

ARTICLE

Supporting self-management in early dementia: a contribution towards ‘living well’?

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SUMMARY

There has been increasing interest in how to assist people to ‘live well’ with advancing and incurable conditions late into life. This article considers the progress made in mental health services for adults of working age which promote active involvement in their care and how these principles can be applied to older adults with dementia. The concept of ‘recovery’ and its applicability to dementia care are discussed. The Wellness Recovery Action Plan (WRAP) and how it could be translated and modified to the needs of people with dementia are explored. This is especially important in light of the UK National Dementia Strategy, which emphasises early diagnosis and intervention to promote improved care and quality of life.

DECLARATION OF INTEREST

None.

in the context of person-centred services for older people (Hill 2010), but the tools, guides and evidence have yet to be established to support service development in dementia care.

This article considers the possible benefits and applicability of the recovery-oriented principle of supporting people with dementia and their carers in self-management.

‘Living well’ with dementia

Dementia is a general term encompassing conditions that cause global deterioration of higher cortical functioning. Alzheimer's disease, the most common form of dementia, causes short-term memory loss with decline in speech, comprehension, judgement and personality as the illness progresses. This leads to a decline in the ability to carry out day-to-day tasks and ultimately, through progressive deterioration, to death. There is no cure for dementia, but treatments, both medical and psychosocial, aim to reduce distress and improve quality of life.

The National Dementia Strategy *Living Well with Dementia* (Department of Health 2009) promotes personal and therapeutic approaches that focus on how to live well even in the context of an incurable and progressive disorder. It emphasises the importance of early diagnosis and intervention to improve care and treatment in a cost-effective way. Up to half of people with dementia in the UK have not received a diagnosis, as many clinicians shy away from making a diagnosis that carries such stigma and lack of hope (Rice 1994). Husband (1999) found that only 4% of carers reported that a diagnosis of dementia had been shared with the person they cared for. The introduction of drug treatments such as acetylcholinesterase inhibitors have increased the referral rates from primary care, but there are still many people who are not aware of their diagnosis and are therefore unable to be actively involved in decisions about their care. This was recognised by Tom Kitwood (1997), who identified the ‘malignant social psychology’ that dominates from the early stages of dementia

Social and demographic changes and advances in acute medicine are leading to an ageing population. Many, perhaps most, people will now live for significant periods with long-term health conditions and illness. There are over 800 000 people with dementia currently living in the UK, with an estimated cost of £23 billion to the National Health Service (NHS) and associated care agencies (Alzheimer's Research Trust 2010). By 2021 it is predicted that the figure will increase to 1 million people with dementia living in the UK.

Alongside a continuing search for effective treatment and prevention, there has been a growing interest in how to live and how to ‘live well’ with long-term, incurable health conditions. This has been accompanied by increasing recognition of the value of enabling people to become actively involved in their own care and illness management, as a route to enhanced quality of life.

Mental health services for working-age adults have embraced this with approaches emphasising recovery, self-management, personalisation and inclusion. There is growing interest in exploring the potential benefits of applying these principles

and serves to disempower the person and take away their right to make choices and decisions about their condition. Although taking care to avoid 'romanticising' dementia, Kitwood (1995) wanted to emphasise the 'human functioning such as relationship, emotion and sensation' that still remain important in every individual, rather than primarily focus on cognitive and other deficits when considering people with dementia. He described this humanistic emphasis as a form of 'personal growth' and 'positive change' that can occur over the course of an advancing dementia.

There have been many projects, usually initiated by pioneering individuals, developed to support people with dementia from the early stages of diagnosis to considering end-of-life care. Some examples are given in Box 1. Emphasis is on treating dementia with positive attitudes and enabling choice and decision-making, thereby promoting quality of life.

Recovery and dementia care: concepts in conflict?

The current national mental health outcomes strategy, *No Health Without Mental Health* (Department of Health 2011), is oriented around six aims, the second of which is that 'more people will recover'. In clarifying what it means by 'recovery', the strategy notes that this has acquired a specific meaning in mental health, which is based on Antony's (1993) almost universally accepted definition of personal recovery:

'A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life, even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life.' (p. 16)

The strategy also underlines the broad applicability of the values and vision of this definition across the scope of this 'all age' approach by noting that, 'Although the term is not used in relation to children and young people, the underlying principles of the recovery approach are equally applicable'. But, the question remains of whether it is legitimate or helpful to talk about recovery, so defined, in dementia care.

In an earlier article in *Advances*, we (L.H. and G.R.) noted the close parallels between the values, principles and practices of person-centred care in older people's mental health and those of recovery approaches commonly used in mental health services for working-age adults (Hill 2010). We also acknowledge the difficulty of reconciling the word 'recovery' to the care of people with progressive and deteriorating conditions. However, the basis

for Antony's definition and the recovery approach in general centres on recognising that you can have an illness and yet be well, and that clinical variables such as symptoms are only loosely related to personal variables such as quality of life, hope, happiness and satisfaction. Moreover, the loose coupling between the presence of illness and experience of well-being provides a possible rationale for working to preserve or enhance well-being even for people with persistent or advancing illness. This has been a guiding principle in hospice care for many decades.

However, it may strain conceptual credulity to breaking point to call this recovery. Seeking to develop a recovery-oriented approach to dementia may risk offering false hope of cure and alienate the very people who could gain much from support for active engagement in optimising quality of life. This does not mean that the fundamentals of the recovery approach do not apply in dementia care, as the values, principles and many of the practices clearly do, but it does acknowledge the limits of using the word recovery to describe this. Fundamentally, the important issue is in developing approaches that are useful and experienced as helpful by the people we seek to serve.

BOX 1 Community support for people with dementia

Dementia/memory cafés (Alzheimer Café UK 2010)

Dr Bère Miesen, a clinical psychologist in The Netherlands, pioneered the idea for an Alzheimer's café for people with dementia and their carers in 1997. He aimed to create a welcoming and relaxed environment where people could discuss their fears and worries about dementia and receive help and support. This concept came to the UK in 2000 and is run along the lines of a structured programme of talks, discussions and invited speakers. In recent years this culture has developed into more informal café-style settings where people with dementia and their carers meet regularly for informal support and information-sharing, rather than structured psychoeducation. There are thousands of these cafés across the UK and they are often supported by the third sector, such as Age UK.

Dementia End of Life Care Project (DeLcAP) 2008 (Ghiotti 2009)

This project's aim is to support families caring for people with late-stage dementia at home. It is funded by the Big Lottery Fund and provides training, consultancy

and additional respite care. The project's development entailed bringing together palliative care practitioners, primary care workers and staff from dementia services to help families care for their relatives at home.

End of Life Care in Advanced Dementia (ELCAD) Project 2012

This project was a collaboration between the King's Fund and University College London to support and train Jewish Care nursing home staff caring for residents with end-stage dementia. Staff received training sessions to complement the Gold Standard Framework sessions given to all the home's managers. One outcome was increased staff confidence in holding difficult conversations about subjects such as advance decisions and whether to attempt resuscitation. Following the training, a higher percentage of residents died in the care home and fewer in hospital, and more people had advance wishes in place. For more information, see www.endoflifecare.nhs.uk/search-resources/resources-search/case-studies/imported-case-studies/the-end-of-life-care-in-advanced-dementia-project.aspx

Daley *et al* (2013) sought to evaluate whether a conceptual framework of recovery developed for working-age adults holds value for older people with mental health problems, including those with dementia. They found that the fundamental principles of recovery had resonance with older people and that taking a recovery-oriented approach was acceptable within the limitations of the concept. They also identified similarities and differences. Working-age adults and older people similarly gave emphasis to the impact of having a mental health problem, the importance of personal responsibility and valuing a number of coping strategies including self-help information and feeling connected to others and their community. However, older people, including those with dementia, sought to cope with their difficulties not so much by seeking a new sense of meaning and purpose as through a desire for stability and to 'continue being me', associated with the importance of holding on to an established and enduring sense of identity.

Daley *et al* also found that older people were much more likely to associate and seek support from family rather than peers, and there was a routine need to consider the impact of living with coexisting mental and physical health problems and developing coping strategies for both. For people with dementia there was an additional need to include the changing experience of the condition over time and the increasing need for support from others as mediators of well-being.

Overall, there was a close correspondence between Daley *et al*'s findings and the principles of recovery identified by service users in seminal papers on the subject (Repper 2003; Shepherd 2008), including key components of sustaining hope, maintaining control over life and symptoms, and creating opportunities to build a life beyond the illness, which are equally applicable to people living with dementia and their supporters. This ethos is also advocated by the Social Care Institute for Excellence (2006) which, when considering the needs of older adults with mental health problems, states that "Recovery" and well-being approaches to mental health issues developed by younger adult service users and working-age mental health services are equally applicable to older people' (p. 19); and furthermore, 'Recovery is [...] making it possible for people to have quality of life and a degree of independence and choice, even those with the most enduring and disabling conditions' (p. 20). This strongly implies that specific tools and discoveries in working-age adult recovery-oriented practice may have applicability in older people's mental healthcare, too.

Valuing self-management

Historically, much of our effort in seeking better outcomes has come through developing better treatment, where effectiveness is largely measured in terms of symptom reduction and improvement attributed to high-fidelity concordance with taking or receiving the treatment itself. More recently, there has been a growing interest in the contribution people can make themselves to their own health and well-being through becoming active participants rather than passive recipients. The Salzburg Global Seminar (Elwyn 2011) went as far as describing actively participating patients as 'the greatest untapped resource in healthcare'. Enabling people to take an active stance to their own health and well-being through supported decision-making and self-management planning has emerged as a major emphasis in recovery-focused approaches (Department of Health 2007; Alakeson 2012; Baker 2013).

Self-management has an established role in recovery-based care and was highlighted through the NHS Plan as one of the key building blocks for a patient-centred health service (Department of Health 2005). It features as a key component in the White Paper *Our Health, Our Care, Our Say* and in *Supporting People with Long-Term Conditions to Self Care* (Department of Health 2006a,b). It has been adopted at a local and national level in skills training programmes (Expert Patients Programme self-management courses) and condition-specific patient education programmes, for example DESMOND for type 2 diabetes (www.desmond-project.org.uk). Targeted investment in self-management interventions can increase people's confidence in managing their health and well-being and improve their quality of life and, collaterally, there is a possibility of additional economic benefits for the NHS (Expert Patients Programme 2010, 2011).

Self-management can be defined as 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition' (Barlow 2002). It focuses on empowering patients to manage their own conditions by increasing their knowledge and involvement in their care (Coster 2009; Jonker 2009), and has been associated with a range of highly desirable benefits, as described in Box 2.

Supporting self-management in dementia

Self-management strategies have been developed as a response to enabling people to live more satisfactorily with recurrent or long-term conditions. Dementia is a long-term condition,

BOX 2 Benefits associated with successful self-management

- Increases quality of life
- Helps the person become more aware of resources in their social environment
- Gives the person skills to manage their illness
- Helps the person with decision-making
- Increases self-efficacy
- Reduces the psychological distress associated with the condition through helping the person to manage the emotional consequences of the disability
- Increases knowledge about the condition

(Martyn 2002; Mountain 2006; Reid 2008; Rethink 2011)

yet very little is known about the efficacy of using self-management approaches with this population. Mountain (2006), in a review of issues about self-management and dementia, argues that in order to adapt self-management for people with dementia, several issues would need to be considered such as problem-solving, information-sharing, locating local resources, making an early diagnosis, supporting the impact of the diagnosis, and focusing on the person's changing needs.

The National Dementia Strategy (Department of Health 2009) re-emphasised the importance of providing more information regarding external support services, putting service users at the centre of their care plan, delivering care according to individual need and helping the person and carer to live alongside the dementia. However, this has yet to be developed into coherent guidance on supporting people in self-management accompanied by appropriate tools. There are also recurring dilemmas in dementia care which might be better addressed by engaging people in supported decision-making about their own care and treatment (Box 3).

BOX 3 Situations in dementia care where supported self-management might help

- Negotiating understanding and disclosure of diagnosis
- How to share this diagnosis with people
- Giving people information about their condition
- Increasing people's awareness of support services
- Care planning, including carers' perspectives
- Eliciting, preserving and remembering personal preferences
- End-of-life planning

The aim of self-management approaches in dementia is to enable the person to be at the centre of their care, drawing on and valuing their experience of their own condition, their preferences and capacity to express views on the relative merits of alternative forms of care and treatment in line with person-centred and recovery-principled approaches.

Adapting self-management planning from adult services to dementia care

The concept of self-management in relation to health has grown from the field of long-term physical conditions, but is increasingly being used in mental health services. Internationally, the most popular self-management tool for maintaining mental health is the Wellness Recovery Action Plan® (WRAP®) (Slade 2009). This has been incorporated into the SAMHSA National Registry of Evidence-based Programs and Practices in the USA, with a recommendation for wide dissemination (Substance Abuse and Mental Health Services Administration 2010). It has also provided the core model for many subsequent self-management frameworks in adult mental health services (e.g. Perkins 2007) and is therefore the best candidate to draw on and adapt to dementia care.

WRAP was developed by Mary Ellen Copeland and other user-contributors who were seeking a means of regaining control of their lives and wanting to develop ways of effectively working on their health and well-being (Copeland 1992). This resulted in formulation of an accessible self-management plan based on what people found worked for them. It aimed to 'promote wellness, decrease the need for costly, invasive therapies, reduce the incidence of serious mental health difficulties, decrease traumatic life events caused by crises, and to raise hope' (Copeland 1992; see also www.mentalhealthrecovery.com). Typically, this involves a focus on a 'wellness toolbox' which is a list of individually tailored resources that can be used to stay well. A daily maintenance plan helps to keep the person on track and reduce stress. WRAP also focuses on identifying early warning signs of relapse, potential triggers and actions people can take to reduce distress and restabilise their health. It includes a plan to enable the person to survive a crisis with an advance directive if needed. The plan is written, owned and used by the individual who chooses whether and when to share it with others at their own discretion.

Copeland's group have also developed, through extensive experience, an accompanying set of values and ethics through which WRAP is taught and shared. These include promoting self-

determination, personal responsibility, empowerment and self-advocacy, which are seen as the foundations for positive outcomes and are broadly concordant with an international review of key recovery processes (Leamy 2011).

WRAP has arisen as a group learning experience where everyone is treated equally and people are led to support one another in developing their own mental health experience into expertise, although it can be used individually. Medical and diagnostic language is avoided in favour of plain English and experience-based descriptions.

WRAP has not been targeted at or developed in the context of dementia, but as an established model with an extensive body of experience gathered over the 20 years it is a viable candidate from which to develop an illness-specific approach to self-management in dementia. A way forward would be to consider how to customise this self-management planning tool in the context of the similarities and differences between working-age adult mental health needs and those of older people with dementia. Some principles are held in common and others would require modification in the light of different needs profiles, particularly the routine involvement of family and other supporters, progressive deterioration, loss of memory and loss of capacity as a result of the neurodegenerative nature of dementia. In particular, this self-management tool must engage with the potential challenges faced by people with dementia around future planning for loss of capacity and end-of-life care, but yet be sensitive enough to be adaptive to change as the dementia progresses (Box 4).

Concerns and limitations in promoting self-management in dementia

Some critics of recovery have worried that promoting self-management can be used as a way of cutting services for people with complex needs (Mind 2008). This criticism is likely to be unfounded in dementia care because individuals will need considerable help and support in completing and maintaining self-management plans, especially as their dementia progresses. The use and ownership of self-management plans is likely to shift over time and the responsibility for working with the plan will devolve to the people around the person with dementia when capacity is diminished. However, this can be seen as a way of sustaining an awareness of personal preferences and positively linking the person with dementia with various supports around them in terms of family, the third sector, mental health services, general practitioners and care agencies. A well-formulated and regularly updated self-management plan can be used as a vehicle to support communication and an opportunity to continuously learn from experience about what an individual finds useful to enhance their well-being, particularly as the dementia progresses.

The contents of self-management plans constructed in adult mental health settings are constantly modified in the light of changing experiences of mental health and what people find works best for them. In adult services, self-management plans are typically constrained by an expectation that mental health problems will be episodic and when crises occur they will eventually resolve, with the opportunity to learn from that experience how best to avoid or cope with recurrence (i.e. 'post-crisis planning' in WRAP parlance). There is a hope, supported by a growing evidence base (Substance Abuse and Mental Health Services Administration 2010; Health Foundation 2011), that successful self-management will be accompanied by increasing stability, health and well-being and reduced use of services, particularly due to unforeseen crises. Self-management planning with people with dementia means working with a different set of expectations, and needs to be modified to account for the fact that success is defined as having the ability to live well with a deteriorating condition. However, within this declining condition there will be many fluctuations, and seeking to learn what modifies such changes and what choices can be made to optimise health and reduce symptoms are all potential benefits.

When considering using a self-management approach with someone who has dementia, it is

BOX 4 Developing a self-management plan for people with dementia based on the Wellness Recovery Action Plan® (WRAP®)

Features directly applicable

- A daily maintenance plan recording what needs to be done every day for the person to stay well
- A record of personal experience of what people have found works best for them
- A person-centred written plan prompting and reminding people of their options and preferences
- A structured plan describing different actions to be taken in response to successive levels of symptomatic difficulty or disability
- A 'crisis plan' or advanced statement describing personal preferences when needing others to act on the person's behalf

Differences to account for

- WRAP is characteristically developed in a group context supported by peers
- Peer experience and shared learning will be substituted by practitioners
- Shared ownership of plan with family and other carers
- An emphasis on supports for preservation of personal identity
- Combined planning for physical and mental health needs
- Routine inclusion in advance statement of enduring powers of attorney
- Fluctuations in health are set against progressive deterioration rather than episodic remission
- Eventual and permanent loss of capacity

important to consider the individual's complex and changing relationship with their condition and what coping strategies people may wish to use in accommodating a progressive illness. In the context of early psychosis, McGorry (1992) framed this as 'avoid adding insight to injury', which may be an equally applicable concern in early dementia. At the time of assessment, an individual may not have insight into their condition and be minimising or denying the extent of their difficulties. This makes giving a potential diagnosis very difficult, especially as the person's denial may preclude them from receiving medical or psychosocial intervention. Their capacity towards self-management and care will therefore be compromised if it depends on an understanding and acceptance of a diagnosis but may still be possible if people are able to acknowledge difficulties and needs. It also raises the possibility of developing self-management strategies with carers to optimise their health as well as offering them a structure and rationale for actions and decisions made on the behalf of others. These issues highlight the importance of gaining informed consent before assessment and the value of pre- and post-diagnostic counselling.

Adapting self-management to the needs of dementia also raises the issue of end-of-life care. The person with dementia may not be prepared to think about the end stages, but there needs to be some recognition that delaying consideration of this may mean that they lose mental capacity before it is discussed in a meaningful way. In these circumstances the person's wishes may not have been considered and family members may have to make difficult decisions about nursing care and end-of-life choices on their behalf. Introducing a self-management plan may be a way of broaching these sensitive and life-changing issues at a time that is right for the person.

Conclusions

The prevalence of dementia is set to progressively increase, but negative trials have led to reduced expectations of finding a medical cure in the near future and several major pharmaceutical companies are downgrading drug research in this area (Laurance 2012). However, as with other long-term conditions, there may be considerable and currently unexplored potential to support people in optimising their quality of life through developing structured support for self-management. There has been considerable interest in developing self-management in adult mental healthcare as part of developing recovery-oriented approaches, and there is a timely possibility of learning from

approaches such as WRAP and considering how these could be translated and modified to the needs of people with dementia.

Giving people more information about dementia and focusing on strategies to manage memory difficulties and the emotional consequences of the condition may provide valuable gains in enhancing self-efficacy, hope and control. This approach resonates with numerous government policy initiatives on recovery, person-centred care, inclusion, dementia, co-creating health and long-term care, as well as addressing clinical need and service demand. There is currently a lack of research indicating whether the application of these principles to a neurodegenerative illness is acceptable or effective, and what would need to be included in a self-management plan for people with dementia to optimise its value as a support for 'living well'. However, as dementia services realign to prioritise early diagnosis and intervention services, developing strategies to support self-management could provide a valuable contribution towards interventions aimed at fulfilling the national strategy.

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MCQ answers

1 a 2 b 3 b 4 c 5 e

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MCQs

Select the single best option for each question stem

1 The National Dementia Strategy *Living Well with Dementia*:

- a promotes early diagnosis and intervention of dementia
- b encourages care to be mainly family based
- c does not require involvement of service users
- d promotes medication as the front-line approach
- e states that early intervention can arrest the development of dementia.

2 Self-management has been useful in:

- a diabetes
- b mental health
- c chronic obstructive pulmonary disease

d dementia

e cancer care.

3 WRAP needs the following modifications in dementia:

- a a crisis plan or advanced statement
- b an emphasis on supports for preservation of personal identity
- c to be taken over by the carer when the person with dementia loses mental capacity
- d a daily maintenance plan
- e a post-crisis plan.

4 The recovery approach:

- a is not relevant for people with dementia
- b is not relevant for older people

- c can be applied to enhance well-being in advancing and deteriorating conditions
- d can only be applied to people with mental health problems
- e is only applicable in the early stages of dementia.

5 Projects promoting 'living well' with dementia focus on:

- a promoting quality of life
- b intervening in the early stages of dementia
- c working with the individual with dementia only
- d supporting families
- e enabling choice and decision-making for the person with dementia.