Responses of Persons With Dementia To Challenges in Daily Activities: A Synthesis of Findings From Empirical Studies

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OBJECTIVES. The purpose of this study was to obtain a better understanding of strategies initiated and used in response to problems in performing daily occupations by persons with dementia in a mild to moderate stage.

METHODS. The results from seven in-depth, qualitative studies conducted by the author and coworkers describing such response strategies were analyzed and synthesized using aggregated analysis. Synthesized categories describing different types of response behavior were identified and the variations within them investigated.

RESULTS. In general, the strategies used by persons with mild to moderate dementia were intuitively employed and characterized as “common sense behavior.” The main goal of the strategies was understood as retaining a sense of control and mastery over everyday life matters. It is argued that the users implicitly or explicitly experienced a need to adapt; further exploration of how awareness of ability and disability in daily life occupation may be experienced and expressed in persons with dementia seems important.

CONCLUSION. Findings suggest that therapists and caregivers be open to detecting and supporting the response strategies used by persons with dementia as long as they appear to be useful from the perspective of the individual rather than strictly from an efficacy point of view.


Dementing diseases such as Alzheimer’s disease have a major disabling impact on the afflicted individuals’ ability to perform everyday occupations (American Psychiatric Association [APA], 1995), giving rise to major adaptive needs to meet occupational challenges. However, according to the Model of Occupational Adaptation (MOA; Schkade & Schultz, 1992a) persons with dementing illnesses are likely to face great difficulty in daily occupations because of their inability to respond to problems and to evaluate and integrate their responses. In order to develop supportive interventions, occupational therapy—defined by Frank (1996) as the science of adaptive responses—needs knowledge of the actions people take to counteract challenges to everyday occupations, as well as of the interfering mechanisms and conditions. There is little literature concerning adaptive responses that are initiated and used by persons with dementia and similar progressive diseases. In a series of qualitative, in-depth, empirical studies by this author of small samples of participants with dementia in its mild to moderate stages, the participants’ actions and efforts at problem solving in daily life have been explored. Although findings of these studies cannot be widely generalized, they provide an opportunity to develop our knowledge through a synthesis of the characteristics of responsive behaviors and adaptations found in persons with dementia using a method of aggregated analysis (Sandelowski, Docherty, & Emden, 1997).
Literature Review

Research evidence shows that persons with dementia are unlikely to learn new strategies for improving memory function or performance in everyday activities (Brodarthy & Lie, 1998; De Vreese, Neri, Fioravanti, Bellio, & Zanetti, 2001). Since they encounter an ever changing situation as the disease progresses (Agüero-Torres, Fratiglioni, & Winblad, 1998) adaptive strategies seem highly needed to cope in everyday life. However, in contrast to the traditional view of massive cognitive loss in dementia, findings in the field of cognition indicate that persons with mild dementia retain their ability to solve complex problems in daily life relatively well (Willis et al., 1998). This may be due to the association between higher-order cognitive skills and problem-solving abilities, which suggests that persons with mild dementia are capable of making relatively realistic estimations of their competence (Willis et al.). Other findings similarly suggest that persons with mild dementia may be aware of their cognitive deficits despite failing to comprehend their severity (Clare, 2003; Phinney, Wallhagen, & Sands, 2002). Moreover, when persons with dementia respond to problems they are most likely to use subconsciously employed strategies (Cotrell, 1997; Derouesné et al., 1999). Since they fail to fully comprehend the severity of their cognitive deficits, it seems likely that they have difficulty comprehending and consciously responding to the consequences of these deficits in everyday occupations. Hence, Rusted, Gaskell, Watts, and Sheppard (2000) concluded that since persons with dementia are less likely to initiate strategies that require a conscious effort such as memorizing, intuitive and incidentally applied strategies would be most effective for them.

These current understandings concerning adaptive strategies in persons with dementia stems mainly from deductive studies designed to evaluate the effectiveness of specifically identified strategies, the main focus usually being on memory functioning. For instance, one such study evaluated the effectiveness of schemata, defined as “knowledge structures or sets of expectations based on past experience,” as a memory support (Rusted et al., 2000, p. 350). They found that persons with cognitive decline were more likely to remember schema-consistent than schema-inconsistent items and suggest that this approach could be a promising route for optimizing episodic memory. Whether schemata consistency can be utilized to support the response to challenges in everyday activities is not known. However, the common emphasis on familiarity as a main facilitator of performance in dementia may be viewed as a parallel to schemata that are based on past experience.

Evidence has also suggested that the most fruitful way for persons with dementia to adapt to everyday cognitive and occupational challenges is by utilizing skills that are relatively well-preserved, such as implicit memory and procedural knowledge (Bäckman, 1996; Cotrell, 1997; De Vreese et al., 2001; Josephsson, Bäckman, Borell, Nygård, & Bernspång, 1994; Rusted et al., 2000). A few studies have investigated the utilization of preserved capabilities (i.e., procedural memory and performance), in the occupational performance of persons with dementia (Josephsson et al., 1993, 1994). These found some evidence that persons with dementia could use environmental support, building on procedural memory and performance of well-known tasks. However, none of the studies above took the subjects’ intuitive and individual responses into account.

From a theoretical perspective, it has been proposed that the less competent individuals become, the less able they will be to adapt to variations in the environment and that environmental resources are likely to be best used by persons with higher levels of competence (Lawton, 1985). While proactive adaptive behavior is known to involve the active adjustment of circumstances to meet an individual’s preferences (i.e., actively modifying the circumstances to obtain goals), reactivity in contrast implies adjusting one’s preferences to meet circumstances and the constraints (i.e., accommodating preferences and goals to obstacles) (Lawton, 1985; Slangen-de Kort, Midden, & van Wagenberg, 1998). Proactive adaptation for a person with dementia could involve using a speaking clock to be reminded of when it is time to get ready for a certain valued activity. In contrast, reactive adaptation could mean that the person withdraws from the activity rather than attempting to solve his or her problem to keep track of time. Each individual’s objective and subjective efficacy also influences the response: Low efficacy yields reactive or passive responses, whereas high efficacy is expected to promote proactivity (Knipscheer, van Groenou, Leene, Beekman, & Deeg, 2000; Lawton, 1989). Moreover, the perception of being in control over one’s behavior has been suggested to be more important for coping with problems than actual control (Slangen-de Kort et al., 1998).

In the MOA (Schkade & Schultz, 1992a, 1992b; Schultz & Schkade, 1997), the issue of adaptation involves not only the person and the environment but also the interaction between them. According to the MOA, the internal adaptive processes are driven by the striving for relative mastery, which is related to each individual’s values (Schkade & Schultz, 1992a, 1992b; Schultz & Schkade, 1997). Hence, both perceived efficacy and perceived control or mastery seem to be important aspects when adapting to disability.
In summary, empirical studies agree on the fact that persons with dementia can utilize support for remembering and functioning well into the course of the disease. However, they need more support than the healthy elderly do and they are less likely to use conscious strategies even when supervised. Consequently, identifying strategies that persons with dementia initiate and use without conscious implementation in their everyday occupations—rather than in experimental cognitive tasks—seems to be of the utmost importance to increase the knowledge of how caregivers and family members could best provide support (Gillies, 2001). Developing guidelines for better support of persons with dementia in mild to moderate stage is an issue of great importance, since improvements in diagnostic procedures and pharmacological treatment have led to longer time of living in community housing. Although occupational therapy promotes a client-centered ideology, very few publications target the issue of how persons use their own initiative to adapt. Consequently, the knowledge of how persons generate adaptive responses and of how adaptation takes place without conscious implementation needs to be developed (Crosson et al., 1989; Schultz & Schkade, 1997).

With this background, the primary aim of this study was to increase the understanding of adaptive and responsive behaviors in everyday occupation initiated and used by persons with dementia in a mild to moderate stage in relation to the restrictions imposed by the disease.

**Methods**

Aggregated analysis, a meta-analytical approach for qualitative studies (Estabrooks, Field, & Morse, 1994; Sandelowski et al., 1997), was employed in analyzing the results of a selection of qualitative, empirical studies that explored the management of daily life of persons with dementia. Aggregated analysis is a kind of meta-synthesis developed to make an in-depth analysis of isolated qualitative studies possible, with the aim being to deepen understanding and obtain interpretative explanations, rather than to produce a predictive theory. An aggregated analysis is suggested to be well-suited when pockets of research have been created, such as studies led by the same senior researcher in a specific area or in the same group of researchers (Estabrooks et al., 1994; Finfgeld, 2003; Sandelowski et al., 1997).

**Aggregation of Findings**

The author was one of the primary investigators in all of the seven studies included here (see Table 1). The following recommended selection criteria (Estabrooks et al., 1994)

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Methods of Data Collection Adopted</th>
<th>Form of Analysis Adopted</th>
</tr>
</thead>
<tbody>
<tr>
<td>i Nygård &amp; Borell, 1995</td>
<td>2 participants with early onset AD</td>
<td>Repeated observations (participant) and conversational interviews over 7 months in the home and in its immediate vicinity</td>
<td>Comparative analysis (Bogdan &amp; Biklen, 1992; Strauss &amp; Corbin, 1990)</td>
</tr>
<tr>
<td>ii Nygård, Borell, &amp; Gustavsson, 1995</td>
<td>2 participants with early onset AD</td>
<td>Repeated observations (participant) and conversational interviews over a 7 months' period in the home and in its immediate vicinity</td>
<td>Comparative analysis (Bogdan &amp; Biklen, 1992; Patton, 1987; Strauss &amp; Corbin, 1990), Hermeneutic interpretation (Ödman, 1985)</td>
</tr>
<tr>
<td>iii Nygård &amp; Borell, 1998</td>
<td>2 participants with early onset AD</td>
<td>Repeated observations (participant) and conversational interviews over 3 years in home and in its immediate vicinity</td>
<td>Phenomenological interpretative method; EPP method (Karlsson, 1993)</td>
</tr>
<tr>
<td>iv Nygård, Öhman, &amp; Borell, 2001</td>
<td>3 participants with dementia (7 workplace respondents*)</td>
<td>Interview with participants in clinic using an interview guide</td>
<td>Comparative analysis (Bogdan &amp; Biklen, 1992)</td>
</tr>
<tr>
<td>v Nygård &amp; Johansson, 2001</td>
<td>3 participants with dementia, 3 relatives*</td>
<td>Interviews (interview guide) with participants and relatives in a clinic</td>
<td>Comparative analysis (Bogdan &amp; Biklen, 1992)</td>
</tr>
<tr>
<td>vi Nygård &amp; Öhman, 2002</td>
<td>/ participants with AD, mild to moderate dementia</td>
<td>Repeated interviews (interview guide) and observations (participant and nonparticipant) in home and in its immediate vicinity</td>
<td>Phenomenological interpretative method; EPP method (Karlsson, 1993)</td>
</tr>
<tr>
<td>vii Nygård &amp; Starkhammar, 2003</td>
<td>10 participants with moderate dementia</td>
<td>Interview (interview guide) and observations (nonparticipant) in home</td>
<td>Comparative analysis (Bogdan &amp; Biklen, 1992)</td>
</tr>
</tbody>
</table>

*Same two persons in Study I, II, and III.
*Same two persons in Study I, II, and III.
*Same two persons in Study I, II, and III.
*Results from workplace respondents were excluded from this analysis due to their focus being adaptations undertaken by the workplace and not by the person with dementia.
*Results from relatives were included in this analysis because they focus on the management strategies of the persons with dementia.
were used to select the studies. Potential studies should focus on similar populations or themes, they should use similar research approaches, and the results of the selected studies (themes or categories) must be clearly rooted in the data. In total, the selected publications comprise 33 noninstitutionalized primary participants with dementia and 10 secondary informants. The selection of the studies was based on the researcher’s comprehensive knowledge of the empirical data, the methodology, and the theoretical frameworks used in each study, as recommended. The selection comprised all empirical studies exploring similar themes within this specific pocket of research and hence no potential study was excluded. In Table 1, an overview is provided of each study’s methods and participants.

**Method of Analysis**

The method of aggregating findings uses the results from already completed studies to perform a new analysis. No single method of qualitative analysis has been suggested as most suitable for aggregated analyses (Finfgeld, 2003; Sandelowski & Barroso, 2003). Rather, the researcher embraces and conceptualizes former categorizations when performing the synthesizing analysis, with the aim to enlarge the interpretive possibilities of findings and constructs (Sandelowski et al., 1997). Hence, the aggregated analysis was performed by comparing and contrasting former results across studies, as recommended (Estabrooks et al., 1994; Sandelowski & Barroso, 2003). In this process, all the response strategies of the participants that were described in each of the seven studies were compared to each other to determine the nature of the responsive behavior. The following question was first posed: “What takes place and what actions are taken by the participants in each identified strategy?” Eventually this comparison of the content of the former results led to new categories of strategies being created in a recategorizing process.

This initial recategorization was followed by a recontextualizing procedure (Estabrooks et al., 1994) with new questions being formulated as follows, “How can this response be understood?” and “What is required for this strategy to work for a person with dementia?” Vulnerability to dysfunction was expected in areas such as memory function, activities of daily living (ADL), meta-cognition, encompassing awareness and executive functions (i.e., volition, planning, purposive action, and effective performance), and also in areas such as problem solving, abstract thinking, and language (Agüero-Torres et al., 1998; APA, 1995; Lezak, 1995; Thomas, 2001).

Comparisons among all the results (i.e., the categories presented in each of the studies) and all the emerging themes of strategies were continually made in a back and forth process while posing these questions. Each of the seven specific study contexts was also taken into continuous consideration in this process. Finally, each synthesized category describing types of responses was conceptualized, taking the specific features of the strategies found and the meaning they seemed to have to the users into account, as well as the framework of known conditions.

**Findings and Comments**

In Table 2, an overview is presented of the synthesized categories of response strategies that were used by the participants in the studies to overcome challenges in occupational performance.

**Perceptual Input**

**Visibility.** Vision was used by the participants when they sought support in daily occupations from items and information that were visible in the environment. This could mean, for example, paying attention to deliberately provided cues at home or to certain visible objects in an unfamiliar environment.

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**Table 2. Overview of Strategies Initiated By Participants With Mild to Moderate Stage Dementia in Response to Occupational Difficulties**

<table>
<thead>
<tr>
<th>Category of Response Strategy</th>
<th>Ways of Applying the Strategy</th>
<th>Originating From Studies</th>
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</thead>
<tbody>
<tr>
<td>Perceptual input</td>
<td>Visibility</td>
<td>I, V, VI, VII</td>
</tr>
<tr>
<td></td>
<td>Tactility and other senses</td>
<td>I, VI</td>
</tr>
<tr>
<td></td>
<td>Auditory input</td>
<td>V, VI</td>
</tr>
<tr>
<td>Temporal modification</td>
<td>Pacing</td>
<td>V, VI</td>
</tr>
<tr>
<td></td>
<td>Isolating objects or sequences</td>
<td>I, VI</td>
</tr>
<tr>
<td>Reinforced attention</td>
<td>Anticipatory and momentary attention</td>
<td>VI</td>
</tr>
<tr>
<td></td>
<td>Retrospective and momentary attention</td>
<td>VI, VII</td>
</tr>
<tr>
<td></td>
<td>Controlling actions</td>
<td>I, V, VI</td>
</tr>
<tr>
<td>Random repetition</td>
<td>Spoken language—communicating with oneself</td>
<td>I, VI, VII</td>
</tr>
<tr>
<td>Use of verbal language</td>
<td>Written language—traditional information seeking</td>
<td>I, IV, VI</td>
</tr>
<tr>
<td>Body language and concretization</td>
<td></td>
<td>I, VI</td>
</tr>
<tr>
<td>Support in the social environment</td>
<td></td>
<td>IV, V, VI, VII</td>
</tr>
<tr>
<td>Support from habituation and familiarity</td>
<td></td>
<td>VI, VII</td>
</tr>
<tr>
<td>Device use</td>
<td></td>
<td>IV, V, VI</td>
</tr>
</tbody>
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iar environment where assistance in orientation was needed. At home, the participants spontaneously or purposefully arranged the 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. The use of visual support in the environment appeared to be “common sense behavior” (i.e., common and most often unreflective actions in the course of ordinary behavior). Visual support represented actions that seemed to compensate mainly for former cognitive capacity, such as spatial orientation or memory. As such, it could be understood as providing an instant “information channel” with a low demand on memory.

Tactility and Other Senses. 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. For instance, a sandwich might be identified from tactility and vision, although not from vision only. The spontaneous use of this intuitive, multisensory approach seemed to compensate for a diminished ability to identify items from different perspectives and to perform abstract reasoning. Hence, the approach may indicate that persons with dementia need to reinforce by tactility the perceptual input regarding shape and perspective-related form to identify what have formerly been familiar objects.

Auditory Input. In the data, 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. Like the other perceptual strategies, the use of sound is not exclusive to persons with dementia, but rather, it seems to be an example of common sense behavior where a trigger is used as a reminder to compensate for deficits in memory and in the ability to read the time.

Comments. The visual strategies seemed to be vulnerable to failure because they rely on modifications of behavior based on anticipation and on cognitive operations, such as the visual identification of cues and continuous analysis of which objects belong together, both of which may be disturbed early in dementia. Similarly, the use of hearing as a compensatory measure requires conscious actions such as the appropriate choice of which sounds to pay attention to and awareness of what the sounds indicate. Both vision and hearing often involve being restricted to a particular place, such as staying in the kitchen until the water on the stove has boiled. And finally, the intuitive use of tactile senses requires that objects are within reach. Consequently, this is only relevant for objects or subjects in the individuals’ proximal vicinity. Although reinforced use of perception seemed to be somewhat useful to facilitate occupational performance, it did not generally solve the problems that the participants faced.

Temporal Modification

Pacing. Many participants paced themselves by making sure that there was always a surplus of time to avoid stressful situations. Furthermore, some immediately did what they felt had to be done to prevent forgetting the task. Allowing additional time was understood as compensation for an inability to keep track of time and for difficulty speeding up or managing stress. In comparison, doing things immediately appeared to be compensating for distractibility, memory loss, and declining attention. Both ways of pacing time seemed to be common sense, although suggestive of perceived vulnerability to possible difficulties.

Isolating Objects or Sequences. Another way of modifying time use was evident when 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. This strategy was understood as compensation, sometimes deliberate and sometimes not, for an inadequate ability to attend. It implied a radical limitation of perceptual influence and facilitated concentration while limiting distraction.

Comments. The adoption of temporal strategies appeared to require an awareness of vulnerability to occupational difficulties or failure by the person. Temporal strategies also required an ability to make choices, consciously or spontaneously, and to focus on one aspect of an occupation at a time. Although adjusted temporal aspects of daily activities seemed to reduce stress and the fear of failure in the participants, it was, however, also inconvenient for many aspects of social and occupational life where timing one’s activities to fit in with others is necessary, as for example, when participants could only manage to socialize with only one person at a time. The temporal strategies seemed to be time-consuming, but they did offer some success in daily occupations.

Reinforced Attention

Anticipatory and Momentary Attention. One type of attentive behavior was exhibited in the participants’ strategic attempts to reinforce their anticipatory and momentary attention. Careful anticipation and concrete planning were used in deliberate attempts to avoid improvisation. Increased caution, rigorousness, and attention were evident.
in the continual striving to sharpen their senses and avoid moments of inattentiveness during occupations. This attentive anticipatory approach was understood to be compensation for memory deficits and other cognitive shortcomings that appeared in daily occupations. The approach seemed to be a deliberate effort to stay one step ahead in preventing possible failures that were expected as a consequence of the disease.

Retrospective and Momentary Attention. The participants also made an effort to sharpen their senses by deliberately attending to something both momentarily and retrospectively. 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. This approach could be understood as a form of relaxation in the midst of occupational engagement as well as applying concentration and exercising the memory.

Controlling Actions. Yet another type of reinforced attentive behavior 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. These checks appeared to compensate for memory deficits and a decreased ability to deal spontaneously with problems.

Comments. Anticipatory attention seemed to require an understanding of why improvisation or lack of caution might be risky and, hence, insight, implicitly or explicitly experienced, was required. The employment of the anticipatory attention strategy seemed to depend on former occupational styles. For example, whereas a person who was used to keeping strict anticipatory order and following routines in daily life was aided by the same strategy after the dementia diagnosis; another person who always had been very spontaneous might be reluctant to use this style although realizing its necessity. The retrospective attentive strategy also appeared to require an awareness of disability, albeit not necessarily explicit. The attempts to work backwards to regain what had been lost or forgotten depended heavily on memory function or help from the social environment in the form of backward guidance, which seemed to make the strategy vulnerable to failure. When used in anticipation, controlling actions seemed to be rather cognitively demanding since they require awareness, watchfulness, and the ability to benefit from the result. However demanding, this common controlling strategy seemed to bring a sense of having “tried” with it, and thereby it might be experienced as useful although it was not consistently effective.

Random Repetition

The participants sometimes responded to problems with an approach characterized by random repetition or trial and error. This approach appeared in two forms: First, participants tried or repeated sequences of actions until they succeeded, gave up, or asked for help. Second, they might take chances and try solutions that they recognized to be inappropriate such as using an old list when buying groceries because the current list could not be found when needed. They sometimes also just waited and seemed to hope for a solution to appear. This approach was understood as spontaneous, but nonflexible, compensation in response to inadequate recognition of the nature and cause of a problem.

Comments. Although repeated attempts often led to failure for the participants and much time was spent repeating a series of actions, this strategy seemed to bring about a feeling of “at least trying.” When change did result, it was often by chance. Overall, just letting go or giving up the attempts to solve a problem, as for example asking a relative to make certain telephone calls, seemed to provide relief in leaving the responsibility to somebody else.

Use of Verbal Language

Spoken Language—Communicating With Oneself. The participants very commonly communicated 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 seemingly in order to memorize. These verbalizations were understood to be consolidating actions of the person, either in the search for confirmation from another person or as a self-guiding procedure. It appeared to be employed to keep the attention focused and the memory alert by using additional sources of stimulation. This communication with oneself seems to be common sense, but could easily be misinterpreted by the social environment as a request for help when the communication sometimes was expressed as questions.

Written Language—Traditional Information Seeking. Verbal cues were not the only ones used; memos, questions to remember, and notes of what was to come or what had passed were often noted in a diary or on pieces of paper. The use of written information meant that information could be stored beyond the memorizing capability of a person to help maintain control over everyday matters. Such commonplace behavior seemed to take on a new significance in the daily lives of the participants because their
memory deficits called for extensive reminders, but, at the same time, their ability to systematically use such behavior gradually decreased, a dilemma for the person.

Comments. Communicating with oneself seems to be a multisensory and spontaneous approach, and less cognitively demanding than using writing. In contrast, using written information requires extensive abilities: being able to write, understanding what has to be written and its purpose, identifying the message, reading it, and benefiting from the notes—all at the appropriate time. Using a calendar also requires orientation in time. In the data, diary use often failed because notes were made on the wrong day or duplicated notes led to new problems. Although note keeping was reasonably successful in reminding the participants, the amount and inadequacy of notes also raised new difficulties.

Body Language and Concretization

In a spontaneous form of compensation, 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. In addition, the presence of an “automatic pilot” in familiar environments could assist some participants by guiding their movements and orientation without obvious or conscious thinking. Overall, the body language and concretizing approach could be understood as reflecting a need for things to be concrete and tangible when the access to the world in its abstract and imaginative dimensions is disturbed because of the disease. The approach seems to be related to former personal style as each individual’s way of expressing him or her self.

Comments. Although this type of compensation seems to place a low cognitive demand on the users, it still requires certain environmental conditions. For example, concretizing demands the presence of tangible items to relate to while not being misled by other visible cues, and body language requires direct presence (e.g., cannot be used in telephone communication). The spontaneous use of an “autopilot” is dependent on environmental familiarity and items remaining in their place. Overall, these strategies were seldom sufficient for effective compensation (i.e., most often they could not solve the problems that study participants encountered in their daily occupations).

Support in the Social Environment

Seeking support from others in the social environment by asking for and accepting advice, information, and help was common although not always explicitly expressed in the data, especially among cohabiting couples. For instance, following the spouse in a routine manner could give both partners the impression of performing independently in spite of the implicit guidance, and thus they may not have perceived the situation as one of providing or receiving support. Being dependent on support from others may be viewed as a balance between need and supply. A person’s situation (e.g., habits, roles, and lifestyle) also seem to influence the use of support. For example, there may be considerable differences between individuals regarding how important they find fulfilling certain roles or being independent. Much of the social support that the participants in the seven studies sought reflected their need for confirmation of their actions being correct and relevant. Often, it seemed related to their doubts about their own abilities.

Comments. First and foremost, relying on support from others for occupational performance requires the presence of other people, but also involves trusting others and adjusting to the need. It is probably possible to learn to follow another person habitually since this strategy seemed to have been adopted after the onset of the disease.

Support From Habitation and Familiarity

Participants remained in familiar places and conducted habitual sequences of activities consciously with the explicit intention of retaining capability. Familiarity was, however, also used for identification and for making sense of new items by comparing them to similar but familiar items. Using and nurturing the force of habit could be understood as an energy-saving strategy for being able to rely on automatic behavior rather than needing to consciously reflect on a situation.

Comments. The common sense behavior of relying on habits and familiarity seemed to require the opportunity of practicing habits, preferably in a familiar environment, since habits that are not practiced are likely to be lost. Comparing unfamiliar things with what is known also requires the ability to reflect on similarities and differences, as well as on utility. Although participants leaned heavily on these strategies, they were not infallible. First, these strategies failed when changes in daily activities or environment occurred, thus a strictly controlled life seemed to be required in order to be successful. Secondly, mistakes could be made through the force of old habits (i.e., continuing to do something in a usual way instead of adjusting to the specific and different demands of each situation).

The term “automatic pilot” refers to Rowles (1991), “…the body’s ‘automatic pilot,’ or learned awareness of the context…” (p. 267).
Device Use

Occasionally, small tape recorders and calendars, diaries, hourglasses, kitchen timers, adapted watches, and alarm clocks were used as reminders. Dosettes for medication were also used. In the use of devices, a conflict seemed evident between the idea that tangible items could replace or compensate for loss of internal skill (e.g., memory) and the fact that such devices required experienced insight and sometimes new skill to be of advantage.

Comments. The use of available devices and remembering to bring them along required a memorizing capability, which often failed. Using any device also required certain skills, which was sometimes found to be problematic for the participants. Some devices were vulnerable to external disturbances; for instance, a watch that was not waterproof was not considered fully reliable. Furthermore, their use introduced the risk of a person being revealed as disabled in public when, for instance, a speaking clock announced the time during a social event. Items that would not be recognized as devices, such as regular calendars or clocks that were publicly available seemed to be easier to accept.

Discussion

The results of this aggregated analysis of seven completed studies support the notion that persons with dementia in a mild to moderate stage initiate and use a variety of strategies to overcome problems in daily life occupations. The results also suggest that their strategies are often intuitive rather than concisely planned, in accordance with suggestions in the field of cognitive psychology (Rusted et al., 2000). Thus, intuitive “common sense acts” are used whenever possible to overcome problems in performance of daily occupations.

The very presence of spontaneous response efforts suggests that the participants experienced a need to compensate—both explicitly, as when they spoke about the need to be careful and to consciously plan their actions, and implicitly, as when they did not verbalize their needs but spontaneously used adaptive strategies. In fact, all these efforts were the results of their own initiatives, based on their experienced needs. Consequently, the results indicate that persons with dementia in a mild to moderate stage may be able to consciously use strategies in daily life occupations, and that the strategies are embodied and needed. This interpretation of the findings suggests that the awareness of disability in daily occupation may be present to a greater extent than what is commonly assumed in persons with dementia. These findings also suggest the need for greater understanding concerning how awareness of disability may be experienced and exhibited in the course of daily life occupations in persons with dementia.

The results of this aggregate analysis also indicate that strategies for responding to occupational difficulties among persons with a mild to moderate degree of dementia tend to be proactive. Occasionally, such as when the responsibility is passed on to someone in the social environment, elements of reactive behavior or passive accommodation may show. While this finding may be influenced by the focus being on responses to occupational problems rather than on coping with overall changes in everyday life, it seems remarkable considering the commonly held view that persons with dementia lack personal resources for being active agents (Herskovits, 1995).

In the analytic efforts to understand what the response strategies meant to the participants, the meaning that seemed to run through all strategies was maintenance of basic control over everyday life matters. In other words, the participants did not seem to employ the strategies in order to achieve a full degree of efficacy. Rather, the goal in all cases seemed to be to prevent losing overall control over the seemingly taken-for-granted daily life realm. Although this interpretation is based on what was revealed in data when the participants in the seven studies engaged in daily occupations, the meaning of their response behaviors seemed closely related to the meaning each activity had for the individual and to culture-specific values. This interpretation is in accordance with the emphasis on perceived control and striving for mastery based on the individual’s standard rather than efficacy norms, as the main goal of occupational adaptation (Schkade & Schultz, 1992a; Slangen-de Kort et al., 1998).

The findings also lend support to Lawton’s (1985) hypothesis of environmental docility that in that one-sided modifications of the environment were rare. The participants’ responses seemed to take place as interaction between the person and the environment, as, for instance, when perceptual input or spoken language was used. This calls for further investigation of the interactive processes between the person and his or her environment in order to reach a better understanding of occupational adaptation. Participants’ responses most often seemed to be hyperstable or fixed in nature, as conceptualized by Schkade and Schultz (1992a). This suggests that the strategies were often of low efficacy and flexibility and not well-suited to provide sufficient support in the persons’ encounters with the challenges of daily life.

The fact that modification of a person’s behavior seems to be the primary source of adaptation in persons with dementia also demonstrates that there are serious limitations to their potential to adapt effectively. Because dementia
disorders first and foremost interfere with the overall cognitive higher order abilities, which in turn influence the executive ability to plan and perform activities in daily life (APA, 1995; Lezak, 1995; Passini, Rainville, Marchand, & Joanette, 1995), adaptation based on a person’s adjustment of behaviors seem doomed for failure. When diseases such as dementia influence the ability to benefit through learning and restrict the flexibility to alter one’s behavior (Cotrell, 1997), the prerequisites for successful adaptation are weak and it is likely that problems will occur. Hence, more research is needed to uncover the implicit lived experience and awareness of persons with dementia in order to develop better support principles. The mechanisms of response strategies in persons with dementia also need further exploration. For example, we need to better understand how such strategies develop and change over time and how they may be supported and maintained. Considering the sparse use of devices and the vulnerability in their use in the present data, in contrast to the common, optimistic view of technology as a supportive resource for persons with disabilities, in-depth studies exploring the prerequisites in persons with dementia for using assistive technology are needed.

Clinical Implications

Findings from this aggregated analysis demonstrate that persons with dementia in its mild to moderate stages may use a rich variety of response strategies in everyday life. The findings may be used as a source of inspiration for the therapist or caregiver who wants to be more sensitive to the resources of the client with dementia. Thus, the first implication for practice is that awareness of the potential resources should guide efforts to support everyday management in persons with dementia. Since the person’s strategies are most likely to show as intuitive, momentary, common sense behavior, recognizing these behaviors as indications of personal resources may take careful and open-minded exploration by the caregiver.

Since the results indicate that the goal for the person with dementia may be to maintain a sense of control over everyday matters, rather than to be able to perform tasks as effectively as before, both proactive and reactive adaptations may be perceived as goal directed. Hence, strategies that are ineffective when judged by time use and outcome may still be useful from the perspective of maintaining a sense of control. Therefore, the strategies should not be expected to be necessarily effective or to replace support or guidance from other persons. Rather they should be taken advantage of as points of departure in identifying each individual’s resources and the kind of support needed.

The most common element of modification proved to be the individual’s own behavior. This suggests that support could be aimed at maintaining adequate adaptive behavior as long as this seems to be beneficial to the person. This support could, for example, include facilitating the perceptual input from the environment and providing the opportunity to practice existing habits and routines without making intrusive environmental adaptations. Support could also be given by explicitly taking the person’s own preferences and use of cues and arrangements in the environment into account.

Finally, the overall goal of providing support that builds on the resources of the person with dementia is to improve their quality of life. It may be important to encourage the person to abandon too demanding strategies and to relax while letting go and flowing with the moment with the support of others when this seems to be the most comforting solution for the person.

Methodological Considerations

Studies using an aggregated analysis approach are not common in the qualitative research tradition and the scope; limitations and strengths of the methodology need some comment. As Estabrooks et al. (1994) have argued, this approach offers a route to synthesize findings from pockets of research because the products of a synthesizing analysis create stronger elements than isolated empirical studies. The generalizability of the findings also increases if the researcher can show comparability of categories across studies. Certain criteria, however, need to be fulfilled. While the criterion of similarity among participants has been met in this study, the criterion concerning similarity across methods has only been partly met in that the analyses in the included studies encompass both comparative and phenomenological approaches (Table 1). The fact that the studies and the synthesizing analyses were conducted by the same researcher may, however, compensate for this discrepancy, in that the studies are still sufficiently compatible in their epistemological and theoretical frames of reference to be subject to an aggregated analysis, and the “salient features” of the studies have already been identified (Sandelowski et al., 1997).

Although the researcher’s in-depth knowledge of all empirical data and of the analyses assure that new findings are grounded in data (third criterion, Estabrooks et al., 1994), the researcher’s perspective and subjective interpretation of all findings also bring about a risk of a restricted view. Therefore, the researcher’s preunderstanding was under continuous consideration with the intention of allowing new dimensions and characteristics of the data to
emerge. The frames of reference in interpreting the results from the individual studies have also been considered in the analysis (Sandelowski et al., 1997), and peer reviews (Gliner, 1994) have been undertaken during the process.

Another issue is the small number of studies included in this synthesizing analysis. In contrast to traditional meta-analyses, an aggregated analysis is designed to focus on a small number of studies and 4 to 10 studies are recommended as suitable for an analysis (Estabrooks et al., 1994; Sandelowski et al., 1997). Nevertheless, the findings from this study are limited by the same sampling strategies and contextual factors as the studies that are included in the analyses (Finfgeld, 2003). Although aggregated analyses of qualitative studies are important for reaching higher generalizability, the generalizability of the results must be considered in terms of analytical or naturalistic rather than statistical generalization (Kvale, 1996; Sandelowski et al., 1997). Further studies are needed to investigate the extent to which the findings from this aggregated analysis may be generalized to the experiences of larger populations of persons with mild to moderate stage of dementia living at home.

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References


