



Understanding high mortality rates among people with multiple and complex needs: exploring underlying factors and opportunities for prevention in Newcastle and Gateshead

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Evidence for Practice Guide

Understanding high mortality rates among people with multiple and complex needs

Individuals experiencing multiple and complex needs (MCN) may face issues of homelessness, substance misuse, repeat offending, and/or mental ill-health. Individuals facing these issues experience disproportionate levels of health inequalities and mortality rates. Furthermore, there is little evidence on strategies to prevent the high mortality rates.

Through a peer-informed qualitative study, the underlying reasons for the high mortality rates among those with MCN were explored. Additionally, the study aimed to:

1. Pinpoint opportunities to identify people at risk
2. Explore potential interventions to prevent these unnecessary early deaths

Individuals Involved

Co-led by Fuse and Fulfilling Lives Newcastle Gateshead

3 Focus Groups (21 people):

- Lived experience of MCN
- Frontline Staff
- Managers and Commissioners

A regional event for stakeholders across the North-East

1) Understanding Premature Mortality

The following were identified as factors contributing to mortality rates:

- Double burden of mental health conditions and substance misuse
- Poor service provision and multi-agency collaboration
- Lack of hope for change and acceptance that death was common



I am facing this maze of doors and every time I open a door, there's another door, set of doors. There's no coherent structure within the system that says, "Here's a person who is asking for help, who's engaging with everything that we're giving, can we please pull this together so we can actually provide the help that this person needs."— Person with lived experience

2) Identifying Opportunities to Intervene

Windows of opportunity are brief and not always easy to target, but with the right support in place **critical life events** (bereavement and relationship breakdown) and **significant transitions** (completion of treatment, release from prison, or service discharge) could be targeted.

3) Possible Interventions to Reduce High Mortality Rates

Four areas for intervention were suggested:

- Introducing holistic, person-centred approaches
- Developing communities
- Improving connections and supports across the system
- Placing a focus on prevention



I think there needs to be a focus on it being really a person-centred approach and say, "This isn't working at the moment and that's how I would like things to be," and giving them that sense of responsibility. – Frontline staff

4 Main Recommendations for Policy, Practice and Research



Actions to prioritise prevention and health promotion:

- Make every contact count not just those in health and social care
- Target preventive interventions at 'critical life events'
- Ensure timely and effective access to support services



Actions to assist in focusing on the individual:

- Collaborate with people with lived experience for service provision/development and research
- Create a tiered person-centred treatment/care pathway that is trauma informed and free of stigma



Actions to implement a whole-system approach:

- Improve collaboration and communication across all areas of service provision (especially mental health and substance use)
- Improve service continuity and navigation
- Introduce whole system commissioning models



Actions to explore opportunities to support supporters:

- Create supportive work environments to ensure the MCN workforce has the required supports to continue providing exceptional care
- Ensure families and carers of people with MCN have access to support to prevent burn-out and improve early recognition of support
- Create conditions that empower community led peer support services

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Executive Summary

Background

Multiple and complex needs (MCN) include issues of homelessness, substance misuse, repeat offending and mental ill-health. People facing these issues experience severe health inequalities and have extremely high death rates compared to the general population – the all-cause mortality rate is almost seven times higher for men and twelve times higher for women. However, limited evidence is available on underlying factors and prevention efforts in these populations.

Aims

Using a peer-research approach, this qualitative study aimed to understand factors underlying high mortality rates among people with MCN, opportunities to identify people at-risk and explore potential preventive interventions.

Methods

Peer researchers (Experts by Experience) from Fulfilling Lives Newcastle Gateshead contributed to all stages of this study including developing the aim, methods, data collection, interpretation and recommendations. Three focus groups (n=21) were held in July 2019 with people with MCN, and those working in the health, social care and voluntary sectors supporting people with MCN in Newcastle and Gateshead (North East England). A participatory workshop was held with stakeholders (33 organisations) to present and discuss key messages, reflect on findings and develop recommendations for policy and practice.

Key findings

The burden of co-occurring mental ill-health and substance misuse was highlighted as playing a significant role in premature deaths. Deficiencies in service provision and multi-agency collaboration increase individual's vulnerability and risk of early death. **Those with lived experience of MCN had vast experience of loss** amongst their peers and this, coupled with a **lack of hope** that things could change for the better, meant they had become desensitised to death as an outcome. **Potential opportunities to identify people at-risk** included critical life events (e.g. bereavement, relationship breakdown) and significant transitions (e.g. release from prison, completion of drug treatment).

Recommendations for policy, practice and research focused on **prioritising prevention and health promotion**, ensuring support is **person-centred**, implementing a **whole-system approach**, and exploring opportunities to **support carers, providers, and families**.

Conclusion

This study found there were a complex set of factors that contribute to high mortality rates among people with MCN. Early prevention and targeting interventions at "critical life events" could be important in reducing deaths in MCN groups. Future action should focus on effective collaboration, cross-service learning, and listening to individual needs. Developing effective and sustainable interventions to address the high mortality rates will require an understanding of the intersecting nature of MCN to adequately address current challenges.

Introduction

Health inequalities are unjust and unnecessary, and the health gap is widening between rich and poor areas in England [1]. It is now well-established that the social determinants of health – the conditions in which people are born, grow, live, work and age – drive inequalities in health. People who have become socially excluded, for example those who are homeless, have a history of offending or who have substance misuse issues are at a much greater risk of experiencing ill-health and premature death compared to other social groups [2]. These populations dealing with multiple and complex needs have mortality rates that are almost seven times higher for men and twelve times for women compared to the general population [3]. The average life expectancy for homeless rough sleepers is 44 years, compared with the UK national average of 81 years. As Professor Sir Michael Marmot puts it, “social exclusion is deprivation on stilts” [4].

Behind these mortality rates are real people who are part of real communities. The impact of a death can be devastating for those bereaved, many of whom may be contending with multiple and complex needs themselves. A few studies have attempted to quantify mortality and morbidity rates within people who have multiple and complex needs [2, 3, 5]. Few of which focussed on identifying ways to reduce these high mortality rates or captured the experiences of people who live or have lived with multiple and complex needs or those who work in services to support them.

This report summarises findings from a qualitative study applying peer-research approaches to explore the reasons underlying the high mortality rates among people with multiple and complex needs in Newcastle and Gateshead. First, the report focuses on the background to the research, including what we mean when we use the term “multiple and complex needs” and the scale of the issues, before identifying the aims and objectives of the study. The methods undertaken in the study are then described, followed by a summary of the key findings. The report concludes by considering the contribution of this research to the existing knowledge base and how the recommendations could be taken forward in policy and practice.

What do we mean by multiple and complex needs?

As an emerging area of research and understanding, there are several definitions currently used to describe the nature of a person facing more than one complex issue, such as poverty, mental ill-health, substance misuse and homelessness. “Severe and multiple disadvantage”, “multiple exclusion homelessness,” “inclusion health” and “multiple and complex needs” are some of the alternative terms currently used [6]. For the purposes of this report “multiple and complex needs” (MCN) will be used as the overarching term to describe co-occurring issues of homelessness, offending, substance misuse and mental ill-health.

People with MCN find it more difficult to engage with services and are often referred to as ‘hard to reach’ [7]. They find that specific services may not fully understand the breadth of their issues, and therefore their holistic needs are unmet. People with MCN often rotate through various services and systems, which can actually make their problems worse rather than helping them, at a cost to both the individual and society. Additionally, they may become frustrated by a lack of appropriate services and/or the

lack of coordination between available services. This frustration, when vented, can lead individuals to being deemed as 'difficult clients', often resulting in further exclusion and disengagement from support and society [7].

How big a problem is it?

Traditionally services that support people who have MCN address each need individually. Limitations in data sharing across these services mean that it is difficult to estimate the number of people experiencing MCN in a given population. In its 2015 Hard Edges report the Lankelly-Chase Foundation attempted to link data from a variety of statutory and voluntary services to estimate the number of people with lived experience of MCN in England. It estimated that over a quarter of a million people a year have contact with at least two out of three of the homelessness, substance misuse and/or criminal justice systems, and at least 58,000 have contact with all three [2]. Research suggests that poverty, childhood trauma and economic and social marginalisation are common features shared among those living with MCN [3].

People with lived experience of MCN experience severe health inequalities. There is a substantial burden of mental and physical health conditions, including an increased risk of developing communicable diseases (e.g. Hepatitis B and C), cardiovascular and respiratory conditions [2, 3]. Additionally, mortality rates among this population are high; the estimated mortality is almost seven times higher on average for men and almost twelve times higher for women. To put this into the context of health inequalities, all-cause mortality for those living in the most deprived areas of England is estimated to be 2.8 times higher for men and 2.1 times higher for women compared to those living in the least deprived areas [8].

While it is acknowledged that not all drug-related deaths will comprise individuals experiencing MCN, there is considerable overlap. It is also the case that the number of drug-related deaths have increased sharply in recent years. In 2018, there were 4,359 deaths in England and Wales; this represents a 16% year-on-year increase and is the highest number since records began in 1993. Drug-related death rates are higher in the North-East than any other region in England and Wales [9].

The issues highlighted here also have a clear economic impact. People living with MCN often require support from a range of public services. It is estimated that the public cost of supporting one person living with MCN is at least £20,000 per year, and can be significantly higher, for example, if that person is an offender. The overall conservative estimate of the cost of supporting people with MCNs is £10.1bn per year in England [2].

Where did this project come from?

A regional research and practice workshop was hosted by Public Health England and Fuse to foster collaboration across organisations in North-East England in June 2018. At the event, attendees had the opportunity to pitch a research idea to a panel in a bid to be awarded a small seedcorn funding to progress the idea. This project is the outcome of one of those successful bids.

The project design and methodology were developed with a group of Experts by Experience (peer researchers) and frontline staff who work for Fulfilling Lives

Newcastle Gateshead. Both groups expressed concern about high mortality rates among people with lived experience of MCN and felt this was a priority area for research. To put this into the local context, in the first three years of the Fulfilling Lives Newcastle Gateshead programme there had been 27 deaths representing just over 10% of the client cohort.

Organisations involved in the study

Fuse, the Centre for Translational Research in Public Health in the North East Universities of Durham, Newcastle, Northumbria, Sunderland and Teesside in a unique collaboration seeks to deliver world-class research to improve health and wellbeing and tackle inequalities. Collaborators from Newcastle University and Teesside University were part of this project.

Fulfilling Lives Newcastle Gateshead (FLNG) is an eight-year learning programme looking to improve the lives of people with complex needs and build a trauma-informed approach within the services that support them across Newcastle and Gateshead. It is one of twelve programmes linked together across England funded by the National Lottery Community Fund, looking to influence the system nationally. A Core Partnership of Changing Lives (lead partner), Mental Health Concern and Oasis Community Housing lead the programme's activity.

FLNG's vision is to build a culture of learning, hope and collaboration across Newcastle and Gateshead; helping the workforce create a community that understands and welcomes people experiencing homelessness, substance misuse, mental ill-health and offending. Together we develop ways their voices can be heard, their views valued and actively influence and shape the services, policies and practice that exist to support them. FLNG have developed a unique peer research approach to support this activity.

This project also links in with the *Health Inequalities and Marginalised Communities* arm of the **National Institute for Health Research (NIHR) North East and North Cumbria (NENC) Applied Research Collaboration (ARC)**. The aim of this arm of the ARC is to undertake high quality, applied, implementable, impactful, cost-effective research to support the NENC region's health and social care system to reduce health inequalities and improve the health and wellbeing of disadvantaged and marginalised groups.

Study aim

This peer-informed qualitative study aimed to explore the reasons underlying the high mortality rates among people with MCN. In particular, the study aimed to pinpoint opportunities to identify people at-risk and explore potential interventions that may be helpful in preventing early death.

Methods

This was a qualitative, peer-informed research study, which actively involved those who have lived experience of MCN as well as those who support them across Newcastle and Gateshead throughout the process. First, we undertook focus groups with adults (aged 18 years and over) with lived experience of MCN and those working in the health, social care and voluntary sectors that support people who have MCN. Next, we discussed the focus groups findings with a range of policy and practice stakeholders, in order to reflect on emerging themes, consider their implications, and develop recommendations for future policy and practice.

Peer researchers were part of the Experts by Experience network of Fulfilling Lives Newcastle Gateshead and had lived experience of MCN. They had NVQ-level training in peer research skills. Peer researchers contributed to all aspects of the project, including defining the research aim, data collection, interpretation of results and developing recommendations.

Qualitative focus groups

Study population

As this is a qualitative study, the sample size was not a priori identified. We used a combination of convenience and maximum variation sampling techniques to recruit: 1) adults with lived experience of MCN; and 2) service providers/commissioners. Service providers/commissioners were split into the categories of “frontline staff” or “managers/commissioners” based on their role.

1) *Adults with lived experience of MCN*

Participants with lived experience of MCN were recruited via the Fulfilling Lives Newcastle Gateshead’s Experts by Experience network. Given the sensitivity of the topic being discussed, a decision was taken to recruit participants through the Experts by Experience network on the basis that these participants have an established support network to discuss any issues that emerge through participation.

Inclusion Criteria

- Participant is willing and able to give informed consent for participation in the study.
- Male or Female, aged 18 years or above.
- Has experienced MCN e.g. overlapping issues such as homelessness, repeat offending, substance misuse, mental or physical ill-health.

2) *Service providers and commissioners*

Services identified through an initial narrative literature review and through peer researchers as having a role within the care and support of individuals with MCN were invited to a focus group session.

Inclusion Criteria

- Delivers or commissions an identified relevant service to MCN groups
- Operates within Newcastle or Gateshead

Representatives from a range of voluntary and statutory organisations were included in the focus groups, including participants working in local authority commissioning, mental health, substance misuse, housing and family support services.

To protect anonymity, particularly given the sensitivity of the topic, participant characteristics (e.g. age, gender, roles) are not described.

Ethical Considerations

Ethical approval for the project was obtained from Newcastle University. A participant information sheet and consent form were made available to all participants.

Informed consent was sought from all participants. Consent forms were signed by participants immediately before the data collection occurred.

Data collection

Three homogenous focus groups were held in July 2019 for each of the following groups: 1) people with lived experience of MCN (n=5); 2) Staff: Frontline (n=7): and 3) Staff: Managers/Commissioners (n=9).

Topic guides for focus groups were co-produced between FLNG, peer researchers and Newcastle University.

Topic guide for focus group with individuals with lived experience

- Awareness of mortality within their peer group
- What factors/life experiences do they think contribute to premature mortality within their peer group.
- Any concerns they have about this personally or for others
- Do they think anything could have been done to prevent people dying?
- Can they describe this?
- What types of help and support would they like to see being developed/ provided?
- How would this be best offered?

Topic guide for focus groups with staff (frontline and managers/ commissioners)

- Awareness of premature mortality within MCN groups
- Awareness of risk factors for premature mortality
- Current approaches to identify those at risk – perceptions of effectiveness
- What would help the services identify/ target those at risk
- Current interventions – perceptions of effectiveness
- Types of interventions/approaches they think should be in place
- How could this be taken forward

Data analysis

All focus groups were transcribed verbatim. Analysis was conducted using QSR International's NVivo 12 software.

Thematic analysis was undertaken [10]. An initial coding framework was developed based on a narrative literature review and an initial review of the transcribed data, to which a peer researcher contributed. Each focus group transcript was analysed individually, and the coding framework was adapted inductively to ensure the key themes and sub-themes were identified. Primary coding was conducted by the lead researcher (RP). A section of one focus group transcript was second coded by two other members of the study team (EG and GM) to check for consistency [11]. Final themes and sub-themes were then agreed by the full study team prior to being finalised.

Participatory Workshop

Focus group participants offered a wealth of experience and insight into this highly topical and sensitive area. In order to start translating their input into recommendations, stakeholders working across North-East England were invited to a participatory workshop hosted by Fuse in February 2020. The purpose of this event was to present and discuss key messages from focus groups, reflect on findings and develop recommendations for policy and practice. Stakeholders were invited via the Fuse Network and Associate Members mailing list.

Findings

Findings are presented in line with the three overarching aims of the study: 1) understanding premature mortality in MCN groups 2) Identifying opportunities to intervene 3) Possible interventions to reduce mortality.

There was a clear uniformity of themes across all three focus groups. Participants from the workforce (frontline staff and managers/commissioners) typically focussed more on issues relating to the system in which they worked whereas the focus group with individuals with lived experience were more focussed on personal issues.

1 Understanding Premature Mortality in MCN groups

1.1 Impact of mental ill-health

The severe burden of mental ill-health in people with lived experience of MCN was identified as a key concern in all focus groups and felt to contribute directly to premature mortality. Three key issues emerged:

1.1.1 Co-occurring mental ill-health and substance misuse (dual diagnosis)

Issues were raised in relation to dual diagnosis, where an individual experiences co-existing mental illness and substance misuse issues (for individuals with confirmed or perceived dual diagnosis). While it was acknowledged that this is a complex issue, there was a commonly held view that support for those struggling with dual diagnosis could be improved to support wellbeing and reduce vulnerability:

- *“Most of the people I know that’s died, their mental health has just been shot to bits, it’s all about the drugs. They’re taking the drugs because of mental health, is that bad? I’d say more the mental health killed them...the drugs just done that job”*
 - *Individual with lived experience of MCN*
- *“I just find that people who have got mental-health issues and also have addiction problems fall through the gaps, time and time again”*
 - *Frontline staff*

1.1.2 Self-harm and suicide

Self-harm and suicide also emerged as important themes in the analysis. In relation to self-harm, a theme from frontline staff related to the concern that risky self-harm behaviour could lead to unintentional severe harm and even death:

- *“I think a lot of the time we do have concerns for people that might be self-harming in really drastic ways, to the point where they might not be actually wanting to end their life on a specific day, but it could just happen.”*
 - *Frontline staff*

In relation to suicide, the key issue raised was the need for more timely communication between agencies following attendance at Accident and Emergency departments as a result of a mental health crisis or suicide attempt. Participants working in support services noted that delays in or a lack of communication meant they were unable to

provide effective support for individuals. Whilst it was acknowledged that service providers are currently working under tremendous pressure, a lack of timely notification represents a risk.

- *“I think it’s a lack of communication at the hospitals when they release them at that time. I know they’re really busy, but there has to be a better way”*

- *Frontline staff*

1.1.3 Access to support services

Timely and effective access to support for mental ill-health also emerged as a key theme. Access to formal, statutory mental health services (e.g. Child and Adolescent Mental Health Services) was noted to be an issue by frontline staff. Not all support for an individual’s mental health is, however, provided by formal services and a further sub-theme emerged around a perceived lack of effective support for low to moderate mental health need in communities. It was highlighted that this lack of support could lead to the exacerbation of much more severe mental illness if unaddressed.

- *“The waiting list for CAMHS is ridiculous. You’ve got to be well up there on the scale to get referred. Someone with a little bit of anxiety is not going to get put through to CAMHS, whereas that anxiety will then just carry on getting worse and worse and worse, and then you end up with someone with real mental-health issues”*

- *Frontline staff*

1.2 Substance misuse

Alongside the adverse impact of dual diagnosis, two other clear sub-themes emerged relating to use of illicit substances in particular:

1.2.1 Changing drug markets

Participants in all focus groups highlighted concerns around the evolution of novel psychoactive substances (NPS). These substances can be highly potent and unpredictable and their impact on people who use them, as well as reasons underlying their use were raised:

- *“These [NPS] are completely changing the conversation to what they were 10, 15 years ago because these drugs, how they work, how quickly they hit, how quickly they can be produced, how quickly for many of them you’re on cloud 9, you’re away from it, 15 minutes later you’re back as a normal person. Within those 15 minutes what damage you could have done to yourself, to your life, to other people, to other people’s lives”*

- *Individual with lived experience of MCN*

- *“And there’s a reason why people are taking spice, because oblivion is better than reality. That’s the truth of it. It’s a much better option facing up to what society is”*

- *Manager/Commissioner*

1.2.2 Impact of relapse

In line with concerns raised around the changing drug market, some participants noted that there are substantial risks involved in cases where an individual living with MCN relapses. In part this was linked to the risks associated with NPS, however it was also notably linked to an individual's reduced tolerance following a period of abstinence.

- *"...if they got clean for a while and they start to use again you tend to think back to when you used to use and how much you used to use if you go to do the same thing again. It's way too much. Drugs are cut with different things now."*

- *Individual with lived experience of MCN*

1.3 System Factors

There was a commonly held view that weaknesses in the health and care system led to some people with lived experience of MCN falling through gaps which increased their vulnerability and risk of premature mortality. Service access, provision and the links between the many agencies involved in supporting people with lived experience of MCN were identified as key sub-themes by participants in all three focus groups.

1.3.1 Service design does not always meet need

Individuals with lived experience of MCN often struggle to engage in traditional models of care which typically focus on each need individually rather than a holistic approach to care. As a result, they are not always able to access the services they need in a way that worked for them:

- *"I'm facing this maze full of doors and every time I open a door, there's another door, sets of doors. There's no coherent structure within the system that says, "Here's a person who is asking for help, who's engaging with everything that we're giving, can we please pull this together so we can actually provide the help that this person needs."*

- *Individual with lived experience of MCN*

1.3.2 Reduction in support services

Another emerging sub-theme was a perception that there had been a sharp and sustained reduction in support services available to prevent the development and exacerbation of complex needs, for example youth services, in recent years. Participants felt that this meant that the right support was often only provided in extreme circumstances, once problems had become acute:

- *"There are no youth services left...there's nothing left, and that was a huge safety net. It was a learning experience, it was preventive, and it was a place of safety for youth, and it's not there anymore."*

- *Manager/Commissioner*

- *"It's often such a desperate situation that we're having ridiculous conversations that we want someone to be sectioned or we want someone to go to prison just so they're in some kind of contained environment where we feel we can try and manage some of the risks"*

- *Manager/Commissioner*

1.3.3 Multi-agency communication and collaboration

Communication between agencies was highlighted as an issue. For example, some service provider representatives reported that clients had been automatically discharged from planned clinical services as they had failed to attend on multiple occasions. Social workers were often not aware of the missed appointments until the individual was discharged when they would have to then re-refer for support.

- *“He had four no-show appointments, he really needed intervention, and then four months after, that young boy is no longer here anymore. Now, is that because the parents couldn’t take him or is that because the services should have flagged up to the social workers that he wasn’t able to attend the appointments? Or should there have been more conversations around why he hasn’t attended, what’s going on?”*

- *Manager/Commissioner*

Frontline staff and managers/commissioners also identified that while there were some systems in place to foster learning across agencies (e.g. drug-related death panels), more could be done to ensure this learning was embedded across the system. In line with this perspective, some participants also noted difficulties in securing representation from some busy clinical services (e.g. primary care) to contribute to discussions.

- *“Where there was a gap, was in GP surgeries. I think that was to do with the GP just having the capacity and the time, because they’ve got such a huge volume to see, they just couldn’t come along to the meeting, but their contribution, their information sharing was vital and it was a huge gap”*

- *Frontline staff*

1.4 Lack of hope

One of the most striking sub-themes to emerge in the analysis was the vast amount of loss experienced by people with lived experience of MCN. There was a real sense from individuals with lived experience that deaths among their peers was so common that they themselves had become desensitised to death as an outcome. This feeling was said to be compounded by a lack of hope that things could get better for them and others in the situation. There was also a view among those with lived experience that some support services felt transactional and lacked a clear optimistic vision. While it was suggested that this reflected the pressures staff are working under, it had the effect of compounding their hopelessness.

- *“You don’t see another way...it’s just doom and gloom and like you say this one’s dead, this one’s in prison, there’s nothing ever...it’s like being in the sort of devil’s dungeon, to be honest”*

- *Individual with lived experience of MCN*

- *“You go to the appointment and it’s like, “You’ve got 10 minutes, have you used?” “No.” “Brilliant.” If I used, “Yes.” “Well, I’ll ring social, bye.” It’s just- nobody believes in what they’re giving you and that’s a way out.”*

- *Individual with lived experience*

1.5 Health-seeking behaviour and stigma

The degree of social exclusion faced by people with lived experience of MCN has a big impact on the way they see and experience the world. All three focus groups noted issues around the role stigma could play in exacerbating health inequalities.

- *"I think we've got a situation where a lot of people who are in these kinds of situations are being blamed for the situation that they find themselves in"*
 - *Manager/Commissioner*
- *"I think that word as well, like, junky really boils my blood, heroin addict is much better. Just picking up the junky, junky, junky, that's all we get."*
 - *Individual with lived experience*

As well as facing broader stigma in society, more specific points were raised around how stigma affected the way individuals chose to access healthcare. In particular, frontline staff noted that many young people they worked with felt intimidated by going to see their GP and instead chose to self-medicate with illicit substances. In the long-term this could have serious adverse consequences for the individual:

- *"...this doctor at the time of appointment isn't going to be able to comprehend even a tiny touch of what your life is"*
 - *Individual with lived experience*
- *"We talked to the young people who have got mental health issues and they're kind of like, "Oh no, I don't want to talk to anyone, I don't want to tell them I've got a problem. I'd rather just smoke some weed or take some grass and I'll be okay."*
 - *Manager/Commissioner*

1.6 Wider determinants of health

Those working with people with lived experience of MCN also highlighted the impact that the wider determinants of health – in particular, poverty, unemployment, and housing – can play in contributing to the difficulties faced by people with lived experience of MCN. Participants noted the impact of the rollout of Universal Credit in their locality, noting the difficulties people had navigating the system. Frontline staff also raised concerns that individuals, having waited for an initial payment would then receive a bulk payment, which could be a high risk for an individual who has substance misuse issues.

- *"My staff are supposed to spend their time navigating and signposting and supporting people into other services, probably about 60% of their time is now spent doing benefits stuff, just so that people have got enough money in their pockets."*
 - *Manager/Commissioner*

2 Opportunities to intervene

Focus group participants were asked to suggest key signs or events that might indicate an individual was at increased risk of harm (including death) on the basis that this might identify key windows of opportunity for intervention.

Critical life events, for example bereavement and relationship breakdown, were identified as moments that could place an individual at high risk of increased need. Significant transitions were also a clear theme when thinking about windows of opportunity where an individual may be more receptive to intervention and support. These transitions included completion of drug and alcohol treatment, release from prison or discharge from hospital.

- *“We all know times of peak vulnerability, they don’t need to be necessarily shared emotionally...people leaving prison ...loss, bereavement, grief, divorce”*

- *Individual with lived experience*

A critical sub-theme raised by participants in all focus groups was that windows of opportunity were often brief and difficult to exploit. As an individual with lived experience noted, it was easier to make a call to a dealer than wait for all the many agencies involved in supporting an individual with MCN to develop a coordinated plan of care.

- *“There’s often an inability to exploit windows of opportunity where...support workers will try and get all their ducks in a row. So the mental health stuff, the mental health treatment, housing, benefits, all of that sort of stuff, it’s rare that you’re going to manage to get all of that sorted in the two hours of window opportunity you’ve got. Then the ship sails sometimes and you don’t know whether that’s going to come back again or when it’s going to come back again.”*

- *Manager/commissioner*

The positive role that social support played, from family, friends and carers as well as through valuable peer support communities was highlighted as important in exploiting windows of opportunities and providing support:

- *“Just having somebody, my head was so cloudy and I knew what to do, I just needed that little bit, somebody to speak some little bit of sense into us. Her saying, ‘Come on, you’re not alone.’”*

- *Individual with lived experience*

3 Possible interventions to reduce high mortality rates

Having considered the underlying factors behind high rates of mortality and where windows of opportunity may lie, the third key aim of this study was to consider what effective interventions to reduce mortality might look like based on the knowledge and experience of participants. Four main themes emerged:

3.1 Holistic, person-centred approach

Participants in all groups explained that a “one size fits all” approach cannot cover the multiplicity and complexity of needs experienced by this cohort.

Limitations around service capacity were acknowledged, for example frontline staff participants identified that while home visits for some individuals might be appropriate this may not be feasible within some services. Small steps were suggested, for

example taking the time to review service provision with individuals to ask what was and was not working for them:

- *"I think there needs to be focus on it being really a person-centred approach and say, 'This isn't working for me at the moment and that's how I would like things to be,' and giving them that sense of responsibility"*
 - *Frontline staff*

3.2 Developing communities

Building a sense of community was raised as a possible solution in all focus groups as a means of overcoming the social exclusion faced by people with lived experience of MCN. Discussion ranged from supporting integration with the wider community in which people with lived experience of MCN reside, to building effective and powerful peer support communities:

- *"It's about us being able to have the community as part of normal society."*
 - *Individual with lived experience*
- *"It's harnessing the strengths, that's a really important point about harnessing the strengths within communities."*
 - *Manager/Commissioner*

3.3 Improved connections and support across the system

Participants in all focus groups considered that some solutions lay within the health and wider care system. Solutions typically focussed on how individuals could better communicate and support one another, particularly given the complex landscape individual service providers are working within:

- *"We need as people for services to be talking to one another to be sharing our data, to be aware of all of the needs because ...that's how we get rounded people by having well rounded service provision"*
 - *Individual with lived experience*
- *"We exist in a competitive tendering landscape and we need to leave that aside and come together and share good practice and learn from what's happening across the world"*
 - *Manager/Commissioner*

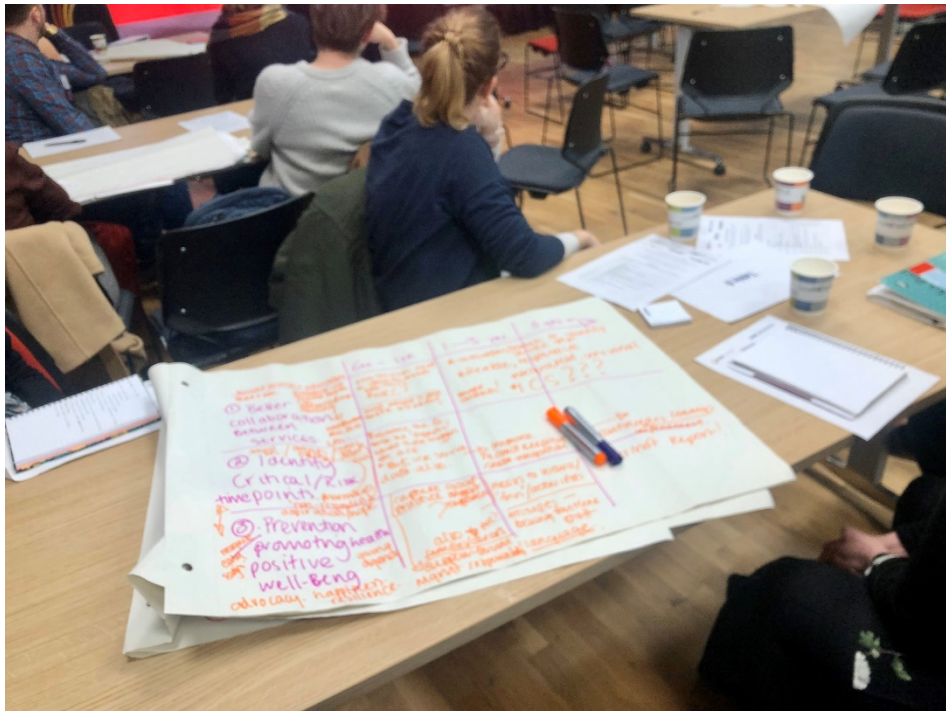
3.4 Prevention

There was an acknowledgement by participants that many of the issues encountered by people with lived experience of MCN have a root in early childhood experiences. Supporting young people who experience adverse childhood experiences could, it was felt, prevent the development and exacerbation of long-term needs and inequalities.

- *"Preventive measures early on may stop the numbers of people coming through with multiple and complex needs. So it's the preventive, it's the community centres, it's the youth centres, it's those things where the learning happens."*
 - *Manager/Commissioner*

4 Stakeholder Involvement

In February 2020, 56 participants from 33 different organisations from across North East England attended the participatory workshop to share and discuss study findings. Representation from a diverse range of academic, local authority, NHS, police and voluntary/third sector organisations were present.



Stakeholders reported that they did not find it surprising that participants highlighted the difficulties faced by people with lived experience of MCN in navigating the system to get the complex care they needed, nor were they surprised about the degree of stigma encountered. What they did remark on was the powerful role that individuals with lived experience can play in shaping and contributing to improvement in a highly difficult and sensitive area. Stakeholders were also surprised by the extent to which individuals with lived experience felt desensitised to death and felt a lack of hope.

The stakeholder session represented an opportunity to get representatives from across the system together to reflect on the findings through facilitated table discussions, one participant commented:

- *“I loved yesterday, it was so helpful just to have people round the table who were doing different jobs, a safeguarding lead, a copper, a researcher, someone running a co-located hub for homelessness, and a children’s safeguarding officer...massively helped my perspective to know where other people are coming from in relation to health and homelessness, with the research as a basis for that discussion – excellent!”*

In addition to reflecting on the findings from the study, stakeholders discussed key priorities for action and change in policy and practice as well as ways to improve support available for people working with and caring for people with MCN. Within this discussion four broad areas were identified to address the high mortality rates from a

policy, practice and research recommendation perspective: 1) prioritise prevention and health promotion, 2) focus on the individual, 3) implement a whole system approach, and 4) supporting supporters. These recommendations have been outlined in a subsequent section in this report in combination with recommendations related to the focus groups. An evidence for practice guide was also produced following the workshop and is available at the beginning of this report.

Discussion

This peer-informed qualitative study has explored the reasons underlying the high mortality rates among people with MCN. We also sought to pinpoint key opportunities to identify people at-risk in need of support, and to explore potential interventions that may be helpful in preventing early death. In doing so, our study responded to a research need highlighted by local people with lived experience of MCN themselves, as well as service providers, policy makers and campaigners across the UK. For example, the charity *Faces and Voices of Recovery UK*, highlighted concerns about a lack of action on drug-related deaths in Scotland in their 2019 campaign, “You keep talking, we keep dying”.

Many of the themes that emerged during the focus groups held with service providers and people with lived experience of MCN reflect those from previous work in this area. Specifically, the need for effective collaboration across the system, issues around dual diagnosis, and the impact of stigma and social exclusion on health.

We found that both people with lived experience of MCN and those involved in providing relevant services saw the heavy burden of mental ill-health and (often co-occurring) substance misuse as a key contributor to the high mortality rates in this group. Participants, particularly those service providers working in the system, noted that coordination and collaboration between the many services involved in supporting people with lived experience of MCN is challenging and could be improved.

The reality of many individuals with MCN is a journey dominated by navigating a siloed system to meet a plethora of needs and experiences. Participants highlighted that the co-occurring nature of MCN leads to an inability to access services or falling through system “cracks”. Participants shared stories of being unable to get adequate support to overcome substance misuse problems, which further perpetuated experiences of disadvantage. Participants with lived experience of MCN shared experiences of facing stigma across society, including the professional services designed to provide support. This stigma compounds a deep sense of hopelessness within people experiencing MCN. High quality social networks among individuals experiencing MCN can provide emotional support, empathy, practical help, inspiration, and motivation for positive change. With social networks being threatened by loss and death, the potential for ripple effects across friend groups and increased feelings of isolation and exclusion are pertinent. One of the most striking findings of this study was that this sense of hopelessness, coupled with sustained exposure to death within their immediate peer group has created a sense of apathy about their future, in essence, whether they live or die.

Windows of opportunity where individuals may be more receptive to intervention were mostly linked to critical life events, for example completion of drug and alcohol treatment or release from prison. These windows were noted, however, to be often short and therefore difficult to effectively exploit. Strong social support from family, friends and peers was seen as playing a big part in chances of an intervention’s success. However, this led to the additional challenge of how services can best support these supporters during challenging times.

As the term suggests, “multiple and complex needs” are just that and there is no single solution. Focus group participants offered a range of potential avenues for further exploration, including a focus on person-centred approaches to care, development of strong communities of support, improved connections across the varied network of support services as well as a long-term view on prevention and health promotion. At the stakeholder workshop recommendations for future action were discussed. Recommendations aligned with the study findings while placing particular emphasis on the need to create an integrated care system that places the person at the center. Additionally, stakeholders emphasised a need to ensure carers, families, and service providers have supports in place to prevent burn out.

The novelty of this study is it has shown the value of listening to individuals with experience of MCN and empowering peer researchers in shaping the research agenda around a sensitive topic area. This enabled a deeper exploration of an issue that directly affects their community and supported understanding of some of the underlying issues, as well as some avenues for possible preventive interventions. Creating an approachable data collection environment, providing an insider status, and contributing unique insights were some of the positive benefits peer researchers contributed to the study. The insights specific to opportunities for service provision take into consideration the lived experience, which can lead to more equitable service delivery and engagement.

The interest in the study from stakeholders working across the system indicates that this is an area of importance for them too. There is clearly no instant solution, and any change will require significant policy change and investment in order to be effective. What is most important is that hope can be restored, for individuals living with MCN and for those who support them. The real stories contained within this report provide unique insight and compel action.

Strengths and limitations

Peer researchers (Experts by Experience) were fundamental to establishing this study and in shaping and interpreting the findings. Through sharing difficult, often traumatic stories, they have courageously explained the reality of their vast experience of loss and the impact this has had on the lives of themselves and their peers. As trained peer researchers they provide credibility and offer us an insight to the real-life human stories that lie behind the mortality statistics.

This study aimed to explore factors underlying high mortality rates in people with lived experience of MCN and discuss potential ways to reduce observed rates. Although this study was comprised of only three focus groups, stakeholders from across the local system were invited to contribute their experiences. That said, services supporting people with lived experience of MCN are often working under extreme operational demands and therefore representatives were not available from certain services, for example primary care and hostel providers. In order to develop credible recommendations, the stakeholder event aimed to reach a broader audience to sense-check our findings and contribute to the development of our recommendations.

Recommendations for policy, practice and research

Peer researchers (Experts by Experience) were instrumental in setting the agenda for this study in order to tackle what they felt to be one of the biggest issues facing them and their peers. A wealth of information has been gathered as part of this study and, in order to support the peer researchers in their quest for action, a set of recommendations for policy, practice and research have been developed. With the exception of recommendation 4, which focuses solely on suggestions from the workshop, the following set of recommendations are based on both the research findings and feedback from the stakeholder event:

Recommendation 1: Prioritise prevention and health promotion

- Prioritise early prevention and put pressure on central and local government to re-instate non-statutory low-level support services in the community (youth services, community centres, mental health promotion etc)
- Make Every Contact Count – first responders, community venues (not just health and social care)
- Target preventive interventions at ‘critical life events’
- Ensure timely and effective access to support services at the earliest point to prevent issues from getting worse
- Enhance training opportunities for building resiliency, mental wellbeing, and coping skills

Recommendation 2: Focus on the individual

- Collaborate with people with lived experience of MCN (and their carers) to find out their service need
- Create a tiered person-centred treatment/care pathway that is co-produced with the individual and free of stigma
- Shift in organisational processes and cultures to support and facilitate a transition from a medical model approach to holistic/person-centred or trauma-informed approaches
- Foster a community for individuals with lived experience
- Increase the co-production of further research and intervention development; link development with identified gaps in workforce skills

Recommendation 3: Implement a whole systems approach

- Improve collaboration and communication across services and reduce service provision silos, e.g. social services; education providers; statutory/non-statutory; substance use; mental health; criminal justice; welfare; employment; housing; healthcare; local authorities, including adult social care
- Introduce a whole system commissioning model (pooled budgets and resources) at a defined geographical footprint for people with MCN
- Ensure the system created is easy to navigate for service users and addresses concerns of dual diagnosis and MCN
- To address concerns about reduction in services, review existing services across localities to prioritise service areas and repurpose resources where appropriate to eliminate duplication of efforts

Recommendation 4: Explore opportunities for supporting supporters

- Create supportive work environments that focus on wellbeing and identifying and preventing burn-out
- Ensure families and carers of people with MCN have access to support services, carer assessments, and peer networks
- Create conditions to support strong peer support services within a community

Conclusions

People with lived experience of MCN experience persistent, severe health inequalities and mortality rates are extremely high when compared to the general population. This study found there were a complex set of factors that were felt to contribute to high mortality rates among people with lived experience of MCN, including issues relating to a high burden of mental ill-health and substance misuse issues, feelings of hopelessness and the impact of stigma and social exclusion. Targeting early prevention and targeting interventions at 'critical life events' is one of the ways to prioritise prevention and health promotion and ensure individuals will be able to access the right level of support at the right time. Services and support need to be free of stigma and centred around an individual's need. Furthermore, reducing system silos through effective collaboration and learning across support services could be beneficial for reducing mortality rates. Highlighted during the stakeholder workshop is a need to further explore and understand opportunities to support carers, families, and service providers for this population to ensure support and care is provided continuously. Developing effective and sustainable interventions to address the high mortality rates will require an understanding of the intersecting nature of MCN to ensure current challenges are addressed.

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