

Engaging Eastern and Central European migrants with newly and/or unsettled immigration status in palliative care services and research

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Importance of peer advocacy

- There is a need for peer advocacy for those with unsettled immigration status, to support access to healthcare services.
- Existing research highlights the benefits of peer advocacy far outweigh the potential costs of removing the distance in the client-patient relationship (MacLellan et al., 2017).
- This field is somewhat in its infancy, with research continuing to explore the area.

Need to build trust within migrant community

- Trust is central to enabling individuals with unsettled immigration status to feel encouraged and comfortable accessing healthcare services.
- It is particularly important to build trust in culturally appropriate healthcare to encourage immigrants to accept clinicians' information and disclose personal information.
- Current research highlights an overwhelmingly negative experience of trust in healthcare services for those with unsettled immigration status.

Being attentive to migrants concerns and needs

- It is pertinent that we take migrants' perspectives and everyday experiences of healthcare more seriously.
- Striking a balance between considering migrants past experiences defined by their 'home country', and knowledge they have acquired since living in the 'host country' is difficult, but essential.

Key Issues:

In 2019, there was an estimated 3.6 million EU born migrants living in the UK, comprising 5.5% of the total UK population, and 38% of the migrant population (Office for National Statistics, 2020). Ongoing political issues such as Britain's departure from the European Union (Brexit), have caused considerable complications for this migrant population, including alterations and difficulties regarding immigration status. Free movement between Britain and the EU ended on 31st January 2021. The European Union Settlement Scheme (EUSS), introduced throughout Britain's EU exit, aimed to offer EU citizens living in

the UK the opportunity to protect their residence in post-Brexit Britain. Amongst a number of inclusion criteria, settled status could be granted to those who had lived in the UK for 5-years continuously. The deadline for applications to the scheme was June 30th, 2021. As of September 30th, 2021, there had been 6.2 million applications. Notably, those that had been processed and concluded granted 52% settled status, 42% pre-settled, 3% refused, and the remaining 4% void or invalid (Home Office, 2021). Concerningly, at the time of this report being written, the UK government have just accepted a Nationality and Borders bill (UK Parliament, 2021). Though the specifics of the bill are to be debated in early 2022, it can be assumed that regulations surrounding immigration, including changes to immigration classification, will contribute to further complications for many groups of people currently residing in the UK.

This classification of settlement status has widespread impacts for migrants living in the UK. Importantly, those with unsettled immigration status have no recourse to public funds (NRPF). This prohibits them from accessing some benefits (including welfare), and some aspects of healthcare. Due to the aforementioned settlement regulations, immigrants are likely to be forced to live with NRPF for several years. During this period, they may be declined access to essential healthcare, including palliative or end-of-life care. There are an estimated 131,000 EU nationals aged over 65 in the UK (Age UK, 2020). Data published in June 2020 showed that approximately 1/3 of these had not applied to the EUSS scheme, despite meeting all criteria to be granted settled immigration status. This is an alarming revelation, as these populations will grow older in upcoming years, and likely require access to palliative care services. Unless they apply and gain settled status, their access to such services will be considerably more difficult, and perhaps even declined.

The regulations surrounding palliative care services are somewhat unclear and are subject to many interpretations. As hospices often receive large charitable donations, these are not considered public funds: theoretically, those with unsettled immigration status should still be able to access them. However, this is often not the case. Even for those with settled immigration status, access to palliative care is often not straightforward. There are many fears around palliative care, an often taboo topic. The most common barriers for Eastern and Central European migrants in accessing palliative care are language difficulties, and a limited understanding of how the services work (Phung et al., 2020). This lack of awareness, coupled with distrust and language barriers make it unlikely that these migrants will receive appropriate and necessary end-of-life care.

A holistic approach to palliative care means to provide support for the whole person: looking at their physical, spiritual, emotional, and social wellbeing. Consequently, palliative care should support caregivers, offer symptom support at a younger age, bereavement and grief needs, and end of life wishes. However, whether this palliative care need can be met trans-nationally is an ongoing debate within the field. The European Association of Palliative Care have utilised a task force, investigating refugee and migrant access to palliative care. Further, a toolkit published by St Christopher's aims to enable palliative care professionals to support people, while also facing the additional challenge of have NRPF due to immigration status. This task of considering palliative care needs trans-nationally is addressed within the aims of the current workshop.

The Workshop:

The workshop was funded by the Sheila Kitzinger Programme within Green Templeton College, University of Oxford. It was held online (via Zoom) on April 29th, 2021. The aim of the workshop was to begin to develop culturally sensitive, novel palliative care research and services engagement ideas, by bringing together researchers, health and social care professionals, and third sector workers.

The key speakers presented during the workshop. Namely, Fenella Jolly (Clinical Nurse Manager at Three Boroughs Health Inclusion Team) discussed healthcare access for those with unsettled immigration status. Dr Taulant Guma (Lecturer in Human Geography at Edinburgh Napier University) spoke of experiences of healthcare services amongst Czech-and Slovak-speaking migrants living in Glasgow (Guma, 2018). Finally, Dr Gemma Clarke (Senior Research Fellow at University of Leeds and Marie Curie) discussed access to and concepts of palliative care.

Key Themes:

Negative Experiences of Healthcare

One key theme was immigrants and refugees' negative experiences of healthcare in the UK. Reports included GPs described as *"impersonal, not doing proper checks, giving their own medicines, also being cold and somehow untrustworthy and also not really caring about the health more like it's for them like following a certain procedure."* resulting in people *"feel[ing] like they're being processed."* Concerningly, *"There were cases where people were receiving some derogatory remarks when they were visiting GPs",* eliciting *"feelings of frustration and people feeling like their health concerns weren't taken seriously."*

Recent research from Higginbottom et al (2019) in a systematic literature review looked at maternal care for immigrants in the UK. Negative experiences included perceptions of health professionals as rude, discriminatory, and insensitive to cultural and social needs. This caused the avoidance of essential pre-natal care. This was also mirrored by findings from Kang et al (2019), who studied the experiences of asylum seekers and refugees. Importantly, they found evidence of issues of acceptability, with participants experiencing perceived discrimination from practice staff surrounding their race, religion and immigration status. It is essential we encourage healthcare services to be more accommodating and culturally sensitive to allow those of any race, religion, or immigration status to have equal opportunity to access services.

No Recourse to Public Funds (NRPF)

Issues associated with NRPF recurred throughout the whole workshop: there was a vicious cycle between housing issues, healthcare access and gaining appropriate support. For example: *“...subsets of people with no recourse to public funds may be more likely to experience mentally distressing events. So, it’s really important. There’s also issues around rights to housing, food, isolation, etc...”*. Citizens Advice reported a 91% year-on-year increase in NRPF issues since the beginning of the Covid-19 pandemic (Citizens Advice, 2020). As of December 2020, Immigration Rules changes mean that rough sleeping is a ground for refusal or cancellation of permission to stay in the UK: this was predicted to affect more than 1 million people with NRPF (Citizens Advice, 2020). How we treat dying people is a huge reflection on our society. Yet, many immigrants and their families are not supported to have a good death or cannot access the services they require due to NRPFs.

Peer Advocacy & Support

Another theme was the importance of peer advocacy for those with unsettled immigration status, to allow them to become aware of appropriate healthcare services, but also to offer them support. Extracts from the workshop include: *“...actually, getting community members and giving them mentoring roles so that they are supporting their community”* and *“We found that very successful in helping people to actually get to appointments and understand what’s going on.”*

Peer advocacy appears to be an emerging theory within health research. Souza et al (2021) have registered a review protocol aiming to investigate the impact of peer support on quality of life of immigrant women who are breast cancer survivors. Further, Page-Reeves et al (2021) have registered a

randomised controlled trial investigating a peer support group for reducing depression in immigrants. Peer advocacy is, however, something that has been recommended from evidence in other research fields for immigrants and refugees, including peer-support for sexual violence recovery (Ogbe et al., 2021).

Holistic vs. Reductionist Care

Reductionism and holistic approaches to healthcare recurred throughout the workshop. It is likely that the negative experiences of patients could be overcome by a more holistic approach to healthcare for immigrants. Perhaps peer advocacy could be an element of this holistic care: involving the wider family in one's end of life care.

One example of reductionism was utilisation of drugs as a prescriptive solution, as opposed to looking at the full image: *“Whenever you go and visit your GP, they give you Paracetamol and say goodbye. They use these kinds of painkillers for any problems that they have”, “Thrush was found but he was discharged by the GP because there was nothing else found. So that reductionist type model in regard to that one problem was sorted.”*. In addition to reductionism in treatment, it was also evidenced in assumptions about people: *“A blanket approach of just sending an appointment and the expectations that people get there. I don't know if it's naive or ignorant. It's not equal access to health.”*. The aforementioned St Christopher's Toolkit moves towards understanding patients holistically, by considering all elements of their care.

Political Issues

Underlying these key themes are political issues. In addition to immigration laws and settlement regulations are Brexit (*“Brexit complicates all these issues even further for people for example pre-settled status will face even more difficulties than before”*). and Covid-19 (*“Especially through COVID and everything else. There's a limited amount of support we can offer with the resources that we have.”*). The addition of these political factors make access to palliative care for groups potentially more complicated still. Though this was not discussed in the workshop, it is worth noting that one pertinent political issue within the current, uncertain climate is access to Covid-19 vaccinations for marginalised/disadvantaged groups. Though many services are utilising additional adapted approaches such as reach-in clinics, this will not be equal across cities throughout England. The Core20PLUS5 is a national NHS-led approach which acknowledges the need to tackle inequalities in health. Nonetheless, having input and influence in how we ensure all our cohorts are included is a challenge.

Key Lessons:

How can we improve peer advocacy?

A pertinent takeaway from this workshop is that we should encourage peer advocacy for those with unsettled immigration status, to support access to healthcare services. There is some evidence about the use of peer advocacy in healthcare. Interviews with peer advocates aiming to help hard-to-reach populations with hepatitis C highlighted that any potential costs of this engagement are far outweighed by the benefits (MacLellan et al., 2017). A review by Barker and Maguire (2016) looking at peer advocacy for homeless individuals suggested several possible processes that underlie effective peer support. These include shared experience, role modelling and social support. Research is ongoing in this area, with a recently published protocol by Rathod et al (2021) aiming to conduct a mixed-methods study into the effects, processes, fidelity, and acceptability of peer advocacy for homeless individuals. It may be recommended that research is conducted in collaboration with healthcare providers to develop a blueprint for immigrant peer advocacy, and to understand the benefits of this support.

How can we build trust within the immigrant community?

Trust is central to enabling individuals with unsettled immigration status to feel encouraged and comfortable accessing healthcare services. To date, a large proportion of research evidences negative healthcare-related experiences of immigrant communities, resulting in a lack of trust. Research into diabetes care by Dahal (2014) revealed 4 key dimensions of trust in culturally appropriate healthcare, critical to establishing a trusting patient-practitioner relationship. This suggested trust was pertinent in accepting healthcare providers information accuracy, disclosing private information and on recommendation uptake. Building trust requires honest, open communication, frequent communication via outreach, and offering small incentives (Lee, 2019).

Being attentive to migrants' concerns and needs

The various examples provided throughout the paper and their analysis emphasise the importance of taking migrants' perspectives and everyday experiences of healthcare more seriously. While there seems

to be a growing recognition of the relevance of migrants' past experiences in their countries of origin/CEE for understanding their problems, views, and needs in the 'host society', often such efforts stop at providing overly simplified and essentialising cultural explanations for individual's situation or actions. Likewise, it should be acknowledged that migrants acquire new knowledge and experiences in the receiving country; therefore, they are not determined solely by their past experiences, nor do they uniformly lack knowledge of 'the system here'. Rather, their everyday encounters with people, institutions, and systems in the places in which they come to live, including experiences of everyday prejudice and various forms of discrimination, impact on what these migrants perceive as health problems and risks and how they negotiate them.

Working Document Statement

The current report is a working document. We welcome and encourage responses.

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