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‘This is the peer reviewed version of the following article: 
Cations, M., Laver, K. E., Crotty, M., & Cameron, I. D. 
(2017). Rehabilitation in dementia care. Age and Ageing, 

which has been published in final form at 
http://dx.doi.org/10.1093/ageing/afx173

The Accepted Manuscript (AM) is the final draft author 
manuscript, as accepted for publication by a journal, 
including modifications based on referees’ suggestions, 
before it has undergone copyediting, typesetting and 
proof correction. This is sometimes referred to as the 
post-print version.

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Rehabilitation in dementia care: why not call a spade a spade?

Abstract

Multidisciplinary rehabilitation is increasingly accepted as valuable in the management of chronic disease. Whereas traditional rehabilitation models focussed on recovery, maintaining independence and delaying functional decline are now considered worthwhile aims even where full recovery is not feasible. Despite this, rehabilitation is notably absent from dementia care literature and practice. People with dementia report frustration with the lack of availability of structured post-diagnosis pathways like those offered for other conditions. Alternative terms such as ‘re-ablement’ are used to refer to rehabilitation-like services, but lack an evidence-base to guide care. This commentary will discuss possible reasons for the resistance to accept multidisciplinary rehabilitation as part of dementia care, and identifies the value of doing so for people with dementia, their families, and for health professionals.
In early 2017, the World Health Organization launched their ‘Rehabilitation 2030’ call to action [1]. The campaign aims to raise the profile of rehabilitation as a health strategy relevant to the whole community, across the continuum of care. The campaign emphasises that rehabilitation should be offered for all conditions alongside prevention, promotion, treatment, and palliation. This initiative reflects the evolution of rehabilitation from historical models when it was primarily considered a means to support recovery and reintegration following physical injury. Rehabilitation is increasingly accepted as a holistic approach to chronic disease management with goals to optimise independence and prolong engagement [2].

Given this shift, it is surprising that dementia care is seldom mentioned in efforts to promote and expand rehabilitation services. Although the goals of rehabilitation align with the widely-accepted ideals of person-centred dementia care there appears reluctance to use rehabilitation terminology in this context. This commentary identifies the value of embedding rehabilitation in dementia care and considers possible reasons for resistance.

**Relevance to dementia care**

Symptoms of dementia can include impairments in memory, executive function, language (including speech), motor control, functional independence, and social cognition, as well as neuropsychiatric and behaviour change. Associated falls, delirium, weight loss, incontinence, sleep dysfunction, oral disease, and frailty are common [3]. These symptoms reduce capacity to actively participate in community and complete tasks that are essential to daily life [4]. From this perspective, rehabilitation has utility as it does in any other chronic health condition. Non-pharmacological interventions can delay functional decline [5] and improve quality of life in people with dementia [6], and treatment of medical symptoms and comorbidities improves cognition [3]. A structured, multi-disciplinary rehabilitation program
can address specific symptoms and identify goals that are meaningful to the person, regularly adapting as needs change. Maintaining functional independence was cited among the most important research priorities in a recent Delphi study of 201 dementia experts [7]. It is repeatedly referenced as an essential priority among consumer groups, who consider access to services to help maintain engagement a human right [8]. It also appears in many calls to tender for dementia care funding. In most contexts, however, rehabilitation-like concepts come packaged under alternative names like ‘re-ablement’, ‘restorative’ or ‘goal-oriented’ care. In their recent commentary, Poulos et al. [9] describe a comprehensive ‘re-ablement’ approach that references rehabilitation principles. The term ‘rehabilitation’ is relatively absent from academic literature in the dementia field. Additionally, many patients participating in geriatric rehabilitation programs have comorbid cognitive impairment or dementia but this is seldom the condition primarily under treatment. Other conditions have specific rehabilitation pathways despite also being common in old age.

The increasing emphasis on ‘re-ableing’ or ‘restorative’ dementia care reflects that, to date, post-diagnosis models of care have typically been fractured and unpredictable. Which service a person will receive depends on demographic and practitioner factors [10], and people living with dementia report dissatisfaction with care pathways that focus on their disabilities rather than maintaining their abilities [8]. This contrasts with post-diagnosis care following onset of other conditions. Research in stroke, for example, has established clear evidence for acute stroke units, and inpatient and community stroke rehabilitation are widely implemented as part of the usual care pathway [11]. Multidisciplinary rehabilitation programs are also recommended following diagnosis of degenerative neurological conditions such as multiple sclerosis [12]. Accordingly, defined standards of rehabilitation care exist to provide clear expectations for patients and guidance for practitioners. The same cannot be said for dementia.
Explaining the reluctance

The reasons for the scarcity of ‘rehabilitation’ literature and practice in dementia are unclear and barriers have not been formally investigated. An assumption exists that health professionals view rehabilitation as having limited utility in dementia because of the progressive nature of the condition. While a therapeutic nihilism underlying these attitudes has been noted in dementia care [13,14], the barriers are likely more nuanced than this. Delivering rehabilitation in dementia will involve treatment strategies and goals that differ from the bulk of a rehabilitation practitioner’s training. Although rehabilitation is conceptually agreed as separate from curative health strategies [2], moving away from higher participation (particularly occupational) goals will require a reframing of practice.

Health professionals may also be apprehensive about giving people with dementia false hope [15]. Misunderstanding may still exist among patients that rehabilitation is intended to aid recovery, and therapeutic ‘over-optimism’ could foster unrealistic expectations about the inevitable decline. This can have negative emotional and psychological consequences in the long run [16,17]. Where a practitioner is able to present realistic goals, convincing patients of their value (when functional decline is still inevitable) may be difficult.

Allied-health professionals have also reported scepticism about the relevance of their services in dementia care [18]. Where embraced, they are considered a temporary addition to usual care for acute injuries or illness and are accessed via similar means as older people without dementia. Professionals are not convinced of their relevance in specifically managing the symptoms of dementia. This may reflect some misunderstanding about the breadth of impairments caused by dementia. Reframing dementia as a set of symptoms or disabilities could help to address this problem and has been suggested by some advocates [19]. For example, a disability care plan that specifies the person is experiencing expressive aphasia
and anomia may help a speech pathologist to understand the relevance of their profession for that person.

It is also relevant that delivering rehabilitation to people with dementia is challenging, perhaps more so than in other groups. Memory and other executive impairments can limit adherence, and additional strategies and resources may be needed to address this [20]. There is already reluctance to refer or accept people with dementia for rehabilitation following acute injury [21]. Nonetheless, cognitive impairment only has a small impact on long-term rehabilitation outcome [22] and people with dementia benefit from geriatric rehabilitation following hip fracture despite their impairment [23].

**Dementia rehabilitation in practice**

In practice, how rehabilitation is delivered to people with dementia will depend heavily on the extent of their impairments. Efforts to stay engaged in community immediately post-diagnosis (when symptoms are mild) will be less relevant as the person approaches and enters long-term care. Rehabilitation can nonetheless have a place in this context, albeit with more modest goals. Reduced functional activity profoundly impacts the quality of life of residents in long term care [24]. ‘Medical’ conditions (e.g. declining mobility, pressure ulcerations) and behavioural symptoms can be framed as central to activity limitation and reduced participation. Supported rehabilitation to reduce these barriers is plausible from this perspective.

Some rehabilitative therapies are already sporadically applied in dementia care. Cognitive rehabilitation has been translated from stroke and traumatic brain injury (TBI) units, targeting cognitive impairments directly by capitalising on remaining memory abilities and finding ways to compensate for difficulties [25]. In dementia, the goals of cognitive rehabilitation are regularly revisited and revised as cognition declines. Clare [25] argues that using
rehabilitation terminology in reference to other non-pharmacological interventions (e.g. exercise programs, dyadic interventions) would confuse the purpose of cognitive rehabilitation, diluting its focus on the intrinsic deficits caused by dementia. ‘Re-ablement’ or ‘restorative care’, in her view, are adequate to describe these complementary (though arguably rehabilitative) services.

However, semantics are important as the choice of terms may affect standards of care and design of health policy. Rehabilitation is well-defined, with clearly understood and aims and outcomes that are valued by medical and allied-health professions. Although practice varies, standards of rehabilitation care are generally agreed and often mandated in policy [2]. Re-ablement is poorly defined, with little understanding of what it looks like when achieved. It is not well understood among consumers and standards of care are not regulated. Using separate terms also underestimates the breadth of impact of dementia. Interventions to address non-cognitive symptoms (e.g. mobility) should be considered as central to its treatment, rather than complementary. There is no reason why cognitive rehabilitation cannot be offered as one component of a comprehensive, multi-disciplinary rehabilitation program.

**A rose by any other name: embracing rehabilitation**

The move toward embracing ‘rehabilitation’ in dementia care is already happening. Despite the affinity for alternative terms, researchers, policy-makers, and consumers agree about the importance of services targeted at maintaining functioning. Conceptualisations of how rehabilitation care might be structured and offered within current dementia care systems exist [9,25]. Rehabilitation appears as a core recommendation in the recent World Health Organization Global Action Plan on Dementia [26].

Nonetheless, work remains to promote acceptance of rehabilitation terminology and practitioners as relevant to dementia care. This will require a double-pronged shift in attitudes
away from traditional views of rehabilitation as a purely remedial approach and toward valuing interventions that help to maintain functioning in dementia. Practitioners must be willing and able to set realistic expectations for their clients with dementia for as long as curative treatments do not exist. Ultimately, people with dementia have established their wishes (and rights) to maintain their autonomy and to be centralised in discussions regarding their treatment and care. We must accept rehabilitation as a feasible means to achieve this.

References


