Chapter 14
Promoting functional independence in dementia

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Abstract

Dementia causes loss of functional independence and this worsens through the course of the disease. This loss of independence is distressing for the patient with dementia and their families, with high societal costs. Supporting the person to remain as independent and active as possible are therefore key components of effective dementia care. This may include efforts to maintain the patients´ ability to carry out activities of daily living, to maintain functions important for their identity, to participate in social activities and functions and in society in general. Interventions to promote independence in patients with dementia need to be individually-tailored as individuals have different goals of care and interests as well as differing cognitive and health deficits. Potential approaches may include tailored programs, cognitive support tools, support with communication, balance and strength training and other interventions. The chapter will provide a framework for mapping the needs of patients with dementia and approaches to address these. Evidence for these approaches will be presented along with cases.

Keywords

Dementia; Alzheimer's disease; Social function; Activities of daily living; Independence; Rehabilitation; Family carers

Abbreviations

AD = Alzheimer's disease

BADLs = basic activities of daily living

bvFTD = behavioural-variant frontotemporal dementia

CST = cognitive stimulation therapy

DLB = dementia with Lewy bodies

IADLs = instrumental activities of daily living

RCT = randomised controlled trial

15.1   Introduction

The presence of dementia inevitably indicates that there has been a loss of functional independence. The World Health Organisation's criteria for even mild dementia indicates that cognitive decline 'interferes with everyday activities' and once dementia reaches its moderate stages, there is expected to be 'serious handicap to independent living' (1). However, it should be a goal of clinical management in dementia to minimise the loss of independence caused by dementia through environmental adaptations, psychological therapies, and social support, involving both the patient with dementia and their wider milieu. These treatments have the potential to improve the quality of life for the patient with dementia and their family members and to markedly reduce the high societal costs required to provide care.

A major focus of dementia care during the past 10-20 years has been making early diagnoses of people developing symptoms (2, 3) including, in some countries, incentivisation and targets (4) and case-finding in high risk populations, such as older people admitted to hospital (5), for improving diagnostic rates. This approach has aimed to ensure that the condition is recognised, that treatment can be initiated, and that risky behaviour arising from cognitive impairment can be mitigated. However, there has been criticism that this rising rate of diagnosis has not yet been matched with development of post-diagnostic care (6) to support patients with dementia and their families to maintain functional independence and live well. Provision of high quality psychosocial care has therefore been identified as a current global priority area (7).

Functional independence can be conceptualised and defined in several ways, as described in more detail below. For the purposes of this chapter, maintaining functional independence will refer to preservation of the ability of a person to complete one or more of a range of activities. As considered in previous research, (8) maintenance of functional independence can include the provision of support from family, friends, or professional carers, which means that the patient with dementia is not acting entirely alone in their functional activities, but that there is a degree of interdependence between patients with dementia and their support networks, which enables patients with dementia to live relatively independently.

Dementia is linked to difficulties in maintaining function for several reasons. Cognitive decline impairs the ability to manage self-care, and other common neuropsychiatric symptoms such as agitation and apathy (9) further inhibit independence. Dementia is also associated with complex multimorbidity whereby around three-quarters of people diagnosed with dementia have at least two other chronic conditions (10, 11) and cognitive impairment in dementia influences the effect of physical illness on independence (12). The interplay of cognitive decline, behavioural and psychological symptoms and physical ill-health combine to

create challenges for a patient with dementia, as well as carers and practitioners aiming to support independence.

Functional independence is important for patients with dementia. Dependence on others, and the impact on personal relationships is one of the consequences of dementia most feared by people without dementia (13). Impairment in activity of daily living functions is associated with poor quality of life, particularly in patients with more severe dementia (14, 15). Impairment in social function correlates with poor quality of life in patients with dementia of all severity (16), and maintaining social relationships, a key component of social function, is an important predictor of better wellbeing (17). Functional independence also matters to family members of patients with dementia, with difficulties in completing instrumental activities of daily living being strongly linked to higher rates of carer burden (18) and distress (19).

This chapter aims to describe the loss of functional independence in dementia, how this progresses over the disease course and what disease-related, social, and psychological factors affect this. It will outline approaches to assessing functional independence and then consider evidence-based interventions addressing different domains of functional independence, including activities of daily living, social function and physical function. Finally, it will consider the application of interventions in different settings and mechanisms for delivery, such as remote delivery through internet-based approaches or other technology.

15.1.1 Functional independence in patients with dementia

The range of functions impaired in dementia are commonly conceptualised as comprising basic activities of daily living (BADLs), which are simple self-maintenance activities such as bathing, toileting, dressing, or eating; instrumental activities of daily living (IADLs) (20), which are more complex activities such as handling finances, navigating, shopping, or preparing a meal; and social functions such as maintaining social contact with friends and relatives and participating in social hobbies and leisure activities (21). This chapter will focus on clinical approaches to maximising independence in activities of daily living and social functions. We will also consider how maintaining physical functions, facilitating communication, and supporting family members can facilitate independence.
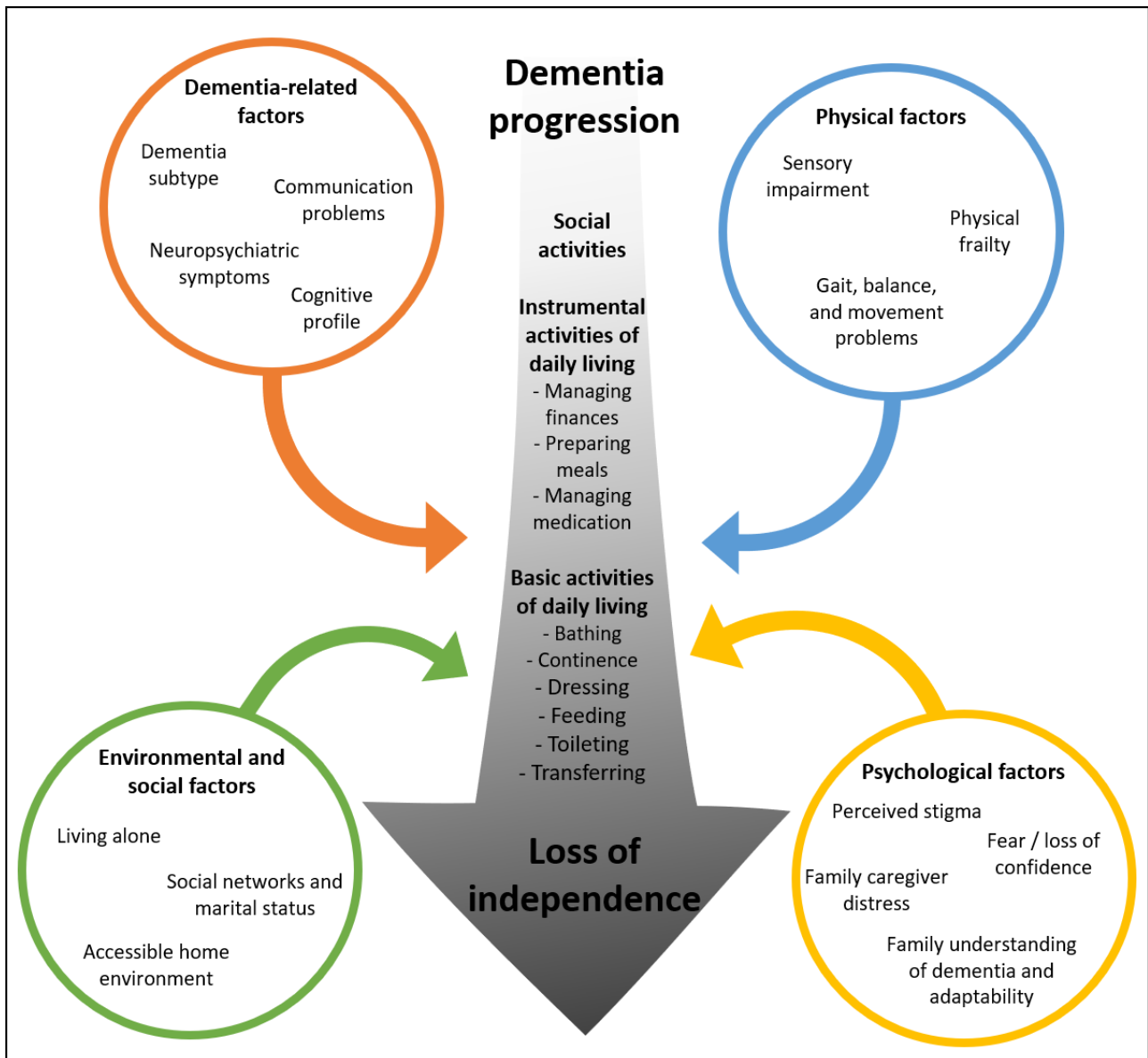
Another conceptual approach is to consider independence as maintenance of current living circumstances, usually meaning the individual continuing to live in their own home for longer (22). This is a potentially relevant marker of independence, as impairment in function is associated with patients with dementia having shorter time between diagnosis and moving from independent living into care settings (23, 24). Another model suggests that, rather than considering the level of independence as a domain of dementia,

alongside cognition and behaviour, independence itself should be the unifying construct in defining dementia disease severity (25).

15.1.2 Loss of independence over the disease course

Loss of functional independence in dementia varies according to the activity or function being studied. This progressive loss, and factors which affect it, is summarised in figure 15.1. Dependence has been reported to occur for some complex activities very early in the course of dementia, such as in a study of Japanese elderly patients with very mild Alzheimer's disease (AD) where around half of people were noted to have difficulty in managing medication and preparing meals and 60% had lost independence in managing finances (26). Other complex functional tasks such as maintaining social activity (27) and IADLs (28) may even be impaired during the prodromal stages of dementia, over 5 years before diagnosis.

Figure 15.1. Loss of functional independence during the course of dementia progression and disease-related, physical, and environmental and social factors affecting independence

Dementia-related factors

Dementia subtype

Communication problems

Neuropsychiatric symptoms

Cognitive profile

Dementia progression

Physical factors

Sensory impairment

Physical frailty

Gait, balance, and movement problems

Social activities

Instrumental activities of daily living
- Managing finances
- Preparing meals
- Managing medication

Basic activities of daily living
- Bathing
- Continence
- Dressing
- Feeding
- Toileting
- Transferring

Loss of independence

Environmental and social factors

Living alone

Social networks and marital status

Accessible home environment

Psychological factors

Perceived stigma

Fear / loss of confidence

Family caregiver distress

Family understanding of dementia and adaptability

In patients with established dementia, studies of patients with dementia in the UK (14) and Europe (29) examining 6 BADLs (bathing, dressing, toileting, transferring, continence, and feeding) in over 1000 people with dementia suggested that bathing, continence and dressing were the activities most susceptible to loss of independence in early dementia, and that feeding, toileting and transferring were relatively preserved until the later stages of dementia. Bathing and continence were impaired in over half of patients with mild dementia, dressing became additionally impaired in the majority of patients with moderate dementia, and toileting and feeding were also impaired in over 50% of patients with severe dementia (14), findings which are supported by other research (30).

Studies which have examined the length of time until the person moves from living independently into a care home setting have reported varying results. For example a German prospective cohort study of older

people living in private homes found that median time from dementia onset to residing in a nursing home was 2.75 years (31) and mean time for patients with dementia onset after 65 years in the Netherlands was 4 years (32).In addition, half of patients in a US sample were institutionalised over 2.5 years (24), and Australian studies have reported institutionalisation in 25% of people 3 years after diagnosis (23) and 76% of people 5 years after diagnosis (33). This variation across different study populations and settings likely reflects differences in baseline patient characteristics – some may have been diagnosed with dementia at a later stage. The diverse findings are also explained by societal differences such as different approaches to state provision of care, and cultural differences (34), whereby it is customary in some settings for older people to live within wider family units where support can be given informally by the family, and in others to live alone in older age, where there is less support at hand to maintain current living circumstances.

Several factors appear to make institutionalisation more likely, and therefore should be of interest to clinicians aiming to prolong living at home, including being widowed or divorced compared to being married (24, 31), neuropsychiatric symptoms (23, 32, 35), rapid dementia progression and family caregiver psychological morbidity (33, 34).

Some aspects of social function appear to decline during the course of dementia. A cross-sectional study of ratings by family carers of 299 patients with dementia of varying disease severities (16) found that mean score in social functioning domains related to 'spending time with other people' and 'communicating with other people' declined significantly with increasing dementia severity. This suggests that patients with more severe dementia may be less motivated to maintain social activity, possibly related to apathy, have difficulty arranging social engagements, maintaining communication (36), or be concerned about the potential challenges of these situations and so avoid these. Perceived stigma for a patient with dementia who anticipates that they will struggle with functional and social activities (37) and anxiety of family members who have limited knowledge of dementia and difficulties adapting to their relative's condition are additional barriers to functional independence (8).

15.1.3 Other factors affecting loss of independence in dementia

There is variation between patients with dementia in maintaining independence and several factors which can be classified as relating to the dementia process including dementia subtype, profile of cognitive deficit and neuropsychiatric symptoms; physical health including level of sensory impairment and physical frailty; and wider environmental and social factors affect the progressive loss of independence. These contributory factors are summarised in figure 15.1.

Variations in functioning have been reported according to dementia subtype. Patients with mild AD were rated by family carers as performing better on a range of IADLs than a comparator group with mild vascular dementia (38). Those with AD also are more independent than patients with dementia with Lewy bodies (DLB) on BADLs and IADLs (39). Comparison of patients with AD and behavioural-variant frontotemporal dementia (bvFTD) in financial calculations and errors found that patients with AD were more likely to make errors related to poor memory, but those with bvFTD advocated spending excessively with less concern for negative consequences (40). Loss of independence in social functions related to impairments in social behaviour is also characteristic of bvFTD and has been shown to be worse in patients with bvFTD than in those with AD (41, 42).

These differences according to dementia type are likely to be related to several disease-related factors. Firstly, the profile of cognitive impairment, such as the prominence of amnesia in AD compared to executive function and behavioural symptoms in bvFTD. Secondly, associated neuropsychiatric symptoms are clearly linked to worse ADL function (23, 32), so the higher rate of hallucinations in DLB (43), or apathy in bvFTD (44) are likely important drivers of functional decline in these conditions. Thirdly, associated somatic symptoms such as Parkinsonism in DLB or stroke-related impairments in vascular dementia increase frailty which impairs independence. Some studies have endeavoured to describe the detailed neural correlates of functional dependence (45) finding, for example, that impairment in IADLs in Alzheimer's disease is linked to lower medial frontal cortex volume (12), but the complexity of many functional tasks makes it difficult to conclude that these are localised in specific brain regions.

Physical frailty is a risk factor for losing functional independence in those with and without dementia (46, 47). A Canadian longitudinal study of activity of daily living independence in patients with mild dementia at baseline found that 18% of the sample did not lose functional independence over 5 years follow-up. Those who maintained independence were likely to have no problems with gait, balance or movement, and have maintained sensory functions (48). Other factors associated with independence were age, the presence of extrapyramidal symptoms, and having less education.

Finally, environmental and social factors are key considerations in assessing propensity to lose independence of patients with dementia. As discussed previously, living alone and being unmarried are risk factors for institutionalisation as there is an absence of a carer to support previous levels of function. Wider social networks, including the availability of friends and relatives who are aware of, and can make reasonable adjustments to, the patient with dementia's impairments are particularly important in maintaining social functions (37). The level of psychological distress and burden on family relatives is also important, making it a relevant area to assess when approaching clinical management, and having an

accessible and adaptable home environment may also facilitate maintenance of independence. Box 1 describes two case vignettes with different factors affecting loss of independence in dementia.

Box 1. Case vignettes: Factors affecting independence in dementia

Mr A is a 76 year old widowed man who was diagnosed 3 months ago with mild Alzheimer's disease dementia after complaining to his primary care doctor that he had become forgetful and was having difficulty navigating when driving his car. He lives alone in a second-floor apartment, and has family living 100 miles away who he speaks to regularly on the telephone, although this is difficult due to hearing impairment. He is feeling lonely as he has stopped going regularly to his local social club.

Mrs B is an 82 year old married woman who was diagnosed with dementia with Lewy bodies 4 years ago and has developed rigidity, bradykinesia, and a stooped posture affecting her balance and gait. She has distressing visual hallucinations which are worse in the evenings and she cannot manage to wash or dress independently. Her husband, with whom she lives, is struggling with low mood and anxiety symptoms and no longer leaves her alone in the house.

15.2   Assessment of functional independence in dementia

Approaches to maximise functional independence in dementia require the clinician to have an accurate appraisal of existing ability, especially considering that individuals vary in which domains are impaired and retained. There are several approaches to this assessment, including using proxy-report scales and observing performance on functional tasks (45), and there is potential for future approaches to further improve the assessment of function in dementia. Box 2 illustrates key approaches to assessing functional independence in the case vignettes.

15.2.1   Proxy-report scales

There are a large range of scales which are used in clinical and research settings to assess levels of functional independence and ability. These usually rely on asking an informant – a relative or friend who knows the patient well, or a professional carer or other healthcare professional – about the patient's daily functioning, as it is usually thought that a patient with dementia would not be able to accurately gauge their own performance. A range of scales and their aims is presented in table 15.1.

Scales assessing instrumental activities of daily living are considered useful in clinical settings, with a large pan-European study of memory clinics finding that the Instrumental activities of daily living scale (49) was used in over one third of these settings and the Katz scale (50) used in around one quarter. There is

however limited evidence for the psychometric properties of many of these, and a systematic review found that only two were of overall moderate quality and that the rest were of lower quality (20). The two scales favoured in this review were the Bristol Activities of Daily Living Scale, which aims to assesses change in ADLs in patients with early dementia as it lacks floor and ceiling effects and possible sensitivity to detect change, and the Disability Assessment for Dementia questionnaire, which assesses function in patients with dementia living in the general community which has established validity and reliability. Aspects of social function are often included within IADL scales, but few instruments specifically aim to assess social function.

Table 15.1: Examples of assessment scales for measuring function in dementia

Domain of function	Scale	Aim
Basic or instrumental activities of daily living	Instrumental activities of daily living scale (49)	Assesses ability in eight daily living tasks, e.g. shopping, housekeeping, and takes 5minutes for completion. Commonly used in dementia assessment services.
	Bristol Activities of Daily living scale (52)	Questionnaire assessing 25 activities of daily living and completed by professional or family carer, taking around 15 minutes. Sensitive to change and can be used in clinical practice or research settings including clinical trials.
	Disability Assessment for Dementia (53)	Interview-based questionnaire with a proxy respondent aiming to evaluate functional disability in community-dwelling patients with Alzheimer disease. Assesses 40 domains including leisure activities.
	Functional independence measure (54)	Assesses overall disability, covering self-care, continence, mobility, communication, and psychosocial and cognitive function. Can be used in hospital settings, particularly inpatient rehabilitation.
	Katz Index of Independence in activities of daily living (50)	Assesses independence in six key areas of daily living activity including bathing, dressing. Rated by an informant and completed in less than 5 minutes. Designed for general population of older people but is frequently used in dementia clinical services.
	Barthel Index (51)	Assesses functional ability for older people with a focus on physical functioning, and should be used only to assess impairments caused by physical function. Completed by an informant and has been widely translated and validated.
Social function	Engagement and Independence in Dementia (55)	Self-report scale comprising 26 questions examining sense of independence and social engagement for a patient with dementia, with acceptable psychometric properties for research settings.
	Social functioning in dementia scale (21)	Assesses 17 domains of social function in three key areas including spending time with others and communicating with others and has patient- and carer-rated versions. Primarily for use in research.
Overall function	Informant Questionnaire on	Administered to an informant to assess for presence of dementia by detecting changes in tasks, including recalling information and function, e.g. using new objects. Takes 10 minutes for completion.

15.2.2   Performance-based assessment

The other main approach to standardised assessment of functional independence is through directly assessing the performance of a patient with dementia in specific tasks (57). This approach has potential to provide a more objective and valid evaluation than a scale completed by an informant and may be more qualitatively rich and informative. However, this process of assessment is more time-consuming and costly and may require the expertise of allied healthcare professionals including occupational therapists and physiotherapists. Assessments of this sort are often conducted in clinic or hospital settings, although could be administered in the patient's own home.

Examples of scales which are validated in dementia include the Direct Assessment of Functional Status (58), which assesses a range of BADLs and IADLs, including dressing, feeding and shopping and takes around 45 minutes, the Performance ADL Test, which additionally assesses gross and fine motor control, the Erlangen Test of Activities of Daily Living (59) which assesses five activities such as eating and self-care, and the UCSD performance-based skills assessment (60) which assesses IADLs in around 30 minutes and is more sensitive in early disease. Other scales focus on specific functions, such as assessing in more detail ability to manage finances using the Financial Capacity Instrument (61).

15.2.3   Safety

A key consideration in assessing functional independence is the safety of the patient with dementia, meaning that risk should be evaluated and managed, ideally at home where unidentified areas of risk can be seen. Family members may have a different, often lower, threshold for tolerating risk than professionals or patients with dementia themselves as they may be the ones who are most affected, so assessment also needs to obtain different perspectives.

A common principle of risk management is to allow people to have acceptable level of risk to minimise restrictive strategies and permit patient autonomy, which usually requires assessing the mental capacity of the patient with dementia to make risky decisions related to poor judgement, apathy or forgetting and usually accompanied by lack of insight (62). Key risks which should be evaluated are floods, fire or gas from leaving on cooking appliances, dehydration and malnutrition from forgetting or being unable to eat, forgetting to take medication, financial exploitation by others, unsafe driving and risk of getting lost or being harmed when out of the house for example due to poor road safety awareness (63).

Management of risk includes many of the measures and interventions discussed in the next section, as well as avoiding patients with dementia being left in dangerous situations, wearing personal pendant alarms, using medication aids, use of 'telecare' devices (64) and smoke, fire and gas sensors, and preventing people unable to drive safely from doing so. Risk changes throughout the course of dementia so needs to be reassessed and managed regularly.

15.2.4 Other approaches

There is significant potential for future technological approaches to improve the assessment of functional independence with greater ecological validity. Remote monitoring devices in the home including sensors to detect the interaction between a patient with dementia and their environment, such as their movement and use of appliances, has been tested in older people (65) and suggested for those with dementia (66) but are not used routinely in clinical settings. Mobile telephone technology could assess social functions such as time spent with or communicating with other people, and navigation (67). Such technologies will require exploration of potential ethical issues related to privacy as well as evaluation of their accuracy and validity in this patient group.

Box 2. Case vignettes: Assessment of functional independence

Mr A was assessed by the occupational therapist who completed the UCSD performance-skills assessment. It was identified that Mr A had difficulties in using the telephone related to hearing impairments, and that he struggled to manage navigation in unfamiliar settings. Safety assessment, including telephone conversation with his daughter, indicated that Mr A's apartment did not have functioning smoke sensors, and that he may not be able to drive safely due to difficulties with navigation. He was willing to stop driving but identified his primary goal as wanting to continue to meet his friends at his local club. He explained that he had gradually stopped going because he was worried about getting there but also that he found it difficult to keep up with conversations once he arrived.

Mrs B's husband completed the Bristol Activities of Daily Living Scale where it was noted that she had deficits in several basic ADLs, including dressing and hygiene, and instrumental ADLs such as preparing food and managing finances. Mrs B had previously fallen in her home, where the lighting was poor, and she did not wear a safety alarm and she was observed in her home to have poor safety practices when attempting to prepare a cup of coffee using a gas cooker. Mrs B's husband was seen by a psychologist who assessed his stress and burden; he explained that he worried a great deal about her safety and so found it easier to do things for her rather than getting her to try for herself. Mr and Mrs B identified several goals related to doing pleasurable activities out of the house together, and increasing social contact with others.

15.3 Interventions for promoting functional independence

The research evidence for the efficacy of interventions to promote functional independence is variable and there is no consistent evidence from high quality research studies for any one particular approach. The studies which have shown efficacy in improving function for patients with dementia have all been delivered individually, rather than in group settings, allowing tailoring to the individual needs of patients with dementia (68). This should therefore be the principle of clinical approaches to promoting independence and these may focus on supporting independent living, maintaining activities of daily living, promoting social function, maximising physical function, and improving communication. Box 3 describes approaches to managing the case vignettes.

15.3.1 Supporting independent living

A recent systematic review found 11 randomised controlled trial (RCT) aiming to support patients with dementia to live at home for longer (22), two of which reported effective interventions. The Maximising Independence at Home study focused on optimising the home environment and supporting family carers using a model based on the needs and goals of the patient with dementia. The advocates that specific needs are identified and then mapped to a list of care strategies which can be carer-focused, self-management or involves other resources or services. This study used well-trained non-clinical staff as the coordinators of care, supported by clinicians such as nurses and physicians. This approach is potentially scalable to larger settings and findings of a RCT including 303 patients with dementia had 37% lower risk of moving from their homes during the 18 months following the intervention (median difference in time spent living at home between the intervention and control groups = 9.5 months), which may have been related to better safety management and advance care planning (69). The intervention also improved quality of life relative to controls and led to less input being needed by family caregivers (70).

The other effective intervention was the New York University Spouse Caregiver Intervention which was primarily delivered to the family carer through two individual and four family sessions tailored to the caregiver's individual needs and with a focus on relationships and accommodating the dementia course to enable recovery, as well as providing telephone contact and support group participation. The intervention reduced nursing home placement risk in patients with dementia by 28% (median time to placement was 18.3 months longer for those receiving the intervention compared to controls) (71)and was most effective delivered for patients with mild or moderate dementia, rather than severe disease (72). It has also been adapted to address the specific needs of adult-child caregivers of a parent with dementia, by changing the format of intervention delivery and incorporating additional sources of family support, and this adapted NYUCI showed maintained efficacy in a further RCT (73).

Other promising research which have shown encouraging pilot data are in process, such as the interdisciplinary home-based reablement program (74), a multicomponent intervention over 4 months including occupational therapist, nursing and other healthcare staff input, environmental adaptations to the home of the patient with dementia and carer support, and showed feasibility and potential for efficacy in a small pilot study (75). The New interventions for Independence in dementia study (22) is also ongoing and is an eight-session family carer-focused intervention aiming to support the patient with dementia to remain living independently at home. And the Promoting Independence in Dementia project (76) incorporates cognitive, physical, and social activities delivered individually over three sessions and guided by a manual and can be delivered consistently and acceptably to patients with dementia (77).

Summary

Evidence from research interventions aiming to maintain a patient with dementia living in their own home therefore suggests that key components are that the clinician 1) identifies care needs and goals for the patient with dementia and their families; 2) prioritises these needs using therapy strategies aiming to minimise functional impairments and promoting self-management where possible; 3) offers support to family carers and gives them ongoing support through a single point-of-contact; 4) forges links with other services and resources which are involved in patient care. These interventions are often relational, meaning that they are not simply about the patient with dementia continuing to do everything for themselves but involve building a supportive care environment which relies on interdependence for the patient with dementia and their informal and professional support networks.

15.3.2   Maintaining activities of daily living

Several research studies have aimed specifically at improving a patient with dementia's ability to fulfil their activities of daily living. These tend to be occupational therapy-led interventions training patients with dementia to improve their performance at ADLs and, where function is impaired, developing compensatory strategies (68). One US RCT found improvements in ADL function, which examined independence in ADLs as a secondary outcome in a study aiming primarily to reduce behavioural symptoms of dementia. The Tailored Activity Programme (TAP-VA) (78) involved 8 sessions with occupational therapists in the homes of patients with dementia, tailored to the interests and abilities of the patients with dementia, aiming to customise activities and teach their family caregivers about dementia and how to maintain activities. In 160 dyads, the people receiving the intervention had fewer activities on which they were dependent on another person at 4 months follow-up, although this benefit did not extend to 8 months, possibly suggesting that gains from this intervention are lost and indicating the need to consider longer-term interventions or reassessment of needs at appropriate intervals.

Cognitive rehabilitation may be an effective approach to maximising ADL independence (79); it aims to improve everyday function by helping patients with dementia to set individual goals and use strategies to achieve these. In a large RCT of 475 patients with mild dementia in the United Kingdom, the 'Goal-oriented cognitive rehabilitation for early-stage Alzheimer's and related dementias study', cognitive rehabilitation was given in ten therapy sessions over 3 months and then four maintenance sessions during the subsequent 6 months, delivered by occupational therapists or nurses to a patient with dementia and, during parts of the sessions, their caregiver. Sessions focused on three specified goals and aimed to model effective strategies and skills towards these goals, with encouragement for the patient and carer to continue these approaches between sessions. Improvements in participant-rated goal attainment, as rated by the patients and carers, were shown at 6 and 9 month follow-up, and this was considered to be cost-effective, although there was no effect on secondary measures such as quality of life (80). In another RCT, cognitive rehabilitation in patients with mild AD in 40 clinical sites in France resulted in better functional ability and delayed institutionalisation compared to usual care (81).

Other studies have examined before/after effects of interventions without comparator groups. For example a small Spanish pilot study (82) of 21 patients with dementia found that an occupational therapist-led 12 week programme of activities, cognitive stimulation, home modification, and ADL training led to large increases in functional independence, and that top-up sessions 6 weeks later led to further improvements. However, the lack of control groups in studies such as these makes it impossible to know what aspect of this intervention may have been helpful.

Other studies have not reported significant improvement in ADL function. For example, an RCT which focused on ADL ability as primary outcome, using nine sessions of 'errorless learning', which guides people in activities to prevent them from making mistakes, and compared this to a simple trial-and-error approach to activities (83), did not find significant benefit of the therapeutic approach on task performance at 4-6 months in 161 patients with AD or mixed dementia. This type of intervention is sometimes referred to as cognitive training and is dealt with in chapter 13. Another study which included occupational therapists working in patients' home settings over 5 weeks with patients and their caregivers to identify and encourage meaningful activities, showed no difference in ADL performance for people who received the intervention compared to the control group (84).

Summary

The best approach to improving activity of daily living independence may be through cognitive rehabilitation. It appears likely that prolonged intervention over at least 8 sessions is important and this may be best led by occupational therapists. As with interventions aiming to maintain independent living, it

is likely that individualised approaches, involving family members, and setting appropriate patient-led goals are key to efficacy.

15.3.3 Promoting social function

Few studies have aimed primarily to promote social function in patients with dementia although improving social function is often a potential secondary outcomes or mediator of other effective interventions. For example, group-based cognitive stimulation therapy (CST) (85), which involves group sessions led by a trained therapist consisting of social activities, cognitive exercise and reminiscence is recommended for all patients with mild dementia in the United Kingdom (86) due to the beneficial effects reported for cognitive outcomes. It may also confer benefits in social interactions, with moderate effect size (87), and therapeutic group-based interventions of this sort may be an appropriate first management step for patients with dementia whose social function is impaired. Individualised CST, delivered by a family caregiver with support and training, was not effective in improving cognition, but may improve the quality of family relationships (88). CST is discussed further in chapter 13. Other approaches such as support groups, which are popular with many patients and family carers, may also be beneficial in improving social function (89), and one RCT of support groups in the US reported improvements in quality of life which may have related to better social functioning (90).

Summary

There is no clear evidence for the best approaches to maximise social function in patients with dementia, but this may because few studies which have attempted to promote social activity alongside ADLs have considered social function as an outcome. Social function is a potential candidate for novel technological interventions as, for example web-based communication has appeared promising in mild cognitive impairment (91), and social robots have been advocated for increasing the amount of social interaction for isolated people and those with advanced dementia (92).

15.3.4 Maximising physical function

Physical functioning is an important domain of function, which is closely linked to functional independence. Mobility, endurance, strength and balance all enable individuals to maintain daily functions, in particular basic activities of daily living, but these areas are also vulnerable for patients with dementia, who have high rates of other physical conditions, because of the bidirectional relationship between physical and cognitive health and shared risk factors for physical illnesses and dementia.

Several studies have shown efficacy in approaches to maximise physical function. Eight of nine RCTs of moderate or high quality which were included in a systematic review (93) found that intensive exercise

improves physical functioning in patients with dementia. These studies tended to adopt more than one exercise modality, including strength and balance training or aerobic training, for example using a stationary bicycle. Effective interventions had to be frequent (at least twice weekly), with progressive intensity, last at least 12 weeks, and be either individual or group-based.

There is variable evidence for the effect of these interventions on independence more broadly. Some have shown efficacy in improving BADL performance (94). A Finnish RCT of a combination of either group-based exercise at day centres, or a goal-oriented tailored home exercise programme, each delivered once weekly for 1 hour by specialist physiotherapists, focusing on endurance, strength, and balance and executive function tasks led to less functional decline those who received the intervention individually, but not in a group, compared to controls (93). However, the Dementia And Physical Activity (95) trial of moderate to physiotherapist-delivered high intensity group-based exercise training in 494 patients with mild to moderate dementia found no improvements in ADL performance measured as a secondary outcome, and similar lack of efficacy were found in two other group-based interventions (96, 97). See also chapter 13 for further discussion on physical exercise and cognitive function.

Summary

There is strong evidence that intensive exercise interventions improve physical fitness and function in patients with dementia. Such interventions delivered in individual, but not group, settings may improve overall functional independence.

15.3.5　　Supporting sensory function and communication

As effective communication with others is an essential component of independence, supporting better sensory function including hearing and vision, and facilitating better communication is a potentially important facet of clinical care. As hearing is crucial to communicating with others, hearing loss should be identified and evaluated, and treated where appropriate with hearing aids, although the evidence for the efficacy of this as an intervention on function in patients with dementia is variable (98, 99).The increasing awareness that hearing impairment may confer negative effects on cognition, including elevating the risk of dementia (100), is likely to lead to more research in this area in future.

There is also limited research on the efficacy of correcting visual impairment, but this should be a priority of good quality clinical care, either by locating and cleaning existing spectacles, or assessment of visual acuity and provision of new glasses. Particular dementia types such as the posterior cortical atrophy variant of AD are associated with specific visual deficits (101) and these should also be assessed and environmental adaptations made to account for these to potentially improve function and reduce the risk of falls.

Several studies have aimed to improve communication between patients with dementia and their informal or professional carers. In a systematic review of these interventions in nursing home settings, approaches which were delivered to patients with dementia at set-times such as reminiscence, walking programmes including communication, or activity therapy, were ineffective, but those which aimed to incorporate improved communication into general daily care such as by training professional caregivers' to provide better communication, were effective in improving communication outcomes (102). Particular problems with communication are encountered by those with rare dementia subtypes such as primary progressive aphasia and though there is currently a lack of clear research evidence and clinical pathways (103), approaches such as carrying picture books and cards may help in addition to structured therapeutic approaches (104).

Box 3. Case vignettes: Management of functional independence

Mr A attended a hearing assessment and was provided with hearing aids which improved his communication. He stopped driving and was provided with taxi transport to his local social club, which he was reminded to attend by a daily telephone call from his family. His hearing aid helped him to follow conversations better and he told one of his friends at the club about his dementia diagnosis which he had been worrying about. His family were signposted to local specialist dementia services. His apartment was fitted with functioning smoke sensors. Mr A received regular review of his functional needs and goals.

Mrs B's home underwent adaptations, with improved lighting to reduce falls risk, the gas cooker replaced by an electric alternative, and the installation of a telecare service including a 'pendant alarm' which Mrs B wore to alert others to falls or injury. She received visits from a neighbour three times weekly to socialise and to enable Mr B to leave the house alone to meet with a friend in a café. Mrs B had pharmacological management of hallucinations optimised, and Mr B continued to see the psychologist to receive structured therapy aiming to reduce his burden and stress and develop helpful strategies for supporting his wife.

15.3.6 Other essential considerations for delivery of interventions

In addition to considering the patient characteristics, needs, and goals, clinicians should consider other important aspects related to the delivery of effective interventions including the setting, the mode of delivery, and the role of different members of multidisciplinary teams.

15.3.6.1 Setting

In planning the delivery of interventions aiming to promote functional independence, clinicians should consider the setting in which these will be delivered. For example, maintaining functional independence in

people living in independent homes is different to those who reside in settings with additional care support, such as residential homes or care homes. Although these settings by definition indicate that the patient with dementia has lost their independence to some extent, it remains an appropriate goal to maintain the current level of functional independence, which is likely to require collaborative working with care staff to devise, enact and maintain care strategies. Similarly, those who live in private homes alone compared to those who live with others will have different care needs and in these settings, having a supportive family member and/or high-quality professional care is important.

Rurality may also affect independence, as access to local amenities may be more impaired, in particular due to loss of driving ability (105). Finally, there are international differences in current levels of post-diagnostic support for patients with dementia and models of care and funding for these, as well as significant disparities within countries for those from minority ethnic groups and deprived socioeconomic backgrounds (6). Promoting equity in healthcare should be a priority, meaning that those at greatest risk of losing functional independence should be most supported.

15.3.6.2   Mode of delivery

As previously discussed, most evidence points towards individual, rather than group, treatments for patients with dementia, but there may be a role for group therapies where they are valued by patients and their family carers. Technological approaches to promoting functional independence include cognitive aids to remind people to take medication and prompt activities of daily living; robotic approaches to help with eating, washing and mobility; communication aids and technology to deliver music, images or video; and interventions to provide companionship (100). These are in use already, primarily to maintain safety (64), and these are gaining increasing interest but there is a need for well-designed high-quality research evidence for these (106).

Assistive technology for supporting memory includes electronic pill dispensers or electronic diaries but in a recent Cochrane review, there were no high-quality studies meeting their predefined eligibility criteria examining functional independence, quality of life, or maintained independent living (107). In a systematic review of qualitative studies, carers generally found use of assistive technology acceptable and viewed potential benefits in terms of promoting social interaction, maintaining autonomy and safety and therefore quality of life (108); however, they reported potential barriers related to loss of personal aspects of caring, and technical problems. A subsequent high quality RCT comparing the effect on caregiver burden of provision of assistive technology and telecare following a structured needs assessment against simple safety measures such as smoke alarm and pendant alarm found no benefit for the technological approach (109). However, the use of technology often does not reflect the recommendations of assessors (110) and a

review found that lack of personalisation may adversely adoption of technological approaches for patients with dementia so this is an important future area for development (111).

Socially assistive robots, which have a social interface allowing interaction with a patient with dementia aiming to improve their wellbeing, take several forms, including human-like and animal robots. The most extensively research socially assistive robot is PARO, the seal-like companion robot which makes sounds and movements to interact with patients with dementia and there is provisional data suggesting that it is engaging for patients with dementia and reduces agitation (112). Telepresence robots aim to promote social communication through interactive video calls between patients with dementia and their social contacts. Despite technical problems affecting their use in certain settings, they have generally been deemed acceptable by key stakeholders in small pilot studies (113, 114) though rigorous RCTs have not yet been conducted. Homecare assistive robots, which provide supervision or monitoring to patients with dementia aiming to support BADLs and maintain safety have been described in the literature (115) and are viewed as feasible and acceptable (116) but there is scarce data on their efficacy.

The COVID-19 pandemic has accelerated the use of technology (117, 118) to provide remote care for people in settings where social and physical distancing has been necessary to reduce transmission of the disease. The evolution of care to address challenges is welcome, but may risk perpetuating isolation in patients with dementia so technological approaches should be evaluated and held to the high standards used for other non-pharmacological approaches, with consideration given to their acceptability to patients with dementia and potential adverse effects.

15.3.6.3   Role of multidisciplinary teams

There is a clear need for involvement of several members of the multidisciplinary team in managing promoting functional independence for patients with dementia. The role for physicians may be in clinical assessment of needs and risk and consideration of physical illness. Occupational-therapists or physiotherapists may conduct performance-based assessment of function and lead or supervise interventions; specialist dementia nurses can offer additional support; neuropsychologists may evaluate cognitive profile in detail and clinical psychologists lead on delivery of psychological interventions for family carers and patients with dementia; speech and language therapists may assess communication and devise strategies to promote this. An aim of several research studies has been to develop scalable interventions (22, 70) which often means that they are delivered directly by non-clinically trained staff, such as support workers, with supervision provided by more experienced staff, so there is role for other staff members in with different levels of clinical experience. Collaborative working within and between teams is an essential component of clinical care.

15.3.7   Conclusions

Functional decline is one of the core features of dementia and so should be a focus of clinical care. Assessing areas of deficit allows clinicians to identify goals for improvement and develop strategies for promoting functional independence. The evidence base for interventions is growing, and the areas with strongest evidence for intervention, summarised in figure 15.2, appear to be multicomponent approaches which aim to tailor exercise programmes, cognitive rehabilitation approaches and home adaptations to dyads of patients with dementia and their family carers. There is a need to provide these treatments to people after the diagnosis of dementia and these have the potential to slow the loss of functional independence, save valuable resources and improve the quality of life of patients with dementia and their carers.

Figure 15.2. Interventions to promote functional independence in dementia and essential characteristics of interventions
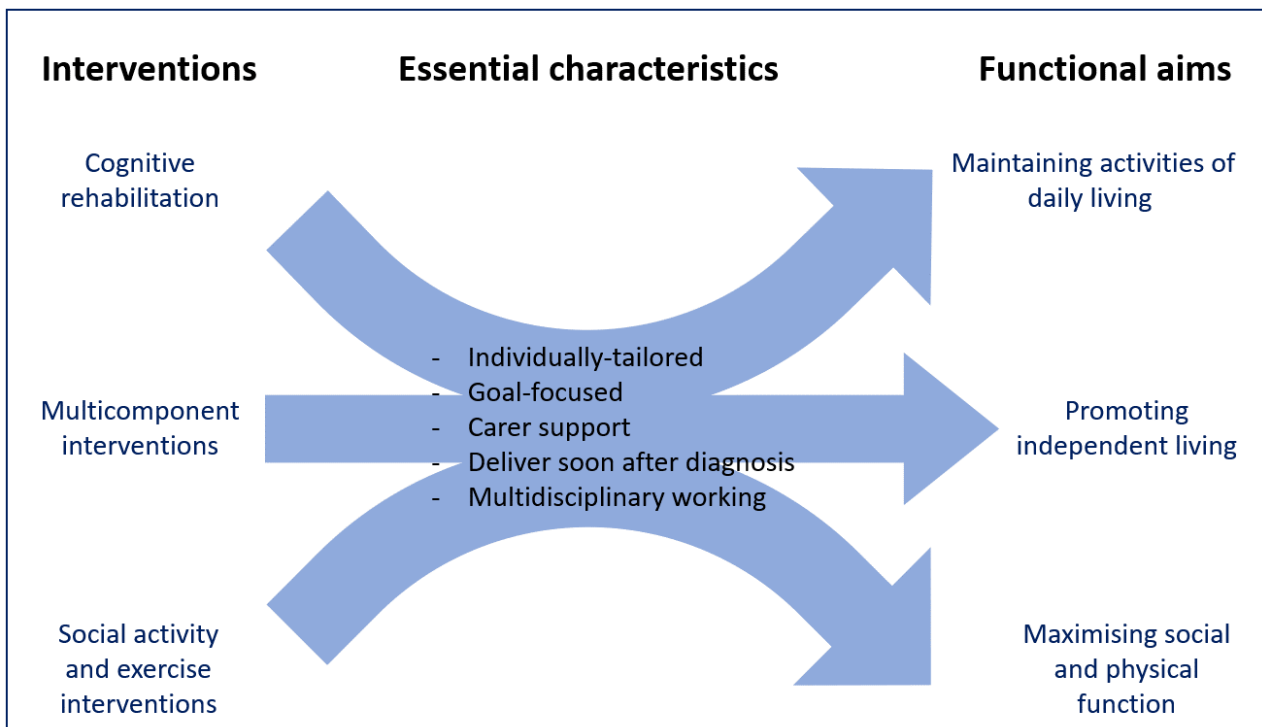
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