

Self-initiated management approaches in everyday occupations used by people with acquired cognitive impairment

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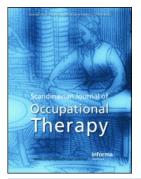
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ORIGINAL ARTICLE



Self-initiated management approaches in everyday occupations used by people with acquired cognitive impairment

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ARSTRACT

Background: Striving to cope with day-to-day challenges is a basic human behaviour. Self-initiated management approaches provide a resource that has yet to be discovered and systematically used in occupational therapy practice. This resource might be especially important for people with dementia who are less likely to adopt management approaches initiated by others. Aims/objectives: Based on the findings of former studies on management and problem-solving actions among people with cognitive impairment, this article aims to identify and categorize the study participants' self-initiated management approaches and how these may be manifested in strategies in everyday occupations.

Material and methods: The study utilized a form of meta-synthesis; an aggregated analysis, where findings from 11 studies published 2004-2020 were compared and categorized, incorporating the views of participants with dementia/mild cognitive impairment, or acquired brain injury.

Results: Thirty strategies were identified and grouped into seven categories of management approaches, used in a variety of everyday occupations and situations. A majority of the strategies were found in both populations, suggesting that management approaches are more similar than different across populations with cognitive impairment.

Conclusions and significance: Attending to the rich variation of self-initiated management approaches/strategies among persons with cognitive impairment offers possibilities for developing occupational therapy interventions.

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KEYWORDS

Agency; acquired brain injury (ABI); dementia; everyday rehabilitation; mild cognitive impairment (MCI); problem-solving

Introduction

Throughout their history, occupational therapists have continuously searched for new ways to facilitate their clients' management of their occupational lives. In agreement with Burns et al. [1], we propose that striving to cope with day-to-day challenges is a basic human behaviour regardless of health status or disability, both within familiar as well as new occupations, environments and situations. This means that all humans use a variety of management approaches; manifested in a variety of response actions or strategies in their everyday lives—although this has received little attention in research. Such self-initiated management approaches provide a resource still to be discovered and systematically used in clinical occupational therapy practice to support our clients' management in everyday life. This resource is particularly important for clients with cognitive impairment, who often are less likely to adopt management approaches initiated or invented by others [2,3]. Consequently, in this study we set out to identify and categorize selfinitiated management approaches and strategies from

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empirical research among people with cognitive impairment with the intention to increase the awareness of such strategies among occupational therapists and other health professionals, as well as researchers.

Cognitive impairment follows from many conditions such as progressive dementia, stroke or other acute acquired brain injuries (ABIs). The consequences and potential for systematically using self-management approaches might differ depending on the condition causing the cognitive impairment. While rehabilitation in the field of ABI rests heavily on selfmanagement programs facilitating the clients' management approaches and strategies in everyday life [4,5], this is not the case in the field of dementia. In the past, it has often been thought that people with cognitive impairment due to dementia (i.e. a progressive, irreversible neurological condition) have a lack of awareness of their disability and consequently are less able to learn new or consciously prevent and solve problems in everyday life [2]. This view has been challenged and more recent studies have shown that problem solving still can be preserved and supported in everyday life among people with mild to moderate stages of dementia [6], although these people may have difficulty consciously implementing management strategies suggested by others [7]. In line with this, it has been proposed that self-generated information or habits are more likely to be maintained among people with cognitive impairment than instructions provided by other means are [8,9]. This supports the idea of systematically attending to and supporting self-generated strategies used by the person with dementia rather than externally generated ones [1,7]. If occupational therapists were prepared to pay attention to such self-initiated strategies and support those that seem to work well, they could help to support ones that would be likely to benefit their clients' maintenance of agency and autonomy in managing their everyday lives. Taking this point of view, we set out in this study to compile empirical evidence of self-initiated management approaches and how they translate into strategies that are used, spontaneously or planned, among people with cognitive impairment due to dementia, mild cognitive impairment (MCI) or acquired brain injury (ABI) in order to prevent and overcome challenges in daily life occupations.

Self-initiated strategies have been defined in many different ways in the literature. Within occupational therapy, Toglia et al. [9,p.226] defined strategies as 'tools or plans of action used for accomplishing a task or achieving a purpose'. They also stated that strategies are always goal directed and include 'the

application of "how to" knowledge' [9,p.226]. Notably, according to Toglia et al., in essence cognitive strategies are related to mental plans of actions approaching *new* tasks in everyday life, linked to both learning, problem solving and adaptation. Based upon our interest in (older) adults with dementia, MCI or ABI, such a focus on *new* tasks and learning is less applicable.

Even if the conceptualization of our diagnostic population's primary disability is mainly cognitive in nature, this is not to say that all their approaches to manage everyday life are purely cognitive. Hence, we have chosen not to categorize the strategies as cognitive. This is because we focus on the self-initiated actions in response to challenges in everyday life without classifying them according to the nature of their origin. Rather, we view the approaches and strategies as dynamic meaning-making in the moment by moment transactions in everyday life occupations and situations that by far exceed the cognitive domain. This view is inspired by the pragmatist and transactional approach originating from John Dewey [10,11]. People are seen as inquirers who continuously seek to overcome problems they meet in any situation they engage in [12]. In this ongoing process, transactions take place 'through which habit, context, and creativity are coordinated towards a provisional yet particular meaningful outcome' [11,p.164]. This means that whenever problematic situations are expected or encountered, peoples' creativity in thoughts and actions is stimulated and enacted in a continuous process of transactions (e.g. through restructuring the environment, adapting ones behaviour and actions) in order to achieve relative harmony [10,13]. As this view does not separate person and environment, this means that strategies cannot be divided into common categories such as internal and external ones, as other researchers have done [1]. Rather, in our view, person and environment are part of and creating each other. This also applies when it comes to management strategies in everyday occupations. Furthermore, it is also worth noting, that based upon this view, management strategies may be planned and preventive, as well as an immediate response to the situation without explicit awareness [12]. Even more importantly, our focus emphasizes the value of the views of people with cognitive impairment and how they strive to manage, acknowledging their competencies and agency.

Notably, we differentiate management strategies in everyday life occupations from general life management strategies [14] and coping [15]. However, we do

not focus on specific activities of daily living, ADLs, as Tomaszewski Farias and colleagues [8] did in their questionnaire where concrete management strategies were sorted under six areas of daily living, e.g. shopping, cooking, transportation, with particular strategies being explicitly tied to each of these activities. In contrast, our exploration and categorization of management approaches and strategies leaves this open; the approaches and strategies we present are general and applicable in different activities and areas of daily living, with the intention being to provide a generic overview. One reason for this is that we intend to use this overview to create a screening tool that is as widely applicable as possible in clinical work as well as in research, which will be reported elsewhere. Further, Tomaszewski Farias et al.'s [8] strategies were drawn from literature and provided by expert scientists; the intended questionnaire respondents in their study were proxies for persons with and without cognitive impairment. In contrast, the strategies we aim to identify in our study are all self-initiated and used by people with cognitive impairment, found in explorative empirical research focussing on these people's own views. With this choice, the intention of our study is to build on findings from earlier research to emphasize the perceptions that people with cognitive impairment have of their management strategies, rather than focussing on their proxies' perceptions. Based on the findings of our former studies on management and problem-solving actions among people with dementia, MCI or ABI, this paper aims to identify and categorize the study participants' selfinitiated management approaches and how these may be manifested in strategies in everyday occupations.

Methods and material

The identification and categorization of self-initiated management approaches and strategies is based upon published, empirical research from two research teams in Sweden (Karolinska Institutet, KI, and Luleå University of Technology, LTU). This research applied an aggregated analysis of findings from 11 studies published between 2004 and 2020 as well as incorporating participants with MCI, mild to moderate stage dementia, or ABI. All included studies had received ethical approval.

An aggregated analysis is a form of meta-synthesis where previous findings from earlier, qualitative studies are analysed [16], but it does not include a reanalysis of primary data from those studies. It is recommended for pockets of research that have been created within a specific area or a team of co-workers, especially in qualitative research. We took the point of departure in the findings of an earlier aggregated analysis of management strategies, initiated and used by participants with mild to moderate stage dementia, based upon seven empirical studies [17]. Based upon our awareness of more recent research findings within our research groups, we knew that the categorization of strategies presented by Nygård [17] was inconclusive [18,19]. Hence, we continued to systematically search for strategies in later studies from our research groups; i.e. management approaches and strategies found in samples with ABI (Larsson Lund's research group) and in samples with MCI or mild to moderate stage dementia (Nygård's research group), treating the latter as a combined population. This was based upon a former study showing that the management strategies among people with MCI or mild to moderate stage dementia seemed to be more similar than different [12].

As recommended by Estabrooks et al. [16], we decided that eligible publications should focus on similar populations (i.e. in this case similar in terms of cognitive impairment due to MCI, dementia or ABI), use similar research approaches (i.e. qualitative approaches) and all findings must be clearly rooted in empirical data. The publications should also provide an adequate theoretical ground in that they all should describe or illustrate links or relationships between concepts [19]. The first and last authors (LN and MLL) checked findings from potentially relevant studies. The final literature comprised of 11 published studies [7,12,13,17,20-26], one of which [17] was built on seven empirical studies. Some of these studies had explored management strategies in everyday life activities in general, while others had focussed on the management of everyday technologies, ETs, within daily life activities (See Table 1).

We performed a continued aggregated analysis by a back and forth process of comparing and contrasting the descriptions of management approaches and strategies found in these 11 studies until consensus was achieved and no new management strategies were identified. As a result of the expansion based upon new data from the more recent publications, we relocated some strategies from Nygård's study [17] to another category—i.e. another approach type—than the original one. Further, we refined and renamed some of the original strategies based upon the additional data from the studies included. For example, the original strategy 'Isolating objects or sequences' [17] was now called 'Taking one thing at a time, one

Table 1 Overview of the analysed studies: participants and methods

Study	Participants	Methods of data collection adopted	Form of analysis adopted
Brorsson et al. [13]	Six persons with Alzheimer's Disease (AD), mild stage	Individual interviews in homes and participatory observations in public space	Grounded theory
Brorsson et al. [20]	Six persons with AD, mild stage	Two focus groups in combination with photo elicitations, and individual interviews	Grounded theory
Hedman et al. [21]	Five persons with MCI and one person with AD, mild stage	Repeated individual interviews (two occasions)	Grounded theory
Rosenberg and Nygård [12]	10 persons with MCI and 10 persons with AD, mild stage	Individual interviews in homes	Grounded theory
Rosenberg and Nygård [7]	Seven persons with AD, mild to moderate stage	Individual interviews and participatory observations in homes (one occasion)	Phenomenological interpretative approach
Nygård. [17]	Seven empirical studies, with in total 33 persons with mild -moderate stage dementia and 10 secondary informants	Interviews in homes (one study in clinic), and participatory observations in homes and surroundings; data collected at single or repeated occasions, or longitudinally (3 years)	Aggregated analysis. In the Seven studies: comparative analysis, hermeneutic interpretation, phenomenological interpretative method, case analysis
Häggström et al. [22]	11 persons of working age with Acquired Brain injury (ABI)	Qualitative interviews in homes or clinic setting	Content analysis
Larsson Lund et al. [23]	13 persons of working age with ABI	Qualitative interviews and observations in homes	Grounded theory
Kassberg et al. [24]	Nine persons of working age with ABI (seven moderate disability, two severe disability)*	Qualitative interviews and observations in workplaces	Constant comparative method
Olofsson et al. [25]	Eight persons of working age with ABI (seven moderate disability, one good recovery) ^a	Qualitative interviews on 2–4 occasions in home or the investigators office	Constant comparative method
Olofsson et al. [26]	Two persons of working age with ABI (both moderate disability) ^a	Repeated semi-structured interviews and participatory observations in home and community/public places	Narrative analysis

^aAccording to The Glasgow Outcome Scale Extended (GOSE). Severe disability includes people who are dependent on assistance. Moderate disability include people who are independent in activities in daily life but are not able to resume their previous capacity to perform work, leisure, and social activities. Good recovery includes people who have no or only minor problems in daily life compared to those experienced prior their injury. This information was not available for studies 23 and 24.

step/action a time' and organized under the category Shaping up/Getting your act together. Other original strategies from Nygård [17] were split into more specified ones based upon the character of the new data. For example, the original strategy 'Support in the social environment' [17] was further developed, resulting in two distinct strategies: 'Asking for help, doing together or having someone around' and 'Leaving it to someone else', both in the category Relying on support from other persons. One reason for this emphasis on a concrete and self-explanatory language was that we aimed to develop this into a screening tool, presented in a forthcoming paper.

When the findings from an aggregated analysis are used to create a new categorization, it is necessary to also investigate if there are other research publications that would add new aspects beside those found in the pocket of research [18]. This is to make sure that the categories that are developed from this pocket of research will provide an adequate ground to identify a phenomenon. Therefore, a review of literature outside Larsson Lund's group was performed in parallel in the field of ABI [27], including research within the latest 15 years in the databases Pubmed, CINAHL, Psycinfo and Amed, and recent literature in the field of dementia outside Nygård's group was reviewed with a scoping approach. No new categories appeared from these steps. Later in the process, a third author, based in clinical practice (CR), was invited to critically reflect upon the strategies in terms of the appropriateness of their internal categorisations, their transparency, logic, and clarity [19]. Moreover, collaborators from a variety of disciplines were also engaged in the work for the same reason (AA, JB, AMPL, A-CN, MI). Finally, when consensus was reached on the categorization, the authors LN and MLL returned to the publications once more to reassure that clear evidence for each strategy was present.

Findings and comments

Thirty strategies were identified and grouped into seven categories of management approaches (Table 2). Each category describes an overall approach to management,



Table 2. Categories of management approaches and strategies and their origins in the 11 empirical studies.

Category of management approach	Ways of applying the approach; i.e. strategies	Origins in publications among persons with MCI or dementia	Origins in publications among persons with ABI
Using language as support	Writing; e.g. notes, reminders to yourself in the calendar	[13,17]	[23,24,25]
and any and an analysis	Utilising written material for support, e.g. cribs or	[12]	[23,24]
	instructions for use		. , .
	Talking aloud to yourself	[13,17]	_
Relying on support from other persons	Informing and/or showing others what works best for you, or how you would prefer things to be	<u> </u>	[22,23]
onici personi	Asking for help, doing together or having someone around	[7,12,13,17,20,21]	[23,24,25]
	Leaving it to someone else	[12,21]	[23]
	Learning new together with others	[7]	[24]
	Following others, do as other people do	[20]	_
Relying on support from habits and from what is well known	Holding on to your habits and routines	[7,13,17,21]	[23,26]
	Simply trying again, repeating	[12,13,17]	[23]
Relying on the body's patterns of habits	Showing objects, using body language and gestures e.g. if you lose words	[13,17]	_
,	Using memorized embodied movements, e.g. the bodily memory of codes	[7,17]	[23]
Reinforcing and relying on the senses	Leaving things visible, or memorizing visible cues	[13,17]	_
	Listening for sounds, e.g. in order to remember, recognize	[17]	_
	Touching objects in order to e.g. identify them, remember	[17]	_
	Being one step ahead, prepared	[17,20]	25
Shaping up/getting your act together	3	. , .	
-	Being particularly attentive or concentrated	[13,17,20]	[24,25,26]
	Going backwards in memory in order to e.g. find things, find the topic/thread	[13,17]	_
	Repeatedly controlling e.g. that you locked the door	[17]	[24]
	Taking 'one thing/activity a time', 'one step/action a time'	[17]	[23,24]
	Using associations e.g. in order to remember codes	_	[23]
Specifically selecting and prioritising	Specifically selecting WHERE you do different activities (based on e.g. light, sound, distance, usability,	[12,13,17,20]	[22,23,25]
	attitudes, safety and risk)		
	Specifically selecting WHEN you do different activities	[12,17]	[25,26]
	Making sure to have plenty of time at your disposal	[13,17]	[24]
	Using rests and brakes	-	[24,25,26]
	Using assistive devices/technology to e.g. recall, find the way, manage disturbing sounds	[7,12,17,21]	[23,26]
	Choosing not to use technologies/assistive devices/tools	[12,13,21]	[23]
	Planning activities over time, e.g. choosing not to do, or to prioritise activities	[13,20,21]	[22,23,25,26]
	Specifically selecting new social contexts and/or find new friends	_	[22]
	Searching for information about specific solutions, what kind of help is available	_	[22]

while the strategies show the variety of ways in which the approach was applied in the 11 publications. The management approaches and strategies were used in a variety of everyday occupations, as exemplified by quotes from data. Hence, they are not bound to specific occupations but often applicable across occupations and situations. The majority of the management strategies (18 out of 30) were found in empirical research among people with MCI or dementia as well as among people with ABI (see Table 2). Seven strategies were found only in publications based upon participants with MCI/dementia, spread over five of the seven categories. Similarly, five strategies were found solely in publications based upon ABI samples, with a spread across three categories. Their origin in publications is also reported in Table 2.

Using language as support

This approach embraces three strategies covering the utilization of written or spoken language in different ways. The first two were often used deliberately, while the third strategy seemed to be spontaneous and used without conscious intention.

Writing; e.g. notes, reminders to yourself in the calendar

This strategy built on the person's active writing in different ways, e.g. memos, reminders, codes and passwords. It was found in studies originated both from people with MCI/dementia and people with ABI.

MCI/Dementia: "One way was to bring a note that not only listed what to buy but also described what to do" [13,p.4].

ABI: 'Some participants had written their own notes... . This included ... reminders about when they needed to do tasks, such as vacuum-cleaning...' [23,p.170].

Utilizing written material for support, e.g. cribs or instructions for use

This strategy meant using text that already had been written by the person with cognitive impairment or by someone else. Also this strategy was found in both populations.

MCI/Dementia: 'The most common preventive management strategy was using written notes and printed instructions such as manuals for using the washing machine or the DVD player.' [12,p.668].

ABI: 'Some participants had written their own notes or used manuals when they used their ET. This included ... instructions on how to do tasks, such as putting on the washing machine.' [23,p.168]

Talking aloud to yourself

This strategy was only shown in research among people with dementia based upon participatory observations - but never told of in interviews. Hence it seemed to be purely spontaneous.

MCI/Dementia: 'The participants very commonly communicating spontaneously with themselves by talking aloud, although this strategy was never mentioned specifically. They seemed to guide themselves with ongoing commentaries and reasoning aloud, posing questions and replying, and naming aloud items they touched ...' [17,p.440]

Relying on support from other persons

This approach embraces five management strategies, where support from other people were used in different ways. These strategies seemed to vary in how consciously and deliberately they were used, ranging from the most deliberate *Informing and/or showing others what works best for you, etc.* to the spontaneously applied *Following others, doing as other people do.*

Informing and/or showing others what works best for you, or how you would prefer things to be

This strategy was found only in people with ABI who deliberately instructed and explained their condition or predicament to others in order to help others to give them appropriate support.

ABI: 'Another way to enhance their sense of participation was to explain how they felt and what they could do and demonstrate their capability to others. This was a way to correct others' false perceptions, and also a way to reach out to others.' [22,p.93]

Asking for help, doing together or having someone around

With this strategy, people with MCI/dementia or ABI strived to maintain active engagement in occupations, facilitated by getting help from someone, or just by the mere involvement or presence of another person.

MCI/Dementia: 'May relied on being able to get help from the salesman in the shopping mall to solve immediate problems with her new cell phone.' [7,p.5]. 'Some of the informants preferred to walk with others, e.g. relatives, when the traffic situations were expected to be complex.' [20,p.1132].

ABI: 'Participants described their need to have colleagues nearby constantly whilst using ET as they made them feel safer during its operation and reduced stress because the participants could ask for support whenever errors occurred.' [24,p.278]

Leaving it to someone else

This strategy differs from the one above (i.e. *Asking for help*...) in that this one means that the person with MCI/dementia or ABI did not take part in the activity anymore but had left it to someone else.

MCI/Dementia: 'Brita seemed to experience it as a relief and even a privilege to have another person available who could free her from this task. She reasoned in a similar manner regarding her daughter-in-law taking over much of the housework, such as cooking and cleaning, which made Brita stop using household technologies like the vacuum cleaner.' [21,p.6]

ABI: 'After re-evaluation, the participants described that they acted simply by not doing the task that included ET, e.g. watching a movie on the DVD player, or left to others the tasks which included using ET, e.g. managing finances and buying travel tickets.' [23,p.170]

Learning new together with others

In this strategy, people with MCI/dementia or ABI took active and deliberate measures to learn new things together with others, emphasizing the social dimension of learning.

MCI/Dementia: 'May found it crucial to engage in new learning contexts after retirement and she had put herself in different situations where she could learn



together with others. She had, for example, taken courses in computer use and was engaged in a learning community where older adults support other older adults in computer-related skills.' [7, p.6]

ABI: 'Colleagues were also important when it came to learning how to use new pieces of ET; as one participant expressed it: "When I was going to do this for the first time [scan documents into the computer] I thought I will never learn to do it by reading instructions. I really tried, but I failed until someone showed me".' [24 p.278].

Following others, doing as other people do

This strategy was only found among people with dementia, shown when they trusted and imitated other peoples' actions and went along with these in the very moment of a situation.

MCI/Dementia: 'When the informants' trust in their own decisions became vague, they acted in the same way as other pedestrians; they reported that they followed the flow of pedestrians at the zebra crossing. This could mean that the informants could go even when the light turned red if a lot of pedestrians were crossing at the same time.' [20,p.1133]

Relying on support from habits and from what is well known

This approach embraces two strategies, both relying on habitual actions and routines as well as the use of actions and items that are well-known or repeated.

Holding on to your habits and routines

When this strategy was used by people with MCI/ dementia, it could be both deliberately and spontaneously applied. In the ABI-population it seemed to be mostly used deliberately.

MCI/Dementia: 'Marianne, May and Peter had purchased new cell phones and had all looked for models similar to their old ones with the idea that they could rely on their habituated repertoires of actions when facing the challenge of learning to use the new cell phone.' [7,p.5]

ABI: 'On the one hand, she needed routines to be flexible because of her daughter's needs; on the other hand, the consequences of the ABI required her to develop organized routines.' [26,p.198].

Simply trying again, repeating

This mostly spontaneous strategy was used in both populations. It meant that actions aimed at responding to difficulties appeared random or that the person simply repeated the same actions even if these actions just had failed.

MCI/Dementia: 'In shops, informants often just walked around in an unstructured way and hoped to suddenly find the intended product.' [13,p.6]. 'When using a trial and error strategy, participants said that they hoped they would get it right by chance or come up with an idea of how to solve the problem simply through doing.' [12,p.669]

ABI: 'Another category that emerged from the participants' descriptions and observations was the use of response actions that were random and inflexible. These responses were usually repetitive and ineffective as the participants tried to overcome the difficulty by continuing to apply the same action over and over again, without adjusting it or choosing another response.' [23,p.169].

Relying on the body's patterns of habits

This approach embraces two non-verbal strategies, based upon the use of objects, pictures, gestures or the body's habitual movements.

Showing objects, using body language and gestures; e.g. if you lose words

This spontaneous and bodily strategy was found in a variety of situations but only in studies with people with dementia.

MCI/Dementia: '... concrete details or objects such as photographs could assist participants in reasoning about abstract matters and general coherence (e.g., showing a photograph in order to explain "who" a person was). Body language was also used to compensate when verbal expressions were missing.' [17,p.441]. 'Another action was to signal to the drivers that they wanted to pass by, for example, raising a hand in the air, and one informant had found that raising her cane in the air made the drivers let her cross.' [13,p.5]

Using memorised embodied movements; e.g. the bodily memory of codes

Persons with MCI/dementia as well as persons with ABI were found to use habitual and embodied patterns of movement, for example in navigating in space and when codes were required. This strategy was used both deliberately and spontaneously.

MCI/Dementia: 'Peter said that he could partly use his habituated repertoire of actions when using the new cell phone ... ' [7,p.5]

ABI: 'The participants frequently described how they trusted their habitual positions and movement patterns of hand and fingers when they used ET that required a PIN code or a ticket machine.' [23,p.169].

Reinforcing and relying on the senses

This approach covers three strategies building on the senses of vision, hearing and touch, all found only in studies among people with MCI/dementia.

Leaving things visible or memorising visible cues

The visual strategy seemed to be used both deliberately and spontaneously among persons with MCI/ dementia, for example to provide wayfinding guidance and memory support.

MCI/Dementia: ʻAt home, the participants spontaneously or purposefully arranged environment to provide themselves with visible reminders. They also chose specific, strategic locations for objects, for example, giving important objects such as eyeglasses certain places for storage to minimize the ever-present risk of forgetting or losing them.' [17,p.438-439]. 'To enhance recognition of products in the shop and to choose the wanted products, informants carefully observed illustrations on products to understand their intended use. For example, they searched for pictures of cats to find cat or for other familiar packaging designs.' [13,p.6].

Listening for sounds; e.g. in order to remember, recognise

The auditory strategy seemed to assist some persons with MCI/dementia by providing reminders, planned or spontaneously used.

MCI/Dementia: '... sound was used to provide a reminder of urgent matters or of the time, for example, relying on announcements and program schedules heard on the television set as a reminder of clock time.' [17,p.439]

Touching objects in identify them, remember

This tactile, mostly spontaneous, strategy was found to assist some persons with dementia in recognising and identifying objects.

MCI/Dementia: 'The tactile sense was often used in combination with other senses by touching items and turning them around to inspect them from different perspectives in an obvious attempt to identify them, sometimes while simultaneously naming them aloud.' [17,p.439]

Shaping up/getting your act together

This approach covers six strategies that were mostly consciously used, all related to maintaining one's control, executing attention, and performing actions systematically by reversing in memory, checking repeatedly, avoiding simultaneous actions or steps, and by using associations.

Being one step ahead, prepared

This strategy was found in both populations, often viewed as an ideal but challenging ambition to be prepared and avoid problems before they would happen. While appearing to be deliberate, the strategy had to be spontaneously applied in a variety of situations in order to work.

MCI/Dementia: 'Another action to avoid the crowding at the zebra crossing was to wait some time before starting to walk on the green light when they did not want to jostle with the crowd of people at the zebra crossing.' [20,p.1132].

ABI: 'The participants said that planning preparatory tasks in detail was necessary for them to engage in occupations outside their homes. At the same time, planning and preparations were described as cumbersome, and their difficulties meant that sometimes planning and preparations were carried out and, at other times, they were not.' [26,p.490]

Being particularly attentive or concentrated

Similarly to the strategy Being one step ahead..., this strategy was often seen as an ideal and deliberately aimed for in both populations, but difficult to live up to in the moment in many evolving situations.

MCI/Dementia: 'A common action was to use extra caution and extra attention and observe carefully when crossing a road....They felt a need to really concentrate in order to relate to everything happening in the traffic situations.' [13,p.1133]

ABI: 'The participants expressed that the effort required to concentrate and attempt to ignore unnecessary stimuli while accomplishing tasks depleted their energy entirely.' [26,p.489].

Going backwards in memory in order to e.g. find things or the topic/thread

Reversing in order to pick up what just had been lost was usually spoken of as a deliberate strategy among people with MCI/dementia, but it was not found among those with ABI.

MCI/Dementia: 'They would pause in the middle of an activity, concentrate and focus their attention in order to regain control, but they also tried to retrace events retrospectively as for example in reversing and searching backward step by step when an item was mislaid.' [17,p.440]

Repeatedly controlling e.g. that you the door

To repeatedly double-check or control e.g. that actions had been taken was seen in both populations,



sometimes used spontaneously and sometimes deliberately planned.

MCI/Dementia: 'Yet another type of reinforced attentive behaviour was exhibited by the way that the participants checked and monitored their actions. One aspect was organizing routines to show when an activity was to be repeated or checking that certain actions had been performed to prevent undesired results, such as checking written reminders or notebooks many times a day in fear of forgetting something important.' [17,p.440]

ABI: 'Commonly used strategies were for the participants to ... engage infrequent double-checking of their own performance.' [24,p.278]

Taking 'one thing/activity a time', 'one step/action a time'

This strategy meant giving one aspect or step of an activity undivided attention, spontaneously or deliberately. It was used by people with MCI/dementia as well as people with ABI.

MCI/Dementia: '... some participants isolated objects or sequences of action that required their undivided attention. The data demonstrated that they isolated tasks or steps of a task, often performing one step of a task at a time (e.g., when preparing coffee and cake for a guest) in a time-consuming succession.' [17,p.439]

ABI: 'One common action was to take one step at a time when the ET was used, e.g. by taking time to stop, reflecting, and rechecking. This is illustrated by a description given by a participant while being observed: If I boil water, I take the kettle and then begin to think [stops and reflect] about how I should be able to choose the right knob. . I put the kettle on the ... then I confirmed for myself that it is the right hot plate [reflecting] I will use ... by feeling with the hand if the hot plate gets hot [rechecking] ... when I feel it gets warm, then I get the confirmation that it is the right hot plate [reflecting].' [23,p.167].

Using associations in order to e.g. remember codes This deliberate strategy was only found among persons with ABI.

ABI: 'Another response action... was the use of unreliable and complex memorizing when using ET that included the management of serial numbers or letters. This participant used a different memorizing system and related numbers to luck and bad luck, country codes or dialling codes, and letters of brand names of clothes companies.' [23,p.170]

Specifically selecting and prioritizing

This final approach embraces nine different strategies, all characterized by deliberate choices and precautions in terms of preferred places and times, allocating enough time for activities as well as for rest and choosing how activities are sequenced into patterns, selecting or refuting technologies as well as social relationships and services.

Specifically selecting WHERE you do different activities (based on e.g. light, sound, distance, usability, attitudes, safety and risk)

Selecting the potentially best place for the intended activity involved deliberate decisions and often also planning. This strategy was found in both populations.

MCI/Dementia: 'To avoid getting lost, informants commonly went to small shops within walking distance of their homes.' [13,p.5]. 'Commonly, participants ... avoided stressful situations when using demanding technology, for example by choosing a calm place and time when using the cell phone or cash machine.' [12,p.668]

ABI: 'The participants described how minimizing disturbances in the environment and ensuring peace and quiet during their task performance were common types of response actions.' [23,p.168–169]

Specifically selecting WHEN you do different activities

This strategy could mean different types of time considerations based upon a variety of reasons: choosing an optimal time of the day, or choosing immediate action to avoid forgetting, or planning an ideal sequencing of activities during the day. The strategy was found in both populations.

MCI/Dementia: 'Furthermore, some immediately did what they felt had to be done to prevent forgetting the task.' [17,p.439]

ABI: 'She said, "I had made reservations for a specific table early in the evening because I thought it would be quiet and less people".' [26,p.199]

Making sure to have plenty your disposal

For a variety of reasons, allowing extra time for an activity or situation was a deliberately used strategy among people with dementia as well as among those with ABI.

MCI/Dementia: 'Many participants paced themselves by making sure that there was always a surplus of time to avoid stressful situations. Allowing additional time was understood as compensation for an inability to keep track of time and for difficulty speeding up or managing stress.' [17,p.439].

ABI: 'The participants needed to spend extra time and make a greater effort to carry out their work tasks with ET than would normally required.' [24,p.277-278]

Using rests and brakes

This conscious use of basic energy saving through resting or taking brakes was only found among people with ABI.

ABI: 'For some participants, the difficulties that they experienced in using the ET meant that they were forced to take breaks whilst performing their work.' [24,p.277]. 'Their engagement outside the home also resulted in the need to rest upon returning home, and several participants described needing to rest the next day as well.' [26,p.489]

Using assistive devices/technology to e.g. recall, find the way, manage disturbing sounds

Devices and everyday technologies, ETs, were to some extent used as support in both populations.

MCI/Dementia: 'Occasionally, small tape recorders and calendars, diaries, hourglasses, kitchen timers, adapted watches, and alarm clocks were used as reminders.' [17,p.442]. 'For example, a woman with MCI told how she was guided by the computer program when using Internet banking. She trusted that the program would communicate to her how she should proceed to get the financial transaction right.' [12,p.671]

ABI: 'Some participants had also purchased new ETs to be able to use another ET. For example, a GPS and a digital camera were used to find the way to public transport...' [23,p.169]. "When I go out for a walk or go to the store, I plug in the ear-phones that block out all sounds and they must be tight and the music needs to be high enough to disturb all other sounds, then it works. I can be in my own little world". Shutting the world out was a strategy that John had developed to avoid unexpected events and distracting stimulation other than the music he chose.' [26,p.200].

Choosing not to use technologies/assistive devices/tools

Also refuting or decreasing one's use of ET showed as a deliberately used strategy in both populations.

MCI/Dementia: 'When her cognitive impairments debuted Frida had tried using the Google calendar for reminders. However, she experienced the reminders as very stressful and switched back to using her usual pocket calendar, despite having recurring problems remembering to check it ... ' [21,p.6]. 'For example, a man with MCI said that he had given his calculator to his grandchildren because he found it too complicated to use.' [12,p.668]

ABI: 'One participant also described how ... she had limited the time and number of ETs used.' [23,p.169]

Planning activities over time, e.g. choosing not to do, or to prioritise activities

How activities were organised over the course of a day or a week was an often deliberately planned strategy found in both populations.

MCI/Dementia: 'It could also be a conscious strategy, as for Eric who had stopped watching TV with his wife in the evenings. Knowing that he at that time of the day did not have enough energy left to follow the plot of a TV program, he instead chose to go to bed early to read something "easily digestible".' [21,p.5]

ABI: 'The informants' experiences reflected how their participation was enhanced by prioritization of activities conducted with those who made them feel good, such as people close to them, persons who had their own experiences of having a disability and pets.' [22,p.93]. 'They not only carefully considered how risky a certain occupation would be but also weighed it in relation to the demand for other occupations that they needed to perform during the day or week, including work and household occupations.' [25,p.491]

Specifically select new social contexts and/or find new friends

Deliberately choosing to engage in new social relationships was found in the ABI population, but not among people with dementia.

ABI: 'Yet another strategy was to get involved in new establishing social contexts by relations.' [22,p.93]

Search for information about specific solutions, what kind of help is available

Also this conscious strategy of searching for information or for available resources was found only among people with ABI.

ABI: 'They also sought out information from different sources to inform them of their options and rights.' [22,p.92]

Discussion and conclusions

The findings show that six out of seven management approaches were found both in studies among people with MCI or dementia and studies among people with ABI, suggesting that management approaches are more similar than different across these populations with cognitive impairment. Only the approach Reinforcing and relying on the senses, applied as three strategies, was solely based on studies in the MCI/ dementia population. Additionally, the majority of all management strategies (18 out of 30) were found in empirical research in both populations (see Table 2). Seven strategies were found only in publications based upon participants with MCI/dementia, and five strategies solely in publications based upon ABI-samples. It is however important to note that the 11 studies

that our analysis is based upon had been undertaken with a variety of aims (see Table 1), consequently with a similar variation in foci in findings in each study. It is therefore likely that some strategies that showed in one of the two populations could be found in the other population in new studies. This suggests that continued research is necessary to investigate the transferability and usability of these management approaches and strategies across populations with cognitive impairment due to a variety of causes.

Interestingly, many strategies in our findings were used both spontaneously and deliberately by both populations. In our view, a strategy does not have to be consciously planned—it can just as well be spontaneously used in the moment [11,17]. Such momentary strategies are likely to be more common among people with dementia because of their memory impairment and lower ability to make general assumptions about what problems might appear in forthcoming situations [2]. From our perspective on management strategies, transactions develop in the continuous interplay between peoples' actions and context in any specific situation [10]. This means that management strategies cannot be understood as separate entities: for example, as outcomes of a person's cognition, but only as organic phenomena in interplay with others in each situation. This is also a reason for our recommendation that therapists should pay attention to different kinds of strategies that their clients make use of, including the spontaneous and momentary management strategies, as well as noting the situation and context that might influence how it works. Attention to this complexity is likely to be decisive in clinical practice: Some strategies might be supported and strengthened in some situations if made more conscious, but the person might just as well need support to abandon strategies that are used but do not help him or her [17].

The categorisation displays the rich variation in management strategies and unpack well-known and taken for granted aspects, as exemplified in the category Relying on support from others. This category eventually came to embrace five different strategies that together show extensive breath, from Informing others what works best for you, to Following others, doing as other people do. If we in clinical practice want to support our clients' own strategies, supporting either of these two strategies would differ profoundly, suggesting that we need to look more closely also at common aspects such as support from others. Moreover, some strategies seem to be less useful, or even likely to bring about risks, such as the example we gave in Following others..., where pedestrians with dementia chose to follow the crowd at zebra crossings [20]. Acknowledging each person's own management resources is likely to strengthen the person's agency, which is fundamental for wellbeing [28], but this also requires better insights into how management strategies are used and how useful they might be for each person. The richness of our findings suggests that attending to the identified management approaches/strategies in programs supporting active everyday life among persons with dementia or ABI has potential to develop rehabilitation. Based upon explorative studies with people with dementia [7, 12], we propose that occupational therapists need to pay more attention to how people with cognitive impairment try to maintain their know how and strive to learn, because the individual's view of him-/ herself might be more decisive than limited to their cognitive functioning, for example.

The results, in terms of the management approaches and how these were applied as strategies, turned out to be rich and covering an extensive variation of occupations, situations and environments. Yet we do not know if there are other self-initiated management approaches or strategies to be added to this categorizations, or if the present strategies could be further refined to better mirror the management strategies of people living with cognitive impairment [18]. In the examples presented in our findings, it is striking how large the variation of application situations is both within and across strategies. How occupations are performed, and what objects are used (e.g. devices) change continuously, and therefore too specific and concrete strategies will soon be outdated. This means that a categorization where strategies are defined as specific tasks, e.g. such as the one developed by Tomaszewski Farias et al. [8], seems more limited, because the items might not be generally applicable across everyday occupations. Furthermore, some strategies and situations were more commonly exemplified than others in the 11 studies we analysed. Yet, we chose not to report this aspect in the findings because there might be many different reasons for a strategy to having appeared often or seldom, the most apparent being the specific aims of the included studies. Similarly, although some of the 11 studies reported how useful or challenging certain strategies were as perceived by the participants in specific situations, we chose not to include that aspect in this analysis. This is mainly because that topic is important in its own right: as the approaches and strategies we identified can be applied in so many different situations and for so many different reasons, their qualities and usefulness are likely to be equally varying across individuals and situations. Research is needed to investigate all these issues.

Methodological considerations

As with all methodological approaches, the aggregated analysis [16] comes with potential risks. The main risks are that the authors of the original publications may have misinterpreted the data, or that those publications are weak, either of which would interfere with the validity of original findings that are used in the aggregated analysis. To avoid this, familiarity with the original studies is highly recommended, as well as the analysis being undertaken by senior and experienced researchers [16]. In the present study, the main analysis was performed by the two senior research group leaders (first and last authors), who were very familiar with the original studies as well as with each other's work. However, as this might bring about a high level of subjectivity, we invited co-authors from the clinical field and from a variety of disciplines later in the process, to serve as a critical audit of the emerging categorisation. This step led to minor refinements and clarifications, but no major amendments.

It is also worth noting, that the aggregated analysis was first introduced to create mid-range theory from qualitative research [16]. As our main aim with this categorisation of self-initiated management strategies was to eventually develop a tool to support practice, we were also influenced by the guidance from Gilgun [18]. This led us to pay more attention to pragmatic issues, for example that the phrasing of the categories should work in forthcoming interviews rather than viewing them as building-blocks of a theory. Our next step is to test this categorization in the form of a screening tool to be used as a dialogue support in interviews with people with cognitive impairment due to MCI/dementia or ABI. By this, we aim to explore how this tool can be used in clinical practice and research, shedding further light on management approaches among people with cognitive impairment, how they work, and how they can be supported.

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