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Improving community health networks for people with severe mental illness: a case study investigation

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Scientific summary

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Scientific summary

Introduction

Policy drivers in mental health to address personal recovery, stigma and poor physical health indicate new service solutions are required. Reconfigurations to health services highlight a need to understand the resources that individuals with severe mental illness (SMI) access and the balance of formal and informal connections to support well-being for this population. Our study was carried out to understand how social contacts, meaningful activities and places that people with SMI had connections with were utilised to benefit health and well-being. We examined what happened in people's lives using a network-mapping technique termed the community health network (CHN) approach; how community assets were used to support recovery; and the influence of primary care and secondary mental health practitioners in personal networks.

Study aims

The main aim of the study was to understand the personal networks of people living with SMI from their own perspective and how personal well-being was supported by resource exchanges. Through this, we come to better understand how personal networks of people with SMI may be supported by practitioners and mental health providers. Specific research questions were:

1. How do people with SMI use their personal networks to support their health and well-being?
2. How do community-based practitioners and organisations support people with SMI to use their personal networks to support their health and well-being?
3. How do primary care, community-based mental health providers and other organisations work together to develop personal networks for people with SMI to improve their overall health and well-being? What were the barriers and enablers to achieving this?

In our study the use of the term 'network' had two meanings:

- as a technical term in the field of social network analysis to describe the structure of ties between different nodes such as people or organisations
- as a lay understanding of networks and networking which describes connections and relationships more generally.

Methods

A five-module mixed-methods design was undertaken in two study sites. A patient and public involvement team participated in tool design, data collection, analysis and write-up:

- in-depth interviews ($n = 30$) with organisation leads to understand the local service and policy context for supporting people with SMI
- network mapping of individuals with SMI ($n = 150$) to collect personal network data on people, places and activities as well as measures of social capital, well-being and health functioning
- in-depth follow-up interviews ($n = 41$) to explore how individuals with SMI managed and developed their connections over time.

- Practitioner telephone interviews ($n = 44$) with general practitioners (GPs), psychiatrists, care co-ordinators and third-sector staff to understand their role in facilitating growth of social, activity and place connections.
- In-depth interviews with 12 stakeholder leaders in primary care, commissioning and mental health service delivery organisations to share study findings and gain policy updates.
- The study was largely descriptive but we undertook detailed interpretative analysis, following a three-stage synthesis process including independent lived experience feedback, to build explanations to support our conclusion and recommendations addressing the ways in which people with SMI shape their personal networks and the potential for services and practitioners to work alongside them.

Results

The primary analyses described personal networks and revealed critical issues about locality and organisational context:

- Three types of personal networks of people with SMI were generated by k-cluster analysis to understand heterogeneity within and similarities between people in our study in terms of network characteristics: diverse and active; family and stable; formal and sparse. These incorporated dimensions of people, place and activity, an approach that was broader than measuring social ties alone.
- Only a few factors in our data set explained variance in network type, and the significant factors found could potentially be altered, although this was challenging to do: living alone or not; housing status; formal education; long-term sickness or disability. Network type differed significantly by diagnosis but, when controlled for other factors, did not explain variance; though participants in the schizophrenia/psychosis group had significantly fewer social ties than other diagnostic groups, 42% of this group had diverse and active network types.
- Some key observations about network types:
    - Diverse and active networks had higher numbers of people, place and activity connections. Those with these networks had the highest proportions of new connections and highest network satisfaction. Qualitative analysis found active management of connections, resources and network opportunities, but that big was not always better. Diversity and variety could be associated with enhanced personal well-being and more durable networks, but for some people connectedness caused stress and distress. Manageable routines were important and stigma featured prominently; as networks diversified, the potential for mental health discrimination increased.
    - Family and stable networks had the highest access to social capital and health resources, but lower levels of activity and place connection than diverse and active networks. Participants with these networks spent most of their time at home but tended to live with others. Qualitative analysis found high levels of social support and building blocks for wellness and recovery through family connections; however, such support could also restrict access to wider social capital and well-being resources. Reciprocal relationships were highly valued.
    - Formal and sparse networks were significantly smaller with lower access to social capital and health resources, poorer functioning and well-being. They were the least active, having fewer friends, family and wider contacts, and practitioner contacts were more dominant. Qualitative analysis found mental illness featured most strongly in these networks framing decisions and experiences. We found agency in some of these networks, despite limited resources, and potential building blocks for recovery; others needed help identifying potential opportunities. Formal and sparse networks were sometimes considered beneficial for supporting individual well-being. Strength was also gained from identities developed away from diagnostic labels and there were signs of resilience and determination to move on from mental illness. These networks also revealed the resentment that some people feel when relying on practitioners to support mental health and well-being.

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- The study investigated access to health and social capital. We found these resources were mostly accessed through family and friends, with practitioners generally having a more limited role, although practitioners were more prominent in networks lacking informal social support. Connections to activities, including employment, and places were important, as they were gateways to social ties. Our study participants had access to lower social capital than the general population.
- The qualitative interviews helped us to explore heterogeneity within the study population. We found individual agency across all network types and surfaced tensions, including relationships with practitioners or families; dealing with the impact of stigma; employment and financial frustrations. The value of connectedness in countering the risk of isolation and loneliness within personal networks and supporting recovery was evident. Connectedness shapes identity, providing meaning to life and sense of belonging, gaining access to new resources, structuring routines, helping individuals 'move on' in their recovery journey.
- Networks in London showed more bridging capital properties, with higher numbers of wider contacts and access to more diverse relationships and place types. These networks had fewer family contacts, and lower social capital.
- Networks in the south west showed more features of bonding capital with close family and friend ties and dense interconnected lives. Challenges for practitioners lie in working with individuals with networks where family ties were negative or absent.
- Health-care and third-sector providers were reportedly keen to promote a recovery-focused approach. In a demanding and changing context, we found a contrast between recovery ideology, contained in mental health policy, and recovery practice, with few specific examples of how social interventions and outcomes were prioritised within and between organisations.
- Health-care and third-sector practitioners, including GPs and psychiatrists, recognised social factors were important in recovery but reported system-level barriers (workload, administrative bureaucracy, limited contact time with clients). Skilled care co-ordinators acknowledged the importance of network development but currently did not believe they had enough time to sufficiently focus on 'the social'.
- The health and social care system currently does not deliver fully integrated multiagency networking solutions to support SMI and recovery. We also found competing tensions in policy agendas shaping provision of mental health services; primary and secondary care were not using the same approach to the management of SMI.

Perhaps the most striking issue emerging through our work was the heterogeneity of personal networks. The three types generated by the cluster analysis provide another lens for policy-makers and practitioners to view the lives of individuals with SMI without reducing the diversity of experiences and meaning located in personal networks. We found that, as well as a pattern of interactions with people, places and activities, personal networks generated a map of meaning, helping others to understand SMI and connectedness, identity, recovery, stigma and resilience as well as providing insights into the social management of well-being.

Individual agency in developing and maintaining networks was found, but many people with SMI require support. Identifying the building blocks of individual agency, which can be nurtured with the help of others, is a vital aspect of recovery, particularly where individuals lack belief in themselves and inner resources.

Service systems appeared to thwart the agency of practitioners, creating obstacles to person-centred outcome-focused care, even within the third sector, where people wanted to work in this way but were restricted by commissioning arrangements. Developing the personal networks of individuals with SMI was not an organisational priority in the way that management of symptoms, medication and risk was. As long as this remains the case, it seems unlikely that this population will be able to build personal networks that make use of the *full* potential of inner and external resources.

Implications for health care

This was an exploratory study piloting the CHN approach, adding places and activities to social networks as a means of understanding the lives of people with SMI. The approach allowed consideration of what connections were important to individuals as well as what was missing. Many participants reported the mapping interview useful as a way of reflecting on their circumstances, and at follow-up interviews some reported already making changes.

The study has a number of limitations. It was carried out in two geographically distinct areas but these were not representative of the UK as a whole and sample bias in the network-mapping component from low response rates (24% in the south west and 15% in London) weakens conclusions. For example, we cannot be sure about whether one network type is more dominant in the whole SMI population or not, or indeed if other network types exist. Findings must be viewed in this context.

The network types produced through clustering are, however, a potentially useful way of viewing the lives of people with SMI, providing an alternative to mainstream diagnostic symptom clustering. The following developments are recommended as a consequence of the research:

- *Developing the CHN methodology as a tool to understand connectedness and support recovery.* Important elements of networks are recognised within recovery frameworks, and practitioners draw on aspects of this work in current practice, particularly meaningful activities and social support. Having a structured approach to social and community asset mapping could support more social interventions in mental health care. A connectedness tool would require adaption of a research process into a clinical intervention.
- *The need for improved organisational collaboration.* Several service 'silos' were in operation and we found there was a significant community resource knowledge gap; many practitioners rely on their own interests and professional networks to learn about community opportunities to support clients. A system that could encourage interorganisational community information sharing, and ideally practitioner and service use feedback on the value of local resources, was recommended. It was acknowledged that keeping such a system updated would be a major challenge.
- *Supporting people with SMI to make active use of social resources.* Meaning and direction must come from people with SMI themselves but practitioners have a vital connection-building role, in part by showing that networks and the resources within them matter to recovery, alongside medication and psychological therapies. Organisations also have a key role to play and, in times of change or restructuring, this includes planning how changes in community resource levels might impact on vulnerable populations such as people with SMI.
- *Primary care*. GPs need a greater understanding of the value of social recovery for SMI. They also need to develop closer working relationships with other providers; particularly the third sector when providing for individuals who have been discharged from secondary services.
- *Health and social secondary care*. Skilled care co-ordinators acknowledge the importance of network development, but need support to make it a larger part of their role. Creating shared care processes with primary care and the third sector will become fundamental in the management of SMI; being alert to the importance of connectedness through people, places and activities should feature in care planning.
- *Mental health third-sector services*. They have an important network development role linking, facilitating, empowering and encouraging, but often in isolation from other services. They could develop these models further and include group and peer elements; and are likely to be more efficient if more closely linked to primary and secondary care.

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- *Commissioning*. A crucial gap in practice was the lack of any overarching framework for the provision of services to people with SMI following a recovery approach. Social outcomes of care are largely absent in the current NHS outcomes framework which applies only to secondary care. Building a set of social outcome indicators for SMI and including network indicators that operate across service silos would incentivise joint working and promote social inclusion. New models located in primary care are worth exploring. Payment or incentive systems would need to be developed; existing direct payments or emerging payment by results tariffs could be utilised.

Recommendations for research

We recommend research be undertaken to develop and evaluate a simplified version of CHN mapping as a formulation and monitoring tool with therapeutic benefit through its effect on individualised outcomes. It could be used in primary care, secondary care and shared care models of mental health provision. Research could examine which practitioners, including peer support workers, are best placed to deliver CHN mapping, and the potential for a version which individuals with SMI use without support. It would also enable further exploration of heterogeneity in networks, assessing connectedness and personal network meaning for different subgroups recruiting larger population samples to further develop network-type clusters.

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