CHIEF SCIENTIST OFFICE

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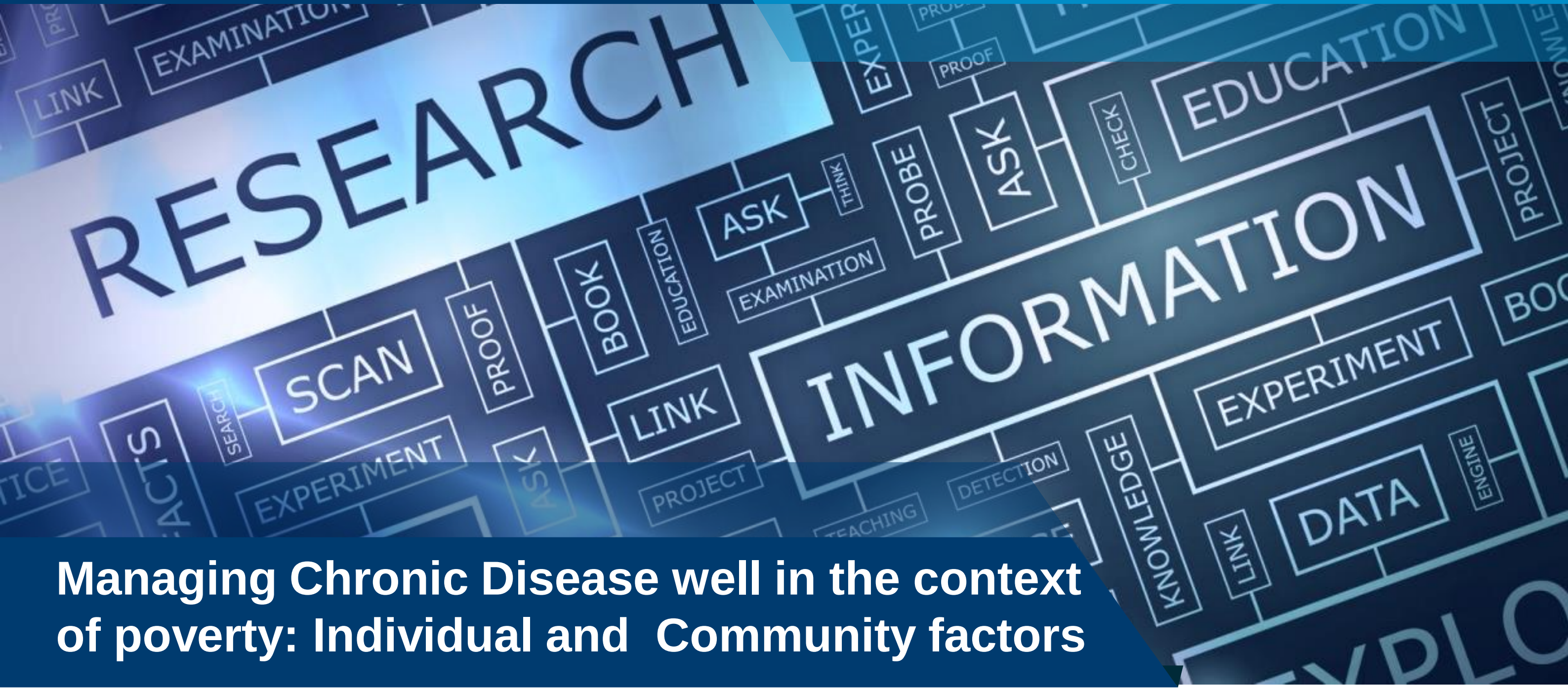
RESEARCH PROJECT BRIEFING



Managing Chronic Disease well in the context of poverty: Individual and Community factors

AIMS

People living in areas experiencing poverty have worse health outcomes compared to the general population. This project explored the factors (individual and community) that help people manage multiple chronic illnesses well in the context of poverty. It also explored whether an existing theory (Burden of Treatment Theory) was applicable in this context.

KEY FINDINGS

- Current interventions studies aimed at people living with multiple conditions do not consider social context, or the resource and work the intervention requires. Moreover, the experience of those taking part in such trials is rarely explored. Future interventions must account for the importance of social contexts, allow flexibility in approach and include those living with multiple conditions in the design process.
- It is possible to measure capacity to manage illness at a population level. Poverty influences capacity directly and indirectly. A capacity measure would inform the design and evaluation of health services.
- Identity, and meaning, in relation to illness, is important; not exploring issues that arise regarding this impacts managing disease well. Recognising, and supporting, concerns in this area could increase capacity to manage chronic illness.
- For communities experiencing high levels of poverty, shared community experiences of stigma negatively impact access to health care. Feeling that "none of the systems are working" and not being "seen" by wider systems means people often quietly disengage.
- Community groups offering authenticity, a safe space, challenge and peer support, are particularly effective in communities experiencing poverty. Person centred care, is also important in this context, especially power sharing.
- Burden of Treatment Theory could be extended to incorporate wider community shared experiences, as well as recognising the impact of identity and meaning.
- Future work to reduce poverty-related health inequalities could incorporate community values and voice in healthcare design and support person-centred care. These empower, while combating shared experiences of stigma and systems not working.

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WHAT DID THE STUDY INVOLVE?

This study had three parts:

1. A review of current literature on health interventions for people living with multiple conditions. The synthesis sought to understand participant experience of interventions and if social context, or the resource required to participate, was explored.
2. Statistical analysis of the West of Scotland Twenty-07 cohort: a dataset of 4513 participants collecting information (over 20 years) on health, social and community factors every 5 years. It explored whether individual and community factors, identified as important by Burden of Treatment Theory, were associated with death or hospital admission
3. An ethnography (observation of populations in context) exploring community resource, and how wider community factors interact with individual factors to influence management of multiple chronic conditions. This involved two years of observation in one community experiencing high levels of poverty in the West of Scotland. This included observation in four community groups and interviews with 25 people with multiple chronic conditions. Findings were then explored with participants using workshops and focus groups.

WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

Literature Review: Current Interventions for People with Multiple Chronic Conditions

- Few studies ask participants what they think of their experience; only four asked the opinions of people who did not find the intervention helpful.
- No interventions explicitly considered whether potential participants had the resource or capacity to participate, and none explored the impact of extra work. Social context was only considered when the intervention was targeted in a set geographical area. While several interventions wanted to provide more person-centred care, they rarely asked the participants their opinions, focussing instead on health professional views
- Successful interventions appear to manage a tension between a strong evidence-based structure with a flexibility that allowed interventions to fit around people’s lives.

Statistical Analysis: Impact Burden of Treatment Factors on Mortality and Admissions

Most previous statistical analyses exploring factors that may influence management of chronic disease focused on one factor at a time. This study looked at four groups of factors:

- Underlying individual resources people may have (e.g. income, access to a car)
- Factors that may affect whether people can use that resource (e.g. literacy, self-esteem)
- Wider community factors (e.g. how you feel about your community, problems like litter)
- Work required to manage illness (e.g. number of medications, GP appointments)

It is the first study, to our knowledge, exploring if individual factors impact mortality or hospital admission, even when accounting for other factors within the group. In addition, because variables were collected repeatedly over time the analysis demonstrated these factors changed over time, and accounting for these influenced the association with outcomes compared to using the baseline value alone.

There were expected associations with mortality and hospital admissions for factors that had individually been known to influence management such as literacy and income. In addition, how people feel about **walking in the dark** demonstrated **strong associations with mortality and hospital admission**(Hazard Ratio for mortality (95% confidence intervals): Do you walk on your own in the dark: never (ref group) 1; try and avoid 0.68 (0.56-0.83); feel uncomfortable 0.65 (0.5, 0.81), no worries 0.69 (0.58,0.81). **Perception of control** was **also potentially important** (Mortality Hazard Ratio "I have little control over what happens to me" Strongly agree (ref group) 1; Agree 0.53 (0.23,0.99), Disagree 0.51 (0.27, 0.96), Disagree Strongly 0.46 (0.24, 0.88). Degree of poverty experienced is known to influence capacity to manage chronic disease; early exploratory analysis suggests this is through both direct and indirect (i.e. by its influence on another factor) pathways.

Ethnography: Observation in one community experiencing Poverty in West of Scotland

Observations over two years revealed important findings about how chronic disease is experienced and managed when living in a community experiencing high levels of poverty.

Impact on Individual Factors:

- In this study income, housing and transport were not important to managing health when people had them, but a lack created significant barriers to being able to manage health well.
- Diagnosis of chronic disease can have significant impact on your identity (how you see yourself). It may limit your ability to work or take part in activities that provide meaning. Where a diagnosis impacts on identity, or meaningful activities, people may need to readjust, and spend time working through the question of "why me?" They also may need to work on developing a new identity; if this does not happen, or people get "stuck", then this has a particularly negative impact on their capacity to manage.
- The shock of a diagnosis is not always negative, it can be a catalyst to make change.
- Activities that are "grounding", or that gave people meaning and purpose, are important, though not always recognised. Prioritising these increased underlying capacity.

Impact of Community Factors

Key shared community experiences fundamentally altered how people approached most statutory services, including health. Participants described this as "scheme life across Glasgow", common in those communities experiencing poverty. Identified key shared experiences were:

- **Being Known** People felt known within their community, they knew their neighbours and lived in a community where people helped each other. This was remarkably positive and meant their community was a safe space
- **Stigma:** People were aware that their community, and therefore themselves, was viewed negatively by wider society. For some this experience of stigma meant places outside of their community felt unsafe, with the potential to be judged, so were avoided.
- **None of the systems work:** Widespread experience of none of the systems (health, benefits, housing etc) working, not just for them but for almost everyone that they knew.

Burden of Treatment Theory

In the context of poverty, the underlying constructs of Burden of Treatment Theory, particularly capacity, was applicable for people living with multiple chronic conditions. However, findings recommend the extension of the framework to recognise:

1. The impact of wider shared community experiences on individual capacity.
2. Identity work, and supporting this, is foundational for people to manage chronic illness well.

Areas that may enhance management of chronic conditions in the context of poverty

- **Community groups engaging where healthcare fail**

For some, community groups were successful in engaging, and creating positive change, in vulnerable populations. Where this was successful there were several key factors:
Authenticity: the groups, and workers within them, were seen as being “for” the community, as being “real”; this was essential for people to trust and consider engaging with the group.
Safe Space: these groups and their (often very experienced) workers worked hard to create safe, non-judgemental spaces that were easy to access and where people felt welcomed.
Challenge and The Power of the Peer: These groups did not simply create a safe space, they also supported people to make positive changes. They offered timely challenge at the pace of the participant and used peers with lived experience. Challenge and peer support was always delivered in the context of safe space.
These values are in direct contrast to many health interventions and services, which are practitioner led, in healthcare settings and are often short term and inflexible.

- **Person centred care turning healthcare into a service that is “for us”**

Certain characteristics of healthcare services, especially primary care, empowered people to manage their health, appearing to represent person-centred care in this context:

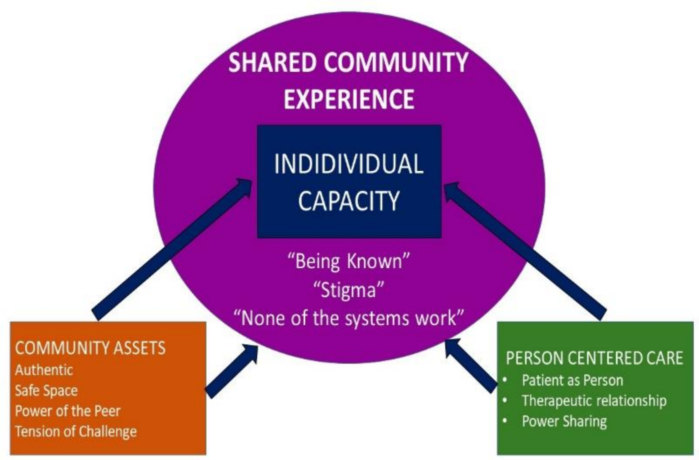
- **Patient as Person:** Patients experience their disease within their own unique context, their personhood being recognised, rather than simply their condition, was highly valued.
- **Therapeutic Relationship:** A strong practitioner relationship was critical, and often therapeutic in itself: trust, continuity of care and appropriate challenge were hallmarks.
- **Power Sharing:** True power sharing involved patients feeling confident expressing their concerns and being willing to challenge their doctor. It rarely occurred, but where it did it was always in the context of a therapeutic relationship, with a significant beneficial impact on capacity. Barriers to power sharing included lack of agency (in the relationship or the health system), not understanding diagnoses or the desire to be seen as a “good patient”.

In this context, the Person Centred Care characteristics, valuable in themselves, dilute the impact of shared community experiences of stigma and none of the systems working, moving healthcare teams, especially primary care, to being a service “for us”

In the context of poverty:

- **Individual capacity to manage chronic illness is influenced by wider community factors**
- **Community groups demonstrate qualities empowering change**
- **Person centred care enhances capacity**

Incorporating community voice, and values, and supporting person centred care, could be explored as ways to improve health in this context



WHAT IMPACT COULD THE FINDINGS HAVE?

- Inform future intervention and health service design for people living with multiple conditions to consider the resources required, and the extra work interventions generate.
- Interventions must be both evidence-based and flexible, and require robust evaluation, which must include the views of participants.
- As capacity can be measured at a population level, these results can be built on to create a validated measure that could show what enhances/diminishes capacity and potentially allow cost-benefit analysis for capacity factors.
- Expand Burden of Treatment Theory recognising the importance of identity, and community factors, especially in the context of poverty.
- This expanded version could form an evidence base to design interventions, and health services, for people with multiple conditions.
- Future work to reduce poverty-related health inequalities could explore using community values, and voice, and supporting and enhancing person centred care.

HOW WILL THE OUTCOMES BE DISSEMINATED?

The results of this project have been presented at several international conferences where they have generated significant interest. They have also been written up as scientific papers and are being submitted to peer reviewed journals.

The results have been directly shared with many of the participants, and we are currently working with each of the community organisations, to share findings with their service users, staff, and, where relevant, their funders.

CONCLUSION

Individual and community capacity factors influence the self-management of multiple chronic conditions; they are associated with mortality and hospital admissions but rarely considered in current health care interventions. This study presents an expanded version of Burden of Treatment Theory (incorporating the impact of identity, and wider community experience) that could inform the structure for interventions, and health care design, for populations experiencing multiple chronic conditions in the context of poverty. Incorporating community voice and values and supporting and resourcing person centred care are also important in this context.

RESEARCH TEAM & CONTACT

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