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Compassionate communities and collective memory: Developing a conceptual framework towards addressing the epidemic of loneliness.

Introduction

It is estimated that in the United Kingdom (UK) there are currently 1.2million chronically lonely older people, and approximately 500,000 of these will not see or speak to anyone for at least five or six days a week (Age UK, 2016). The chronic loneliness epidemic is not unique to the UK. It is being increasingly recognised as a growing global public health crisis as the world's population ages and social isolation increases (Vozikaki et al, 2017; American Association of Retired Persons, 2010). The effects of loneliness and social isolation on a person's health and well-being are well-documented (Cattan et al, 2005). Loneliness has been found to be a risk factor for increasing cardiovascular disease, stroke, depression and increased mortality (McDaid, Bauer & Park, 2017). It is commonly cited as being as bad for your health as being obese or smoking fifteen cigarettes a day (Holt-Lunstad, 2010). In addition to the cost to the individual, loneliness has an economic impact on health and social care services. A recent study by researchers at the London School of Economics calculated the economic cost of 'an epidemic of loneliness' to be £6000 per person per year in health and social care (McDaid, Bauer & Park, 2017).

However, loneliness is not just a problem found in old age. Recent reports found that younger adults aged between 16 and 34 years reported feeling more lonely than those in older age groups (Mental Health Foundation, 2010; ONS, 2018). Despite this, there is little evidence on the impact loneliness has on young people, or the effects loneliness may have on their health and wellbeing in later life. One study that aimed to examine the profile of loneliness in a prospective, UK representative cohort of 18 year olds (n=2,232) found that up to a third of participants reported feelings of loneliness 'some of the time' (Matthews et al, 2018). Lonelier 18 years olds were also more likely to describe clinical symptoms of depression, anxiety, have greater alcohol and cannabis dependence and to have

attempted suicide. While in this younger age group there were no indicators of any impact on their physical health, this study found lonelier participants were more likely to be daily smokers and participate in less physical activity, which could lead to poorer health outcomes in later years (Matthews et al, 2018).

A recent report produced by NHS Health Scotland (2018) that collated data from a number of Scottish surveys, found there is a significant minority of people reporting feeling disconnected to the community within which they live; having limited neighbourhood support and few contacts they could approach at times of personal crisis. Furthermore, there have been three profiles of people identified as most at risk of loneliness within the UK population (ONS, 2018). These are: young people who rent with little trust or sense of belonging to their community; single middle aged people with long term health conditions; and widowed older homeowners living alone with long term health conditions (Office for National Statistics, 2018). Hence, we argue that any appropriate response to the epidemic of loneliness must be intergenerational in nature, as to focus solely on the elderly would be to ignore a significant part of the issue.

Thus, an urgent question is emerging over how society addresses this issue now and in the future. It has been accepted that health promotion activities are important to tackling loneliness and social isolation, yet there is little evidence supporting which interventions are effective in tackling loneliness (Luanaigh and Lawlor, 2008). Allan Kellehear, reporting for Marie Curie, noted that two of the current challenges are a 'lack of systematic or comprehensive coverage' and that responses are 'led by health services as 'services'' (Kellehear, 2017). Kellehear proposes that solutions to tackle loneliness and social isolation lie within local communities, not health or social care services. This focus on community development to tackle loneliness and social isolation is reflected in similar strategic plans in other charitable organisations (including MacMillan and Age UK), but also in recent strategic policy development of national governments, such as the Scottish and UK Governments who have both identified the need to tackle social isolation. Whatever the organisation, and whatever age group

forms the focus of study, there is a similar narrative: the problems of loneliness and social isolation are increasing; the funding is diminishing; there are multiple small-scale community based programmes, but there is no underpinning theory or coherent strategy beyond the adoption of a public health approach to tackle loneliness.

Our argument here is that the current approach to considering loneliness and social isolation focuses on the traditional service response to isolated individuals. We propose that a more effective approach to both meet the needs of the community and utilise resources other than traditional health and social care services, would be to develop a theory-based approach based on collective memory. By doing so, we propose this would aid the development of policy and practice to shift the focus to understand the work of community actors and how they draw on deeply embedded notions of community and social responsibility. This approach will enhance the practice of community nurses who face caring for lonely and isolated older people and we hope will offer them a conceptual framework on which to build new ways of working within, and for their communities.

Compassionate communities

In recent years there has been an increasing focus on communities taking responsibility for their own health, and utilising a public health model. This approach, known as 'compassionate communities' has primarily developed from the concept of 'compassionate cities' (Kellehear, 2005). The aim of these social movements has historically centred on facilitating local communities to support people who are dying or nearing the end of life. This is following a growing recognition of the medicalisation and professionalization of death and dying to the detriment of community involvement and knowledge (Gomes & Higginson, 2006; Kellehear, 1995). The model for compassionate communities (figure 1) highlights two major components: naturally occurring networks (close connections including family and friends) and supportive resources (that are available within the community in which you live). A compassionate community is the combination and activation of both of these elements to enhance

the lives of individuals and create benefits to the local community. The focus is working *with* communities, not *for* them and is in contrast to the traditional health and social model of care currently used within the UK. Different communities will have different needs and therefore there are a variety of community projects across the UK.

Figure 1. Model for Compassionate Communities (Compassionate Communities UK, 2019)

There are international examples of compassionate communities; one project leading the way in Scotland is Compassionate Inverclyde, which aims to promote compassionate citizenship (Compassionate Inverclyde, 2018). It does this through a variety of initiatives that are supported by the local community (including workplaces, schools and individuals) and is outlined in table 1. They do not view contributors as volunteers, but as local people driven by kindness and friendship.

Compassionate Inverclyde
<ul style="list-style-type: none"> • No one Dies Alone <ul style="list-style-type: none"> ○ Aims to support people who have no family or friends available to be with them in the last hours of life in the local hospital. A rota of Palliative Care Companions (specially trained volunteers) ensures there is always someone with the person until they die to ensure that they do not die alone. • Back Home Boxes

<ul style="list-style-type: none"> ○ Boxes containing provisions are gifted to anyone being discharged from hospital, regardless of age or need, who live alone. The boxes include essential items such as tea, milk, bread, a get-well card made by local school children and a blanket. Local people and community groups knit the blankets. People, businesses, organisations and groups across Inverclyde donate the provisions. This community act of kindness allows recipients to make a hot drink and light snack for a few days allowing them to concentrate on getting better without having to worry about shopping. ● The High Five Programme <ul style="list-style-type: none"> ○ An emphasis is made on the power of kindness and is delivered over a five week period. The programme has been delivered to pupils at schools across Inverclyde as well as the local college, bereavement groups, public groups, Youth Club and Amazon staff and more recently in the local prison. ● Back Home Visitors <ul style="list-style-type: none"> ○ Is a visitor scheme, which will be based on neighbourliness whereby a visitor and a young person will visit a socially isolated person, aged over eighty who live alone. The idea developed out of learning from the Back Home Boxes that showed that the majority are given to people over eighty who live alone.
<p>Operational since May 2017 and results up to May 2019:</p> <p>2,000 people have received Back Home Boxes – mainly aged over 80 years</p> <p>58 people have benefitted from the NODA project</p> <p>20 primary schools engaged</p> <p>3 secondary schools engaged</p> <p>160 local people trained and 135 directly involved the different programmes</p>

Table 1. Summary of Compassionate Inverclyde Services

These cross-generational initiatives utilised by Compassionate Inverclyde, support the argument that building compassionate and resilient communities that support people nearing the end of life, also builds capacity and capability within the community to look after their ageing population despite the growing numbers of our oldest old (Rosenberg et al, 2015). We therefore argue, that these principles of engaging with local communities to take responsibility for their own health and wellbeing can be utilised to tackle loneliness and social isolation *across* generations, benefitting all.

Though there are multiple forms of compassionate communities, one key component is that the models rely on volunteers; or what Compassionate Inverclyde refers to as companions, helpers or visitors depending on the initiative. These are members of the community who donate their time to engaging with lonely or hard to reach individuals. In turn, this action supports the overall aim of the compassionate communities model to reconnect isolated individuals back into a community network. Though there is clearly a need for isolated and lonely individuals to be connected in order to increase wellbeing and decrease public costs, what is not clear here is why the volunteer is compelled to act and what role the community plays in facilitating and supporting this. One explanation, and the one we explore here, is that community identity, developed through community memory, is a key driver in the volunteer's desire to act. In order to develop this theory, there are two key concepts that need to be explored: one is community memory and then how community influences individual action. This dual focus will enable us to analyse *why* an individual feels compelled to act and *how* an understanding of community identity enables and encourages that action. It is through an understanding of the interaction between community and the individual that we may begin to develop a theoretical understanding of how to tackle loneliness.

Community Memory

First discussed by Durkheim in the late 19th and early 20th centuries and then developed further by Maurice Halbwachs, community memory is described by Barbara Misztal 'as one of the elementary forms of social life' (2003). In essence, it is a way of describing the development and maintenance of

trans-generational community identity. Community memory is the 'way in which societies take cognizance of their past' (Hulzinga [1929] 1950), which then enables them to assert a present identity. In other words, community memory is a series of remembrances and the way in which they are remembered, passed down and re-enacted and inform how a community thinks about and describes itself. Though Simine notes that 'collective memory is never simply [...] the authentic voice of a group or community' (Simine, 2013), but rather a 'socially constructed notion' (Coser, 1992), there is within this a sense of workable, continuous line of heritage that informs the present via the past.

Importantly, community memory can be differentiated from 'autobiographical memory'. The latter can be defined as the 'memory of events that we have personally experienced in the past', whereas community, or collective memory, requires 'the support for a group delimited in space and time' (Halbwachs, 1951). Moreover, Simine suggests that there is no neat separation between what Halbwachs refers to as 'individual memory' and 'collective memory' and that the two necessarily inform each other:

One might say that the individual remembers by placing himself in the perspective of the group, but one may also affirm that the memory of the group realizes and manifests itself in individual memory. (Halbwachs, 1951)

What this suggests, in terms of community-based approaches to the alleviation of loneliness, is that individual and community identity are interlinked and informed via collective memory. The social practicing of collective memory consists of the continual reinforcing of community and individual identity through the utilisation of cultural memory. In other words, communities maintain their social identity, their transgenerational permanence, via frequent formal and informal reference to a collective memory. Social isolation, one of the key drivers in loneliness, has the effect of depriving an individual of their connection to a wider social identity by limiting the frequency of social remembrance. The significance of this, as Simine suggests, is that 'memory is not just an instrument to stake out collective identities but is always played out in the dynamics between individual and social

frameworks' (Simine, 2013). It is those dynamics that are lost through loneliness and re-established by community-based interventions.

Community Memory and Community Identity

As community memory is passed down from generation to generation it helps to define the relationship between the community and individuals within that community. Indeed, Simine (2013) suggests that the link between the community and the individual cannot be changed, as an individual's memory can only be developed within a social context. This is supported by Misztal, who describes the interface between community; identity and remembering; and identifying collective memory as a key element in the development of individual and social identity, as explored above. The key component here is the intergenerational passing down of memory in order to inform contemporary community and individual identity and the notion that the identity of a contemporary social group is fundamentally informed by continuity with the past.¹ For Halbwachs, remembering, and so the affirmation of identity, occurs through engagement with others who have shared memories. Applied to the tackling of social isolation, this would suggest that what community volunteers do to address loneliness is establish the context in which common remembrances can be shared. Hence, though the theoretical link between community memory and individual identity is well established, what is less clear is what motivates the volunteer to act. To address this, we need to draw on Bourdieu's theory of *habitus*, which helps to explain the effect of the community on the individual's actions.

¹ In terms of memory studies, this intergenerational 'passing down' can perhaps be seen in the same way as Hirsch (2001) describes 'postmemory', what Abraham and Torok describe as 'transgenerational haunting' (1974), or 'prosthetic' memory as described by Landsberg (2004). Common to all of these is that the handing down of the cultural memory of a traumatic event not directly experienced by the individual, nevertheless constitutes a potent signifier of individual and communal identity. Thus, in some ways, the received memory of an event remains deeply significant to those who have never experienced it. However, 'intergenerational' and 'passed down' are not necessarily synonyms. Kurin, when describing the flow of ICH describes it in terms of sons and daughters following in their parents' footsteps (2004).

Community and *habitus*

Habitus concerns the idea of individual motivation within the context of the community. Bourdieu questions how an individual's agency can be 'regulated without being the product of obedience to rules?' (1994). In other words, if the individual is not acting as a response to rules (nobody orders community volunteers to engage with lonely individuals), then what does motivate them?

Bourdieu describes *habitus* as '[s]ystems of durable, transposable dispositions, [that] function as structuring structures' (1990, *The Logic of Practice*). These dispositions are the individual's everyday, mundane practices that are developed over time and in reference to the 'structuring structures' of the community. That is, living within a community and understanding the various elements of history that defines that community influences the way an individual responds or acts in any given circumstance. Here, the volunteer's knowledge of the community leads to the development of dispositions that enable community-specific responses. Hence, community memory equips the volunteer with the appropriate community knowledge and strategies for engagement that enable them in the first instance to make contact with the isolated individual and then, over time, to successfully negotiate numerous modalities that effectively enable them to act as a bridge between the isolated individual and the wider community. What the addition of Bourdieu's theory allows for in the context of tackling loneliness is an understanding that volunteers recognise community as simultaneously a collection of individuals, groups and institutions that exists at a certain moment (and so one that is subject to significant change over time) and as a site with deep roots. This duality enables volunteers to act with reference to shared, perhaps unarticulated, community values whilst also providing practical knowledge of the networks and services available to isolated individuals.

Conclusion

Perhaps the significance of considering the work done by community-based volunteers in tackling of loneliness through using collective memory is that it reinvigorates community networks and re-establishes the individual within a community-based nexus. Holbwachs (1995), suggests that '[t]he

reality is that we are never alone [...] because we always bring with us and always bear in us a lot of people'. In turn, this suggests that individuals working within a community employ the culture of that community to re-establish culture affirming networks via community memory. Consequently, it is the act of the volunteer in using their local knowledge, community-based networks and free time that can be seen as belonging to an established theoretical framework. In turn, this helps to describe why community-focused solutions to tackling loneliness are arguably effective and should be utilised by community nurses to drive community, rather than service based, solutions. This explicit focus on the community, positions community nurses at the centre of developing strategies for local interventions based on the particular need of the community in which they are serving. This approach therefore ensures that strategies for connecting isolated individuals are community-specific and use community knowledge and community memory as a mechanism for addressing an increasing societal issue.

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