

ORIGINAL ARTICLE

Self-perceived problems in daily activities and strategy building in people with different stages of dementia

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Abstract

Background: People with dementia experience severe problems in their daily lives. However, little is known about self-perceived problems in the course of dementia. The aim of our study was to assess self-perceived problems with daily activities as well as individually developed strategies of older people of different cognitive status.

Methods: Semi-structured interviews were conducted with 25 participants (mean age 67.6 years, 56% female, 24% healthy, 28% mild dementia, 48% severe dementia). Questions addressed problems in daily activities, their occurrence and the behaviour toward them, and their developed strategies. Information was summarized quantitatively and evaluated using the chi-squared and Kruskal–Wallis tests.

Results: Self-perceived problems included awareness of physical and cognitive deficits in managing daily life, disturbing factors, and lost autonomy. Increased cognitive impairment was associated with more problems in daily life, even though people with severe dementia seemed not to recognize them. The most frequently reported strategies included orderliness, doing things immediately, and the use of external aids. While healthy people and those with mild dementia developed strategies, those with severe dementia reported only few strategies.

Conclusion: Our findings indicate that self-perceived problems in daily life and strategy development are strongest in mild dementia, while people with more severe dementia tend to perceive no problems at all while correctly reflecting their current state of dependency. Importantly, despite memory loss during early stages of dementia, strategies are still being developed. Accordingly, strategies for daily living should be taught in early dementia to sustain an independent lifestyle.

INTRODUCTION

A global health priority is the maintenance of effective functioning in daily life of the older population, especially among those who experience severe cognitive decline in older age. Cognitive impairment is the major symptom of dementia, which is associated with an increasing loss of the ability to perform daily activities.^{1,2} The challenge in dealing with this loss is that it is not known how and what kind of problems people with dementia subjectively perceive in their daily lives and how they cope with or adapt to the experienced problems.

Published research only refers to frequent complaints about impaired vision and hearing, less strength, and memory problems.^{3–5} Less is known about the cognitive characteristics of the experienced problems. This could be because it is believed that people with severe dementia have a lack of awareness, whereby no consensus can be observed in the literature as to whether unawareness could be associated with dementia or whether unawareness increases with the progress of the disease.⁶ In terms of memory awareness, it is thought to decrease along with progression of the disease^{6,7} and people thus tend to overestimate their memory function.⁸

It is very likely that people with dementia actively cope with the problems that they perceive in their daily functioning. The theory on successful ageing¹² presents three strategies, selection, optimization, and compensation (SOC), that are used to manage daily life. Selection means setting priority goals that involve convergence between environmental demands and individual skills. Previous studies reported that older people and those with mild dementia rearrange their homes according to their functional disabilities and rely on supportive others for performing and managing daily life activities.^{9,10} Optimization concentrates on the enhancement of existing resources (e.g., cognitive training), while compensation refers to the use of alternative means, like external aids and mnemonic strategies, to reach the same goal.^{11,12} Evidence from previous research suggests that strategies to overcome problems by people with dementia seem to be mnemonic strategies, maintaining order, using external aids like diaries or calendars, grocery shopping lists, and pill organizers, as well as placing items in prominent locations.^{9,13}

Reported strategy usage by people with mild dementia and those who experienced a progressive memory decline¹⁴ indicate that they have coping capacities to handle their losses and problems. With

decreasing cognitive resources, it is to be assumed that there is a loss in strategy usage.

Given the lack of evidence on subjectively experienced problems with decreasing cognitive status, the aim of our study was to assess self-perceived problems with daily activities as well as individually developed strategies of older people of different cognitive status.

METHODS

Study design

Participants were recruited via convenience sampling by handing out flyers in pharmacies, nursing homes, adult education centres, and fitness centres for seniors. We included 25 participants in the analysis that were 60 years and older and had either a diagnosis of dementia (Major Neurocognitive Disorder subtypes probable Alzheimer's disease, vascular or unspecified), experienced trouble with their memory performance, or were cognitively healthy. People with a history of mental disorders and severe brain injury were excluded from the study. Participant characteristics are presented in Table 1.

The semi-structured interview took place either at the participant's home, in a nursing home, or in the lab of the university, and lasted between one and two hours. Inclusion criteria were the participant's ability to provide informed consent; understanding of the research purpose, the consequences of participation, and the confidentiality; and the signing of an informed consent form. If there was a legal guardian, they provided signed informed consent prior to the interview. If the participant requested it, the legal guardian was present during the interview. An experienced, trained person administered the interview. Participants received a payment of 20€ for their study participation.

The study was approved by the ethics committee (reference number mh/mk 09072018 Nr. 5) of the University of Kaiserslautern and was conducted in adherence to the standards of the Declaration of Helsinki.

Cognitive functioning

Subjective cognitive decline (SCD) was assessed using 14 questions that were also used in the LIFE-Adult study of the Leipzig Research Centre for Civilization Diseases. They address issues of subjective

Table 1 Characteristics of the study participants

Participant characteristics	Frequency (n, %)/(Mean, SD)
Age (years)	67.64 (23.63)
Education (≥ 12 years/ < 12 years)	8 (32%)/17 (68%)
Sex (female/male)	14 (56%)/11 (44%)
Vision aids (yes/no)	22 (88%)/3 (12%)
Hearing devices (yes/no)	7 (28%)/18 (72%)
Motor restrictions (yes/no)	5 (20%)/20 (80%)
SCD	
Recognizing no memory problems (score: 0–5)	9 (36%)
Realizing some memory problems (score: 6–10)	10 (40%)
Experiencing frequently memory problems)	6 (24%)
IADL	
Low function, dependent (score < 7)	15 (60%)
High function, independent (score: 7–8)	10 (40%)
MoCA	
Healthy (score: 26–30)	6 (24%)
Mild dementia (score: 16–25)	7 (28%)
Severe dementia (score: < 16)	12 (48%)

SCD, subjective cognitive decline; IADL, Instrumental Activities of Daily Living; MoCA, Montreal Cognitive Assessment.

memory impairment such as possible problems with remembering appointments, keeping items, and worries about decreasing memory performance.^{15,16}

The Montreal Cognitive Assessment (MoCA) was used to assess cognitive status. The MoCA is a short clinical test with 30 questions on different cognitive functions such as attention, executive functioning, memory, language, visuospatial abilities, conceptual thinking, calculation, and orientation.¹⁷ Normally ageing participants score between 26 and 30.¹⁷ The MoCA was used to categorize patients by their cognitive status: A score of 16–25 was categorized as mild dementia and a score below 16 as severe dementia.

Instrumental Activities of Daily living

The Instrumental Activities of Daily Living (IADL) questionnaire was used to assess independent living skills¹⁸ in eight domains, including food preparation, shopping, housekeeping, telephone, and transport usage.

Semi-structured interviews

Participants were asked, in a semi-structured interview, open-ended questions about their daily activities including problems, developed strategies, and useful external aids. The focus of the interview was on daily situations with which the participant experienced difficulties, the occurrence of and behaviour toward a problematic situation, whether the problem was avoided or an attempt was made to control it, as well as the strategies applied to support daily activities. The interview started with the activities addressed in the SCD and IADL and allowed the participant to elaborate on those topics.¹⁹ The interviewer further asked about incidents, events, and happenings in a person's life in relation to managing daily life.²⁰ If the participant already mentioned problems, strategies, and external aids before, the interviewer used this as a base for further elaboration. The interviewer explicitly motivated the remembering of problem situations, helped naming problems in daily life, and inquired the use of strategy in those situations (when, how they were applied, what problem they prevented).

Data Analysis

Interviews were transferred into digital text files by either transcribing verbatim audio-taped interviews or by digitalizing interviewers' notes. Afterwards, the text

files were loaded into NVivo12 qualitative software. First, one coder marked text passages that contained the components of self-perceived problems in daily activities as well as the developed strategies and external aid used to circumvent the reported problems. Each participant's text file was open coded by assigning concepts and ideas emerging from the collected data via an iterative line-by-line reading. In this process, conceptual labels were identified and summarized to a code that was descriptive rather than interpretative.²¹ A constant comparative approach among text files was used to create, define, refine, as well as validate an established code or to expand the coding scheme. Second, the codes were then discussed among the team and subsequently refined. Third, codes were grouped to broader conceptual categories. These categories were further condensed and integrated into a category network through the elaboration of a core category following a selective coding technique.^{19,22,23} Codes and categories were discussed periodically by the study team. Data collection and analysis were done in parallel until no new data emerged and saturation of the final categories was reached.

To gain further insights into our research question, we quantified the categories that were identified in the interview. We counted the number of reported problems and strategies. Strategies were further classified according to SOC usage by counting the number of reported selection (straSELEC), optimization (straOPTI), and compensation strategies (straCOMP), including the number of reported external aids (straEXT) for every participant. Since participants seem not always aware of their problems and strategy usage (when they indicate that they have no problems in their daily lives, while reporting that they need help with grocery shopping), we consider also the counterparts to the above-mentioned dimensions by counting the number of each unrecognized problem, unrecognized strategy (unSTRAT), comprising unrecognized applied selection (unSELEC), optimization (unOPTI), and compensation (unCOMP) strategies.

The chi-squared test and Kruskal–Wallis test²⁴ were conducted to examine the association with cognitive status (healthy, mild, and severe dementia). Dunn's test²⁵ was used for pairwise comparison. Further, *t*-tests were performed to compare participants with low ($n = 8$) and high education ($n = 17$), as people with high education are considered to have more cognitive

resources for dealing with cognitive loss in old age.²⁶ All statistical analysis were conducted using STATA and used a significance level of $P < 0.05$.

RESULTS

As expected, decreased cognitive status was associated with more memory problems (χ^2 (4, $N = 25$) = 12.60, $P = 0.013$; mean SCD score: healthy 2.00 (SD 0.26); mild dementia 2.57 (SD 0.20); severe dementia 1.42 (SD 0.19)) and worse daily functioning (χ^2 (2, $N = 25$) = 10.57, $P = 0.005$; mean IADL score: healthy 1.17 (SD 0.17); mild dementia 1.43 (SD 0.20); severe dementia 1.92 (SD 0.08)).

In the semi-structured interviews, four categories were identified: (i) problem awareness, (ii) strategy development, (iii) disturbing factors, and (iv) autonomy level (see also Fig. 1). These are described in the following sections.

Problem awareness when performing daily activities

Self-perceived problems in daily functioning refer to problems stemming from either physical or cognitive ageing. Physical problems involve age-related body changes including motor and sensory deficits. Cognitive changes are perceived in concentration deficits and digression. We observed a great variance in the reports on self-perceived problems in memory performance, ranging from no problems to realizing some or severe memory problems. Participants classified as healthy stated not having experienced problems, e.g., 'No problems' (Participant 7, healthy). Participants with mild dementia were aware of their memory performance problems, indicating that they had realized a change in their memory performance, e.g., 'I get angry when I forget something...' (Participant 22, mild dementia). Participants with severe dementia were not aware of their memory problems and stated that everything was all right with their memory functioning, e.g., 'Know everything, have no problems, good memory' (Participant 23; severe dementia). Accordingly, the overall number of reported problems significantly differed between cognitive status groups (see Table 2). Healthy participants and those with mild dementia named over four times more problems than participants with severe dementia, whereby participants with mild dementia report the most problems.

The number of unrecognized problems significantly different by cognitive status groups, with people with severe dementia being more unaware of their problems

than healthy people and those with mild dementia (see Table 2). For example, 'I have to concentrate on one thing to be able to switch off the other. But this is only possible if the others are quiet' (Participant 14; healthy) and 'I have not experienced problems by myself.... My wife goes grocery shopping, I cannot do this anymore' (Participant 23, severe dementia).

Strategy development to deal with or avoid problems

Self-reported strategies comprised selection, compensation, and optimization approaches. Table 2 summarizes quantitatively the reported strategies, which decline with increasing cognitive impairment. There is an overall pattern of people with severe dementia reporting significantly fewer recognized strategies than healthy people or people with mild dementia (see Table 2). However, this does not hold when counting unrecognized strategies. Selection strategies were reported only by participants with mild dementia who readjusted their goals according to their individual skills, e.g., 'She brings food once a week, I want to order food on wheels, so that I have more free time and less stress because I have to limit my strength' (Participant 12, mild dementia). Unawareness of a problem as in severe dementia seems to come with a passive application of selection strategies, namely allowing somebody to take responsibility over their daily activities. For example, 'The woman regulates all and takes care of financial matters' (Participant 19, severe dementia).

Compensation strategies such as being orderly and sorting things according to a particular schema were reported. Participants stated that problems arose when the order was not kept and something had to be searched, 'Keep everything neat, so that I do not have to look for anything, if the key is not in the same place, then I'm looking for it' (Participant 3, healthy). Another compensation strategy reported was to do things immediately when they came into mind, otherwise they will be forgotten and not executed. Using external aids such as taking notes and making shopping lists seems also to be a helpful compensation strategy. Therein, helpful tools were a diary, pieces of paper, or technical advices with a reminder function. Placing notes clearly visible at a place related to the note was another strategy that was reported. For instance, 'I always write everything

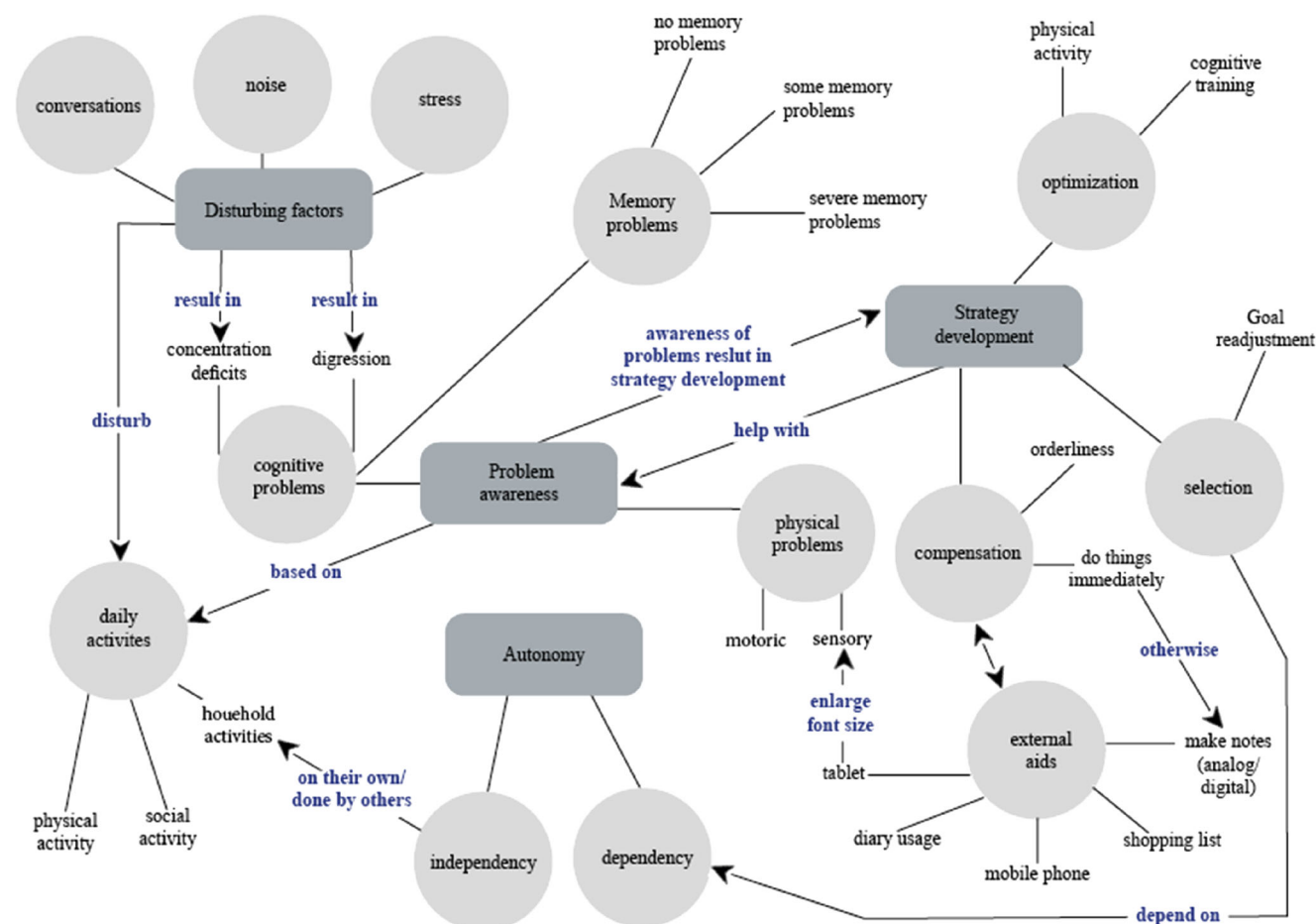


Figure 1 Schematic representation of the results from the qualitative analysis indicating associative and asymmetrical relationships (blue font colour) among core categories (dark grey background), conceptual categories (light grey background), and codes (black font, no background).

Table 2 Formalized qualitative results including the mean and standard deviation (SD) of generated strategies, and problems and tools reported by the cognitive status groups

	Mean (SD) Total	Healthy	Mild	Severe	Kruskal–Wallis Test			Dunn's test		
					<i>P</i>	df	χ^2	<i>P</i> (H:M)	<i>P</i> (H:S)	<i>P</i> (M:S)
Problems	1.00 (1.26)	1.17 (0.98)	2.14 (1.57)	0.25 (0.45)	0.0146	2	8.46	0.1752	0.0345	0.0013
Unrecognized problems	1.24 (1.61)	0.00 (0.00)	0.29 (0.76)	2.42 (1.56)	0.0032	2	11.48	0.3563	0.0006	0.0016
Strategies	1.68 (1.95)	3.17 (2.23)	3.00 (1.41)	0.17 (0.39)	0.0002	2	17.09	0.4819	0.0003	0.0001
Unrecognized strategy	0.96 (1.34)	0 (0.00)	0.71 (1.89)	1.58 (1.00)	0.0111	2	9.00	0.2495	0.0013	0.0088
straSELEC	0.16 (0.37)	0.00 (0.00)	0.57 (0.53)	0.00 (0.00)	0.0931	2	4.75	0.0030	0.5000	0.0007
unSELEC	0.68 (1.03)	0.00 (0.00)	0.57 (1.51)	1.08 (0.79)	0.0278	2	7.17	0.2500	0.0027	0.0164
straOPTI	0.52 (1.05)	1.17 (1.6)	0.71 (1.11)	0.08 (2.89)	0.2266	2	2.97	0.3266	0.0239	0.0600
unOPTI	0.24 (0.52)	0.00 (0.00)	0.00 (0.00)	0.5 (0.67)	0.2096	2	3.13	0.5000	0.0210	0.0163
straCOMP	1.04 (1.06)	2 (1.1)	1.71 (0.49)	0.17 (0.39)	0.0003	2	16.21	0.4571	0.0003	0.0002
unCOMP	0.04 (0.20)	0.00 (0.00)	0.14 (0.38)	0.00 (0.00)	0.8621	2	0.3	0.0996	0.5000	0.0666
straEXT	0.88 (0.93)	1.67 (0.52)	1.43 (0.98)	0.17 (0.39)	0.0014	2	13.21	0.2718	0.0003	0.0019

P (H:M), *P*-value of the Dunn's test when comparing healthy participants to people with mild dementia; *P* (H:S), *P*-value of the Dunn's test when comparing healthy participants to participants with severe dementia; *P* (M:S), *P*-value of the Dunn's test when comparing participants with mild to severe dementia; straSELEC, number of reported selection strategies; unSELEC, number of unrecognized applied selection strategies; straOPTI, number of reported optimization strategies; unOPTI, number of unrecognized applied optimization strategies; straCOMP, number of reported compensation strategies; unCOMP, number of unrecognized applied compensation strategies; straEXT, number of reported external aids.

down when I need something. I have a magnet, so I pin the note on the exhaust hood. And if I can think of something else, then I write it on the list' (Participant 14, healthy). Technical devices are also reported to be used to compensate for sensory deficits, e.g., 'I have a tablet because I have enlarged the font ... can read the letters better when they are bigger' (Participant 14, healthy). People with severe dementia reported significantly fewer recognized compensation strategies (see Table 2).

Optimization strategies, such as 'I take food supplements that should strengthen the memory, what I cannot remember, I build donkey bridges for, I can remember words better in conversation and in context. Summarize talks and try to remember them later' (Participant 4, mild dementia), were reported only by healthy people and people with mild dementia. Participants with severe dementia, in contrast, engaged in physical activity without interpreting it as an optimization strategy, 'Long hikes, cycling with my wife, sometimes in a group, that is different' (Participant 19, severe dementia). People with mild dementia reported significantly more compensation strategies than those with severe dementia (see Table 2). However, we observed a greater amount of unrecognized compensation strategies for people with severe dementia.

Further, participants with more education reported significantly more strategies, especially optimization strategies, as Table 3 indicates. The trend was similar for other strategy types but did not reach significance.

Disturbing factors when performing daily activities

The majority of participants reported to be able to concentrate only on the activity under hand and were unable to ignore disturbing factors such as conversations, music, radio, leaf blowers, rustling of a newspaper, ringing bells, mobile and landline phones, vacuum cleaners, or telephone calls not related to the performed action. For example, 'Conversations are a distraction, do not remember what I wanted...' (Participant 13, mild dementia), 'It bothers me when women talk about food and recipes incidentally while watching a soccer game because I want to concentrate on the game and the conversation distracts me' (Participant 3, healthy), 'So when I read, I like it quiet.

Without radio in the background, I have to focus on what's written' (Participant 14, healthy).

Variations in the autonomy level

The autonomy level reported varied greatly. Most participants with dementia were aware of their lost autonomy as they reported more support and help from others to execute daily activities or the activities were taken over completely albeit their lack of awareness of the problems when asking explicitly after. For example, 'Somebody comes every second week, iron a bit and clean-up' (Participant 21, severe dementia), 'My daughter-in-law does everything every day, drives me to the hairdresser, always looks after me, helps me' (Participant 23, severe dementia). Participants without dementia reported no changes in autonomy level regarding their daily life.

DISCUSSION

There is a lack of understanding of how age-related cognitive impairments affect subjectively experienced problems in managing daily life. The aim of this study was to assess these problems and the strategies that people developed to help prevent difficulties. Our findings confirm that increasing cognitive impairment comes with significantly more problems, even though people with severe dementia tend to not recognize their problems. While awareness of memory performance becomes inaccurate with increasing cognitive loss,^{8,27} people with severe dementia still correctly rate their daily activity performance.^{28,29} It is likely that cognitive loss leads to diminished expectations for performance in daily life, which ultimately comes with a lack of awareness of problems. The perception of a problem requires the interpretation of the situation in a broader context and this ability seems to be impaired in dementia patients. Consequently, people with severe dementia see no reason for concern.

Regarding the perceptions of problems in daily life, participants reported disturbing factors, such as conversations, noise, and stress as well as the loss of autonomy, to such an extent that we felt we have to report these results here. First, the relevance of disturbing factors might be underestimated in the living environments of people with dementia and solutions should ultimately be developed. Second, the loss of autonomy in the conduct of daily life is a natural consequence of cognitive loss, and at the same time a

Table 3 Formalized qualitative results including the mean and standard deviation (SD) of generated strategies and tools according to educational background

	Mean (SD) Total	E	UE	t-test		
				P	df	t
Strategies	1.68 (1.95)	2.86 (2.48)	1.22 (1.56)	0.0582	23	1.99
Unrecognized strategies	0.96 (1.34)	0.29 (0.76)	1.22 (1.44)	0.1180	23	−1.62
straSELEC	0.16 (0.37)	0.14 (0.38)	0.17 (0.38)	0.8900	23	−0.14
unSELEC	0.68 (1.03)	0.29 (0.76)	0.83 (1.10)	0.2403	23	−1.21
straOPTI	0.52 (1.05)	1.29 (1.38)	0.22 (0.73)	0.0189	23	2.53
unOPTI	0.24 (0.52)	0.00 (0.00)	0.33 (0.59)	0.1564	23	−1.47
straCOMP	1.04 (1.06)	1.57 (1.27)	0.83 (0.92)	0.1200	23	1.61
unCOMP	0.04 (0.20)	0.00 (0.00)	0.06 (0.24)	0.5443	23	−0.62
straEXT	0.88 (0.93)	1.43 (0.98)	0.67 (0.84)	0.0636	23	1.95

E, participants with ≥ 12 years of education; UE, participants with < 12 years of education; straSELEC, number of reported selection strategies; unSELEC, number of unrecognized applied selection strategies; straOPTI, number of reported optimization strategies; unOPTI, number of unrecognized applied optimization strategies; straCOMP, number of reported compensation strategies; unCOMP, number of unrecognized applied compensation strategies; straEXT, number of reported external aids.

strategy for functioning in daily life despite cognitive loss. Dependency on other people becomes ultimately stronger during the course of dementia. These social dependencies then ultimately play a role in well-being.

Further, our findings provide information on strategy development. Strategies include orderliness, doing things immediately when they come into mind, making notes for appointments, and the use of a shopping list, mobile phone, and diary to help with daily activities. Strategies such as sorting things according to a particular schema, having prominent locations for certain things like keys, and keeping things in order are in line with previous studies.^{9,13} With decreasing cognitive status, strategy development, especially compensatory strategies including using external aids, decreased. In our study, only healthy people and those with mild dementia reported awareness of problems with daily living activities and the development of strategies. It should be noted that the observed adaptive performance in our study is common with ageing regardless of dementia and can be described by the dual-process model of assimilative persistence and accommodative flexibility, in which compensatory activities are important for maintaining functioning until compensatory efforts become too demanding and exceed the limits of resources.^{30,31} Support for this explanation is also found in the observation that more highly educated people tended to develop more strategies than less well educated people,²⁶ as our findings confirm, because education is considered to give people more competencies in dealing with challenges.

As far as we know, our study is the first to show that despite the initial memory loss at an early stage of dementia, strategies are still being developed to solve perceived everyday problems. This means that new information can be added to an existing repository. When problems are perceived, dissatisfaction and self-doubts begin.^{32–34} By learning new strategies and behaviours that help in avoiding problems, general well-being can be increased. A study from Ghazanfari and Ghadam³⁵ shows that strategy use is related to mental health in terms of anxiety, depression, social function and physical disorder, so that it is all the more important to implement strategy training for older people to strengthen functional ability as well as mental health. For people in more severe stages of dementia, however, strategy learning would only lead to frustration as cognitive resources are no longer available. More research is necessary to identify what are the best strategies that should be taught, and at what stage of cognitive impairment.

There are some limitations that should be mentioned. As we only investigated peoples' perception of their own problems, we evaluated only a subjective perspective. A quantitative measure objectively counting problems and strategies does not yet exist, but could provide more insight. Further research may also consider conducting interviews with key informants to enrich the findings. Our findings cannot fully be generalized since we did not control for dementia subtypes. Including a neurological assessment with imaging data as well as investigating a larger sample size for each cognitive status group would provide a better understanding.

CONCLUSION

Cognitive loss leads to impairments in managing daily life, of which people in the early stages of dementia are aware, as our findings show, and for which they actively develop appropriate strategies. In more severe stages, however, problem awareness decreases even though the interpretation of daily activities and the autonomy level remains accurate. These findings highlight that patients' expectations about managing daily activities decrease over the course of the disease to such an extent that people feel problem-free despite of their state of dependence and inability. Because of the reduced expectations regarding daily life, caregiving activities should prioritize the well-being of patients in severe stages over the functionality of daily activities. This could be achieved by incorporating memory stimulation with familiar objects, bibliographic work with photobooks, or sensory procedures such as aromatherapy or massage, into the care plan.

AUTHOR CONTRIBUTIONS

SR: Conceptualization, methodology, formal analysis, investigation, writing—original draft, validation, data curation, visualization, project administration. JK: Conceptualization, methodology, formal analysis, writing—review and editing. FR: Conceptualization, methodology, formal analysis, investigation, resources, writing—review and editing, supervision, project administration, funding acquisition.

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ETHICS STATEMENT

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human

experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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