



FEATURE ARTICLE

Reconciling mental health recovery with screening and early intervention in dementia care

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ABSTRACT: *If early intervention in dementia care is to be enhanced, it is important to have a critical debate over how this should be realized. In this paper, we offer a synthesis of two approaches to care: mental health recovery and person-centred care, and apply them to early-stage dementia care. 'Person-centred care' has become a catchphrase for good dementia care. However, many people have not experienced improvements in care, and other lynch pin concepts, such as 'mental health recovery', might have utility in driving reform. The similarities and differences between the two approaches are drawn out, and the difficulties of using the word 'recovery' when discussing a degenerative disease are highlighted. The implications of this discussion for early intervention are discussed. It could be seen that the two bodies of knowledge have much to offer each other, despite initial dissonance with the label of recovery in dementia care.*

KEY WORDS: *citizenship, dementia care, early intervention, recovery, screening.*

INTRODUCTION

Since the early 1990s, the promotion of 'recovery' has become an espoused principle or expressed aim of the mental health policies of most Western countries. However, it is by no means clear just what is meant by the term in the different contexts in which it is used (Davidson *et al.* 2006). The Irish Mental Health Commission (2005), for example, refers to the 'recovery model', recovery as an 'orientation', a process, an approach, an outlook, a vision, a philosophy, and a guiding principle. Despite this semantic confusion, the term 'recovery' is part of a wider discourse that has led to a radical shift in the way in which mental health services are thought of and delivered. Mental health recovery challenges the traditional passive-dependent role of the psychiatric patient, and repositions the person in distress as an empowered service user, partner, and collaborator in their own care.

In what could be seen as a parallel but not necessarily cross-informing movement, the work of Tom Kitwood (1997) and the Bradford Dementia Group on person-centred care has had a major influence internationally on dementia care theory, education, policy, and practice. This work acknowledges the negative impact that malignant social psychologies have on the emotions, behaviour, and cognition of a person with dementia. It advocates processes intended to maximize the voice of the person with dementia.

Both recovery and person-centred dementia care are set in a context of an increasingly organized social movement of service users, former service users, and interested people, which emerged from the civil rights and protest movements of the 1960s and 1970s (Lakeman *et al.* 2007). Consumerism, consumer rights, and calls for community and user participation now permeate the provision of health care generally, but mental health care particularly.

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SERVICE REFORM IN DEMENTIA CARE

This paper is not intended to challenge the person-centred care movement and all that it has done for improving understandings of dementia and good care.

The promotion of the concept of person-centred care has had undeniably good effects on dementia theory and practice (e.g. Brooker *et al.* 1998; Woolley *et al.* 2008). What is clear is that 'person-centred care' has become a catchphrase for good care, but there are many more examples of poor care than there are utterances of person-centred care on service philosophies and government papers. Person-centred care provided an initial impetus and focus for service reform but has not greatly impacted on public attitudes towards dementia. Actively considering recovery, even with scepticism, could provide a counterbalance for the entrenched pessimism associated with dementia in the general population.

Mental health recovery discourse may be enriched by the well developed discussions relating to advanced directives in dementia care. Similarly dementia care may benefit from the promotion of social inclusion arising from the mental health recovery discourse. The drive towards social inclusion and consumerism aligned with mental health recovery has culminated in an unprecedented voice for service users at local service and policy making levels. In the UK, the number of independent user groups has increased from a handful in the 1990s to hundreds today (Campbell 2006). The idea of 'self-help' and organized mutual support, such as Alcoholics Anonymous, has spread from the USA to become an expected part of the fabric of mental health services, as has the idea of recovery as an ongoing process, rather than an outcome.

Some innovations in dementia care do demonstrate a shift in approach, in line with the recovery movement, such as the Mental Capacity Act (2005), the Alzheimer's Society's 'Talking Point' (a blog site for people with dementia and their carers), and the International Dementia Advocacy and Support Network. The voice of the person with dementia has been the focus of several recent initiatives, notably the The Scottish Dementia Working Group, which has provided a useful booklet by people with dementia for people with dementia with the aim of being heard, supporting each other, getting better services, and changing attitudes towards dementia. However, the research base reporting first-person narratives or commentary on how to promote citizenship in this population is still scarce. Mountain (2006) asserts that without a concerted effort from a range of stakeholders, including policy makers and advocacy organizations, people with dementia will continue to remain on the periphery of any benefits that can be derived from the current focus of policies that support people with long-term conditions. Given that mental health recovery appears pivotal to service reform of mental health services

at present, dementia care must critically engage with the concept in order to ensure benefits for service users.

WHAT COULD RECOVERY DO FOR DEMENTIA CARE?

Recovery in mental health and person-centred care in dementia care arose in parallel with the exposure of abuses of human rights in institutional care. (e.g. long-term care facilities, orphanages, schools, and asylums) has led to an erosion of trust of those in authority, and an increased scepticism that helping professions necessarily know best. The process of shifting the locus of mental health care from large hospitals or asylums to community settings, known as 'deinstitutionalization', has also returned issues of mental and social health closer to the community. While stigma and discrimination (both targets of concerted media campaigns) continue to be seen as major obstacles to recovery, and indeed, seeking help (Corrigan 2004), there has been a normalizing of at least some forms of mental health problems, such as depression, as evidenced by antidepressants becoming the most popularly prescribed drugs in the USA (Barkmann 1995). There is also a trend towards health professionals and others sharing their biographies or stories of psychiatric treatment and personal recovery (see Bassman 2007), and likewise in dementia (Bryden 2005; Grant 1999; Wilson 2003).

While 'person-centred care' appears to have resonance, no matter what stage of dementia a person might find themselves in, it is not entirely unproblematic, as it has strong etymological connections with the highly-popular and influential client or person-centred care, as first defined by Rogers (1961). Rogers famously proposed that empathy, genuineness, and unconditional positive regard were necessary and sufficient conditions for personal growth. However, such conditions, while desirable, are also unlikely to drive the kind of system change required in many community and long-term care settings for people with dementia.

Clearly, the word 'recovery' is semantically difficult, as colloquially, it connotes improvement or a return to a previous state (Collier 2010). 'Mental Health Recovery' in its various usages is related to, but not the same as, clinical or common notions of recovery, which suggest remission of symptoms of disease or regaining functioning after an accident or illness.

One of the most widely-cited definitions of personal recovery, which helps to clarify some of its dimensions, was a synthesis of various definitions of the time put forward by Anthony (1993, p. 11):

... 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 illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.

Is it worth considering this lynch pin concept in the discussion of a degenerative and terminal set of diseases? Some might assert it has no place in the vernacular, as it offers false hope. However, mental health recovery used here is more than the promise of improvement; it is a rallying cry for a social movement that embodies a set of principles. Perhaps the label should be 'transformation', rather than 'recovery'; however, the provocative nature of the word 'recovery' could be seen as advantageous. Former psychiatric service users, such as Ron Coleman (1999), have suggested that recovery has been an alien concept to many mainstream mental health professionals. Pessimism regarding the possibility of recovery has permeated mental health services which have offered or compelled people to receive unhelpful and even harmful treatments, quashed the hope of service users, and so frequently relegated them to non-citizen, passive recipients of largely pharmacological treatments. The parallel with dementia care and recent reports of over use of sedation in dementia care (Bell *et al.* 2009) are not hard to draw. However, unlike in dementia care, proponents of mental health recovery point out that most people who are diagnosed with schizophrenia achieve clinical or social recovery or both (Drake *et al.* 2006; Harding *et al.* 1987; Kruger 2000), so that in mental health, such pessimism is misplaced. Mental health recovery is relevant to those who could be said to continue to experience symptoms or distress, and for some people, recovery connotes overcoming the adverse effects of psychiatric treatment.

If dementia care providers are starting with the touchstone that recovery is misplaced, then this seriously delimits the potential of any type of recovery. In each epoch, it is tempting to think of the fixed nature of facts, but over time, our understanding of living (e.g. with schizophrenia) now makes it possible to credibly talk of recovery, whereas the original concept 'dementia praecox' suggested an inevitable deteriorating course, and this pessimism has persisted until relatively recently.

Recovery-focused care actively seeks to maintain a person's integrity and autonomy and resists the development of an illness-dominated or saturated identity, which Mancini *et al.* (2005) propose is characterized

by uselessness, worthlessness, hopelessness, and sickness. Others, such as family, carers, and health professionals, can support people in recovery, but they cannot direct the process. Many people in recovery have found it helpful to also assume supportive roles with others. The process of recovery can be aided by others, and it stands to reason that it can also be impeded in various ways through stigma, discrimination, iatrogenic treatment settings, and infringements of human rights. Recovery-focused care supports and promotes, to the greatest extent possible, full citizenship and social inclusion, the rights of the individual to self-determination and choice. It recognizes and supports the personal resourcefulness of individuals and groups, and accepts that people are experts in their own experience (Watkins 2007).

The emphasis in person-centred care is on the behaviour of staff to promote personhood. The recovery discourse emphasizes personal resourcefulness, rather than the behaviour of carers. A recent study of participants with 'expertise by experience' in mental health recovery ranked recognition of personal resourcefulness as the most important competency of mental health workers in helping people recover (Lakeman 2010). This could be seen as problematic in dementia care, as unlike depression, for example, upon diagnosis there is acceptance that certain personal resources, such as a capacity to learn, are with varying acceleration, diminished over time. However, not all resources (e.g. social resources) are diminished, and these need to be mobilized.

We can imagine that using the word 'recovery' might cause confusion for people with dementia and their families. It also creates an expectation in the person with dementia that might be hard to live up to. The provocative issues that the notion of recovery raises ought to be central points of discussion with individuals, families and between health professionals.

Dementia has traditionally been divided into mild, moderate, and advanced categories. Another paper has considered recovery and dementia in relation to the Mental Capacity Act (Martin 2009). Martin presents a model of care that treats the three stages of dementia separately. Here, we are focusing on mild- or early-stage dementia and attempting to translate recovery-orientated dementia practice further. Differences in presentation along this continuum might mean that at some stage, defined by individuals and family members, the flame of recovery is best handed on to family members. However, people with dementia in the early stages are difficult to distinguish from unaffected people even with

sophisticated neuro-diagnostic tools and skilled staff to interpret them. Personal agency is central to Anthony's (1993) definition of recovery used earlier. The personal agency of people with an early-stage dementia might not be much different from anyone else, and thus, their ability to develop new meaning and purpose might be intact for a period of years.

Finally, recovery offers new understandings of debates, such as those around early intervention, which is practically uncontested in international public policy. Debates that are uncontested are dangerous, and while we would largely endorse early intervention, one cannot assume that any early intervention will be a good intervention. Some of the arguments put forward on recovery do cause trouble for early intervention. For example, early diagnosis and intervention could be seen as medicalizing dementia, capturing people in a web of diagnostic drugs and documentation. While some proponents of recovery support the view that recovery starts with acceptance of diagnosis and the need for treatment, in line with the philosophy of Alcoholics Anonymous (e.g. Ohio Department of Mental Health 1999), others who identify with mental health recovery see acceptance of biomedical formulations of mental health problems as irrelevant, harmful, or more of a hindrance to recovery than a help (Stastny & Lehmann 2007). The pivotal issue it would appear is that whatever way problems are formulated, they should not lead to a diminishment in hope, personal agency, or engulfment in a patient role. It is important to accept that there are risks involved in increasing pick up and early intervention. We cannot assume that all services that increase the identification and intervention in dementia care will be positive. The risks have not been systematically examined, but could include increased anxiety or depression in either the carer or the person with dementia. This might certainly be the case if early identification is not followed by supportive intervention in the post-diagnostic phase.

Careful attention to recovery principles (in addition to person-centred care philosophies) can help with planning services that are positive for people, and counter the potentially-oppressive consequences associated with labelling people and prescribing treatments. Above all, services might enable nursing roles that improve access to early intervention in order to enable people to '... develop new meaning and purpose in life and grow beyond the catastrophic effects of [the dementia]' (Anthony 1993). Living with the symptoms dementia poses a similar existential challenge to living with many other symptoms of mental illness.

RELEVANCE TO SCREENING AND EARLY INTERVENTION

A major aspiration in social policy and academic writing on dementia is the need for early identification of dementia to enable early intervention. Logic dictates that the best way to involve people with dementia in their care is to engage them early and then keep them engaged. First, people with dementia in the early stages are more readily able to assert their rights and wishes. Second, proactive engagement of supports can help, so that when such support is badly needed by carers, the person with dementia already has a developed relationship with another caregiver, thus smoothing out the stepping up of care for everyone concerned. Third, people who are more engaged in their community tend to fare better cognitively than people who live alone or have limited social outlets (Wang *et al.* 2002). These views are set in a context that many people with dementia currently engage with services in the moderate to late stages of the disease (O'Shea 2007), thus, the advantages listed earlier are to some extent lost to them.

Early intervention in dementia care assumes that nurses have access to people in the early stages of dementia. As stated earlier, this might not be the norm for a number of reasons. Screening for dementia has received little attention in the literature, and there is no consensus regarding who ought to be screened and what the benefits might be. Large-scale community screening has yielded 16.7% of individuals with abnormal tests, most of whom had no previous knowledge of having dementia (Laurence *et al.* 2003). There is a small but developing body of research into cognitive deficits which are predictive of dementia onset (Jorm *et al.* 2005).

According to Naidoo and Wills (2000), screening is appropriate when the disease is serious and common; it allows identification of asymptomatic disease; when screening tests are simple and have acceptable safety; and when tests are valid and reliable, sensitive (correctly identify people with the disease), and specific (correctly identify people without the disease). Screening should lead to earlier intervention with better outcomes than late treatment; it should be cost-effective, decrease morbidity and mortality, and any risks should be outweighed by the benefits (Naidoo & Wills 2000). There are many tools available which are able to detect mild cognitive impairment with increasing sensitivity (Borson *et al.* 2003).

Screening with a recovery focus should be a two-way process that is co-owned by a person with a perceived memory problem who decides that they need to clarify

their condition and work out its implications for their life. If screening becomes easily accessible to people without needing a referral, is normalized, and carried out in a way that is informative, rather than secretive, this will go some way to creating better understandings of dementia in the general public. Screening, where the person who self-refers remains very much in control of the outcomes and has a health, rather than illness, focus might encourage people to present earlier in the process than is currently the case. People are generally not actively encouraged to present early with concerns and some may not wish to do so. This can perpetuate a norm whereby first engagement with tertiary services is during a painful crisis situation where carers and the person with dementia can no longer cope unsupported (Keady *et al.* 2004).

Screening could contribute to early identification of dementia; however, it clearly brings with it a responsibility for accessible, supportive, follow-up care. Striving to help people with dementia maintain meaningful citizenship could be the first stage of recovery within early dementia.

EARLY INTERVENTION

There are a number of examples of early intervention initiatives. Some can be found on the NHS Greater Glasgow and Clyde Dementia Share Practice website (NHS Greater Glasgow and Clyde 2009). These initiatives have focused on either the person with dementia or the person and their carer gaining access to appropriately-timed information on treatment and lifestyle options, advances crisis planning, and psychological interventions and support.

Early intervention following diagnosis could enable the person and their family to maintain some hope in the face of the diagnosis. It should not cause the person with dementia to become engulfed by the diagnosis, but to focus on their abilities.

Early planning on the part of the person with dementia and their family, with support from health-care professionals, could lead to greater involvement in decision making. If we are to follow through with recovery approaches, then it includes involvement of the person with dementia to whatever extent they wish. If what they wish is not to be involved in decisions about their future, then this of course must be honoured, although conversations might need to be revisited, as it is likely that these wishes will not be static when so much is changing at the time of diagnosis.

TABLE 1: *Top-10 tips for recovery-oriented practice*

After each interaction, the nurse could ask him/herself, did I:

- *actively listen to help the person make sense of their problems?*
- *help the person identify and prioritize their personal (not professional) goals for recovery?*
- *demonstrate a belief in the person's existing strengths and resources in the pursuit of these goals?*
- *identify examples from other service users that inspire and validate the individual's hopes?*
- *pay particular attention to the importance of goals which take the person out of the 'sick role' and enable them to actively contribute to the lives of others?*
- *identify non-mental health resources (friends, contacts, organizations) relevant to the achievement of their goals?*
- *encourage self-management of mental health problems, such as by providing information, reinforcing existing coping strategies?*
- *discuss what the person wants in terms of therapeutic interventions, such as psychological treatments, alternative therapies, joint crisis planning, while respecting their wishes wherever possible?*
- *behave at all times to convey an attitude of respect for the person and a desire for an equal partnership in working together, indicating a willingness to 'go the extra mile'?*
- *while accepting that the future is uncertain and setbacks will happen, continue to express support for the possibility of achieving these self-defined goals, maintaining hope and positive expectations?*

(Shepherd et al. 2008, p. 9).

There are no standardized prescriptions for how to introduce conversations about the future of people with dementia or their families; however, the following suggested tips in Table 1 for recovery-oriented practice do not seem in any way out of place in terms of a general approach to early dementia intervention.

The content of this communication could prepare the person with dementia and their family/carers to live with dementia, while maintaining their rights and sense of personhood. Important areas of early intervention might include, for example, keeping well with dementia and staying active and integrated in the community. With a recovery focus, this might lead to consideration of how a person with dementia might meaningfully continue to use mainstream services, rather than only dementia-specific services. This might require coaching on how to share a diagnosis of dementia publically, or at least how to cope with the disabilities it entails. Assistance and advice with legal issues, such as enduring power of attorney, advanced directives, and advice with financial planning, could also contribute to discussion. Finally, planning for the future; working, driving safely, and future care needs are important areas that the person with a new diagnosis of dementia could usefully discuss with a nurse with specialist knowledge. The timing and pace of such discussion is governed by the principles in Table 1 above.

CONCLUSION

Despite the obvious paradoxes about the relationship between recovery and dementia care, we argue that the recovery movement has much to offer dementia care, and perhaps visa versa. By following recovery principles, we have indicated an approach to early intervention in dementia and suggested some content of such an approach.

Recovery focused care in the mental health literature is essentially skilled, holistic care that has resonance with good care associated with many health related problems. The concept of recovery in mental health is highly contested. Theoretically, the recovery literature and the dementia care literature share some fundamental cornerstones, although with different emphases. These include valuing people and their own agency in making a difference to their own lives, that stigma and discrimination in any guise are damaging to a person whatever their situation, that people are embedded within a life endowed with resources which can be mobilized to help. Recovery focused care encourages the promotion of citizenship and involvement through interaction with health services.

Because of the problems highlighted here, 'recovery' might never be an appropriate model for dementia care delivery in the way person-centred care is. However, some of the strategies and necessary conditions might help service reform through activating people in the early stages of their disease and assisting them to self-advocate to whatever extent they are able to. In this endeavour, dementia care may be informed by the experiences of those who champion mental health recovery.

Nurses might be ideally positioned to take an important role in driving early intervention in dementia in the form of both opportunistic and organized screening initiatives, working collaboratively with multidisciplinary teams throughout diagnoses and supportive interventions following a diagnosis. This might contribute to a reversal of the current trend towards the presentation of dementia in moderate to late stages during an all too often painful crisis situation. In the absence of a cure for dementia, perhaps this is a first step in improving the process of living with dementia, both for the individual and their next of kin.

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