The Community Navigators Study: loneliness in people with complex anxiety or depression

There are high levels of need for support with loneliness and social isolation in people with depression and/or anxiety in secondary care, which are not being met by mental health and social care services.

Preliminary testing of an intervention to reduce loneliness in people with mental health problems, shows it is well received by service users and potentially helpful in reducing loneliness and depression.

Delivering the programme in integrated mental health and social care teams, as a complementary addition to routine care, is achievable.

A randomised controlled trial of the Community Navigators Programme is feasible to establish whether the programme is effective and cost-effective in reducing loneliness and depression.

School for Social Care Research

BACKGROUND

Loneliness has been defined as the gap between someone's actual and desired social relationships. It is subjectively experienced and, unlike objective social isolation (the number of contacts), relates to the quality of social relationships as well as quantity.

It is associated with poor physical and mental health outcomes. People with mental health problems are particularly vulnerable and, for those with anxiety and/or depression, loneliness is associated with poorer recovery.

Programmes to help people develop and strengthen social connections and relationships are advocated in policy but there is little evidence regarding their effectiveness. Programmes to reduce loneliness have potential to benefit people with mental health problems, but evidence is needed regarding their feasibility, acceptability and outcomes.

THE COMMUNITY NAVIGATORS PROGRAMME was developed in this study.

It is a social intervention designed to reduce loneliness and increase social connections of people with severe depression and/or anxiety, who were recruited from secondary community mental health services

The study aimed to: develop a programme to reduce loneliness for people with anxiety or depression treated in secondary mental health services; explore its acceptability to participants and services; and establish the feasibility of evaluating the programme through a randomised controlled trial (RCT).

Methods

The phases of the study involved co-producing the Community Navigators programme (phase 1), testing it with a small group (phase 2), then conducting a feasibility RCT of the programme in a secondary mental health care setting (phase 3).

Forty participants with anxiety or depression were recruited and randomised to an intervention group (n=30), who received the programme in addition to standard care, or a control group (n=10), who received standard care and written information about local community resources. Outcome measures and service use data were collected at baseline and a six-month, end-of-programme time point.

Qualitative interviews with participants and other stakeholders explored experiences of the programme. The acceptability of the programme and the feasibility of evaluating it in a trial were assessed.

FINDINGS

PROGRAMME DEVELOPMENT AND REFINEMENT (YEAR 1)

The co-produced programme involved up to ten meetings with a 'Community Navigator' (a new role developed for this programme) and three group events for all participants over a six-month period.

Community Navigators

Community Navigators were recruited specifically for this programme: they were not required to be mental health clinicians, but brought experience in community engagement roles and had mental health awareness. They worked with people to develop new social contact and connections, and to revive or develop existing social relationships, with the aim of reducing feelings of loneliness.

Navigators were based in the participating mental health teams (Community Mental Health Teams or equivalent services for people with severe depression or anxiety).

Training was delivered by social work practitioners from the involved mental health services, lived experience members of the coproduction working group, and researchers form the study team.

Five days' initial training developed the Navigators' skills in community asset mapping, network mapping and supporting people with goal planning, solution-focused coaching approaches, and responding to participants' distress or safety concerns.

A day's induction in the mental health services and three days' top-up training during the study period were also provided.

Navigators were provided with fortnightly group supervision, facilitated by social workers and occupational therapists from the involved mental health teams.

Programme design

Core elements of the programme included support from the Navigator with:

(i) 'network mapping' – discussing and visually representing the participant's social world; and

(ii) developing and supporting the participant to carry out a personalised plan to increase the quality and/or quantity of social relationships and positive social identities.

The Navigators sought to promote positive social identities of the people they supported, through expanding their sense of belonging to social groups, and used a strengths-based, solution-focused approach.

Phase 1 and Phase 2 findings

Main changes to the programme following preliminary testing were: to provide a less-structured, social focus to group meet-ups and to provide more training for the Navigators on managing endings of support and solution-focused coaching strategies

The study demonstrated that a co-production approach – with practitioners, people with lived experience of mental ill health and researchers working together as equal partners – is possible and works well for developing and delivering a complex intervention of this kind in a research context.

THE FEASIBILITY TRIAL (YEAR 2)

Recruitment and retention

People with anxiety and/or depression were recruited from community mental health teams in two secondary mental health care trusts. 61% of service users screened were eligible for the study. Of 65 eligible service users approached,

40 (62%) agreed to take part. Recruitment in both teams was achieved within four months. No participants withdrew from the study, although one participant died through suicide: this sad event was independently assessed as not study-related.

Participants

Participants ranged in age from 29 to 56, 72% were female and 38% came from non-white ethnic groups. Only two participants were in paid employment, and only one lived with a partner. At baseline, 25 participants (62%) scored a maximum of 11 on the DeJong Gierveld loneliness scale, indicating extreme loneliness. Mean depression score at baseline on the Patient Health Questionnaire (PHQ) scale was 21.6, indicating severe depression.

Programme delivery

Twenty four of 30 participants in the intervention group (80%) met the minimum criteria for being treated 'per protocol' – i.e. they met their Community Navigator at least three times. For these 24, the mean number of meetings was 7.4, and 12 (50%) additionally attended at least one group.

Records completed by the Navigators after meetings confirm that all 24 participants were supported to complete a network map, and 21 completed a connections plan; 64% of meetings took place in a community

venue (i.e. not the participant's home or an NHS setting), and 37% of meetings involved contact with others, as well as the navigator and the participant.

Nine of the 30 intervention group participants accessed the available budget to facilitate social connections, with others relying on their own resources or free activities.

QUANTITATIVE OUTCOMES

Follow-up data collection interviews were completed with 35 (88%) participants. Health service use data were collected for all 40 participants, but, despite having participants' written consent, the research team were unable to gain cooperation from Local Authorities to provide social care use data.

Because of the small number of participants, this feasibility trial was not intended to and did not establish whether or not the Community Navigators programme was effective.

However, as planned in the protocol, the results for two main outcomes are reported here: loneliness and depression, both of which indicate a potential (though unproven) positive effect.

- The Median DeJong-Gierveld loneliness score fell from 11 at baseline to 9 at follow-up for the intervention group, compared to a change from 10.5 to 10 in the control group.
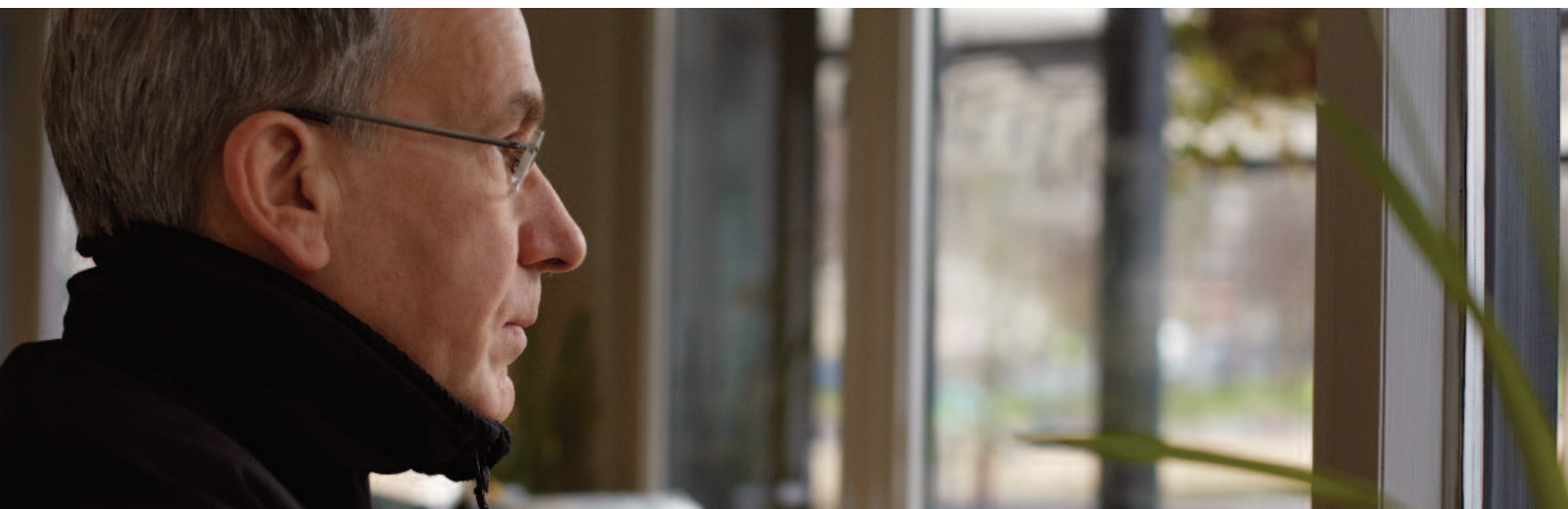
- Mean PHQ depression score fell from 21.6 at baseline to 16.4 at follow-up in the intervention group, and from 21.1 to 18.8 in the control group.

As expected, these results were not statistically significant: hence, it is not certain the programme had any beneficial effects, but it may have had very large beneficial effects. These findings are sufficiently promising to support the need for a future, larger trial which can evaluate the programme's (cost-) effectiveness definitively.

Views on the programme

Interviews (n=32) were conducted with 19 participants, three family members, seven staff from the mental health teams; and all three community Navigators. The research team used an existing framework, developed by Sekhon and colleagues, for evaluating the acceptability of health care programmes to analyse these interviews.

Interviewees welcomed a programme to address loneliness and isolation and improve social connections, describing how this was an area of need that is often under-prioritised by mental health services.

"I just thought that this was the perfect study to get me to interact with people but also to do something that I enjoy doing." Service user

"I think it's an excellent idea, because I think that often with mental health patients we look at their mental health in terms of how they're functioning etc. We often do not look at it in terms of their isolation." Staff member

"I thought it was great because I think it's something that the NHS lack. They work with medication. They have some therapies obviously, which come into play but there is very little practically linking a patient with the community" Family member

Nearly all service users reported that meeting their Community Navigator had been a positive experience. They felt understood, cared about and valued. They praised the community Navigators for their forward-looking and encouraging attitude.

"She is so positive. She is so positive. 'There must be something that you would like to do, [name of participant]. We can do it'." Service user

"So if I could have another navigator, I just wish it could be him again because he was really patient with me. He showed that he really cared." Service user

The programme did challenge people. Going out, using public transport, and especially meeting and spending time with others caused significant anxiety for people, and required them to overcome feelings of low mood and apathy. Sometimes people did not feel

able to face such situations, but at other times, they described how the support of the Community Navigator had enabled them to do so, and where it went well, they felt a sense of achievement.

"I had my panic attacks and my usual difficulty in staying in the room… I knew I was going to go through quite a bit of suffering to manage to stay for three hours in the class. But yes, I managed it and I was really pleased. I've done two weeks now." Service user

For some service users, the programme was not long enough to achieve what they hoped, or life circumstances limited their engagement with it. However, many stakeholders reported changes for service users, including greater awareness of local opportunities, regular attendance at groups and increased contact with other people. A number of service users reporting improved mood and reduced feelings of loneliness.

"It can't be quickly, it can't be ten sessions then you're left. Perhaps it would work if you've got very mild problems and you've gone to your GP practice and you're feeling a bit isolated perhaps." Service user

"I think I'm more social. I've reconnected with friends from secondary school. Yes, I've reconnected with a lot of people and I haven't been feeling quite so lonely at all." Service user

"I would still be moping around, depressed, with nothing to look forward to. Yes, so it helped me a great deal this, yes." Service user

Although the programme was challenging for participants at times, it was broadly acceptable across stakeholder groups, with potential to help people in different ways, including alleviating loneliness and depression.

CONCLUSIONS & RECOMMENDATIONS

There are high levels of need for support with loneliness and social isolation for people with depression and/or anxiety in secondary care, which are not being met by mental health and social care services. Most people taking part in this study scored as high as the scale allows for loneliness at baseline. Service users and staff welcomed the Community Navigators programme as offering something valuable and different from usual care.

The study team had feared this group of service users might be too depressed or socially anxious to take up a programme of support to increase social connections, but this worry was mostly unfounded. Recruitment was readily achieved. Most participants remained well engaged with the intervention, and told us in interviews that working with the Community Navigator had been helpful and the programme was acceptable. This all suggests potential demand for this type of support in practice.

The study has demonstrated that delivering this programme in integrated mental health and social care teams, as a complementary addition to routine care, is achievable, and that evaluating it through a randomised controlled trial is possible.

These conclusions have two implications for mental health and social care practice in England. First, the Community Navigators programme is potentially helpful to the target group of people. The intervention manual and training manual and a theory of change model will be made available on the study website, and provide a detailed guide to implementing the programme. It has been road-tested with people with anxiety and/or depression in secondary care, and is potentially suitable for other clinical groups. In the absence of evidence-based interventions to reduce loneliness for people with severe mental illness, the programme is ready for use in mental health and social care settings, with the caveat that more robust evidence of (cost-) effectiveness is needed.

Second, it has shown that a randomised trial of the Community Navigators programme is feasible (e.g. recruitment is possible and data can be collected). A larger trial of the programme could establish whether or not it is (cost-) effective and whether or not it should be recommended in clinical and policy guidelines and become widely offered to service users.

CO-PRODUCTION

The study team tried to adopt a coproduction approach throughout the study, drawing on experience and guidance from study partners The McPin Foundation. A peer-researcher was employed throughout the study who has led on conducting and analysing qualitative interviews with participants, as well as co-designing the content of the intervention. At the start of the study a coproduction working group was set up, involving lived experience experts, practitioners and academic researchers. This group met regularly to develop the Community Navigators intervention. The group involved six lived experience experts, five of whom remained engaged throughout the project, three practitioners and consistently four members of the research team.

All key decisions on the study were agreed through the working group. Members contributed to the study at many stages including:

- Developing the study intervention: selecting network mapping and goal planning tools, and developing the theory of change

- Developing interview topic guides and participant information sheets, and selecting outcome measures for the feasibility trial

- Shortlisting and interviewing the Community Navigators and study researchers

- Contributing to training the Community Navigators

- Contributing to qualitative data analysis

- Contributing to dissemination, including an end-of-study event for stakeholders and study publications

Service user involvement was framed within a coproduction group, involving service users, practitioners and researchers using their different expertise together, rather than having a separate service user working group. The risk of this approach is that no-one will agree and relationships which require collaboration and trust break down. The benefits of this approach are that people can learn from each other, and decision-making processes are transparent and direct, rather than service users' views "feeding in" to a separate management group. The feedback received from service user members is that this has worked well, and helped provide a richer involvement experience.

Overall this coproduction process, valuing practitioner, researcher and lived experience expertise, worked well and helped to develop an intervention with a good chance of being feasible in practice and acceptable and helpful to mental health service users.

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Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research (NIHR) to develop and improve the evidence base for adult social care practice in England in 2009. It conducts and commissions high-quality research.

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