debates and issues

The Dementia Friends initiative – supporting people with dementia and their carers: reflections from Japan

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Introduction

Globally, an estimated 46.8 million people are living with dementia (ADI, 2015). The figure for Japan is 5 million; this represents 15% of all those aged 65 years and over (MHLW, 2015). With no cure and few effective treatments, policy developments increasingly emphasise ‘living well’ with the condition within supportive families and friendly communities (DH, 2009, 2012a, 2012b; WHO and ADI, 2012). In Japan, this cultural shift started when, in 2004, the government replaced Chiho (idiocy), the term for dementia, with Ninchisho (cognitive impairment) in order to challenge the prevailing stigma attached to Chiho (Miyamoto et al, 2011). A year later, to embed the name change and raise awareness and understanding of dementia, the government subsidised the ‘10-year nationwide campaign to understand dementia and create dementia-friendly communities’ (The 100-Member Committee, 2013).

The 10-year campaign was spearheaded by the nationwide Dementia Friends initiative, which aimed to create one million Dementia Friends (known in Japan as ‘Dementia Supporters’). It was launched in 2005 and is led by the not-for-profit Community-Care Policy Network (CCPN), which is funded and accredited by the government. To achieve the goal of improving the everyday lives of people with dementia and their carers, the initiative aims to raise public awareness and understanding of dementia and translate this understanding into small ‘supportive social actions’ (CCPN, 2010a). These ‘actions’ include offering people with dementia and their carers a helping hand, lending a listening ear, or volunteering in a dementia café or a carers group. Dementia Friends are people of all ages and lifestyles who are offered a one-off 90-minute awareness-raising session and who then sign up. These sessions are delivered by Dementia Friends Champions (ie Dementia Friends who volunteer to undertake further training and deliver such sessions to create more
Dementia Friends). Newly created Dementia Friends may then join in a range of organised supportive actions after receiving post-session support (discussed later).

Japan achieved the initial target of creating 1 million Dementia Friends by 2009 and now has 7.7 million Dementia Friends, 6.1% of its total population; the target is 8 million by 2018 (CCPN, 2016). Inspired by Japan, the initiative is beginning its global journey – starting in England in 2013 (DH, 2012b), followed by Scotland, Wales, Northern Ireland, Canada and Australia. The expansion continues: Nigeria, Germany, Gibraltar, Israel, Mauritius, South Korea and Denmark are all now on board (World Dementia Council, 2016). A key impetus for this global expansion was England’s ‘National Dementia Strategy’ (DH, 2015), which announced its global leadership intentions for the Dementia Friends initiative – which itself earned the descriptor ‘the largest social movement for any disease’ (McVeigh, 2015). This initiative is headed up by the large third-sector organisation the Alzheimer’s Society.

Is the Dementia Friends initiative on the right track?

Although there is a significant appetite for the Dementia Friends initiative (ADI, 2012, 2016; MHLW, 2012a, 2012b, 2015; WHO and ADI, 2012; Alzheimer’s Society, 2014; DH, 2015) and it is increasing apace, there has been little robust evaluation of its quality, role and impact. This raises the important question: is the Dementia Friends initiative on the right track? More specifically, what kind of understanding of dementia are Dementia Friends acquiring? How is this understanding translated into supportive social actions? What is the quality and impact of such actions? Crucially, are the voices and contributions of people with dementia themselves at the heart of the Dementia Friends initiative? Answers to these questions will contribute to our understanding of how far the initiative is achieving its goal of making a positive difference to the everyday lives of people with dementia and their carers. This article explores these questions by drawing on experiences in Japan.1

Creating millions of Dementia Friends – but overlooking the contribution of people with dementia

In 2005, at its launch in Japan, the Dementia Friends initiative reflected the prevailing biomedical model – and, in part, the emerging psychosocial model – in the content of its awareness-raising session and the messages it conveyed. The session comprised disease-focused information emphasising signs and symptoms, and deficits and deterioration (CCPN, 2010a). Although the lived experience of people with dementia was absent, the session did acknowledge that people with dementia were aware of cognitive and other changes and often struggled with these losses, and so highlighted the importance of environments and interactions in understanding and managing dementia ‘symptoms’ (CCPN, 2010b). The session encouraged Dementia Friends to offer support in small ways in their daily lives for people with dementia and their family carers: ‘social actions’. However, people with dementia were constructed as passive recipients of support, rather than active participants with a voice and as potentially contributing to the awareness-raising session and to their community life – as embodied in ‘social citizenship’ theory (Bartlett and O’Connor, 2010).

By 2012, the government and researchers were acknowledging that the expected translation of understanding into social action was not happening (MHLW, 2012a;
The Dementia Friends initiative

Naraki et al, 2013). Many Dementia Friends did not seek, or could not find, opportunities to undertake supportive social actions. In response, the government required local authorities to assist Dementia Friends to undertake social actions (MHLW, 2012a, 2015). Accordingly, local authorities, together with voluntary organisations and businesses, provided post-session support to help Dementia Friends undertake a range of social actions (CCPN, 2010a, 2013; Hayashi, 2014).

However, although some innovative examples were emerging (discussed later), both post-session support and subsequent social actions suffered from a fundamental flaw: they excluded people with dementia, emphasising ‘helping’ rather than empowering. For example, some local authorities have developed a scheme in which Dementia Friends can register as ‘mates’ to accompany people with dementia at home in order to provide respite for their family carers (CCPN, 2010a). However, this scheme seems to address the needs of carers rather than those of people with dementia. Similarly, many companies in the financial and retail sectors have created Dementia Friends among their workforce with the goal of supporting customers with dementia (CCPN, 2010b, 2013). However, feedback is not sought from customers with dementia, raising the question of whether the type of support offered is appropriate.

Equally, the neighbourhood watch-style ‘Safety Network for missing persons with dementia’ is expanding across Japan, with many local authorities adopting it (Hayashi, 2014). This is important as over 10,000 people with dementia were reported missing in 2014: 429 were found dead and 168 were found alive but remain unidentified (NHK, 2015). A ‘model’ of such a Network comes from Omuta City on the southern island of Kyushu. The Omuta Model, created over a decade ago, comprised a Safety Network of over 5,000 Dementia Friends, citizens, businesses, the local authority, shops, transport, local media and the fire brigade (Hayashi, 2016). When a person with dementia is reported missing, the Network members set out to find them. Despite several positive impacts, including a reduction in the deaths of missing persons with dementia, family wishes are prioritised above those of people with dementia – who themselves are not involved in the design and delivery of the Network. They are only the ‘object’ of the searches (Hayashi, 2016).

**Emerging examples – harnessing the contributions of people with dementia**

Since 2013, some people with dementia have become Dementia Friends Champions, volunteering to deliver more creative awareness-raising sessions by focusing on the strengths and positives of living with dementia (Mainichi Newspaper, 2015). For example, in Omuta City, Dementia Friends Champions living with dementia are delivering sessions to schoolchildren using storyboard techniques, drawing on their own lived experiences. Another example can be found in Sendai City in the north of Japan, where, in partnership with his local authority, a Champion living with dementia has created a compelling set of face-to-camera videos aimed at a wide-ranging audience, including children. These videos include positive messages about the potential contributions of people living with dementia, such as peer support and volunteering. The videos also call on Dementia Friends to work together with people with dementia to help each other to create a dementia-friendly society. These videos are publicly available and are beginning to be used across Japan in a range of different contexts and with a number of different audiences. This demonstrates that
people living with dementia are increasingly contributing to the Dementia Friends initiative as Champions.

Similarly, the contributions of people with dementia are being incorporated into a number of social actions. For example, the not-for-profit Dementia Friendship Club in Tokyo provides post-session support to build the skills and confidence of Dementia Friends who wish to register to become Sapo-Tomo (Supporter Friends) (Dementia Friendship Club, 2014). Sapo-Tomo, or ‘Buddies’, support people with dementia to realise their aspirations to contribute to their community through, for example, volunteering, as well as to fulfil their personal wishes, such as scaling a mountain or attending a jazz concert. The Buddy system focuses on the abilities of people with dementia and helps them realise their aspirations. Another example is Champions living with dementia attending public events and media engagements in order to promote a positive outlook on dementia and challenge stigma and negative attitudes (Mainichi Newspaper, 2015).

A further two examples are a little more organic in nature and nationwide in reach. First, every spring, a national softball champion playoff is held in Fujinomiya City, west of Tokyo. The games are organised by people with dementia in partnership with Dementia Friends, the local authority and the local community. All the players and many of those watching the games across Japan are also people living with dementia (Global Communication Centre and Dementia Friendly Japan Initiative, 2015). The event showcases the abilities of people living with dementia and their capacity to participate in everyday activities such as softball games. Moreover, the event can achieve the same goals as the Dementia Friends initiative through experiential awareness of dementia and social action. Second, starting in 2011, the ‘Run Tomorrow’ long-distance relay race takes place annually across Japan. In 2015, 7,775 people – including Dementia Friends, Champions and 655 people living with dementia – took part over a distance of 3,000 kilometres (Ide, 2016). During the event, a symbolic sash is handed from one runner to another across Japan. This event is another example of aiming to achieve the same goals as the Dementia Friends initiative through awareness-raising and social action. All of these examples are regarded as ‘models’ by their proponents and in official reports; however, with scant robust evaluation in place as yet, evidence of quality and impact is limited.

Meanwhile, people with dementia in Japan are increasingly speaking out in unison, culminating in the creation of the Japan Dementia Working Group (JDWG) in 2014. This is the first national dementia campaigning organisation entirely led by people with dementia to inform and improve dementia policy and practice, including the Dementia Friends initiative. However, there is still some way to go in terms of shifting attitudes towards people living with dementia. During a recent JDWG meeting, a member living with dementia shared her direct experience of a training session to become a Dementia Friends Champion. She said that:

“What I felt at the training session was that most of the discussions focused on how carers were struggling and how Dementia Friends could support them…. People with dementia – like me – would feel as though they are seen as a ‘burden’…. Such feedback is so important. We get a chance to write feedback but it doesn’t go back to the top.”4 (Emphasis added)
Conclusion

The Dementia Friends initiative in Japan is ‘on track’ in meeting its policy-set target of creating millions of Dementia Friends and facilitating the development of social actions. Globally, the initiative is growing, with at least 10 other countries now investing in Dementia Friends.

Although it is important to have a sense of the size of a large-scale movement that aims to change attitudes, how far the Dementia Friends initiative includes people with dementia and engages with them as contributors is a more challenging question. Answering this question will indicate how far their contributions have improved the everyday lives of people with dementia: the Dementia Friends initiative’s goal.

Acknowledging the limited evidence about the effectiveness and impact of Japan’s Dementia Friends initiative, this article has provided insights into its nature and some innovative examples of its awareness-raising sessions, post-session support and social actions. A key positive is the emerging contributions of people with dementia, including their becoming Dementia Friends Champions and undertaking a range of social actions. However, a key problem is the persistence of the biomedical deficit-based model of dementia and ‘symptom management’, as well as a primary focus on family carers. The voices, participation and contribution of people with dementia tend to be overlooked.

Although evidence to support the positive impact of involving people with dementia in the Dementia Friends initiative is limited, the need to extend its ambitions to do so underpins the principle ‘Nothing about us, without us’, campaigned for by the JDWG and other dementia groups and activists nationally and internationally (Dementia Alliance International, 2015; Swaffer, 2015). This strongly suggests that involving people with dementia and incorporating their contributions will put the Dementia Friends initiative ‘on the right track’. This is the lesson for Japan and other countries – and evidence for this is urgently needed.

Notes

1. Ethics approval for this study (REF: MR/15/16-506) was obtained from King’s College London Research Ethics Office.
2. An interview with a Omuta City local government official, 3 June 2016.
3. An interview with a Sendai City local government official, 7 June 2016. For a set of the video messages, visit: http://www.getlinkyoutube.com/channel/UChVA9NroOo6R7XcXQbk59oA
4. A member of the JDWG speaking at its meeting in Tokyo on 9 June 2016.

References


