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Community Makers: report on developing an online toolkit for supporting people with dementia to connect during the pandemic and beyond

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SCHOLARONE™ Manuscripts Community Makers: report on developing an online toolkit for supporting people with dementia to connect during the pandemic and beyond

Abstract

Purpose - Community Makers (https://communitymakers.co) is an active UK wide network that evolved rapidly in response to COVID and the negative impact of social isolation and distancing on people and families affected by dementia. The network is led by the XXXXXX, XXXXXXX and XXXXXXX. The aim was to investigate what works for whom and why and in what circumstances as a basis for the development of an online toolkit for people supporting people affected by dementia to connect and reconnect during the pandemic and beyond.

Design/methodology/approach - The development of the toolkit was informed by an iterative approach of engagement with people affected by dementia, learning from a network of community organisations and a rapid realist literature review.

Findings - Four common factors which combine to make a successful support intervention, regardless of its type, size or location were identified:- relationships; purpose, technology and community. The application of the factors, adopted as principles, is illustrated by applying them to three real world examples.

Social implications – The main output was the online tool kit which is a resource of creative ideas to inspire groups with different approaches to digital involvement and help reduce social isolation.

Originality/value – This report offers new insight, based on identification of four principles, into how people affected by dementia can be supported online and offline during a pandemic and beyond.

Key words: dementia, technology, social isolation, purpose, relationships, community,

Running title: Community Makers: an online toolkit to support people affected by dementia

Introduction and context

According to the World Health Organization (2021) there are around 55 million people who have dementia, with over 60% living in low- and middle-income countries. As the proportion of older people in the population is increasing in nearly every country, this number is expected to rise to 78 million in 2030 and 139 million in 2050,' In the UK there are currently around 900,000 people with dementia and this is projected to rise to 1.6 million by 2040 (Alzheimer's Society, 2021).

Social isolation and loneliness are risk factors for dementia and increased loss of social contact with friends, neighbours and family has only exacerbated the situation (Curelaru et al., 2021). Initial COVID-19 restrictions had a particular negative impact on the health and well-being of people affected by dementia and highlights the urgent need for intervention (Alzheimer's Society, 2020). Further, restrictions have enforced changes to routine, causing anxiety and strain in relationships; led to a reduction in skills and confidence; and increased pressure on home carers, not least through the erosion of support systems (Tuijt et al., 2021).

Due to the age profile and vulnerability of the majority of people affected by dementia, the impacts of isolation due to the pandemic will likely be felt for longer than the general population, as they remain vulnerable to infection and dependent on the support of others (Manca, 2020). The pandemic has forced many of those

involved in community-based support to explore the use of technology to support people affected by dementia and to address this core issue of social isolation (Evans, 2021).

Background to Community Makers

Before the start of the pandemic, the XXXXXX worked together with XXXXXX, an XXXXXX to create the Minder programme (https://mindermeetingplace.com/). This programme aims to develop technology to support people living with dementia in their homes to allow them to live more independently for longer. A human-centred design process is used for Minder to ensure that the technology created is suitable for use in the homes of people living with dementia. This was initially performed through regular face-to-face meetings and home visits to discuss the technology with the study participants. However, this was no longer possible once the pandemic began. Instead, these meetings were moved online. In addition to discussing the Minder technologies and study design, it became clear that the participants benefitted from the social aspects of these meetings.

As a result of the regular Minder meetings, the idea of a virtual community centre developed. To take this idea further, the XXXXXX approached the XXXXXX and a small team was established in April 2020 to create the Community Makers project (www.communitymakers.co.uk). XXXXXXX joined the team in May 2020 as there was considerable synergy between its work with Meeting Centres for people affected by dementia in supporting people affected by dementia at the start of the pandemic (Evans, 2021).

The team worked together and drew upon their respective expertise to carry out the various aspects of the project. These included identifying the requirements of people

living with dementia and how this evolved over the pandemic; designing the website; connecting and communicating with community groups across the UK; and coordinating the monthly newsletters and meetings with organisers of the community groups.

Whilst the original impetus was to set up a central virtual community centre it soon became evident that there was a significant number of online support initiatives for people affected by dementia across the UK. It appeared that what was needed was a support network and resource for those already involved with online communities or thinking of moving support online.

Another aspect that needed consideration at an early stage was digital exclusion and barriers to online connectivity. Community Makers was originally largely about leveraging the opportunities that an online environment can offer people in terms of making and maintaining social connections. However, it was recognised early on in the project that many people do not have the technology and/or the digital skills needed to get connected. This can be affected by barriers to those with physical difficulties and for some this might be age-related, barriers relating to the individual such as education and gender and barriers related to the technology itself (Yazdani-Darki et al., 2020). This complex landscape can be challenging for anyone but there is a range of additional barriers for some people with dementia which include memory, language, communication, attention span, sequencing, problem solving, and comprehension. This means that there will be a significant number of people affected by dementia who will not be able to access online support and therefore it was important to consider non-digital solutions.

Project aims

The aim of the project was to identify which resources to include in the toolkit to inform groups supporting people with dementia with technology and how to reach people without technology and skills. Due to the rapid onset of the pandemic and the need to keep people connected time was of the essence.

Methods

Three approaches involving an iterative process were taken to inform development of the resources. These were feedback from online workshops with people affected by dementia, learning from the network of community organisations that evolved and a Rapid Realist Review (RRR) of the literature,

Online workshops and network meetings

Two explorative workshops with fifteen people with dementia and ten carers from the Alzheimer's Society's Dementia Voice National Groups

(https://alzheimers.org.uk/get-involved/dementia-voice) were held. These focused on people with dementia and carers' experiences of accessing support and activities during COVID-19 lockdown and what dementia support and activities they would like to see when lockdown ended. In addition, a range of webinars was held with different groups supporting people affected by dementia presenting on their how they addressed this. The webinars were accompanied by discussion and questions and written up as blogs and insights on the Community Makers website.

Rapid Realist Review

Realist reviews are an approach to synthesising evidence first promoted by Pawson (2002). A Rapid Realist approach (Saul et al., 2013) to the literature review was deemed appropriate as such an approach aims to ensure findings are generated and

disseminated in response to the urgent nature of the situation (Maidment et al., 2021). Whilst the intention was not to inform policy, the urgency of the situation and the application to developing a resource was a good fit.

The purpose of the Rapid Realist Review (RRR) was to create a preliminary theoretical model (programme theory) exploring how different contexts (circumstantial factors) can trigger mechanisms (processes and responses in people and organisations) to produce desirable or undesirable outcomes (i.e. meeting their needs or not meeting their needs).

The RRR did not include a stakeholder/expert panel consultation to design the RRR and validate its results but it has been supplemented by stakeholder consultation. This RRR was conducted in a much shorter timescale (less than one month) than is usual even for the already expediated RRR process (usually 3 to 6 months) and has been conducted in the main by a single researcher with expertise in realist approaches, under direction from the wider Realist Evaluation team, rather than having a dedicated team for the RRR itself. Hence this is less a full review and more an application of a realist logic of analysis to selected literature in the area. However, as stated by Saul et al. (2013): "The RRR methodology allows for the ability to scale the project based on the time and resources available."

Sources included were:

- Extant literature on the use of technology by people affected by dementia.
- Relevant recommended articles.
- Recent articles regarding the topic area gathered in scoping searches of relevant databases.

Search strategy:

Databases: CINAHL Complete & MEDLINE; Social Care Online

Search 1 terms: dementia AND technology AND (participation OR engagement OR involvement)

Search 2 terms: dementia AND technology and COVID and or pandemic AND (participation OR engagement OR involvement)

Search 3 terms: dementia AND support and COVID and or pandemic AND (participation OR engagement OR involvement)

Inclusion criteria:

- Must be regarding the use of technology by people affected by dementia and those who support them.
- Must focus on community support.
- Must be later than 2010.

Ethical considerations

The workshops were held with members of the Alzheimer's Society's Dementia Voice National Groups (https://alzheimers.org.uk/get-involved/dementia-voice). The purpose of the Dementia Voice groups is to help share experiences, insights and ideas to help improve services and products. Participants had therefore already provided consent in terms of participation. Any information was anonymised and no quotes were used.

Results

Online workshops for people with dementia and carers

Key aspects relating to development of the toolkit that were identified by people with dementia and family carers were:

1. A blended offer of online and face to face support and activities

There is a need to reach those who are digitally excluded and in usual times it is likely that most people will benefit from a blended approach to support.

2. Consistent support with getting online

Carers and people with dementia reported varying levels of confidence and skills in terms of getting online and connecting with others in a meaningful way during lockdown. Those who reported being fairly confident using online tools noted that taking part in online groups and activities helped them to stay connected with support services, friends, family and their wider community. For others, a lack of consistent dementia-friendly support and technology to enable them to take part in online activities led to increased feelings of frustration and isolation.

3. Reaching the most isolated carers and people with dementia

It was felt important to work hard to reach the community of people who do not naturally attend groups and flagged the importance of identifying and reaching out to hidden carers.

4. Working with carers and people with dementia

Attendees said that the team should work with people with dementia, carers and community leads to ensure that any hybrid model of support or materials truly meets their needs and is acceptable to them.

Learning from the network

Learning was captured via Insights (https://communitymakers.co/insight-collection/) and a blog (https://communitymakers.co/news/). Key barriers to connecting people with dementia in the community during lockdown which were identified included lack of:-

- Access to technology and the internet.
- Confidence in using certain technologies or the internet once people have access to it.
- Guidance and support.
- Purpose to get connected: people with dementia need a clear reason to overcome intrinsic and extrinsic barriers to getting online and getting involved in support, creative and social activities.

Strategies used by community groups for helping people to get or stay connected included:-

- Enabling access to the right technology alongside information on how to use
 it.
- Training and 1-1 support: to help people get online and make the most of what is available.
- Enabling people to try out new software in a safe environment

- Establishing relationships, for example by having a named contact to support carers and people living with dementia with using the technology.
- Taking a strengths-based approach drawing on local connections and community groups who know the local landscape and have relationships with people in the area.
- Focusing on the most excluded people in the community including both people with dementia and carers.

Rapid Realist Review

The literature search returned 139 articles of which 27 were held to be relevant. This included following up references from the systematic reviews as it appeared that the more relevant articles were pre-2016 indicating that there has been limited research in the area during the last five years (although there has been an increase since the pandemic).

A Realist logic of analysis involves seeking to identify and trace incidences in the data where context can be said to be triggering mechanisms that produce certain outcomes. Contexts are a set of circumstances that may set in motion a response, action or process (mechanism) in a person, group of people or organisation, that then produces a desirable or undesirable outcome.

In the literature reviewed, some of the ways in which contexts were said to trigger mechanisms to produce certain outcomes are outlined and grouped together as themes as follows in Table 1.

---Insert Table 1 here---

Discussion

From the online workshops and RRR there appeared to be four common factors which combine to make a successful support intervention, regardless of its type, size or location and these are relationships, purpose, technology and community.

Relationships

Establishing trust between a user and supporter is essential to persuade people to engage in new digital products and services. This might be through a formalised outreach programme or informally through friends and neighbours. This is particularly important within minority communities built around a shared culture. Often, these relationships will begin offline. This principle came through strongly in the online workshops conducted, though was less explored in the literature found via the RRR. The RRR did identify the importance of following up with people who have technology but have failed to make use of it, for example, and that people can find the use of technology in a group setting easier, as any difficulties encountered will not seem so abnormal or insurmountable.

Purpose

People who are not familiar with, or afraid of, technology need a strong and clear reason to overcome their perceived barriers. Not everyone will want to join a singing group, for instance. This purpose is personal and unique to the individual. There is a role here for drawing on trusted relationships to establish what motivates each person.

The RRR identified that people living with dementia need to see a clear purpose for technology and have motivation to make use of it. This is more likely to happen when

the design and promotion of the technology takes good account of their needs, preferences, ability, activities and circumstances.

Technology

Technology needs to suit the individual in terms of flexibility, usability and alignment with their purpose. This should be considered for both hardware and software. Simply giving someone a device may not be enough, they need to be supported to use it physically and functionally. For example, we heard of a service user who had bad arthritis and could not operate the tablet until they were given a stylus to use with the touchscreen.

The RRR identified the importance of better research to develop technology and avoid replicating ineffective tools, involving people living with dementia in the whole development process. Such involvement not only helps technology to be usable and appropriate but can also help generate enthusiasm and a desire to use it.

Technology should enable people to feel more in control rather than less and is most attractive if it is (better designed) everyday technology that is part of "normal life" rather than dementia-specific, as this is less stigmatising. Those seeking to support people to use technology also need good knowledge of the range of options out there to ensure they select the most appropriate technology available.

Community

Once the technology is in place, and the person has been motivated and enabled to use it they can start to connect with others, helping them to feel less socially isolated and part of a community. This might involve re-connecting with people they fell out of

touch with or joining entirely new groups. This sense of belonging motivates them to stay engaged, fostering new relationships, and deepening existing ones. It is important to remember that as people try technology and gain new experiences, their perception of the opportunity will develop. For example, they may feel that they could not cope with a group chat, only to find that they love listening to the conversation. Alternatively, a digital connection may open up a new hobby or interest shared with an old friend in another part of the world. The RRR identified that technology has strong potential to increase social connectivity, engagement and participation for those who might otherwise find this a challenge.

Whilst the principles are considered separately above it is important to note that the four aspects are interrelated. For example, if someone is to be supported adequately to use the technology then there needs to be a trusting relationship with clear knowledge of individual needs, what technology is available to best suit the person and the task as well as what the benefit might be for that person. Only then can social inclusion and connectivity be optimised. Figure 1 illustrates the interrelationship between the four key principles.

---Insert Figure 1 here---

Applying the principles

As indicated above, a range of real life examples of online support informed the development of the resources and network and future work. The examples covered a range of locations and demographics. Three examples, featured on the Community

Makers website, of how the principles can be applied to existing initiatives supporting people with dementia are set out below.

Chinese Wellbeing (https://communitymakers.co/cuture-and-belonging/) is based in Liverpool and established in 1989. It primarily focusses on the Chinese community, but also works with other ethnic and immigrant groups. As well as providing care services, a large part of their work includes raising awareness and reducing the stigma of mental health issues and disabilities within this community. Language is a particular barrier and this can be exacerbated by the use of technology.

Relationships - as part of engaging someone Chinese Well-being researches peoples' interest in food, music and important relationships to make the process personal and meaningful to the individual.

Purpose – illustrated by an example of a participant who overcame a deep fear of technology to become an enthusiastic participant in art-based sessions and is always first to arrive for each online session.

Technology – use of a Chinese app WeChat, and creation of bespoke 'spot the difference' games to teach members how to use Zoom.

Community - adapted Dementia Care concept to "Tea House Reminiscence sessions" using memorabilia collected on trips to China and aimed at drawing on strengths in long term memory.

Dementia Adventure (https://communitymakers.co/nurture-and-nature/) aims to enable people living with dementia to get outdoors, connect with nature, themselves

and their community, and keep a sense of adventure in their lives taking into consideration whatever 'adventure' may mean to the individual.

Relationships - Dementia Adventure works with families and couples together to create bespoke engagements that suit the individual. They translated this approach from face-to-face to digital supported engagements during the initial lockdown.

Purpose – developed digital engagements around the theme of connecting with nature, bring nature in from the garden, to help people reintegrate with going outdoors.

Technology - developed free-to-access, digitally delivered training materials to teach people how to make the most of nature and the outdoors to support people with dementia

Community – adapted their approaches for example motivated and supported people remotely to go out their front door within their family support bubbles. There is a need to overcome people's low mood and fear of going outside to help them get these valuable benefits. They developed fully funded, free-to-access training available through their website to teach people how to make the most of nature and the outdoors to support people with dementia

Dementia Matters Here(fordshire) (https://communitymakers.co/insights/starting-small/) during lockdown Dementia Matters Here(fordshire) set up online Meeting Points for people affected by dementia and carers. These groups were new and people had not met face-to-face before. The charity started with a group for people with dementia and carers on a Wednesday afternoon and then swiftly expanded with a carers' session on a Tuesday evening. New members were

able to join the online groups and once restrictions became more relaxed people started to meet face-to-face.

Relationships – an online group started up which did not previously exist building new relationships that continued with people meeting up face-to-face.

Purpose – the aim was to help people connect with other people who were feeling isolated and who wanted support. Moving forward the online groups would be a useful means of support in a rural county.

Technology – funding was obtained to provide tablets and data for people who did not previously have it and provided support for people to get online and join the weekly meetings

Community – the number of people attending sessions increased slowly but surely over the first few months and people became more confident in using the technology enabling them to focus on interacting with other people. During the summer people attended less as they preferred to meet face-to-face but attendance increased in the autumn.

Conclusion

The Community Makers project focused on enabling community-based support to be as effective as possible through the creation of a toolkit. While groups have already found new benefits to online communication, there is concern for those who remain digitally excluded. By creating a network of knowledge and experience exchange alongside the toolkit, we aim to increase the adaptiveness and resilience of community groups, not least in supporting members to get online and communicate with families and peers.

Whilst the Community Makers project originally started out as a virtual community centre, it became clear from networking events that organisations were eager to learn and share knowledge with each other. Therefore, rather than being one large virtual social group for people living with dementia and their carers, the project became the Community Makers Network to provide community groups with the advice and guidance they needed to setup their own virtual community groups. This approach built on existing trusted relationships in the community, which proved to very important for a demographic that was nervous about embracing new technologies. Furthermore, the resource can help upskill and empower existing groups which puts them in a better position to offer hybrid digital and face-to-face services as the pandemic restrictions ease.

The learning from the workshops and the network supplemented the outcomes from the RRR to formulate four principles of online community support which in turn was used to inform the on-going development of the Community Makers toolkit.

The four principles that evolved from the exploratory work provide a useful way to think about how digital technologies can be developed to fit the needs of the individual, rather than trying to fit the individual to the technology. Anyone developing a community, outreach programme, or even extending an arm to a neighbour should ensure they understand how all four principles apply to each individual in order to best support a person to make meaningful connections.

As the state of the pandemic has changed and continues to do so, so has

Community Makers. Once restrictions eased in the UK, opportunities arose for

community groups to meet in-person, as well as online. To help with this, the

Community Makers project provided support for groups to take a hybrid approach of

both virtual and physical meetings and to reach those who are digitally excluded. This is in line with Evans et al. (2021) who posit that digital upskilling people with dementia, family caregivers and staff and volunteers is essential not only to mitigate against the impact of a similar lockdown situation in the future but also to help address both social inclusion and digital exclusion in usual times.

Moving forward, a blended approach using remote and face-to-face methods to enable social connections means person-centred support could be optimized and could be used in rural areas to address social isolation. It would enable flexibility and consistency with support and connectivity, should there be future lockdowns.

The response of Community Makers to the pandemic has shown the value of technology for connecting people previously not used to the online world. Hopefully, the legacy of this project will continue beyond the pandemic to help address social isolation for people living with dementia and carers.

Future work is planned to focus on developing the RRR into a full realist review and evaluation. The aim is to better understand how and why community groups are/are not using technology to support people affected by dementia; what technology they are using and why and how this works alongside other types of support.

Conflict of interest declaration: The authors declare no conflict of interest. The project is unfunded and reports on the work undertaken to inform the development of the Community Makers online toolkit.

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Table 1. Contexts triggering mechanisms to produce certain outcomes, grouped as themes

Theme	Context-Mechanism-Outcome configuration (stated as If C, then O, because M)
To do with finding and fostering motivation and purpose for using	If a person's individual needs and preferences are taken into account (C), then they are more likely to use technology and benefit and/or enjoy using it (O) because they will have a clearer motivation and purpose folding so (M). (Riikonen, 2013).
technology	If there is a goodness of fit between preference, abilities and activities in using technology (C), this fosters positive engagement that leads to a sense of satisfaction (O) because individuals' psychological needs are met (M). (Sweeney et al., 2021)
	If people are not involved at all stages of the development of technology (C), this will lead to people not using it (O) because they will feel it is not fit for purpose and does not meet their needs (M). (Rai, 2020)
	If technology is used to enhance a face-to-face activity, such as the use of multi-media for reminiscence (C) this can improve health, well-being and enjoyment (O) because it enables people to better engage with the past as well as the present and it enables spontaneity and flexibility (M). (Goodall et al., 2020)
	If technology is used because it is available rather than because it meets individual need or circumstances (such as face-to-face contact being restricted) (C), then people may not use it and/or not benefit from it (O) because they do not find it meets their needs or see the purpose of it (M). (Evans, 2021)
To do with the flexibility, usability and appropriateness	If people can be involved in all stages of conception, identification of need and design of technology (C), then products will be attuned to meet the actual needs of people (O) because it will be easier to and more attractive for people to use them (M). (Meiland et al., 2017)
of the technology	If people and those providing support are aware of what technologies are available (C), then there is more likelihood that the person will have an enjoyable and beneficial experience (O) because there is more likelihood of identification of the right technology (M). (Meiland et al., 2017)

Theme	Context-Mechanism-Outcome configuration (stated as If C, then O, because M)
	If research methodologies into technology development and use of technology by people with dementia are improved (C), it will help the development of effective technologies (O) because replication of ineffective technologies will be avoided (M). (Meiland et al., 2017)
	If feedback from people on usability and acceptability of technology-based interventions is gathered (C), it can generate enjoyment and enthusiasm in participants (O) as they will feel involved in helping improve the quality of the intervention for the benefit of all (M). (Rai, 2020)
	If everyday technology can be used rather than technology specifically designed for people with dementia(C), then people will be more likely to use it and benefit (O) because they will feel it is part of normal life and not stigmatising or embarrassing as it draws attention to their condition (M). (Goodall et al., 2020)
To do with using technology for communication and	If someone is living with dementia (C), they can benefit from information and communications technology (ICT) interventions (O) because they can help them to create and maintain social engagement and participation (M). (Pinto-Bruno, 2017)
social/ community participation	If people engage in ICT based interventions for social connectivity (C), this can promote more social behaviours (O) because people feel more comfortable in interacting and initiating conversations (M). (Pinto-Bruno, 2017)
	If technologies are used in a group setting (C), then devices feel easier to use (O) because difficulties are not viewed as abnormal or unexpected (M). (Sweeney et al., 2021)
	If access to online support and leisure activity is increased (C), then people will benefit from increased health and well-being (O) because they will be better able to maintain social networks and connections (M). (Masoud et al., 2021)
	If connectedness between participants (not just between facilitators and participants) is encouraged in online environments (C), then this can create a feeling of community (O) because there is a sense of belonging (M). (Masoud et al., 2021)

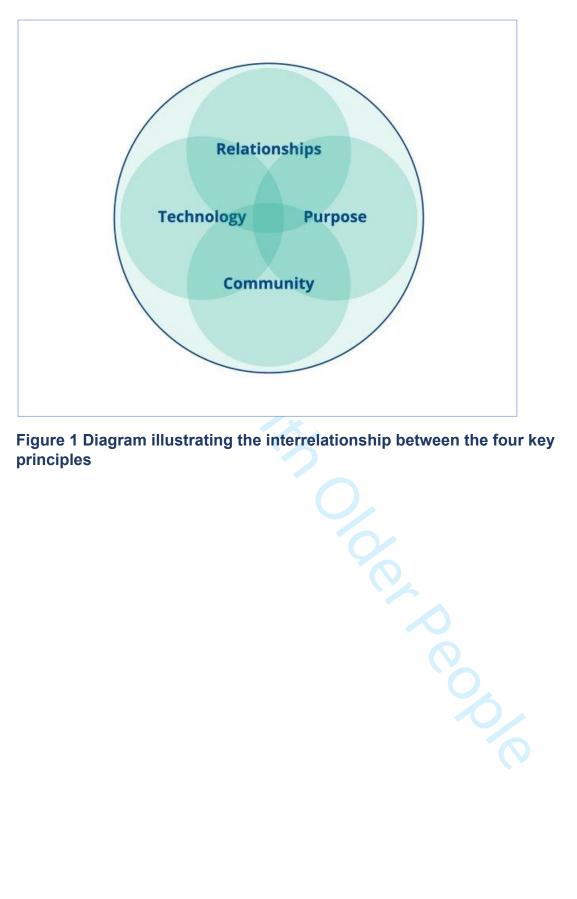


Figure 1 Diagram illustrating the interrelationship between the four key principles