Centre for Mental Health

Peer support and peer support workers in older people's mental health

Authors: Toby Williamson and Dr Graham Durcan
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Introduction

The term 'Older People' is widely used in the NHS to describe people over an arbitrary, but sometimes unspecified age. Yet it otherwise covers the full spectrum of humanity. It is generally applied to people over 'normal working age', which has become an inexact term in recent times due to changes to state pensionable age.

Chronological age may be an obvious indicator of growing older, but differences in ageing are dictated by biological, psychological 'how old do I feel?' and social 'how old am I perceived to be?' factors. Some services for older people are provided to anyone aged 50+ on the basis that factors associated with later life such as retiring or retirement planning, the onset of health conditions associated with being older and children being grown up (and having children of their own) are common events from this age onwards.

Older people are as varied in ethnicity, culture, class, sexuality, gender identity and any other characteristic as younger people, but with added complexities accrued from years of experience in earlier life, just as older people are not a single group, nor are they a single generation. For example, people in their 60s and 70s may have caring responsibilities for parents in their 80s and 90s, and sometimes older parents have caring responsibilities for grown-up children. Over one million people under 50 in the UK are grandparents, so it is not uncommon for there to be three generations of 'older people' in a family.

Using a life course approach to understand health and ageing, it is clear that mental health, and often mental illness, are significantly shaped by a person's life experiences (Milne, 2020). The life experience of someone born in the UK and now in their late 80s, still perhaps with wartime memories, will be very different from someone born as part of the so-called 'Baby Boomer' generation between 1945-1964. Someone born into a relatively affluent family in 1946 in the south of England is likely to have had very different life experiences compared to a person born in 1960 to a working-class family in the old industrial areas of the UK.

Older people who migrated from other countries to the UK after the war for example, or older LGBT+ people, may have life experiences informed by particular cultural heritages, close knit communities and discrimination.

However, it is important to recognise that one common characteristic of older people is that they are unlikely to be in full time employment and most will not be in paid work.

The UK is an ageing society. There are nearly 12 million people aged over 65 in the UK (18% of the population) and it is estimated that this will rise to one in five of the population by 2030. At present 1.6 million people are aged over 85 and this is the fastest growing group of older people. This significant increase is partly due to people living longer (although life expectancy has barely increased over the last 10 years) and partly because the 'Baby Boomer' generation is moving into later life. For the first time in UK history, there are more people aged over 65 than under 18. This is a similar demographic pattern to many other countries around the world.

People living longer is something to be celebrated but it also comes with its challenges. Healthy life expectancy is not keeping pace with overall life expectancy. This means people are living longer with one or more health conditions or disabilities in later life. Although neither dementia nor depression are inevitable for people growing older, the numbers of people living with these conditions are growing significantly.

There are over 850,000 people living with dementia in the UK and this is expected to grow to over one million by 2025. The single biggest risk factor for developing dementia is growing old: one in 14 people over the age of 65 develop dementia but this increases to one in six among people over the age of 80. It is estimated that 25% of people over the age of 65 are affected by depression. Delirium and anxiety are also commonly experienced by older people, together with other mental health problems, alcohol and drug dependencies.

There are also estimated to be around two million older people providing care to family members, friends and neighbours, which can also be the cause of mental health problems (all data: Age UK 2019).

Although the four nations of the UK have developed a range of national strategies and plans over the last 10-15 years to address the challenges posed by dementia, many individuals and families affected by the condition still struggle to get the necessary level of support and care they need.

Many older people with depression have not sought or received help for a number of reasons, such as the mistaken belief held by them or health services that it is an inevitable part of growing old and that one has to just 'grin and bear it'. For example, referrals of older people to Improving Access to Psychological Therapies (IAPT) services only account for 5% of all referrals (even though it appears older people derive the greatest benefits from IAPT – see NHS Digital, 2019).

Older people's mental health services have tended to be the poor relation of mental health services which have focused on working age adults and children and young people. Lack of effective, evidence-based treatments for dementia, recruitment challenges experienced by older people's care services, a lack of confidence in mainstream pharmacological treatments for many mental health problems, and the effects of ageism and age discrimination have also been factors in people not seeking, or not receiving, help.

Peer support

Mental health peer support among older people can include different or additional factors to peer support for younger adults. It may be intergenerational. For example, where 65-year olds are supporting people aged 85 and over, the peer connections may be quite tenuous given that the life experiences of both groups are quite different, even if they both have experiences of mental health problems such as depression. Peer support is also more widely used as a term across older people's services to denote social groups, befriending, and groups that address morbidities faced by many older people, including cognitive, physical and mental health problems. For example, North Yorkshire and Darlington Age UK identify 11 peer support projects they run, none of which has an explicit mental health or dementia focus.

Therefore, what constitutes a 'peer' or 'lived experience' is as complex and nuanced for older people as it is for any cohort. Given that this point has been highlighted across the other thought pieces on peer support written by Centre for Mental Health (Children and Young People, LGBTQ+ and Neuro Diversity), some careful thought needs to be given on how effective sustainable peer support can be delivered to all requiring it.

For the purposes of this paper, 'Older People's Mental Health' covers both mental health problems and cognitive conditions such as dementia.

The distinction between patient and carer is often blurred, and this was particularly felt by those who work with older people interviewed for this paper. For this reason, peer initiatives directed at carers are also considered.

A 2007 report by Age Concern England (now Age UK) emphasised the relevance and value of peer support, but also the need to promote it more as a source of support for older people:

> *"Peer support can provide a social network and decrease the sense of stigma and isolation associated with mental health problems for older people and their carers. Peer support is recognised as valuable within 'adult' mental health services. It needs to be developed further as a model for older people."*
>
> Age Concern, 2007

The growing interest and belief in peer support for older people with mental health problems may be a reflection of a number of factors. These include people having experienced peer support earlier in their lives as it became a more established approach for younger adults and wanting it to continue or be developed as they have grown older.

There is some evidence to show that attitudes about services among the 'Baby Boomer' generation differs from their parents' generation; rather than being passive recipients of services, people are shifting towards more of a self-help, self-management approach, and are more likely to actively seek help and participate in their care (Mental Health Foundation, 2012a).

Mental health services, often led by voluntary sector organisations, are beginning to consider how models of care for younger adults could be used for the growing older population.

Who is an older 'peer'?

In health care and social inclusion settings 'peer' has usually been defined as an individual who has experienced similar health conditions to those they are providing support to. They may be 'in recovery' from that condition, meaning they have strategies for controlling or coping with the condition, even though it may reoccur.

Broadly speaking, for older people with mental health problems or dementia, the same definition can also be applied; peer support for older people with depression or anxiety for example, should be provided by an older person with similar lived experience of these conditions. However, with dementia, it is unlikely that someone with more severe dementia would be able to provide peer support to others in a similar situation because they would be too cognitively impaired. Even if they had some internalised way of coping with their condition, they would struggle to communicate this to others (although the onset of cognitive impairments usually comes later in some forms of dementia such as Lewy Body's disease). Peer support would therefore be limited to people in the earlier stages of most forms of dementia and may need to involve a process that enables someone to step down from the role as they become more cognitively impaired.

Irrespective of the mental health condition there may be additional considerations regarding who might be able to provide peer support, taking into account the diversity of older people as already discussed. These considerations arise, for example, where peer support is offered to different generations of older people (i.e. 'Baby Boomers' or people aged 80+), particular demographic groups (e.g. older BAME or LGBT+ people), older people with physical co- morbidities or impairments, or older carers.

Current peer support provision

Examples of specific peer support initiatives for older people are thin on the ground. This is not to say that older people are not engaged in peer support or that they do not have access to it; just that in most cases, where this is available, it is generic, not age-specific.

For a recent consultation, Centre for Mental Health conducted nine focus groups with people with lived experience organised by local peer support workers. In all the groups there were people in their 60s, 70s, and sometimes older. Sometimes the peer supporters were in these age brackets, but the peer support provision was not age-specific and the focus groups contained people in their 20s, 30s, 40s and 50s. This is not necessarily always a bad thing, but the needs and preferences of those in different age brackets often differ.

One of the differences stressed by those we spoke to was the nature of isolation for older people. Like those of any group with poor mental health, they face stigma, loss of social networks, the vagaries of public transport in less urban areas, and issues of community safety – but also have the added losses of peer group through poor health and mortality, reduced mobility and confidence outside the home, due to physical health conditions, disabilities and frailty and an increase in caring responsibilities.

Peer support initiatives for any age group can consist of both one-to-one and group activities. However, there seemed to be particular emphasis on group activities for older people where specific examples existed and combatting social isolation was a part of this. This was true of activities for those with mental illness, those with dementia and for carers.

There are examples of specific initiatives for older people with dementia, such as schemes where people with very early symptoms are engaged as peer support workers for other people with dementia. One example from London, includes such peer support workers as part of a wider memory service (CNWL NHS Foundation Trust 2016). The Health Innovation Network – South London (2015) has developed a resource pack for peer support for people with dementia. The pack, like the interviewees we spoke to, places emphasis on the importance of group support, breaking social isolation, and supporting carers. Activities might include discussions, sharing of experiences and outings.

Dementia cafés have become much more widespread, and whilst not necessary solely being about peer support, they are a vehicle through which it can be provided and some cafés do have regular peer led groups (for example see Feel Good Factor, 2018). A study of groups led by or actively involving people with dementia that were part of the Dementia Engagement and Empowerment Project (DEEP), a UK-wide network of influencing and involvement groups, found evidence that many of the groups had a positive, informal peer support function (Mental Health Foundation, 2012b).

Examples of peer support being used for people with dementia illustrates how peer support has been more loosely defined in services for older people. Peer support cannot treat or cure dementia but appears to play an important role in maintaining or enhancing a person's mental wellbeing and quality of life. Evidence shows that depression affects well over 20% of people with dementia, so peer support may have a particularly beneficial effect on people affected by both conditions.

Similarly, peer support initiatives for older people more generally may involve befriending, volunteering, social groups and activities that are both preventative and helpful for people with, or people at risk of developing, common mental health problems. But they are unlikely to be structured or focused in a way that meets the needs of older people with severe mental illnesses.

Case studies

Open Doors Dementia Service: Greater Manchester Mental Health Foundation Trust (GMMH)

The Open Doors Service is based upon the promotion of living well with dementia. It aims to engage service users, carers, staff and citizens of Salford in working together to develop user/carer and public participation in mental health services for older people. The Open Doors' innovative and pioneering project has successfully appointed Kevin Barr and Michael Howarth as their Open Doors Support Network Facilitators. Both Kevin and Mike have themselves been diagnosed with Alzheimer's disease and have worked to support patients and their carers who have been diagnosed and are living with dementia. They both have specialist awareness and knowledge in relation to dementia and its effect on individuals and their loved ones. Effective collaboration and partnership working with people with dementia and their carers leads to more meaningful and improved outcomes, both for those affected by dementia and for the services that support them.

Information about Open Doors: https://www.gmmh.nhs.uk/reach-beyond-and-open-doors- project.

Kevin Barr: https://www.gmmh.nhs.uk/living-with-dementia

Standing Together Cymru: Mental Health Foundation

Standing Together Cymru (STC) is a peer support project involving facilitated self-help groups for older people who are lonely or experience poor mental health living in supported housing schemes in Wales. The project builds upon the success and lessons learned of previous peer support projects for older people (see below) run by the Mental Health Foundation, in partnership with several housing organisations. 30 groups are being established over three years, with each group facilitated for six months, but with the aim of recruiting volunteers to sustain them for longer.

One participant, Jean, used the group to talk about the effects of having been in a very controlling relationship earlier in her life (Mental Health Foundation, n.d).

> "*Jean feels people better understand her since she was able to talk about her life, and feels she better understands the others in the group too. By talking about things they wouldn't usually discuss together, Jean feels they have become closer. Jean said: '[STC] helped me talk about things that I hadn't spoken to people living here before. I opened up more…*"
> (ibid).

Men in Sheds: UK wide

The Men in Sheds movement is a UK and international initiative involving the creation of local community spaces for older men to connect, converse and create. Developed around the notion that many men are more comfortable 'doing things' rather than talking in groups about feelings, they are physical environments where men can come together around tangible activities, such as making things and fixing things.

The activities are often similar to those of garden sheds, but for groups of men to enjoy together. They help reduce loneliness and isolation and often lead to men opening up about mental health issues they are experiencing and being supported by peers. Though not badged as 'peer support', Men in Sheds operates in a very similar way, and may well achieve similar outcomes.

Men in Shed Association UK: https://menssheds.org.uk/

Fit as a Fiddle: West Cumbria

Fit as a Fiddle was a £15 million National Lottery funded programme delivered across England by Age UK between 2007 and 2012. Its aim was to promote healthy eating, physical activity and improved mental wellbeing for older people. The programme involved a large number of regional projects, one of which was based at Age UK West Cumbria. The aim of the project was to reduce social isolation among older people and improve their wellbeing through the recruitment and use of volunteers. A key role of the volunteers was to provide peer support and they were recruited partly based on being of a similar age and having experienced similar health conditions to the older people they were working with. 61 volunteers were recruited and there were 967 beneficiaries from the programme.

The evaluation indicated improvements in mental health, although like Men in Sheds, the peer support approach used a loose definition and the people it was provided to were generally not

experiencing more severe mental health problems.

The evaluation included personal stories of impact, such as Audrey:

> *"Audrey has been known to Age UK for several years through various projects. She has carers several times a day and is also involved with the Mental Health Team as she gets depressed and very lonely since losing her mobility. She had to sell her car two years ago and that was the final straw for her. She had several falls which resulted in hospital stays.*
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> *A Fit as a Fiddle volunteer visited Audrey and after the initial introduction Audrey clapped her hands with delight at the prospect of a regular visitor who is not a carer or professional of any sort. The relationship is working wonderfully well for both Audrey and the volunteer. Audrey enjoys her visits from her volunteer and now goes out in a wheelchair when they both feel up to it. Despite having falls now and then, her mood is lighter, and she is much more confident in general."*
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> Age UK, 2013 p.15

Peer support for carers was seen by those experts we spoke to as a crucial and integral part of the framework for supporting older people with mental health problems or dementia. Examples of these provided by the Alzheimer's Society and initiatives funded by a recent set of grants from the Carers Trust were explored for this exercise. Two such examples were provided in London and another in in more rural North East Yorkshire. One of the London examples, a project by the Alzheimer's Society (jointly run with a local charity), provided an ongoing monthly get-together and discussion group for carers, facilitated by a Dementia Support worker. The other two, both time-limited initiatives funded by Carers Trust, were weekly groups.

An important consideration in the provision of such group peer support (and especially for older people with mental illness and dementia) was the frequency of such groups. Not all peer group members will be able to attend all group gatherings, and this may be a bigger issue in the case of monthly groups than for those that meet more frequently.

Another factor which may be critical, regardless of locality, but particularly in less urban areas, is access to transport.

People we spoke to talked about the role of technology in peer support amongst older people, and gave a number of examples where digital platforms, such as Facebook, WhatsApp, Skype and FaceTime, were being used as:

- An adjunct to face-to-face peer support
- An alternative to face-to-face peer support
- Sustainable ongoing support where the face-to-face intervention has been time limited.

Obviously, such platforms have limitations, but are relatively cheap to provide and access. However, those we spoke to still saw a role for facilitation and support in the digital world.

Evidence of need and potential benefits

The evidence of benefit for any form of peer support is limited. This is of course not to say it is not beneficial, but rather that not enough good quality research has been conducted to allow anything definitive to be said, particularly on the topic of cost-benefit. (The exception to this might be in the field of addiction - see Washington State Institute for Public Policy, 2019.) Systematic reviews of the literature tend to conclude that the evidence is mixed with limited good quality studies and that the sum of the evidence is that peer support is at best promising (e.g. Bellemy et al., 2017).

The research evidence specific to older people and peer support is very limited, usually reporting very small-scale studies, and mostly qualitative in nature. There are examples reporting on peer support as an intervention in dementia and for people with mental illness. For example, Chakkalackal (2014) conducted mixed method research on a sample of 21 older people with dementia receiving group peer support interventions. They found some limited evidence of the intervention in maintaining cognitive faculties.

Likewise, O'Conner and colleagues (2018) found some limited evidence that peer support may help to reduce hospital readmission in a group with long-term physical illness and depression – but again, this study had a very small sample (11 people). Chapin and colleagues (2012) found that peer support significantly reduced depression (but not anxiety) in their sample of 32 older people.

Watkins and colleagues' (2019) report on a small qualitative study found some positive evidence that older people already involved in resistance training can help engage other older people in such an exercise regime, and that both physical and mental wellbeing might be improved as a result.

The evaluation of a peer support project called Standing Together run by the Mental Health Foundation also found evidence of positive impact. 19 peer support groups were facilitated in supported housing for older people with cognitive impairments, mental health problems, or experience of loneliness. The qualitative evaluation involving over 40 participants found the groups had a number of positive effects (although the quantitative evaluation did not indicate these were significant):

> *…participants felt that the groups helped to: combat loneliness by strengthening a feeling of social connectedness and belonging; improve wellbeing through discussion among peers and the presence of a kind, caring facilitator; and provide meaningful, stimulating activities around people with whom they felt comfortable. Residents also expressed desire for the groups to continue.*
>
> Mental Health Foundation, 2018

One of the few examples of a larger scale and more robustly designed study (with 235 participants), using a randomised control trial methodology, is reported by Pitkala and colleagues (2011). They tested a closed group intervention run by trained staff that encouraged peer support amongst its recipients, collecting results over a year. Although this was an intervention to encourage peer support rather than a group led by peers, it demonstrated statistically significant improvements in cognitive and mental functioning in people in the intervention group when compared to those in the control group.

It lends further support to what the small number of other studies have suggested and has, in particular, emphasised the potential utility of group-based peer support. Geffen and colleagues (2019), using a pre- and post- design, found that re-engagement in physical activity, isolation, loneliness and wellbeing all improved significantly in their study with 212 people over the age of 60 years.

There is somewhat better evidence for peer interventions directed at carers of those with dementia. Carter and colleagues (2019) reviewed studies of both face-to-face and online interventions. This systematic review found that because of the differences in outcomes measured, the design of intervention and the design of studies, it was hard to pin down any particularly effective model of intervention. It nevertheless concluded that both face-to-face and online interventions could offer effective support.

Challenges and barriers

There is a significant challenge in developing a local system that can provide the breadth of lived experience where this is inevitably so broad and diverse. This is a point about peer support in general, for all ages, but it also applies for older people, who are as varied in need and characteristics as any cohort. Someone regarded as a credible peer by one person may not be regarded as such by another.

In addition to the breadth of lived experience there are a range of other issues in sustaining peer support and the following issues were identified:

- Finance (although usually quite small sums are required these are often quite hard to find. Such funds are for venues, equipment, refreshments, and activities)
- Venues (competition for access to free or cheap venues is high in some areas, impacting on the frequency of any offer)
- Transportation (some older people may struggle to self-transport and public transport is less available in some localities)
- Appropriate training that takes into account older people wishing to provide peer support, but who also may have physical health conditions and impairments (including cognitive impairments). However, it's worth noting that within the older population there will be many people who have considerable experience from their working lives of activities closely related to peer support, such as facilitating groups: for example - retired psychologists, social workers, and teachers.
- Sustaining the 'supply' of lived experience peers (having consistent access to people with the right skills and lived experience can be an issue, for example when people with early stage dementia provide peer support)
- Supervision and support for the wellbeing of those providing peer support
- Flexible employment arrangements for older people who may only want to provide peer support on a sessional basis or as a volunteer, or for health reasons may not want to, or be able to, continue
- Managing and escalating risks (peer support may be the most significant source of social contact some older people have, and it may therefore be the best opportunity to notice changes and deterioration)
- The nature of supervision, support and managing risk may be quite different for those with

poor mental health or dementia (e.g. peer supporters with dementia will likely need a much more robust system of support)
- Carers (of any age) should also have access to peer support
- Diversity in age, ethnicity, gender, sexual orientation, class and life experience among older people is enormous. A peer support initiative that works for women of South Asian origin aged 80+ in London is likely to be very different to an initiative for older men from the ex-mining communities in South Wales.

All of the above indicates the need for a framework that enables peer support to be as diverse as the population it serves.

Workforce implications

As stated previously, what one person will regard as similar lived experience may differ significantly from another, and it may never be possible to provide the full range of peer support opportunities locally. But communication and social media platforms provide a vehicle which could overcome this, allowing people to access a relatable peer support worker, with the right skills who is distantly located. Some peer support workers therefore need to be skilled in using such platforms. Digital platforms can also provide support locally, either as an adjunct or an alternative to face-to-face peer support, or as a sustainable ongoing offer where the face-to-face intervention is limited.

Effective peer support requires an effective support structure to overcome some of the challenges previously described. There is also a role for peer support workers who may or may not have matching lived experience, but whose role is to support and sustain a wider system of peer support, to encourage peers to support each other, to support access to facilities and transport, and to support other peer support workers' wellbeing.

Conclusions

There is very limited evidence on what works and the best models for older people's mental health peer support. While narrowly defined examples of peer support within mental health services are thin on the ground among people in later life, there is some evidence that peer support benefits people with dementia and poor mental health. Combatting social isolation, and cognitive engagement in particular, seem to be features of 'positive' peer support that can prevent or slow down either depression or dementia.

Using a looser definition of peer support that involves befriending, volunteering, social groups and activities (often for older people with multiple morbidities) may make it harder to 'manualise' peer support, but it has a number of benefits. These include the existence of some well-developed and evaluated models, being accessible to a wide group of older people, and being effective both in preventing poor mental health and improving the wellbeing of older people with mental health problems.

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