The precarious future

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Aims/Objectives: What was the purpose what you did? Why is your topic important? What did you want to change? What difference did you want to make?

Young onset Parkinson's disease (YOPD) challenges futures as it is often seen as not fitting in with life courses, self-identity and relationships with others. The aims of this presentation explores the way those living with YOPD imagine their future as they project their bodies into futures. Throughout the interviews we discussed their concerns for the future along with how their visions of the future was changed and challenged. With this being said, participants suggested there is room for creating new narratives beyond chronic illness and disability to inform new ways of being.

Methods/Process: Who was involved? What did you do? (100 words)

This presentation is informed by my PhD project. I interviewed 11 men and 11 women living with young-onset Parkinson's disease (YOPD), with a particular focus on relationships, personhood and futures. Their diagnosis transformed their understanding of the life course, as it marginalised and excluded them from participating in the normative narratives experienced by those without disabilities, particularly in relation to imagined futures. Ethical clearance for this project (ID31721) was obtained from the Monash University Human Research Ethics Committee in April 2022.

Results: What did you find? What changed? What difference did you make? What did you learn?

I learnt that the narrative surrounding degenerative disease leading to impairment is less about occupying a well versed narrative of triumph versus tragedy when it comes to living with chronic illness and disability. Instead it is an embodiment of futures that might and might not happen and how that is expressed and experienced.

Furthermore, participants also discussed a common narrative associated with chronic illness that revolves around a “lack of ability and a lack of independence”, suggesting a need to find new narratives that include impaired bodies.

Conclusion: How could other people use what you found out? What would you recommend other people do based on what you did and what you found out?

Participants' imagined futures directly impact their lived experience within the present. Chronic illness futures within the Western context have been framed and are described by participants as tragic, unimaginable, uncertain and a threat to perceptions of self and their relationships with others. Therefore, many participants actively avoided thinking about their future. Although, avoiding futures proved a useful way of bringing about certain ways of being and maintaining a sense of self and relationships, refusing the future remains problematic as it continues to reiterate how successful futures belong to those who are healthy and unimpaired by chronic illnesses.

Alignment with the Conference Theme: How does your proposal address the conference theme of 'New Frontiers'? How does your proposal showcase something new we can do to make the world a better place for people with disability? (50 words)

My proposal addresses the theme of 'New Frontiers' as it places the future firmly as a starting point to explore disability and chronic illness. Centring the future is vital to ensuring that those diagnosed can take control of their narratives and lives that include their pasts, presents and imagined future.