Mediating engagement in a social network intervention for people living with a long-term condition: A qualitative study of the role of facilitation

Elizabeth James MSc, Senior Researcher\(^1,2\) | Anne Kennedy PhD, Professorial Fellow (Research)\(^1,2\) | Ivaylo Vassilev PhD, Principal Research Fellow\(^1,2\) | Jaimie Ellis PhD, Research Fellow\(^1,2\) | Anne Rogers PhD, Professor of Medical Sociology\(^1,2\)

Abstract

Background: Successful facilitation of patient-centred interventions for self-management support has traditionally focussed on individual behaviour change. A social network approach to self-management support implicates the need for facilitation that includes an orientation to connecting to and mobilizing support and resources from other people and the local environment.

Objective: To identify the facilitation processes through which engagement with a social network approach to self-management is achieved.

Method: Thematic analysis was used to analyse data from a longitudinal study design using quasi-ethnographic methods comprising non-participant observation, video and qualitative interviews involving 30 participants living with a long-term condition recruited from a marginalized community.

Results: Findings centred on three themes about the social network approach facilitation processes: reversing the focus on the self by bringing others into view; visualization and reflection as a mediator of positive disruption and linking to new connections; personalized matching of valued activities as a means of realizing preference elicitation.

Discussion and conclusions: Engagement processes with a social network approach illuminated the relevance of cognizance of an individual's immediate social context and forefronting social participation with others as the bases of self-management support of a long-term condition. This differs from traditional guided facilitation of health behaviour interventions that frame health as a matter of personal choice and individual responsibility.

Keywords
patient facilitation, self-management support, social context, social network intervention, social participation
1 | BACKGROUND

The onset and trajectory of a long-term condition (LTC) often results in a retreat from activities and interactions taking place in the public sphere.1 People with LTCs identify loss of social contact, the ability to reciprocate and contribute to society and receipt of resources from the community and locality.2 The latter has contributed to the burden of illness and preventing living life as fully as possible.3,4 A social network approach (SNA) to self-management provides a means of mobilizing, mediating and accessing support.5 It enables people to access and incorporate the resources and connections that provide support for living everyday life and requires attention to be placed on the local environments as a means of engaging individuals in self-management support (SMS) activities.5 Whilst guided facilitation is recognized as a necessary component of implementing patient-centred interventions and means of engaging with patients in introducing strategies and practices of SMS,6-8 little attention has been given to how to effectively bring into view and facilitate elements of social context relevant to a social networked and broader orientation to SMS.

In theory, the delivery of self-management interventions and shared decision making acknowledges the role of social context.9-11 In practice, the social and emotional aspects tend to be side-lined, whilst SMS trainers’ primary orientation is towards prioritizing pre-determined health behaviour change and individuals’ capacity and responsibility to initiate and sustain strategies for self-management.12-15 Research suggests a risk of creating a sense of disempowerment from a traditional, guided facilitation approach (eg behavioural activation) stemming from the need for individuals to acknowledge that they are unable to cope alone without professionals’ support. This in turn risks compounding feelings of worthless-ness, low mood and loss of a valued identity.16

By contrast, the design of facilitation in a SNA needs to reflect as a central tenet the social context and possibilities for social participation relevant to people’s lives, particularly of those living in disadvantaged circumstances.17,18 Thus, the elements and process of the successful facilitation of socially orientated and networked interventions are likely to differ in terms of processes as well as content. Building rapport and good communication skills are important pre-requisites for facilitating any SMS intervention. However, a SNA differs in its facilitation processes in orientation towards the idea of connections and linkages based on what is familiar to people in their everyday, domestic lives. There is a need to explore and better understand the nuances of these processes and the potential for achieving engagement by focusing on what is external to the person rather than the focus being internal as part of a personalized, therapeutic process.

1.1 | A social network intervention (SNI) and facilitation of SMS

Facilitation of a SNI centres on connecting people to and engaging them in relationships, valued activities and resources through participating in local activities.19 This is informed by a capabilities approach, which suggests that opportunities individuals have to undertake valued activities are shaped by interactions between individuals, their environment and in particular their social relationships and expressions of values and preferences.20,21

1.2 | The social network intervention

An online tool (GENIE—Generating Engagement in Network Involvement) maps social networks, helping people to select their preferences and engage with local support resources. The components of GENIE are described in Table 1.

The role of facilitation.

1. Personal network mapping: A modified, hierarchical mapping technique using three concentric circles to create visual representations of personal communities.22,23 Constructing the network involves the person and facilitator in seeking to understand the actual and potential environment that has relevance for leveraging what is beneficial to living daily life with a LTC.24 This requires the facilitator to place the emphasis on the participant at the centre of the circle and encourage them to think about why and how some people and resources might be more or less important to them.25

2. Preference elicitation and linking to resources: Reflecting on availability and connection to localized support and resources based on personal preferences and acceptability that provide opportunities and encouragement to engage with sustainable health choices.

Previous research suggested that GENIE worked best as a facilitated process (Kennedy, 2016), rather than being completed by an individual alone, but questions remain about the content and mechanisms of facilitation when using a SNA in a community setting. We were interested in exploring the facilitator role when taken up by lay health workers living and working in the same community setting as participants, as they were likely to be familiar with the culture and values of that locality.

2 | RESEARCH AIMS

To explore the role of facilitation of a SNI delivered by lay health workers in a community setting.

To identify the facilitation processes through which engagement with a SNA to SMS is achieved.

3 | METHODS

A longitudinal study design using quasi-ethnographic methods comprising non-participant observation, video and qualitative interviews.
Participants (n = 30) living with a LTC were recruited from a marginalized community. Data collected (T1) comprised visually recordings of intervention delivery, observational notes and audio recordings of post-intervention interviews. The use of videos allowed members of the research team to observe each intervention taking place, rather than a single researcher, and enabled a more accurate, nuanced and collective analysis of the facilitation process.

Follow-up data were collected at 3 months (T2, face-to-face semi-structured interviews) and 6 months (T3, telephone interviews) to capture change over time. The circle diagram captured changes over time in the position of network members on the map (Vassilev, 2018). The mapping exercise was also a heuristic device which could indicate relational shifts in people’s lives over time and enabled the facilitator to elicit people’s underlying rationales for these. Data collected at different time points reflected how things changed subtly, including small changes in relationships and changes in meanings of relationships.

Audio recordings were transcribed verbatim. Thematic analysis informed by framework analysis included a priori codes/categories relating to the role of facilitation and facilitation processes, alongside an inductive approach whereby coding and theme generation were directed by the content of the data. Initial coding and collating were undertaken by researcher (E.J.) to identify broad patterns of meaning prior to the viability of potential themes being discussed and agreed within the team. In addition, parts of the data set were coded independently (AR/AK/IV/JE) to ensure inter-rater reliability and coding consistency. Themes were refined and defined, including a detailed analysis of each theme to draw out key findings.

Most salient to this study was engagement in the network mapping, as an initial exercise. However, we were also interested in how people reflected over time. Engagement means participation in the mapping exercise and what it represents for people in terms of their own micro-social world. Engagement is when people’s attention is on things outside of themselves, for example thinking about the people around them and what these people do. On the participant’s part, engagement also manifests in raised awareness and reflection over time of the benefits of adopting a SNA to SMS.

### 3.1 Sample and recruitment

The sample was drawn from a marginalized community, the Isle of Wight. Separated from the mainland, social, economic and political barriers contribute to the marginalization of the Island, as does an ageing, vulnerable population (27% aged 65+ years, 1 in 6 of whom live alone). The full sample took part in observations and interviews (3 participants withdrew). Table 2 shows participants’ age, gender, LTC and where the intervention took place.

Participants were recruited via two routes. Firstly, lay health workers identified clients who matched the inclusion criteria, introduced them to the study and invited them to participate. Secondly, the researcher and PPI representative visited support groups (eg Diabetes Support Group, Heart Care Club) for recruitment purposes. The facilitator met with the participant on one occasion to deliver GENIE. The researcher was responsible for all the follow-up data collection. Services employing lay health workers were approached to discuss involvement in the research, including training, identifying participants and intervention delivery. Facilitators comprised Health Trainers (n = 4), Care Navigators (n = 3), Community Navigators (n = 1) and Local Area Co-ordinators (n = 1). A PPI representative and researchers (n = 3) were also trained.

### 4 RESULTS

Observational data provided a visual record of facilitation style, how participants related to facilitators and how comfortable they appeared physically. Notes taken on body language and gestures (eg leaning towards laptop screen, pointing to network map, positive response to visual cues) indicated that most participants felt
at ease with the facilitator and engaged in the network mapping. Observations revealed that a natural balance of eye contact between participant, laptop and paperwork on the part of the facilitator helped to maintain engagement and co-production (Box 1).

Facilitation is viewed as something that is initially co-produced but orientated towards individual ownership of the network map and links to favoured activities. Three themes illuminated the social network mapping and preference linking processes:

1. Reversing the focus on the self and bringing others into view
2. Visualization and reflection as a mediator of positive disruption and linking to new connections
3. Personalized matching of valued activities a means of realizing preference elicitation

### 4.1 | Reversing the focus on the self and bringing others into view

An exclusive focus on individuals’ capacity and responsibility to initiate and sustain strategies for self-management can leave those living...
with a LTC feeling stigmatized and labelled as unable to cope with daily activities. In contrast, co-creation and engagement in network mapping provided a shared activity of both ‘doing’ and ‘interacting’ in which respondents began to reverse the focus on the ‘self’ and bring others into view as attention shifted towards relationships with the people around them. Refocusing away from self, towards external, relevant sources of support (emotional, practical, physical, spiritual), helped to reduce the risk of acopia whilst increasing feelings of self-worth.

This respondent shifted focus towards support derived from her daughter and pets, when recently widowed:

If it hadn’t been for my daughter and the dog and cat I wouldn’t have coped… I would probably have just crumbled into a little ball… (the dog) gets me out, gets me going for walks and is very loving. She shows me a lot of love…it’s those stupid little sounding things that keep me going

(HF14)

Facilitator prompts were assistive aspects of co-creating the network map:

I personally think it’s better facilitated because there can be the odd prompt, ‘Where do you think it sits better there or there?’ And then underneath that, why? Because if you are sitting on your own you won’t ask yourself those questions, you don’t do you, unless you are particularly self-aware? Some people will go through that mental checklist but most people won’t

(HF07)

If you are looking at it on a computer you think ‘Right, ok, what support have I got?’ and you wrack your brain trying to think but actually doing it face to face with somebody you can get prompted to think ‘Yes, there are more people’. So, then it’s actually drawing on those resources, friends, relatives, GPs, pharmacist, whoever, to actually help you get what you need and the support you need

(EU09)

Face-to-face facilitation provided opportunities for respondents to cognitively re-frame responsibility for LTC management from ‘individual’ to ‘shared’. Facilitators used name generating prompts to elicit successive recall of types of network members (eg friends, family, groups, pets), encouraging respondents to expand and diversify their networks:

...but I wouldn’t have had all those names down on my own, I certainly wouldn’t. I would have looked at it and said who is important? Oh [stepdaughter 1] is’ and then I would be looking at... yes, the doctor is but I wouldn’t
have been, some of these round the outer ones, I
wouldn’t even dream that they were anything to do with
it. So, it was… you need a bit of a prompt…my outlook
has changed

Conversations embedded in the network mapping activity enabled
respondents to move from network member identification to reflect
on social and emotional aspects of their relationships, environments
and preferences. Facilitated conversation helped to ‘unpack’ thoughts
and beliefs, highlighting the value of social relationships and practices
as respondents considered the nature of support associated with par-
ticular individuals and groups:

Each one has a life of its own, it’s not just a name or just
a club. If I go back to one in particular, the Heart Care
Club, there’s 15 people there, each one of them I know.
I’ve been going for six years now and I know about them
all, I know about their families, I know about their prob-
lems, they know about my problems and that sharing
of information is very powerful in terms of dealing with
things and the inclination to keep it to yourself diminishes
because we all, maybe it’s a masculine thing

Well it makes me think about things more if you know
what I mean? You take a lot of things for granted and
think well that’s happening but unless you have them [fa-
cilitator]come along, I’d just have been accepting all these
things but not putting them in any sort of position in my
life. It’s made me think more about what does [name] do
for me?... or what does another person do for me?

Relying on others and negotiating support was not always easy:

Well, it makes you think of different ways that you could
do things and I suppose it makes you look at yourself as
well... it makes you evaluate what people will do and
what they won’t do. I suppose because I’ve always been
independent and rely on myself and not other people it’s
harder to rely on other people or ask them to help, to be
quite honest

Facilitated conversations around the network mapping exercise
helped respondents let go of expectations from ‘strong’ ties (family)
and value social connections with friends and acquaintances (weak
ties). Expressing a perceived lack of family support (son had no time
to help in the garden; limited contact with sisters), one respondent
was able to re-focus on the value of regular visits, shared time and
activities with ‘more reliable’, long-standing friendships. Similarly, this
respondent was able to acknowledge the importance of ‘weak ties’/
acquaintances in his everyday life:

I get an awful lot of support from people that most of...
a lot of people take for granted. I don’t take the ladies
in Morrison’s for granted... or the staff in the Co-op... or
bus drivers. I’m aware, but... a lot of people aren’t that
aware of that

Facilitation helped people reflect on the value of shared activi-
ties, replacing individual pursuits with joint activities. This respon-
dent took up walking, which became a shared activity with her
partner:

It may have been that the session that we did maybe
made me more mindful of the fact that I needed to do
more walking and stuff...I’ve done some walks, quite
a few walks actually ...and then we [partner and re-
spondent] joined English Heritage and National Trust,
so it went from there really. It was a gentle walking
programme at work...I was keen to do the walking and
found that that was really enjoyable, so I’ve stuck with
the walking...

4.2 | Visualization and reflection as a mediator of
positive disruption and linking to new connections

Visualization and reflection on the completed network map en-
abled sense to be made of a novel means of support and how
it could be accessed. Reflection on existing network member-
ship opened up possibilities for evaluating the present and
anticipating, rehearsing and reconstructing self-management dif-
ferently for the future (Figure 1).

This respondent acknowledged the value of visualization through
reflecting on the meaning and value that new options for the future
might bring in terms of socializing with others:

...a support network tends to go with going out socialis-
ing, because if you are not going out socialising as much
then the support network is not necessarily there, do you
know what I mean? So, I haven’t been going out as much
the last year because of my illness, so I don’t tend to so-
cialise much with people. So, I have been reflecting on
that.... it did help me, just the visual...cos I’m a very visual
learner, so a very visual thing has helped

Rather than SMS being associated solely with the inner mo-
tivational life of an individual in relation to behaviour change,
reflection on network support through visualization enabled
normalization of SMS in everyday life and all it involves in terms of social environment, relationships and activities. The following respondent’s terminology reflects this, referring to the collective ‘we’ and ‘getting on with our lives’, that is not ‘i’, getting on with ‘my’ life:

…it made me focus at a conscious level on the support infrastructure that I have available. And that made me feel good, because we’re trying to get on with getting on, we’re getting on with our lives and at an intellectual level you don’t rationalise what’s going on around you. You don’t think about it, you sort of take it for granted. And I found the process enlightening, because it reminded me of how well supported I am. Which I have to say is very, very powerful. ... it reminded me of what resources I have...It was a useful reminder of how many people there are out there that I can access if I need to

(HF07)

Co-creating a visual image of a person’s support network seemed to enhance the process of identifying and triggering network members:

When you first start off, you start thinking, yes I’ve got my wife, I speak to my mum, I had Diabetes UK... but then everything else it’s like opening up the flood gate! You don’t realise...Oh yes, I have got things that I can do. I have got people that are around me’... it’s actually knowing the amount of people that you’ve actually got around you that you can call on ... I’ve got my healthcare trainer, I’ve got neighbours, podiatrist that I see every six weeks, it opens up a lot more...and yes I’ve got the next circle, yes I go out, I go to Church, I go to bowls, I can speak to my pharmacist and if I don’t want to go down to the doctors I’ll go down and see the pharmacist...so it opens up like a can of worms. ...then the can is getting opened up more and more and then everything spills out and you find out you have got a lot more people around you that you can actually rely on

(EU09)

This respondent commented on the visual design of the three concentric circles acting as an enabler for prioritizing individual network members:

When you actually think about, if you write it down on a list, you can’t make sense of it ... Doing it on there [network map], you’re in the centre and everything works out from around you and when you think about it, like these are the people who are most important... You start thinking about it, pets, support groups, family all those things there. You can actually see it better if it’s actually like a ripple going out. You see where the ones that are most important to you are in the centre near you and rippling out to who you can actually ...so it is actually better having as a circle than just as a list because... It’s actually prioritising who is most important to you and that circle gives the best way of doing it

(EU09)

As respondents typically viewed self-management as something they had to do on their own, many were surprised to see more network members in their completed diagram than they had anticipated:

With your health conditions you’ve got to look after number one and make sure that you are aware of what is going on... I do that on my own... It (circle diagram) was making sense. I just hadn’t thought that...I hadn’t thought about who was supporting me or who is supporting me...I’m surprised that... there are some people in the circle!

(HF01)

4.3 | Personalized matching of valued activities as a means of realizing preference elicitation

Facilitators guided respondents through an online preference questionnaire embedded within the intervention. Questions focused on what people valued doing or used to enjoy doing in the past. Rather than imposing a needs-led framework, guiding people to identify what they enjoyed ensured activities were meaningful and relevant, increasing engagement in accessing community resources. Participants were guided by their own preference and identified 3 activities that most interested them. Most participants (n = 25) contacted/tried a new community resource, 2 participants did not take up activities and 3 participants withdrew (Kennedy, 2016; Vassilev, 2018). Follow-up data indicated that participants enjoyed their chosen activities, suggesting a cognitive shift from thinking to doing.

Perceived lack of status difference between respondent and facilitator further increased engagement and proactivity on the part of the respondent. The lack of status difference was perceived intuitively from the observational data, as participants seemed at ease and open to working together with the facilitator.

Facilitated conversations represented a safe space for respondents to reflect on and express inner hopes and future wishes, enabling them to reconnect with the things that could bring enjoyment in everyday life. The following example indicates how a respondent living with mobility impairment shared his dream about experiencing an aqua-lung in a swimming pool:

I haven’t swum for a long, long time and when I did swim I did get some support and I did have somebody with me the whole time in the water...
Facilitator: Is that something you’d think about again if there was support?

... what I did dream of doing was having an aqua-lung on my back, going underwater and just sitting on the bottom of the pool…just going into a pool or into a large fish tank, sit on the bottom of the tank and look at the fish going round and then stay there for about 5 minutes and then you come back up and that would have given me a lot of pleasure! You know, an achievement. Well, that’s what I would like to do. I’d still like to do something like that – though I would take medical advice even now on that - but that’s one thing I would love to be able to do

(EU02)

Aligning people’s preferences and activity choices with their social connections, relationships and environment increased accessibility to activities and sustained engagement. However, findings also revealed social situations and environments that posed challenges. The following respondent was unable to remain in full-time employment due to a LTC, but had identified a voluntary work opportunity which offered her purpose, social contact and fulfilment. Guided facilitation that took into account social and emotional aspects of everyday life enabled reflection on barriers to pursuing valued activities and future possibilities:

Yes, I love it [voluntary work] But now I can’t go on Fridays because I’m at [partner’s] mum’s and I can’t get there. I find it hard because I need somebody who will take me in the wheelchair. …But everything is on [partner’s] time. It’s when he wants to do it, when he’s ready… and I have to fit in. It’s hard, so hard.

It’s my lifeline really. … That’s why I feel trapped at times. Not every day, not all the time but a lot of the time… I feel trapped because I can’t… it’s not like I can just get on the bus. I’m so dependent on [partner]

(HF06)

The choice of focusing on lay health workers coalesced with the finding from a previous study that a lack of status difference between facilitator and participant was instrumental in allowing a stronger interpersonal element and reciprocity in the discussion to develop (Kennedy et al 2016). In this community-based study, lay health workers met people in a place of their choice, usually at home. This participant comments on who is best placed to deliver the intervention and where this should take place:

Where’s the best venue?… I think we’d have to go back to the home but with the caveat that they must have somebody with whom they feel comfortable…people do feel threatened, it’s weird, isn’t it? Why? I don’t know… because that’s people. It’s got to be non-threatening and in the conflicts context it was always a neutral ground, you went to the pub… but I’m just saying that was what you did. GPs represent authority, like it or not it’s true, what I’ve been trained to believe

(EU12)

5 | DISCUSSION

Findings from the current study suggest that reversing the focus on self and bringing others into view enables a broader approach to SMS contrasting with traditional, narrower approaches that focus on individualized accountability and responsibility. This broader approach allows co-production work initiated by the facilitator to move towards shared ownership, creating a space in which steer alternates between facilitator and respondent. As attention shifts from self (internal) to others (external), the fluid and flexible nature of this engagement opens up new possibilities for living and managing well that incorporate social relationships and societal participation. People living with a LTC are often forced to rely on their own resources. The SNI helped people to make a cognitive shift from individualized, self-management accountability to being ready and receptive to the possibilities of collective effort. This finding resonates with existing research on the purpose of SMS. Morgan et al8 posited that the purpose of support in narrower approaches to SMS centred on individualized behavioural targets such as lifestyle, self-monitoring and medication taking oriented to biomedical goals. Similarly, facilitation focuses on internal motivation of an individual rather than including those around them. A wider view and scope of facilitation explored here in a SNI highlights the need for a broader vision that incorporates other people, things and activities that are relevant to people’s social contexts, life circumstances and lived experiences.

Findings demonstrate that facilitating visualization and reflection and expediting engagement with the network mapping exercise act to assist with positive disruption of established self-management practices. Coherence and shift in perception of SMS from a process that focuses exclusively on the individual to one that incorporates a focus on collective elements and processes occur partly through the co-creation of a visual image of a person’s support network. All respondents entered into the shared network mapping activity with the facilitator and were able to reflect on its purpose in terms of sense making of how those around them operated as a, or potential, source of support or access to resources that would help with self-management. This suggests that when the complexities of person’s life world are presented in a visual format (concentric circles diagram), the information and its implications in terms of personal possibilities and challenges become more accessible, breaking down barriers to health inequality and improving health literacy. In relation to accessibility and sense making, Antonucci22 reported a similar finding when he first introduced the concentric circles hierarchical mapping technique to examine social support networks,
commenting that the technique seemed to ‘transcend culture, age, life situation and crisis’. However, where the current study adds to this proven technique is by using the image of an existing support network to link into new social connections, imagine future possibilities and increase social participation. Moreover, recognition of people’s life worlds and habitus as part of a broader entry into therapeutic landscapes has been highlighted as a means of living life well with a LTC.26

Empowerment and engagement were seemingly attained through the act of facilitation in which meaningful, enjoyable activities were identifiable and alignment could be made of valued preferences with people’s social connections, relationships and environment in order to incorporate these into everyday life (Box 2).

This process suggests that when people identify and are linked to valued activities that match what they enjoy doing, social participation is likely to increase in turn supporting people to manage better in everyday life. Reflecting on what people used to do in the past but no longer do is a powerful means of reintroducing the familiar and for people to reconnect with valued activities from the past.3 It also acts as a counter to traditional approaches to SMS which identify with a predominant focus on education and advice-giving where attention to psycho-emotional issues patients face takes a back seat14 highlighting the need for facilitation to take into account the complexities of social circumstances and emotional responses of people. Implications for future training of health-care professionals in self-management point to the need for a basis of trust, questioning and flexibility.14 The current study points to how a SNA can incorporate the social, emotional and environmental needs required for creating a meaningful life in chronic illness management. In addition to relational aspects of facilitation, other aspects, such as awareness of locality, a sensitivity to and understanding of the bases of the value attributed to relationships and people’s personal networks, collective community and social activities taking place locally, are relevant. Thus, a core element of future facilitation is the requirement of the development of a facilitator’s empathy for the life worlds of individuals, in order that mutual empathy can lead to rapport and co-appreciation of the preferences and choices being elicited and the links forged to others in a personal network. The latter is perhaps a salient quality to add to the facilitator-patient relationship and addition to the lexicon of person-centred interventions taking place in primary care and community settings.

5.1 | Limitations

Data for this study comprised observations of the intervention delivery and qualitative, post-intervention interviews with participants. Data collected directly from facilitators were limited to group feedback from lay health workers who took on the GENIE facilitator role for research purposes. Future research would benefit from conducting qualitative interviews with facilitators.

6 | CONCLUSIONS

Our findings indicate that facilitating a SNI that includes a network mapping exercise as the key object of engagement requires an orientation towards the idea of connections and linkages and skills of enabling the exploration of relationships and interactions within people’s everyday social world and requires an appreciation of the social environment and sense of place in order that the two people involved can work together authentically.

ACKNOWLEDGEMENTS

The authors wish to thank the participants who kindly gave their time and contributed to intervention delivery and interviews; recruiters and facilitators from the lay health workforce on the IoW; and Sandy Ciccognani, the PPI champion.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Access to anonymized data may be granted following review.

ORCID

Elizabeth James https://orcid.org/0000-0001-9355-0295
Ivaylo Vassilev https://orcid.org/0000-0002-2206-8247
Jaimie Ellis https://orcid.org/0000-0003-0068-3318
Anne Rogers https://orcid.org/0000-0002-7231-790X

Box 2. Working example

One participant had been recently diagnosed with diabetes T2 when she went through the intervention. One of the key things she wanted to do was to meet other local people with diabetes type 2 who were a similar age to herself (mid-40s). Working through GENIE together with the facilitator, they identified a local, peer-to-peer support group for people recently diagnosed with diabetes T2, Sugarbuddies. Here, the participant reflects back during her 6-month follow-up interview: ‘I’m excited about Sugarbuddies. I feel that I’m getting more involved with it and they are people of my age group and by talking to them I understand what they’re going through. I’m not on my own...it’s not the end! There is life, you know, and it’s positive compared to this time last year. What is the saying? Knowledge is power? It’s opened up new doors for me...a new world – I’m very excited. There are very exciting times ahead!’ (EU01).
REFERENCES

1. Mossabir R, Morris R, Kennedy A, et al. A scoping review to understand the effectiveness of linking schemes from healthcare providers to community resources to improve the health and well-being of people with long-term conditions. Health Soc Care Commun. 2015;23(5):467-484.

2. Entwistle VA, Cribb A, Owens J. Why health and social care support for people with long-term conditions should be oriented towards enabling them to live well. Health Care Anal. 2016;26:48-65.

3. Brooks HL, Rogers A, Sanders C, Pilgrim D. Perceptions of recovery and prognosis from long-term conditions: the relevance of hope and imagined futures. Chronic Illness. 2015;1:3-20.

4. Scharn M, Oude Hengel K, Boot CRL, et al. Influence of chronic diseases on societal participation in paid work, volunteering and informal caregiving in Europe: a 12-year follow-up study. J Epidemiol Community Health. 2019;73(2):136-141.

5. Rogers A, Vassilev I, Sanders CG, et al. Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. Implement Sci. 2011;6(1):56.

6. Kennedy A, Bower P, Reeves D, et al. Implementation of self management support for long term conditions in routine primary care settings: cluster randomised controlled trial. Brit Med J. 2013;346:1-11.

7. Wolever RQ, Simmons LA, Sforzo GA, et al. A systematic review of the literature on health and wellness coaching: defining a key behavioral intervention in healthcare. Glob Adv Health Med. 2013;2(4):38-57.

8. Morgan HM, Entwistle VA, Cribb A, et al. We need to talk about purpose: a critical interpretive synthesis of health and social care professionals’ approaches to self-management support for people with long-term conditions. Health Expect. 2017;20:243-259.

9. Richards DA, Lankshear AJ, Fletcher J, et al. Developing a U.K. protocol for collaborative care: a qualitative study. Gen Hospital Psychiatry. 2006;28(4):296-305.

10. Reeves D, Blickem C, Vassilev I, et al. The contribution of social networks to the health and self-management of patients with long-term conditions: a longitudinal study. PLoS One. 2014;9(6):e98340.

11. Vassilev I, Rogers A, Kennedy A, Koetsenruijter J. The influence of social networks on self-management support: a metasynthesis. BMC Public Health. 2014;14:719.

12. Holman D, Lynch R, Reeves A. How do health behaviour interventions take account of social context? A literature trend and co-citation analysis. Health. 2017;22(4):1-22.

13. Hughes S, Lewis S, Willis K, Rogers A, Wyke S, Smith L. Goal setting in group programmes for long-term condition self-management support: experiences of patients and healthcare professionals. Psychol Health. 2019;35(1):70-86.

14. Furler J, Walker C, Blackberry I, et al. The emotional context of self-management in chronic illness: a qualitative study of the role of health professional support in the self-management of type 2 diabetes. BMC Health Serv Res. 2008;8:214.

15. Coulter A, Entwistle V, Eccles A, et al. Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database Syt Rev. 2015;3:CD010523.

16. Richards D, Lovell K, Gilbody S, et al. Collaborative care for depression in UK primary care: a randomized controlled trial. Psychol Med. 2008;38:279-287.

17. Kennedy A, Rogers A, Bower P. Support for self care for patients with chronic disease. BMJ. 2007;335:968.

18. Kendall E, Rogers A. Extinguishing the social?: state sponsored self-care policy and the Chronic Disease Self-management Programme. Disab Soc. 2007;22(2):129-143.

19. Kennedy A, Vassilev I, James E, Rogers A. Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study. Implement Sci. 2015;11:27.

20. Entwistle VA, Watt IS. A capabilities approach to person-centered care: response to open peer commentaries on “treating patients as persons: a capabilities approach to support delivery of person-centered care”. Am J Bioethics. 2013;13(8):W1-W4.

21. Protheroe J, Brooks H, Chew-Graham C, et al. ‘Permission to participate?’ A qualitative study of participation in patients from differing socio-economic backgrounds. J Health Psychol. 2012:1:10.

22. Antonucci TC. Social support networks: hierarchical mapping technique. Generations. 1986;X4:10-12.

23. Ajrouch KJ, Antonucci TC, Janevic MR. Social networks among blacks and whites: the interaction between race and age. J Gerontol: Ser B. 2001:56:S112-S118.

24. Vassilev I, Rogers A, Kennedy A, Oatley C, James E. Identifying the processes of change and engagement from using a social network intervention for people with long-term conditions. A qualitative study. Health Expect. 2019;22:173-182.

25. Blakeman T, Blickem C, Kennedy A, et al. Effect of information and telephone-guided access to community support for people with chronic kidney disease: randomised controlled trial. PLoS ONE. 2014;9:e109135.

26. Sanders C, Rogers A. Bodies in context: potential avenues of inquiry for the sociology of chronic illness and disability within a new policy era. In: Pescosolido B, Martin J, McLeod J, Rogers A, eds. Handbook of the Sociology of Health, Illness, and Healing. Handbooks of Sociology and Social Research. New York, NY: Springer; 2011.

How to cite this article: James E, Kennedy A, Vassilev I, Ellis J, Rogers A. Mediating engagement in a social network intervention for people living with a long-term condition: A qualitative study of the role of facilitation. Health Expect. 2020;23:680-689. https://doi.org/10.1111/hex.13048