

Enhancing nursing practice for young migrants with chronic conditions

Abstract

Rising numbers of chronic health conditions present challenges to the delivery of quality health care for young people and their families, with significant gaps in the evidence-base about how best to support young people's self-management of their health. Findings of this qualitative research report highlighted the importance of raising awareness of cultural differences and the impacts on young people's self-management. Health care professionals (GPs and nurses) described communication difficulties when providing care for young people. Enhancing nursing practice in the area of chronic conditions requires appreciation of the impacts of culture and stigma on young people's self-management of their conditions.

Keywords

Culture, Chronic conditions, Nursing practice, Migration

Background

Almost one in five young people aged 10-24 years in the UK live with a chronic health condition such as diabetes, asthma and epilepsy (Shah et al. 2019). Rising numbers of chronic health conditions present challenges to the delivery of quality health care for young people and their families, with significant gaps in the evidence-base about how best to support young people's self-management of their health. However, there is a paucity of research that engages with the perspectives of young people with a chronic condition (Bailey et al. 2015). Research is particularly lacking with young people considered especially vulnerable or marginalised, such as those who have migrated to the UK (Spencer et al. 2018). Although migration is recognised as a determinant of health; affecting access to, and engagement with, health care services (Sime 2014, Castaneda et al. 2015); little is known about the perspectives of young migrants with chronic conditions.

Aim

Funded by the General Nursing Council Trust, we set out to better understand the perspectives of young migrants with chronic conditions – including how migration shapes their health care needs and management of their condition(s).

Literature review

Chronic health conditions including diabetes, asthma and autoimmune disorders affect approximately 15 million people in England and are a leading cause of morbidity, accounting for 50% of GP appointments and 64% of outpatient services (Department of Health 2012). Evidence points to significant adverse effects a chronic condition can have on children's developmental and psychosocial health, their quality of life and health service utilisation (Issacs and Sewell 2003, Van Cleave et al. 2010). Significant health and social care resources are directed towards the care and management of chronic conditions (Barnett et al. 2012), with nursing practice at the forefront of care delivery (Goodwin et al. 2010). Despite increasing prevalence of chronic conditions, little research has focused on the health care needs of young migrants with chronic conditions (Spencer et al. 2018). International evidence highlights the (positive and negative) effects of migration on health outcomes

and access to health care and treatment, and migration constitutes a significant determinant of health (Castaneda et al. 2015).

Much of the available evidence on childhood conditions centres on transitions from paediatric to adult health services – often with a focus on developing children’s autonomy and optimal self-management (Newman et al. 2016). Compliance with treatment regimens is often prioritised in research, with less account of how young people’s own understandings of health shape their self-management. Other research examines the impacts of specific conditions such as asthma (Monaghan and Gabe 2015) and diabetes (Spencer et al. 2013) or takes the perspectives of health care professionals or other significant adults, such as parents as its prime focus (Odgers et al. 2018). Findings from research conducted directly with young people offers important evidence of the emotional and social impacts a chronic condition has on their wellbeing and social relationships (Bray et al. 2014), including how they manage issues of disclosure and stigma (Barned et al. 2016). This area of research provides crucial insights into the differing priorities young people have for their health and offers alternative opportunities for informing the development of quality health care and nursing practice.

Methods

A qualitative study was conducted to understand the health-related perspectives of young migrants with chronic conditions. Methods included an online participatory workshop with 12 participants and seven follow-up interviews. Participants included young migrants (11-18 years) with a chronic health condition (n=2) and their families/parents (n=2), health care professionals including nurses (n=2) working directly with young people and GPs and a consultant paediatrician (n=3); patient advocate groups and representatives from organisations supporting migrants (n=3). Participants were recruited via established contacts with community groups and online nursing forums via our Advisory Group members. The research was conducted during the COVID-19 pandemic; the impacts of which are reported in our final discussion.

One week prior to the workshop, participants were asked to complete a short pre-activity to prompt discussions during the workshop. This activity encouraged participants to identify the challenges they face in terms of care and management of chronic conditions, and up to two priorities for health care. The workshop commenced with a presentation from a young migrant who shared her experiences. Group discussions then followed to ascertain participants’ perspectives on the issues and identify priorities. A live illustrator was present to capture discussions in real time, along with experienced facilitators who made detailed notes about the discussions.

Participants were invited to take part in a follow-up interview to elicit more detailed exploration of the issues. A semi-structured interview guide included questions about participants’ health conditions, treatments and impacts on everyday life, and their migration to the UK. Interviews with health care professionals (nurses and GPs) focused on their roles in supporting young migrants with chronic conditions, and the opportunities and challenges of their practice. Interviews were conducted by both authors and took place online and were audio-recorded and transcribed verbatim. Two participants asked to share their responses in a written format rather than be audio-recorded.

Data were analysed thematically drawing on Braun and Clarke's (2021) approach. Analytical stages involved the (re)reading of transcripts and attaching descriptive codes to the data. Codes were interrogated and grouped together into categories. We then identified core thematic areas that captured the main ideas generated in the data. The research team and project advisory group discussed these thematic areas to enhance rigour and credibility.

Ethics approval was granted by a University Research Ethics Panel. Participation was voluntary, and participants were free to withdraw at any point. For young people under 16 years, we sought informed assent alongside parental consent. Young people were offered an opportunity to be interviewed with a parent present and/or complete responses anonymously online.

Results

Workshop discussions highlighted concerns about a lack of culturally appropriate health service information. Difficulties accessing services led to missed appointments and young people were not always receiving appropriate treatment. Addressing communication barriers with health care professionals and enhancing access to services were key priorities. Cultural variations in differing meanings of health and illness for different migrant groups was also reported as a concern, with some treatments and services seeming inappropriate. These cultural differences extended beyond health care as young people and parents described the stigma experienced at school and in their local community. These negative reactions had implications for the family's social and emotional health and the subsequent management of a chronic condition – and as further evidenced during interviews.

Young people's perspectives

Two young South African women (17-19 years) described their experiences of coming to the UK and navigating health care. Both talked about the differences of living in the UK and South Africa in terms of schooling, friends, and the climate. Although grateful to have access to the NHS, long waits for appointments were compared unfavourably with that of health care in South Africa. Other concerns included the stigma they experienced and being labelled negatively as a migrant, with impacts on their mental health:

I got bullied, people pretended not to understand my accent and excluded me. They'd ask if I preferred my English home to living in a hut in Africa and if I'd ever seen running water before. Even teachers said things like, 'I'm surprised you know what the internet is and how to use it!' I got called a terrorist and told to go home as I don't belong here. I was the subject of a class discussion on how I was a drain on the NHS and stealing it from deserving citizens (Young South African women #1 aged 18).

Having no friends, being bullied, what felt like constant winter, feeling ill every day for nearly a year due to my immune system not being used to public transport and being exposed to the change in climate made me feel really depressed, my wellbeing wasn't being looked after by my school or the healthcare system (Young South African women #1 aged 18).

These experiences are echoed in other research with young migrants and how the processes of settlement affects mental health (DeAnstiss and Ziaian 2010, Posselt et al. 2015). Sampson and Gifford (2010) highlight the critical importance of a sense of belonging in young people's acculturation experiences. These young women's struggles to 'fit in' and be accepted had notable impacts on their mental health.

Parents' perspectives

Parents' accounts of their child's chronic conditions often focused on fear and uncertainty. Adjusting to a new health system, including the different roles of various health care professionals, was met with a degree of 'shock' as one mother explains:

I tried to find a lot of information. I was still communicating with doctors in Lithuania, they told me what I had to ask, how everything had to be done. I went to the GP, knowing what I needed. It was a shock, because I had totally different expectations and understanding from my country. I had a lot of fear [...]. (Mother #1 from Lithuania).

This mother described the importance of GPs better communicating and explaining the NHS to migrant groups. Community advocates with an understanding of the cultural backgrounds of different migrant groups were seen as a positive way to enhance communication and build trusting relationships between professionals and migrant groups.

We had no understanding of how the system worked. I think more communication, it would be worth them [GPs] to have people from communities to help, or they should be more communicating with communities, key people from communities [...]. Understanding about differences of different cultural backgrounds and this system, how it works [...]. It's the most difficult thing to do, to build trust. (Mother #1 from Lithuania).

Health Care Professionals' Perspectives

Challenges described by health care professionals (both nurses and GPs) reflected similar concerns to that of families, particularly regarding access to health services and communication issues. However, professionals described these challenges in different ways and focused more readily on poor communication between professionals and within the health system more broadly. Professionals described the NHS as being too 'complicated' and difficult to understand. Lack of joined-up working and communication added to the complexity.

It's a big, old clunky machine, the NHS, I think there are lots of tiers of hierarchy. [T]hat can certainly slow down communication [...]. Put that together with the fact that the health service and systems are massively complicated [...]. I find it confusing, and I have worked within the NHS for over 20 years. A young person that is going through an awful lot is going to find it hard to navigate (Nurse #1 transition coordinator).

Language and cultural issues complicated navigating health services. Developing trust was a key concern to enhance access to services and work with young people from a range of cultural backgrounds.

Language is the obvious thing for people whose first language isn't English [...]. I suspect some people don't utilise services because of not being able to understand (Nurse #2 community nurse).

Definitely language. And I think another thing is understanding the way the whole system works in the UK. I think even for people who've always lived here it is complicated [...]. And I think some Eastern European migrants often think, 'how can I trust this person when they are not a specialist?' [...]. So it is important to understand the different backgrounds and health systems (GP #1).

The absence of services and support for the mental health of young migrants was highlighted as a further key challenge with the impacts of trauma and adverse life events not being adequately addressed.

If they've had very traumatic journeys, or they've moved from country to country, or even within the UK they have been moved from city to different accommodation, they've had lots of different healthcare providers, or no healthcare providers. So we are seeing poor management, poor control of long-term conditions (GP #2).

I've definitely seen mental health impacted. The very nature of working with young people with long-term conditions means they often need psychological support (Nurse #1 transition coordinator).

Just as young people described the issues of stigma, health care professionals talked about the need to address fear and stigma and to ensure young migrants feel comfortable and able to interact with health care services and professionals. Negative attitudes towards migrant groups were again highlighted as barriers to health care.

I think there is quite a lot of stigma. I think it comes from a place of fear, but a lot of receptionists, and even health practitioners, have a lot of fear, 'Oh, asylum seeker or refugee' or, 'They do not speak English', and I think that some attitudes are not ideal (GP #2).

Discussion

Our qualitative study highlights important insights into the health-related experiences for young migrants and their families in the management of chronic conditions. Challenges centred on cultural and language differences, which often made it difficult for migrant families to access health care. Coupled with a lack of coordination between health care services – particularly at the point of transition from paediatric to adult services meant that young migrants were not always receiving the care they needed. For young people, there is a need to develop support for mental health and through the strengthening of social support systems. Our study and other research (Sampson and Gifford 2010, Posselt et al. 2015) signals the importance of social integration and developing friendships with peers as important to the wellbeing of young migrants. Ensuring young migrants feel part of their local communities is a necessary step towards building their confidence to seek out help with their health. School nurses have an important role to play and can aid the transition and integration of young migrants into the school setting – helping them too to navigate health, education and social services in support of their health.

Parents too need support with family health and supporting their child. In this study, parents described the difficulties they experienced when encountering health care professionals – including communication barriers and a lack of cultural awareness. In particular, parents need help to access relevant health services and treatment for their child and may need further guidance in understanding how the NHS operates. Extending the Family-Nurse Partnership may offer one way to tailor health care to the specific needs of the family and crucially, enhancing relationships between nurses and migrant families.

Our discussions with health care professionals pointed to challenges of providing quality health care in a coordinated and seamless way. Poor communication and coordination across departments often resulted in gaps to service provision and the marginalisation of young migrants in their own care. Health care professionals signalled the need to attend to mental health and the impacts of trauma that many young migrants experience. Lack of support for mental health appeared to exacerbate ‘good’ self-management of chronic conditions, with young people at risk of not receiving appropriate emotional support. Supporting young migrants’ mental health calls for investment in mental health and transition services and specifically, services that are tailored to the cultural needs of the group.

Despite these insights, a note of caution is offered. The Covid-19 pandemic had significant impacts on the project. Our original intention to hold a face-to-face participatory workshop was not possible. The study was moved online but this change had impacts on participation. In particular, young people and families were more hesitant to speak to a relative stranger in an online format and opportunities to build trusting relationships with community leaders and families were limited because of lockdown measures. Community partners and families also spoke about the impacts of BREXIT on the willingness of migrant groups to come forward and take part in a ‘formal’ interview. Thus, we adapted our study methods to encourage recruitment. This included widening our sample nationally and transferring our interview questions to an anonymous online survey. Despite best efforts, we continued to experience recruitment issues. We also experienced difficulties recruiting nurses at a time of unprecedented demand on NHS staff. Again, we sought ways to maximise recruitment by offering alternative methods of participation – online and telephone interviews. However, we continued to experience challenges.

Conclusion

Our findings underscore the nurse's role in enhancing quality health care for young migrants and families. There is a need to develop cultural awareness, including how cultural differences affect young people's self-management of their conditions. This includes the development of communication tools that aid the identification and assessment of health-related needs from the young person's point of view and reduce stigma. Supporting young people to navigate health care may help to improve access and uptake of relevant services and nurses can act as advocates for young people and their families. Our findings suggest that future research must extend understanding of how experiences of stigma impact on young migrants' self-management, including the nurse's role in supporting these young people's engagement in their own health care – addressing too their mental health needs.

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