Change, challenge and injustice

Experiencing career with a chronic illness

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Careers and chronic illness: what's the context?

- Chronic illness: conditions that last at least one year and that impact on daily living; limiting activity, requiring ongoing medical care, or both (National Center for Chronic Disease Prevention and Health Promotion, 2021)
- Cohort of millions
- Little existing research from a career development perspective
- Career with a chronic illness can present significant challenges and barriers (Beatty, 2012)

Careers and chronic illness: why study this?

- How did I end up studying career development and chronic illness?
- Why did I think it mattered?
- How much does practitioner curiosity matter?
- Where is the line between curiosity and bias?
- Did my goals change over the course of my research?
- What impact was I hoping to have?
- How would I know if my research was successful? What was I hoping to achieve?

Career vs chronic illness?

- Work vs health? (Lev and Goldner, 2020)
- Career interruption (Beatty and Joffe, 2006)
- Career identity and goals (Clarke and James, 2003)
- Invisible identities and disclosure dilemma (Clair, Beatty and MacLean, 2005)
- Planning, decision-making and unpredictability (Dickson, Knussen and Flowers, 2008)
- Bias and stigma (Charmaz, 2019)
- Access to (decent) work (International Labour Organization, 2015)
- Policy background (National Disability Strategy, 2021) and lack of support

Methodology

- Part of MA Careers Education and Coaching at the University of Derby
- Semi-structured interviews with 5 participants
- Exploring lived experiences of career identity, choice and support, plus perspectives on career and disability
- Analysed using IPA (Interpretative Phenomenological Analysis)
- Inductive coding led to the selection of three major themes

Theme 1. Identity: challenges and changes

"And all of a sudden I went from that to... being a little bit homeless... in my identity... So I remember talking to people in the park when I was transitioning into a new career and... they'd ask me about myself and I'd say, 'well I used to be a teacher, but now I'm doing this'."

- Identity disruption
- Complex, challenging and changing
- Changes to goals and priorities
- Pragmatic career choices
- Resolution: reintegration of illness and career identities
- Challenge of invisible identities
- Key area for support

Theme 2. Autonomy: regaining control

"For me, working from home has become a massive priority... My priorities have changed massively... setting up my own business... having control of my own schedule... I never really thought I would be self-employed... it's very much triggered a domino effect that in turn has impacted my priorities."

- Emerged as a key priority
- Prompted career changes and guided choices
- Managing illness and unpredictability (controlling what you can)
- Working times, tasks and environment
- Remote working and 'return to work'
- Overcoming disadvantage

Theme 3. Carrying the burden: the cost of illness

"You can have it written in law as much as you like, it doesn't mean that it's actually reflected in reality of where we're at in society... I don't think people realise... just how much we can't do, or how much we could do but, god, it's a hell of a battle to do it, and it really doesn't need to be."

- Burden of illness plus burden of stigma and disadvantage
- Risk management and disclosure dilemma
- Not being seen within careers support
- Able-bodied privilege
- Inclusion and adjustment by the ill
- Sacrifice health for work
- Illness/disability hierarchy

What now?

- More research!
- Spreading the word: how to make an impact?
- Implications for practice: Identification (disclosure) and support? Practitioner confidence? Best practice?
- Sector improvements: training, advocacy, accessibility and disadvantage (Robertson, 2014)
- Who expects research to change you personally?

References

- Beatty, J. (2012) 'Career barriers experienced by people with chronic illness: a U.S. study', Employee Responsibilities and Rights Journal, 24(2), pp. 91–110.
- Beatty, J. and Joffe, R. (2006) 'An overlooked dimension of diversity: the career effects of chronic illness', Organizational Dynamics, 35(2), pp. 182-195.
- Charmaz, K. (2019) 'Experiencing stigma and exclusion: the influence of neoliberal perspectives, practices and policies on living with chronic illness and disability', Symbolic Interaction, 43(1), pp. 21-45.
- Clair, J.A., Beatty, J.E., and MacLean, T.L. (2005) 'Out of sight but not out of mind: managing invisible social identities in the workplace', The Academy of Management Review, 30(1), pp. 78–95.
- Clarke, J.N. and James, S. (2003) 'The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome', Social Science and Medicine, 57(8), pp. 1387-1395.
- Dickson, A., Knussen, C. and Flowers, P. (2008) "That was my old life; it's almost like a past-life now": identity crisis, loss and adjustment amongst people living with chronic fatigue syndrome, Psychology and Health, 23(4), pp. 459-476.
- HM Government (2021) National Disability Strategy (CP 512). Available at:
 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1006098/National-Disability-Strategy_web-accesible-pdf.pdf
- International Labour Organization (2015) Decent work for persons with disabilities: promoting rights in the global development agenda. 3rd edn. Geneva: International Labour Office.
- Lev M. and Goldner L. (2020) 'Work volition in women with fibromyalgia: a phenomenological analysis', Disability and Rehabilitation, 12, pp. 1-9.
- National Center for Chronic Disease Prevention and Health Promotion (2021) About chronic diseases. Available at: https://www.cdc.gov/chronicdisease/about/index.htm
- Robertson, P.J. (2014) 'Health inequality and careers', British Journal of Guidance and Counselling, 42(3), pp. 338-351.

Thank you!

Questions? Comments? Digital throwing of fruit?

Want to chat more? Drop me a line: polly.wiggins@gmail.com