

Dating with a diagnosis: The lived experience of people with Multiple Sclerosis

Kinza Tabassum, Jackie Fox, Sara Fuller & Sinéad Hynes

Discipline of Occupational Therapy,
National University of Ireland Galway

Background

- Multiple sclerosis usually manifests during early adulthood- a critical period for the development and maintenance of relationships. MS symptoms can affect a person's ability to participate in meaningful relationship-focused activities – dating, preparing meals, engaging in sexual intercourse and others.
- Previous research has explored the experiences of people with MS in long-term relationships/ marriage (Esmail et al., 20120; Neate et al, 2019).
- It is known that dating or entering romantic relationships has been shown to be difficult for those with physical disabilities who face stigma, negative societal attitudes and the fear of requiring care from potential partners (Hunt et al., 2018).
- The experience of those with a progressive, complex condition like MS has not been explored in detail to date.

Objective

- To develop a rich understanding of the impact of MS on romantic relationships and occupations related to dating.
- To better understand how living with a progressive, early-onset condition such as MS, interacts with/influences developing romantic relationships

Methods

- This study used a descriptive phenomenological design.
- Data were collected through two online focus groups.
- A purposive sampling strategy was implemented to identify participants that have relevant knowledge or experience to address the research topic.
- Participants self-recruited by contacting the authors and were eligible to participate if they:
 - (i) were aged 18 or over (ii) had a diagnosis of MS. Participants were excluded if they (i) were co-habiting with a partner or married (ii) had a comorbid diagnosis of a neurological disorder
- Used Colaizzi's (1978) descriptive phenomenological method to analyse the data.

Colaizzi's Descriptive Phenomenological Method (Colaizzi, 1978; Morrow et al. 2015)

1 - Familiarization	Listening to the audio-recordings, transcribing and re-reading transcripts
2 – Identifying significant statements	Identifying all statements relevant to the research question
3 – Formulating meanings	Identifying the meaning behind the significant statements – using bracketing and staying close to the participants' words.
4 – Clustering themes	Clustering groups of meanings into common themes – avoiding interpretation or influence of prior reading/theory
5 – Developing an exhaustive description	Writing a lengthy description of the phenomenon of "Dating with a diagnosis of MS" incorporating all the themes.
6 – Producing the fundamental structure	Editing and synopsising the exhaustive description into a statement that reflects the essential essence of the phenomenon
7 – Verifying the fundamental structure	Returning the fundamental structure to the participants to seek feedback – does this statement reflect their experience?
8 – Further analysis	Further analysis and repetition of previous steps, based on the participants' feedback

Results

- Six females and two males participated in the study.
- Participants were aged between 23-51 years.
- Six participants had a diagnosis of relapsing-remitting multiple sclerosis and one participant had a diagnosis of primary progressive multiple sclerosis.
- Years since MS diagnosis ranged from 4-16 years.

Themes

- Disclosing MS diagnosis is a personal choice
- There is a negative or outdated perception associated with having MS
- MS can impact dating and dating activities
- Having MS does not mean that you will change your standards or settle for less
- Online dating experiences are varied and COVID-19 has not impacted dating significantly

Essential structure of the phenomenon – Dating with a Diagnosis of MS*

*Subject to change- awaiting participant feedback

Dating with a diagnosis of MS is effortful. Decision-making about when, how and even whether to divulge your diagnosis is highly personal and often based on prior experiences with romantic partners. Narratives in the public consciousness about MS and disability can complicate how you are perceived as a potential partner.

Dating activities, such as physical exercise or even intimate relations, are compromised for some – but the individual and fluctuating nature of MS makes this complicated to explain to others. Ultimately however, MS is only one aspect of me as a person and acceptance of my diagnosis is an important characteristic worth waiting for in a potential partner.

Conclusions

- Dating with a diagnosis of MS is a highly personal phenomenon, characterised by many individual differences in values and experiences.
- Core to the phenomenon were:
 - the process of personal decision-making about disclosure of the diagnosis,
 - considerations about dating and
 - couple-focused activities that were limited by pain or fatigue and
 - ongoing adaptation to the fluctuating nature of the condition with partners in new/developing relationships.
- Planning for and engaging in dating and disclosing MS diagnosis to dates/partners was considered by some to be emotionally exhausting.
- The findings should help guide health professionals working with adults with MS and help us to understand what the dating experience is like for adults with MS.

References

- Colaizzi, P.F. (1978): Psychological research as the phenomenologist views it. In:Valle RS, King M (eds) *Existential phenomenological alternatives for psychology*. Oxford University Press, New York.
- Esmail, S., Huang, J., Lee, I., Maruska, T. (2010) 'Couples' experiences when men are diagnosed with multiple sclerosis in the context of their sexual relationship', *Sexuality and Disability*, 28, pp. 15-27.
- Hunt, X., Swartz, L., Carew, M.T., Braathen, S.H., Chiwaula, M. & Rohleder, P. (2018) 'Dating persons with physical disabilities: the perceptions of south Africans without disabilities', *An International Journal for Research*, 20(2), pp. 141-155.
- Morrow, R., Rodriguez, A. & King, N. (2015) 'Colaizzi's descriptive phenomenological method', *The Psychologist*, 28(8), pp. 643-644
- Neate, S.L., Taylor, K.L, Jelinek, G.A., De Livera, A.M., Simpson, S., Bevens, W. & Weiland, T.J. (2019) 'On the path together: Experiences of partners of people with multiple sclerosis of the impact of lifestyle modification on their relationship', *Health & Social Care Community*, 27(6), pp. 1515-1524.