily functioning in major life domains in interaction with the environmental factors.

The interviews covered the ICF categories corresponding to WHODAS 2.0 items well. This confirms that the WHODAS 2.0 items address the perceived activity limitations and participation restrictions in community-living PwCI (and their NOK) well. The additional ICF categories identified provide additional

knowledge regarding important factors necessary to consider when assessing PwCI needs in the community setting. These findings suggest that it is crucial to define whether the WHODAS 2.0 is used to *measure effect* of a given intervention or to *identify needs* of the PwCI. This wider understanding at the physical, personal, and societal level is necessary when planning and evaluating person-centred dementia care in community settings.

The interviews with PwCI who did not report any disabilities due to cognitive impairment stress the importance of including the NOK perspective in order to gain a broader understanding of the needs of PwCI in the community setting. The degree of difficulties in all life domains except mobility was also perceived as greater by NOK than by PwCI. This suggests that the NOK perspective can widen the usefulness of the WHODAS 2.0 in the community setting by providing useful information for healthcare and social care professionals. This information can improve communication, clarify roles and responsibilities between healthcare and social care professionals, PwCI, and NOK, and thereby facilitate the development of person-centred dementia care in the community setting (5, 11, 14, 16). Similar to previous research (34, 35), in addition to cognitive impairment, physical impairments also hampered PwCI performance in daily activities and participation. Perceived problems of body functions, such as pain, and muscle stiffness, or more general “balance problems” were connected with perceived activity limitations, such as not being able to take care of the household, and inability to continue with former hobbies or other social activities. The combination of cognitive and physical impairments further increases the risk of a sedentary lifestyle and physical decline, i.e. more time spent at home, less contact with friends and other people, and increasing dependency. Despite these well-known risks, none of the PwCI participated in interventions or programmes targeted at preventing physical decline. However, those who had access to the daycentre perceived that it was important for them to socialize and meet other people in similar life situations. The daycentre service was also highly appreciated among NOK. These findings suggest that there is a need to develop interventions or programmes to prevent physical decline among PwCI, and to further develop adjusted activities at the daycentre.

Methodological discussion

The recruiting strategy of this study made it possible to locate and include community-living persons with perceived cognitive impairment or dementia and their NOK of different ages and in different life situations. This broadened the picture of how cognitive impairment affected their daily lives.

Since most of the dementia costs occur in the social care sector at the municipalities (10), early diagnoses could help the planning of person-centred dementia care (5, 11, 13, 15). This could eventually lead to a better quality of life for people with dementia, their NOK, and even reduce the costs (36).

Starting the interview with an open conversation about how cognitive impairment had affected persons' daily living facilitated the interview situation, as participants gained an opportunity to speak freely before the WHODAS 2.0 questions were applied. This approach is also recommended when conducting interviews with persons with dementia (24). Then, WHODAS 2.0 questions guided the participants to focus on a single life domain at a time, which facilitated a more detailed description of perceived problems in each life domain. This approach also facilitated the analysis of the transcripts. The researcher could first read the interviewed persons perceived functioning and disability in a life domain and then concentrate on the answers in each specific WHODAS 2.0 item. This helped the researchers when deciding which was the most relevant ICF category describing participant's perceived functioning and disability according to the ICF framework (17, 30).

The fact that 6 of the NOK and PwCI were interviewed together might have affected how the NOK or PwCI chose to answer the interview questions, but, from the interviewer's point of view, it helped the PwCI to relax and participate in the interview.

The majority of PwCI were aware of, and described how, cognitive impairment affected their daily functioning. Only the WHODAS item 1.3 (Analysing and finding solutions to problems in day-to-day life), which demands identification and thorough pondering of the problem (21) was difficult for many PwCI to understand and required more explaining. From the interviewer's point of view, an example in the WHODAS question-by-question specifications (21) of what this item means in day-to-day life situations would be helpful.

The interviews conducted reached saturation, and thus the objective of exploring perceived functioning and disability was achieved. The data saturation (32, 33) was used to determine the adequate sample size. Although the concept of data saturation is under continuous discussion, it is still widely used in qualitative research (37). However, the interviews with the 6 PwCI and NOK after the data saturation was reached were considered to confirm that sample size was adequate according to the scope of the study, which strengthens the transferability of the findings to the community setting. The ICF theory-driven content analyses (28) and the ICF-linking method (30) enhance

the transparency of how the data analyses were performed (see also Tables I and II and Appendices S1–4). Investigator, participant, and method triangulation was also used to strengthen the credibility and trustworthiness of the findings (27, 33, 37).

The WHODAS 2.0 user is instructed (20) to specify whether the assessment of functioning is measured with or without assistance and to score "no problem" if the person manages with the help of personal or technical assistance. Most of the PwCI perceived that they manage with the help of personal and/or technical assistance, i.e. "no problem". If this approach had been used in the current study, there would have been an obvious risk that information about the PwCI dependency on any environmental factor would have been lost in an ICF-based (16) health information documentation recommended by the Swedish National Board of Health and Welfare (17). An additional challenge is that the WHODAS 2.0 manual lacks instructions about which ICF categories correspond to WHODAS 2.0 items. This hampers the usefulness of WHODAS 2.0 in the advancement of ICF-based documentation (16) in the community setting.

Ethical considerations

The interview situation can cause stress; therefore interviewing took place in PwCI homes, which was considered a safe environment in which to conduct the interview. The interviewer was also prepared to interrupt the interview if the PwCI showed signs of fatigue or anxiety. However, all interviews were conducted without complications. It is likely that the 4 PwCI who did not report any problems in cognition were not fully capable of considering their participation in the study. The participants were informed that they could withdraw from the study at any time, and were guaranteed confidentiality of findings.

Study limitations

The authors acknowledge that the wording of the WHODAS 2.0 items, and the fact that the interviewer was a physiotherapist, probably influenced how the participants chose to describe perceived disability and functioning in their daily lives. It is also possible that the PwCI and NOK did not want to discuss topics as attitudes of health professionals or other care providers because the interviewer (the first author) belonged to the same group of professionals. The authors furthermore acknowledge that the sample included only community-living PwCI and NOK who themselves wanted to share their perspective on functioning and disability in their lives.

CONCLUSION

It is challenging to measure PwCI-perceived functioning and disability in the community setting, as it is related to many life areas, and often involves interactions between the person, NOK, the healthcare and social care professionals, and the environment. However, the individual interviews guided by the WHODAS 2.0 provided a comprehensive picture of the PwCI's perceived functioning and disability in major life domains. The results of this study advocate the use of WHODAS 2.0 in the measurement of PwCI's perceived activity limitations and participation restrictions in the community setting. For a better understanding of the impact of cognitive impairment on people's daily lives the inclusion of the perspective of NOK and what hinders or facilitates daily living is required in the community setting.

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