

COVID-19 and Long Term Health Conditions: Interaction with Ethnicity and Migration

Stories for discussion

Our three stories for discussion represent an aspect of coping with a health condition and the impact on the pandemic.

Some questions for reflection include:

- How does this story illustrate the skills and experiences related to managing a long-term health condition?
- What does this suggest about the characteristics, strengths and fragilities about systems of support for people with a long-term health condition?
- Are there particular interplays between ethnicity, culture and migration which influence this experience?
- Are there implications for your own practice?

Complexity and Coping

Fatima's* experience shows the interconnectedness of the health impacts. Firstly, the complex and changing situation of the pandemic threw up a variety of responses:

“I enjoyed the fact that... there was a lockdown that I didn't have to go out, I didn't have to do anything... But I think it got to a point where the pandemic was at its high and I didn't enjoy staying at home anymore, the isolation of it, not seeing anyone, people dying, relatives dying.”

A combination of loneliness, increased demands and claustrophobia build up to a paralysis:

“Usually when the kids are out at school you get some time for yourself, you can sit down, you're not moving as much. So when I say that walking or moving, that makes my condition worse than what it is, it gives me more pain. So obviously having the children around and not begin able to get any fresh air, it just sort of, I went into depression and anxiety and all that. I'm in constant pain. Basically I was suffocating my life at home.”

Fatima described her effort to adjust and cope with the situation as hard work – and this could affect their resources and reserves to face future cycles of lockdown and an uncertain future:

“Because I've been through it already, I know how hard I had to work through this whole year just to make me this stable.”

Fatima's experience was not uncommon. Several participants discussed the anticipated difficulty of adjusting back to “normal” after having to change their way of life so radically.

*Not her real name

Layers of Community Life

Sheilagh's* experience shows the rich layers of community support – and the impact of its withdrawal in the pandemic.

At the start of the pandemic, some of the pain of disconnection participants experienced was because they were swiftly cut off from their ways to make meaning and find comfort in a time of fear and uncertainty:

“I'll tell you one of the worst things for me was not being able to go to church. Oh my God, that was a terror. And I would just go outside of a church and just look in a window because I just needed to find God, because he was the only one that was the stable in all of this.”

The fact that these communal buildings were closed was emphasised by the fact that many people's response to the pandemic was to turn inwards rather than connect with others:

“So I think yes, our culture and our faith were the only things but they were very individual. I think always in times of these sort of anxieties we withdraw within and try to deal with it within as a personal issue, because you can't control it outside that.”

However, community networks could still act as powerful connectors between individuals and solve problems – pastoral support gave Sheilagh the individual support in her mental health crisis when she was on the waiting list for NHS therapy:

“So this is what I did, I rang my priest and I asked did he know of anybody I could talk to. Within 24 hours I had a religious nun who had been a counsellor and for the next six weeks she rang me every day. And that was revolutionary. I got the support I needed through my church and that saw me through.”

As the pandemic continued, community groups enabled Sheilagh to experience the world in new ways alongside other people – to be active and to express her creativity:

“I've become very active in the last two years. It started as an online photography group run by [a community centre]... That has been oh my God just the most wonderful thing. And now we're meeting in the flesh... We started a year ago, I've been on one course after another... There's a group of people and we tap into this, yes it's using photography but it's also about looking at the world, this is the religious aspect for me. It's about looking at the world that God created and noticing it. So it's actually very mindful. Very good for the mental health. And that has been an absolute brilliant thing. And the second thing is I've become very active in a badminton group of ladies who especially in the lockdown, we met outside to play badminton. And we continued to do it once or twice a week, just bloody brilliant. For me it didn't stop me, I wasn't going to be stopped. Because if I'm going to go out, I'm going to go out and do something and thankfully I found this group and we've really revolutionised it and made it great so I'm happy with them.”

Finally, the distance provided by this group from the rest of Sheilagh's day-to-day life was particularly helpful:

“This gives me hope, joy and friendship. And also if I'm honest it's a platform to be true [to yourself]. Because they're not your family so you can actually tell them things, especially your worries, it can be that sort of place. So they're very supportive in that way. Your families are used for different things.”

*Not her real name

Using experts in the system for safety

Janet* described how her knowledge of her own health and of the system enabled her to advocate for her health needs when she experienced her life in danger.

“Being taken seriously in A&E has been very hard. Just even prior to the pandemic... I was stuck in A&E for six hours and yeah obviously in a lot of pain and.... I was pretty much dismissed and was made to wait for six hours in A&E and I actually emailed my consultant. Because he’s aware of the challenges I’ve had in A&E he gave me his email address and he’s always said to me “no matter what time it is, email.. Even if I’m not here on shift” I did and I didn’t want to do it. It was a last resort but I emailed him and... I think it was one o’clock in the morning. I emailed him and said I’ve been sat in A&E and that was the only way I got seen because he sent somebody down from his team.

I think it’s a mixture of my ethnicity and being a woman... That was just before the pandemic started so I wouldn’t know what it would have been like if it was the pandemic.

They were sending me home. I spoke to the doctor and he said to me there’s no one to see you this evening, you need to come back tomorrow when there’ll be more staff on call. I said I can’t physically go home, it will be dangerous for me to go home. I’m not well and I know my body very well. I said you know I’m not going to leave, I’m not leaving the hospital. That’s when I decided to email my consultant and I didn’t want to do it. I really didn’t want to do it because he’s entitled to time off as well and I knew he was on annual leave, but for me it was a case of life and death.

If I don’t get seen today then I could go home and die. That’s potentially what could happen because my tubes were all malfunctioning and my stomach had swollen up and I knew that. I know my body very well but sometimes it’s about convincing. You shouldn’t have to convince anyone, but it’s about letting the staff at the hospital know how ill you really are.

I said to [my consultant], “Please don’t retire! Even if you move hospitals can you just let me know and I’ll move with you. I’ll move with you.” “

*Not her real name

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