

The Helen Lester Memorial Lecture 2018:

the leper squint: spaces for participation in primary health care

INTRODUCTION

I want to tell you about the leper squint in St Mary's Cathedral in Limerick City, Ireland. This is an architectural feature in the outer wall of the 800-year-old building that was designed to allow lepers to see Mass without having to come into the main body of the church. This was because lepers were feared and considered socially undesirable. As a consequence, they could not be admitted to the main space of the church where the rest of the worshippers were congregated.

There are examples of the leper squint in many countries, and they reflect the genuine fear in medieval times that leprosy was contagious. However, we also know that behaviour towards lepers was a function of what sociologist Erving Goffman called 'social stigma'. This arises from negative labelling and stereotyping that discredits individuals, dehumanises them, and creates a real distance between 'us' and 'them'.¹

In this fifth Helen Lester Memorial Lecture, I would like to explore how the leper squint is an image that we can use to develop our understanding of spaces for participation in primary health care. I will focus on how these spaces are experienced by migrants, because this resonates with the theme of this year's conference, 'Populations on the Move', and Helen Lester's 2008 article about asylum seekers and the politics of health, which has disturbing parallels a decade later.²

THE CONCEPTUALISATION OF SPACE

In the social science literature about the conceptualisation of space, Doreen Massey's work was ground-breaking. Following interpretive rather than positivist thinking, she emphasised that places and spaces not only have physical dimensions but are also shaped by temporal and social dimensions.³ This means that primary health care is something that is arranged and rearranged in different settings, in different ways, and in different times. It is not a 'fixed' entity: it is amenable to new practices, to change, and to improvement. Therefore — and this is a key point — it is always worth thinking about how primary health care is and how it could be.

There are different spaces for participation in primary health care. First, the notion of patient participation in general practice consultations is deeply embedded

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in the concept of the discipline. We see this in the recurring emphasis placed on the need for conversations between doctors and patients that include and respect the patient's expertise about their own health. When migrants present as patients in general practice consultations without the language of their host country, there is all too often a reliance on informal supports, such as using family members and friends as interpreters, using Google Translate, or miming. This represents a pragmatic wish to keep going amid the challenges in busy general practices. While useful, these informal supports are replete with problems: the use of an untrained interpreter leads to incomplete and inaccurate information exchange; Google Translate or miming cannot capture or convey complex meanings of physical, mental, and cultural aspects of health information. These informal supports cannot replace the quality and accuracy of support from a formal, trained interpreter⁴ and their use severely compromises migrants' capacity to participate in general practice consultations.

Second, there is patient and community participation in the practice setting. This follows the emphasis on communities as a local resource that can shape the development of equitable services and programmes that are appropriate and responsive to their needs.⁵ There is, however, a pattern of under-representation of migrants in established structures, such as patient participation groups in England and community representation on primary care teams in Ireland. This is problematic because, just like other people, migrants can be a resource for shaping the adaptation of services so that they are migrant-sensitive and efficient.

A third space for participation relates to imperatives from governments and funding agencies for patient and public involvement (PPI) in academic research. There is vast

and growing literature about PPI, and plenty of discussion about its practice and the need for a stronger evidence base. For the purpose of this lecture, my interest is in the fact that, when the literature about PPI in health research is reviewed, it is striking that the involvement of migrants is extremely rare. Is this because they are 'hard to reach' for researchers or, perhaps, easy to ignore?⁶

Taken together, this analysis of migrants' participation in general practice consultations, practice development, and academic research shows that there is a pattern of exclusion from these spaces. These are not perfect participatory spaces by any means, but they are spaces in which we congregate to advance health and health care. We need to look at this pattern of exclusion carefully and consider that it reflects a distance between 'us' and 'them' that is a function of the labelling, stereotyping, and stigma mentioned earlier.¹ We need to ask how it has become normalised in many countries to 'get by' with 'handy' untrained interpreters to keep a surgery moving smoothly, and how the idea of actually having access to trained interpreters is regarded as technically correct but a little bit unreasonable to expect. A little bit naïve? We may sometimes consider that, surely, practices can't adapt for migrants as well as/on top of addressing patients' preferences, but are migrants not patients too? Or researchers might like to involve migrants in studies but feel that they don't have time or resources to overcome challenges of cross-cultural research with this population. What I really want to emphasise here is that we need to consider that this pattern of exclusion represents a contemporary leper squint. I think it is important for us to think about how to address this and how to improve migrants' participation in primary health care so that they are not viewing or experiencing care in an inadequate or compromised way.

IMPROVING MIGRANTS' PARTICIPATION IN PRIMARY HEALTH CARE

The rich tradition of participatory health research (PHR) is a resource for improving migrants' participation in spaces for primary health care:

*'Research is not done "on" people as passive subjects providing "data" but "with" them to provide relevant information for improving their lives. The entire research process is viewed as a partnership between stakeholders which may include academic researchers; professionals in the fields of health care, education and social welfare; members of civil society; policy makers and others [emphasis added].'*⁷

From a PHR perspective, drawing on the work of Paulo Freire,⁸ there is need for dialogue between stakeholders so that their expertise can be shared in order to change structures so that they are more accessible, equal, and transformative. Furthermore, if the structures don't permit dialogue, then the structures must be changed. For instance, the methodologies, tools, and techniques that academics use in participatory spaces matter because they can constrain or enable the development of partnerships and dialogues. Participatory learning and action research was used in the EU RESTORE project and proved to be an effective methodology for enabling dialogues between migrants and other stakeholders about guideline implementation. These dialogues led to changes in the space of the consultation and the practice setting that improved migrants' experiences of services 'on the ground'.⁹

SUMMARY

This analysis shows that the spaces for participation in primary health care are not equally open to all patients and community members: there is a pattern of exclusion around migrants' participation in primary health care. This represents a contemporary leper squint that does not resonate with the concept or values of general practice and primary health

care. This is the status quo and it will not change unless we, as a community, make a deliberate and mindful effort to disrupt it. Following Massey,³ changing the status quo is underpinned by conceptual hope because spaces for primary health care are constructed and, therefore, 'for the making' by us. The point is that the 'us' needs to be a respectful, sustained partnership between all relevant experts: migrants with GPs, primary care professionals and academics, health sector managers, service planners, policymakers, and politicians. Changing the status quo is also underpinned by what Dowrick called 'evidence-based hope'.¹⁰ Participatory methodologies show promise as they offer a way to create partnerships and dialogues that enable the inclusion of migrant voices in the research space that, in turn, has the scope to impact on the spaces of the consultation and the practice.

This evidence of movement of knowledge between spaces is exciting, I think. It is the key to change. By working with these two different kinds of hope, we have the opportunity to really eliminate the leper squint currently experienced by migrants, who, quite simply, deserve better.

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This is an abridged version of the fifth Helen Lester Memorial Lecture. The lecture may be viewed in full at the following web page: <https://echo360.org.uk/media/1d68c755-4af8-4ead-a9f7-7f93817042e7/public>.

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