

Perspective

A comprehensive approach to reablement in dementia

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Abstract

As society grapples with an aging population and increasing prevalence of disability, “reablement” as a means of maximizing functional ability in older people is emerging as a potential strategy to help promote independence. Reablement offers an approach to mitigate the impact of dementia on function and independence. This article presents a comprehensive reablement approach across seven domains for the person living with mild-to-moderate dementia. Domains include assessment and medical management, cognitive disability, physical function, acute injury or illness, assistive technology, supportive care, and caregiver support. In the absence of a cure or ability to significantly modify the course of the disease, the message for policy makers, practitioners, families, and persons with dementia needs to be “living well with dementia”, with a focus on maintaining function for as long as possible, regaining lost function when there is the potential to do so, and adapting to lost function that cannot be regained. Service delivery and care of persons with dementia must be reoriented such that evidence-based reablement approaches are integrated into routine care across all sectors.

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Keywords:

Rehabilitation; Dementia; Reablement; Aged; Exercise; Pharmacologic management; Hip fracture; Activities of daily living; Recovery of function; Caregiver; Cognitive impairment

1. Introduction

As society grapples with an aging population and the accompanying increasing prevalence of disability from aging-associated diseases, the concept of “reablement” as a means of maximizing functional ability in older people is emerging as a potential strategy to help promote independence. Policy drivers in support of reablement

include government concern about the growing cost of long-term care in demographically aging populations [1] and the desire to advance a human rights framework embracing healthy aging [2]. Yet, there is considerable variation in the meaning and practical application of reablement within and across countries [1].

In an attempt to expand the debate about the nature and role of reablement, the International Federation on Ageing facilitated an international summit in Copenhagen, Denmark, in 2016, the purpose of which was to provide a platform for knowledge exchange between government officials, industry leaders, experts, and civil society on the subject of improving the capacity and capability of older people

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through reablement (<http://www.ifa-copenhagen-summit.com/about/2015-2016-theme>). In preparation for the summit, a Global Think Tank comprising thought leaders, academics, and practitioners was assembled and tasked with preparing concept papers on reablement as it may be applied to dementia, diabetes, and frailty. The perspectives of the reablement in dementia subgroup are presented here.

Dementia is one of the most significant diseases of aging. It is estimated that more than 46 million people are currently living with the condition worldwide, with that number expected to almost triple by 2050 [3]. Reablement offers a potential means to mitigate the impact of dementia on function and independence. This article presents a holistic reablement approach for the person living with mild-to-moderate dementia, considers gaps in the research evidence supporting reablement, and discusses the implications for policy and practice.

2. The meaning of reablement in the context of dementia

Reablement is a relatively recent term not consistently defined in the academic literature or in policy. It is often used interchangeably with other terms, such as “restorative care”, depending on the jurisdiction and context [1]. Reablement also shares many features in common with “rehabilitation”. The unifying theme across all these terms is a focus on strategies that maintain or improve functional ability and independence, through maximizing an individual’s intrinsic capacity and the use of environmental modifiers [2]. Given the common emphasis on the promotion of function, we can consider these terms as existing within the same spectrum, thus avoiding the distraction of debating the nomenclature in detail.

In general, a reablement approach should have the following characteristics

- It is individualized and goal oriented, taking into account psychosocial and environmental factors, and undertaken collaboratively with the person living with dementia and their caregiver(s) or care staff, where appropriate.
- Goals may relate to cognition, activity (mobility, basic activities of daily living [ADL], instrumental ADL, and leisure activities), behavior, emotion, physical symptoms (e.g., pain), or communication.
- Goals are operationalized based on a careful understanding of the person’s abilities, to ensure that the aims are achievable and realistic, as well as meaningful and worthwhile.
- Strategies to enable the person to work toward the goal are put in place, drawing on a range of evidence-based methods, which may include physical training, learning or relearning skills, or behaviors (*restorative methods*), or modifying activities or ways of doing activities, including adapting the environment or using assistive technology (*compensatory methods*).

For the person living with dementia, the approach is three-fold: maintaining function for as long as possible; regaining lost function when there is the potential to do so; and adapting to lost function that cannot be regained. The approach could also be described as one of ongoing “enablement”, along with specific and targeted interventions that fit within the “reablement-rehabilitation” spectrum as the need arises. We suggest seven broad domains that should be addressed in a comprehensive reablement approach (see Table 1).

3. A comprehensive approach to reablement in dementia

3.1. Initial comprehensive medical/geriatric assessment and pharmacologic approaches

Optimal disease management should be the cornerstone of the reablement approach for the person with dementia. As with other geriatric syndromes, effective management of dementia should start with a comprehensive medical/geriatric assessment, followed by a package of pharmacologic and nonpharmacologic interventions tailored to the needs of the individual and their family, with the aim of maximizing their quality of life [4]. Identifying the likely subtype of dementia, as well as its severity and the presence of other comorbidities, is the first step in guiding management. Alzheimer’s disease will account for over half of cases, with vascular dementia, dementia with Lewy bodies, frontotemporal dementia, and alcohol-related dementia accounting for most of the remainder. Each condition has a characteristic cognitive and behavioral profile that will influence the nature of the functional deficits, the most appropriate approach to management and the patient’s ability to adapt and manage their reablement regimen.

More often than not, dementia does not occur in isolation. Consideration also needs to be given to the presence of comorbid medical conditions and their best treatment, as this will help to optimize intrinsic capacity, and therefore function. Common comorbidities that are likely to be responsive to active medical management are diabetes, Parkinson’s disease, congestive heart failure, anemia, cardiac arrhythmia, chronic skin ulcers, osteoporosis, thyroid disease, and retinal disorders [5,6]. The presence of depression and anxiety will

Table 1
Seven domains to ensure a comprehensive approach to reablement in dementia

1. Initial comprehensive medical/geriatric assessment and pharmacologic approaches
2. Addressing the impact of cognitive disability on everyday functioning
3. Physical and other related nonpharmacologic approaches to support functioning
4. Targeted rehabilitation interventions following acute illness or injury
5. Assistive technology to aid function
6. Support services for the community or residential care sector
7. Caregiver support and education

amplify dementia-related disabilities and may respond to psychological and pharmacological interventions [7,8].

Drugs may impair intrinsic capacity, and a medication review is always appropriate; for example, stopping unnecessary use of sedative drugs and drugs with strong anticholinergic effects, simplifying and tailoring complex drug regimens to personal habits, and promoting adherence through the use of medication aids [9]. If cognitive impairment is more severe, switching responsibility for medication adherence from the patient to someone else paradoxically may help the person become more independent by improving compliance [10]. Ensuring adequate pain relief is essential [11].

Approved drug treatments for Alzheimer's disease (the anticholinesterase drugs, donepezil, rivastigmine, and galantamine; and the N-methyl-D-aspartate [NMDA] antagonist, memantine) have modest cognitive and functional benefits in most patients who take them and are generally well tolerated [12]. There are some reports that benefit may be greater when drug treatment is combined with psychological and physical therapies [13–15].

3.2. Addressing the impact of cognitive impairment disability on functioning

The cognitive disability resulting from dementia affects the ability to engage in everyday activities and participate in family and community life. The effects of cognitive disability can result directly from the underlying impairments or may be secondary, for example, as a consequence of loss of confidence. Reablement interventions address these limitations and restrictions with the aim of enabling the person with dementia to function at the best possible level, given the degree of cognitive disability experienced, and are relevant at any stage of dementia. The term “cognitive rehabilitation” (or “neuropsychological rehabilitation”) is often used to describe this approach to reablement for people with cognitive (or neuropsychological) impairments.

Goals for reablement are identified collaboratively wherever possible and reflect the preferences and needs of the person with dementia, who is engaged as an active participant in the reablement process. Goals could relate to any area of the person's life; frequently the focus is on ADL, activity engagement, communication, and self-care [16]. Structured interviews are available to support the process of goal-setting [16].

Reablement is a problem-solving process [17]. It is usually carried out in the setting in which the person lives or functions to ensure direct applicability, and wherever possible involves carers to help implement changes in daily life. The types of goals selected will depend on the context and on the stage of dementia, as well as on individual wishes. Through a collaborative process, realistic and potentially achievable goals are identified. Therapists assess the person's intrinsic capacity and current ability, evaluate the abilities needed for goal attainment, find out where there are

mismatches between what the person is currently doing and successful goal performance, and examine where these mismatches arise and why. A mismatch could arise at various stages in carrying out the activity and might be due to one of a number of reasons, such as difficulty remembering (cognitive), lack of a strategy for completing the activity (behavioral), or anxiety about some aspect of the activity (emotional). Based on this assessment, the therapist prepares a plan for working toward goal attainment, addressing the areas where help is required to develop the ability to engage in the desired activity. Depending on the nature of the activity and the mismatches between current and desired levels of functioning, this plan may include new learning, re-learning, behavior change or management of difficult emotions, or a combination of these. Specific evidence-based strategies can be employed to address difficulties and support behavior change in each domain; for example, strategies such as expanding rehearsal may be used to support new learning. Where necessary, additional resources such as aids and adaptations may be brought to bear, or environmental modifications made, to augment the person's intrinsic capacity, and tasks can be simplified. This might include the use of assistive technologies (discussed in more detail in the following).

There is a small but growing body of evidence demonstrating the effectiveness of this kind of approach in optimizing everyday functioning, reducing functional disability, and supporting independence [18–23]. The approach requires adaptation for people with rarer dementias that have specific profiles in the early stages; for example, a number of studies using single-case experimental designs have investigated the potential for ameliorating language and communication difficulties in types of dementia where language impairments predominate in the early stages [24,25].

This core reablement approach is complemented by other nonpharmacologic interventions that actively engage people with dementia. These include, for example, interventions aimed at helping people understand and manage the condition such as self-management groups [26], interventions addressing barriers to engaging in reablement, such as psychological interventions for depression or anxiety [8], and broad-based occupational therapy interventions [27]. Interventions providing opportunities for social interaction, general stimulation, or other pleasurable activities can be applied alongside reablement with the aim of enhancing general well-being. Support for carers is essential, although reablement interventions addressing the effects of cognitive disability should be equally available to those individuals who do not have a carer available to participate.

3.3. Physical and other nonpharmacologic approaches to support functioning

There is good evidence for the benefits of exercise on a range of parameters at the population level. Benefits include improved cardiovascular performance, reduced cardiovascular

and metabolic risk, improved balance and reduced falls risk, improvements in mood, and improved cognitive performance [28]. The benefits of exercise also extend to frail older people [29].

There is growing evidence that exercise interventions for people with dementia are also beneficial, across a number of domains. Exercise has been reported to improve ADL performance, balance and mobility, and reduce falls risk [30–32]. Evidence of its impact on cognition, depression, or neuropsychiatric disorders is mixed, but a recent systematic review and meta-analysis suggests that exercise has the potential to improve cognitive performance in both Alzheimer's disease and mild cognitive impairment [30].

The impact of exercise on self-reported quality of life and on caregivers is uncertain [31,33], but other interventions, incorporating occupational therapy and physiotherapy [34], environmental modification, task simplification, or assistive technology [35], have also shown reduced incidence of falls.

A recent review of occupational therapy interventions has shown that they can significantly improve quality of life and ADL function [36]. The conclusion of another review of randomized controlled trials of nonpharmacologic interventions aimed at maintaining physical functioning in community-dwelling people with dementia was that the evidence to date supports a “proof of concept” that these interventions could delay the rate of functional decline associated with dementia [33].

It seems reasonable therefore that a comprehensive reablement approach for people with dementia should incorporate exercise interventions to help maintain physical functioning and mobility, with potential benefits on ADL functioning, cognition, mood, and quality of life, as well as occupational therapy interventions [36] if available. Harm from exercise interventions does not seem to be an issue [31]. However, further research on these modalities is required, including how they can be applied in community settings in a cost-effective manner.

Given that weight loss and undernutrition are common in dementia [37], a healthy-balanced diet should be encouraged and supported to ensure adequate nutrition and hydration and therefore the promotion of function. Weight and nutritional status should be assessed regularly and good oral health maintained.

3.4. Targeted rehabilitation interventions following acute illness or injury

Episodic, intensive rehabilitation to promote functional recovery following acute illness or injury has an important place within the reablement-rehabilitation spectrum. Although the presence of cognitive impairment is reported to be associated with poorer rehabilitation outcome, the issue is often one of degree, or relative outcome, rather than lack of benefit from rehabilitation [38,39].

Patients with cognitive impairment have been shown to experience similar relative gains in function following

rehabilitation as those without cognitive impairment [40–43], and patients with hip fracture and a diagnosis of dementia can respond well to more intensive rehabilitation settings, showing better outcomes (living arrangements, reduced length of stay, and functional gain) compared with less intensive inpatient rehabilitation programs [39,44]. Further, there is no evidence that involvement in rehabilitation results in harm to participants, nor that individuals with cognitive impairment are unable to participate [40,41,43].

The Patient-Centred Rehabilitation Model of Care targeting persons with cognitive impairment was developed and implemented as an interdisciplinary intervention to educate and mentor staff on an active rehabilitation unit to provide person-centered interventions targeting older adults with complex medical conditions, particularly those with cognitive impairment [45]. Evaluation revealed that individuals with cognitive impairment in the intervention group were more likely to be discharged home than those in the control group. Six months later they were more likely to ambulate inside, outside, and go shopping. Of note, pre-admission functional impairment was more strongly associated with poor outcomes than cognitive impairment [46].

In the Netherlands, specialized services providing post-hospital, low-intensity rehabilitation are also delivered in nursing homes. These multidisciplinary programs for frail older people after hip fractures, stroke, joint replacement, amputation, advanced chronic obstructive pulmonary disease, and heart failure are well adapted to people living with dementia. Good results are reported, although there is a lack of subgroup analysis for people with dementia [47].

However, in practice, it is often assumed that older individuals with cognitive impairment will not be able to participate in rehabilitation programs and/or demonstrate progress, and thus, they are generally admitted to programs with lower intensity rehabilitation or are ineligible for admission to rehabilitation settings [43]. This nihilistic belief that a diagnosis of dementia makes the person unable to participate effectively and benefit from a rehabilitation program can lead to reluctance on the part of health care practitioners and administrators to devote scarce resources to patients who are cognitively impaired, no matter where they reside [48].

3.5. Assistive technology to aid function

In the context of reablement, assistive technology can play an important role in supporting people living with dementia. While definitions vary, assistive technology includes devices, equipment, instruments, or software that are available or specifically made for use by persons with disabilities [49]. Various assistive products can be used in reablement by persons with dementia (and their caregivers) to enable participation in valued activities and roles (for example, daily self-care, social, or leisure activities), compensate for limitations, provide support or protection (for example, for body structures

or functions), help train or retrain in activity performance, or prevent bodily impairments or other limitations.

There are many generally recommended products to support independence and safety in daily activities, such as aids and adaptations like bathing equipment, mobility aids, medication organizers and personal emergency alert systems, and other products that have more unique specifications to address the needs of persons with dementia. To account for attention, memory or spatial orientation changes, decreased executive functioning, and judgment for safety, a variety of products are commercially available. Medication reminder aids with programmable alerts can remind someone to take their medications [50], with some devices featuring the capability to monitor whether medications have been taken. Stove timers can provide warnings that a stove is on and automatically shut the stove off after a specified period of time [51]. Personal locating devices using Global Positioning System technology may be used when someone who has the potential to get lost leaves the home or another specified zone [52]. To support cognitive stimulation and social engagement, robotic pets (e.g., Paro the seal [53]) and digital communication technologies to enable reminiscing are available. Although a multitude of products are available on the market, it is recognized that the research evidence on the efficacy and effectiveness of many of these technologies for persons with dementia is limited and further research is recommended.

Various technology-based solutions aimed at supporting persons with dementia are also in the research and development phases. Development is also increasingly engaging persons with dementia and others in their care networks to ensure products are beneficial, customizable to users and their environments, and usable by persons with dementia. Products under development include several types: intelligent cognitive aids, for example, provide reminders or prompts only as the person with dementia requires them; physiological sensors when worn can detect fall events or monitor vital signs for unusual patterns; environmental sensors may, for example, detect movement patterns to alert for any changes in functional activities; and integrated sensor systems, for example, in a smart home, may combine multiple sensors and intelligent algorithms to sense activities and behaviors to provide context-relevant guidance or information to users [54]. Robots to provide reminders and prompts for daily activity completion [55] and exercise [56] are also under active development.

3.6. Support services for the community or residential care sector

When it comes to the ideal model for the delivery of support services for people with dementia living in the community, there is a lack of data on which models are most effective, if at all, in helping people maintain or regain functional ability. This is because published studies on support service delivery, apart from some small pilot studies, have

excluded people with dementia or significant cognitive impairment.

Studies that report the use of a “reablement” or “restorative” approach to service delivery (“doing with” rather than “doing for” the person), along with some form of time-limited allied health or trained care staff intervention aimed at improving functional ability, do claim benefits, including reduced use of home care services; reduced emergency department visits; some improvement in functioning; and increased likelihood that the recipient will remain at home [57,58]. However, recent systematic reviews of home care users, even for people without dementia, concluded that there is still limited evidence to suggest that such interventions can reduce dependency in personal ADL [59,60].

Until studies are done on service delivery models specifically targeting the person living with dementia, no firm statements can be made, but it seems plausible that a reablement model of home care delivery could assist in maximizing a person’s functional ability and helping to maintain them at home for longer. Such a program should include an initial assessment of need and seek to identify and address causes of functional decline that are separate to that resulting from the natural progression of dementia (for example, from acute or comorbid medical conditions, side effects of medications, deconditioning or lack of activity). A short-term reablement approach (addressing everyday functioning and physical functioning, as needed) and identification of potential environmental modifications that could promote functional ability (for example, assistive technologies, guidance provided by informal or formal caregivers, or making accommodation more accessible) should then ensue before, or concurrently with, the provision of support services. Support services should be delivered in a way that supports optimal functioning and minimizes disability.

Consumer-directed and case management models of community care are also described. Although these models are not mutually exclusive, and both can offer a reablement approach in the delivery of care, there remains a lack of good-quality research on which is best for the person living with dementia. Case management does seem to delay nursing home placement, whereas consumer directed models are associated with improved satisfaction [61]. Case management may also be cost-effective [62].

There is emerging evidence that people living with dementia in long-term care can show improvement in physical function and level of physical activity, along with reduced falls incidence, with a “function-focused” approach to care by care staff [63]. Education for nursing assistants to take a restorative approach during care interactions with residents, including those with cognitive impairment, has been shown to result in some improvement in mobility and balance [64].

The above approaches are supported by recent guidelines [4], which encourage staff to “promote functional and social independence” for people with dementia, across both

community and residential settings, through interventions, which include maintaining consistency in staffing and stable living environments; being able to accommodate fluctuations in the person's ability; the use of activities that are both enjoyable and meaningful; and the promotion of independence in self-care so as to prevent excessive disability.

3.7. Caregiver support and education

Supporting caregivers of people with dementia can be enabling for both the caregiver and the person with dementia [65]. The availability of a caregiver provides a greater opportunity for the person with dementia to remain living in the familiarity of a home environment for longer, with potentially greater opportunities to remain more functionally able and with better prospects for community participation. In addition, educating the caregiver about areas of the care recipient's function, which may be amenable to reablement strategies, will also be important.

Family caregivers play an essential role in the care and support of older people living with dementia. Although the experiences of caring for a loved one can be positive, caregiving may also be associated with significant costs—for example, caregiver burden, stress, depression, anxiety, poor health, social isolation, and financial hardship [66,67]. This has led to family caregivers being recognized as “invisible second patients” [67], highlighting the importance of also assessing and addressing the needs of the caregiver, and not just the care recipient [66].

A range of practical interventions to support the caregiver and reduce caregiver burden have been identified [66]. Research shows that multicomponent strategies, which address different needs, are most effective [68]. Strategies include ensuring the care plan/treatment incorporates the needs and preferences of both the care recipient and the caregiver; providing education and training to improve the caregivers' ability to manage the symptoms of dementia and to correctly carry out caregiving tasks (e.g., lifting to avoid back strain); providing respite or other support services to enable caregivers to meet their own health and wellness needs and manage stress; coordinating or referring caregivers to other assistive or support services as necessary; utilizing technology to enhance independence in the care recipient and to assist the caregiver (e.g., mobility monitors or locating devices, home intercom, and sensor systems, including webcams, medication alarms), or to facilitate socialization for the caregiver and care recipient (e.g., online support groups, Skype) [66].

4. Implications for future research, policy, and practice

An enablement philosophy supports the human rights of people with dementia and their caregivers. From a values perspective, it focuses positively on what people can do, with appropriate support. It is person-centered and wherever possible supports self-determination and involvement in

decision-making. The individual implications are that people living with dementia, and their caregivers, can be encouraged to see themselves as actively managing their health rather than being passive recipients of treatment. The societal implications are that we need to move away from a negative discourse around dementia and toward a perspective that focuses on maximizing intrinsic capacity and functional ability.

From a policy perspective, reablement fits with the aspiration to enable people to live well with dementia, and it offers a proactive approach that contributes to continued well-being, the prevention of crises and the potential for continuing to live in the community, independently or with appropriate support, for as long as possible. Enabling people to function at their optimal level and reducing dependency could lead to reduced caregiver burden and potentially delay the need for long-term care.

Although there is growing evidence to support a reablement approach within the seven domains discussed in this article, the availability of high-quality evidence in a number of areas remains patchy. Given the increasing attention being given to reablement in aged and community care policy and practice in several countries, it is prudent for policy makers, funders, and providers to devote resources to reablement interventions for which there is a sound evidence base.

Future research needs to focus on addressing the main knowledge gaps. These include the effectiveness, and cost effectiveness, of reablement models of community care delivery specifically for people with dementia; the efficacy of rehabilitation, and the development of person-centered models of rehabilitation care, for people with dementia following acute injury or illness (although the evidence following hip fracture is good, there is a lack of high-quality studies investigating other conditions); and further research into the components, the “dose”, and the outcomes of allied health interventions that aim to delay, maintain, or improve function in people with dementia.

The cost-effectiveness of reablement approaches in dementia remains poorly understood; however, ADL ability has been shown to be the most important indicator of overall costs of care [69]. Reablement strategies could prove cost effective if they delay functional decline, but more research is needed.

5. Conclusions

Because dementia is a progressive condition and we are yet to achieve a cure or an ability to significantly impact its course, the message needs to be “living well with dementia”, with a focus on maintaining function for as long as possible, regaining lost function when there is the potential to do so, and adapting to lost function that cannot be regained. The reablement approach is iterative, applied as needed in the light of functional decline. Service delivery and care of persons with dementia must be reoriented such that evidence-based reablement approaches are integrated into routine care across all sectors.

Acknowledgments

Authors of this article were supported by the International Federation on Ageing and DaneAge to attend the Global Think Tank on Ageing in Copenhagen, Denmark, in late 2015.

RESEARCH IN CONTEXT

1. Systematic review: The concept of 'reablement' is promoted widely as a means of maximizing functional ability in older people, yet there is considerable variation in its meaning and practical application. Evidence for reablement in the context of the person living with dementia remains mixed. This article draws on the scientific literature to present a comprehensive approach to reablement in people living with mild to moderate dementia, and highlights knowledge gaps and areas for further research.
2. Interpretation: Reablement strategies should be individualized, goal oriented, and undertaken collaboratively with the person living with dementia and their caregivers. The focus is on maintaining function for as long as possible, regaining lost function when there is the potential to do so, and adapting to lost function that cannot be regained. Strategies include both restorative and compensatory methods. Domains to consider include: medical and pharmacological management; non-pharmacological approaches to addressing the impact of cognitive disability and supporting function; rehabilitation following acute injury or illness; assistive technologies; delivery of support services; and caregivers.
3. Future directions: While there is growing evidence to support a reablement approach for people living with dementia, the availability of high quality evidence remains limited. Knowledge gaps include: the effectiveness and cost effectiveness of reablement models of community care delivery specifically for people with dementia; the efficacy of models of rehabilitation following acute injury or illness across a range of conditions in addition to hip fracture; and the components, 'dose', and outcomes of allied health interventions that aim to delay, maintain or improve function in people with dementia.

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