ORIGINAL ARTICLE

Social exclusion in primary healthcare settings: the time for measurement has come

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Abstract

Social exclusion is a concept that has been discussed and debated in many disciplines in recent decades. In 2006 the WHO Social Exclusion Knowledge Network published a report detailing their work explaining the relevance of social exclusion to the domain of health. As part of that work, the authors formulated a complex definition of social exclusion that has proven difficult to adapt or operationalize in healthcare settings. We looked at this WHO work, and at other published evidence, and decided that social exclusion is a concept that is worth measuring at the individual level in healthcare settings. We suggest that the primary healthcare space, in particular, is an ideal setting in which to do that measurement. We have examined existing social exclusion measurement tools, and scrutinised the approaches taken by their authors, and the various domains they measured. We now propose to develop and validate such a tool for use in primary healthcare settings.

Keywords: social exclusion, social inclusion, marginalization, primary healthcare, measurement tools, health inequalities.

Why was this study done?
The concept of social exclusion is complex but very important in relation to health. Primary healthcare settings seem like a logical place to seek to assess and monitor social exclusion in the patients encountered there. This study was done in order to find out what research had already been carried out on this topic and to try and understand the concept more clearly.

What did the researchers do and find?
The researchers conducted and published a scoping review looking at measurement tools used to measure social exclusion at the individual level. They also reviewed the published and grey literature relevant to the topic.

What do these findings mean?
The findings so far support the argument that primary healthcare settings are an ideal place to seek to assess and monitor the social exclusion of individuals. The next steps will be to develop a measurement tool using a process informed by the experience of relevant stakeholders, including people with experience of social exclusion.

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INTRODUCTION

Social exclusion is a term that has been in use in the academic literature and policy documents since the 1970's. It has also been adopted by a number of international organisations such as the World Health Organization (WHO), the European Union and the World Bank, for use when discussing groups that are marginalised in society. The precise definitions of social exclusion, and that of the closely related term 'social inclusion', have been discussed and debated at length[1]. Different authors and thinkers in this area have developed and adapted these definitions when seeking to highlight some of the many facets of exclusion, and the processes that lead to the state. Simply put, social exclusion describes a state of disadvantage faced by specific groups who are thought to be separate from mainstream society, and who cannot seem to participate fully in normal life[2]. While there is no internationally accepted definition, one of the more comprehensive explanations available in the domain of health was formulated in 2006 by the Social Exclusion Knowledge Network (SEKN) of the WHO Commission on the Social Determinants of Health[3]. It explained that:

> "Exclusion consists of dynamic, multi-dimensional processes driven by unequal power relationships. These operate along and interact across four dimensions - cultural, economic, political and social and at different levels including individuals, groups, households, communities, countries and global regions. Exclusionary processes contribute to health inequalities by creating a continuum of inclusion/exclusion. This continuum is characterised by an unjust distribution of resources and unequal capabilities and rights required to: create the conditions necessary for entire populations to meet and exceed basic needs, enable participatory and cohesive social systems, value diversity, guarantee peace and human rights, sustain environmental systems."

This definition clearly set out that social exclusion was concerned with more than economic adversity and poverty, and that engagement and opportunities in social, political and cultural domains were of importance. Groups usually considered to be socially excluded include people who use drugs, people who are homeless, sex workers, undocumented migrants, prisoners, and others[4]. When there is little consensus on the definition of social exclusion, it is not surprising that there is no agreement on what groups in society should or could be classified as socially excluded.

DISCUSSION

Why it is important to measure social exclusion?

In terms of health and social exclusion, we know from the literature that socially excluded groups have very poor morbidity and mortality statistics[5], and this has most recently been recognised in a systemic review and meta-analysis in the Lancet[6]. The accumulation of many years of evidence showing these terrible health outcomes for socially excluded groups has led to the birth of the Inclusion Health movement internationally. This approach has seen new energy and focus on social exclusion and health by acknowledging and then specifically targeting these at-risk groups in order to reduce inequities and improve outcomes[7]. It has been described specifically as "a service, research, and policy agenda that aims to prevent and redress health and social inequities among the most vulnerable and excluded populations."[7]. England led the way with formal discussion of inclusion heath in policy and planning documents[4, 8], and more recently when experts such as Sir Michael Marmot have begun discussing this concept[9]. Interestingly, this inclusion health agenda also specifically seeks to bring clinicians and non-clinicians, mainstream services and specialist services together with the overarching goal of caring effectively for socially excluded groups[10].

How social exclusion is currently measured?

We needed to know if there were tools already being used to measure social exclusion, and to find out what domains of social exclusion they included. We conducted a scoping review of the academic and grey literature to systematically search for relevant tools[11]. Scoping review methodology was used as it is known to be an effective way to demonstrate and discuss gaps in the existing literature, and it brings grey literature into the search. Our review findings showed that there were 22 existing tools for the measurement of social exclusion or social inclusion at the individual level. These had been developed in a variety of ways, and were to be used in a variety of ways. Importantly, none of the existing tools was specific to the PHC context. The majority of the tools were developed for use in mental health services.

What are the social exclusion domains that are currently measured?

The domains that were measured in the 22 tools analysed in our scoping review[11] included:

- Volunteering & Charity
- Financial
- Usefulness & Potential
- Domestic Functioning
- Stigma
- Independence, Control & Identity
- Rights & Freedoms
- Addiction
- Social Networks
- Community & Safety
- Leisure, Cultural & Religion
- Employment
- Education & Training
- Medical & Health
- Housing
- Self-Care

These obviously cover very diverse aspects of life and engagement with the society an individual lives in. Some are considered dependent on external factors, such as Employment and Housing, while others are very much internalised or personal attributes, such as Usefulness & Potential or Stigma.

Are PHC settings the ideal place to engage with socially excluded people?

With all of the above in mind, we feel that healthcare settings, and primary healthcare (PHC) settings in particular, are the ideal place to engage with socially

excluded people. We feel this is the case because PHC has a wide reach and millions of consultations happen in this setting on a daily basis with people across the globe, including those who are socially excluded[12]. We also know that PHC professionals are quite often used to hearing about and trying to deal with the causes, and the results, of social exclusion. Lastly, the WHO World Health Report of 2008 advised that the widespread introduction of PHC itself could seek to ensure that "health systems contribute to health equity, social justice and the end of exclusion"[13]. This was echoed in recent advice from the Lancet authors who wrote "proportionate universalist priority-setting frameworks (whereby actions to reduce inequalities are population-wide, but the amount of investment is proportionate to the level of disadvantage), excluded groups should be highly prioritised, reflecting the intensity of their needs and exceptionally poor outcomes"[7]. It was also echoed in our recent paper on "Do we really know who are left behind and who are at risk of being left behind?"[14].

CONCLUSION

We have concluded that a practical tool is needed to measure social exclusion in PHC settings. This could be used to:

- Discover who of those attending PHC is socially excluded, or who is at risk of becoming socially excluded.
- Assess the level or degree of social exclusion of the individual.
- Monitor their level of social exclusion over time.
- Evaluate effectiveness of health related social inclusion initiatives on the individual.
- Design future social inclusion activities to match specific domains of social exclusion.

There will be challenges in devising such a measure, and there will also be criticisms. Working with a topic as complex and contested as social exclusion means these critiques are inevitable; but we feel that ultimately a tool will be useful to clinicians and health planners, and may help to improve health outcomes for socially excluded people. The tool needs to be easy to use in busy PHC settings by staff (medical and administrative), with basic training in how to use the tool. It should also provide a visual result, or diagram, of where a person is in relation to the various domains of social exclusion included. Results could then be mapped against previous results documented using the same tool. We feel that such a tool could ultimately enhance the delivery and design of most PHC services, particularly those targeted at SE groups, and it may go some way towards reducing the abysmal mortality and morbidity outcomes currently experienced by these vulnerable people.

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Resumo

A exclusão social é um conceito que tem sido discutido e debatido em muitas disciplinas nas últimas décadas. Em 2006, a Rede de Conhecimento de Exclusão Social da OMS publicou um relatório detalhando seu trabalho explicando a relevância da exclusão social para o domínio da saúde. Como parte desse trabalho, os autores formularam uma definição complexa de exclusão social que se mostrou difícil de adaptar ou operacionalizar nos contextos de saúde. Analisamos esse trabalho da OMS e outras evidências publicadas, e decidimos que a exclusão social é um conceito que vale a pena medir no nível individual nos contextos de saúde. Sugerimos que o espaço da atenção primária à saúde, em particular, seja um cenário ideal para fazer essa medição. Examinamos as ferramentas de medição de exclusão social existentes e examinamos as abordagens adotadas por seus autores e os vários domínios que mediram. Propomos agora desenvolver e validar essa ferramenta para uso em ambientes de atenção primária.

Palavras-chave: exclusão social, inclusão social, marginalização, cuidados de saúde primários, instrumentos de medição, desigualdades na saúde.