UK MS Domestic Violence and Abuse Research Initiative: experiences of victim-survivors with MS and healthcare professionals

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Background: MS and Domestic Violence and Abuse (DVA)

- Recent evidence has highlighted the increased risk of people with MS being exposed to a variety of forms of violence, including DVA.[1]
- This has been connected to certain risk factors, including:
  - MS is more common among women[2]
  - Social isolation[3]
  - Unemployment[3]
- In spring 2020, a group of UK consultant neurologists identified an increase in patients with MS presenting with suspected or confirmed cases of DVA but identified a lack of research-informed clinical resources to guide them in supporting patients.
- Recognising this urgent gap, the MS Domestic Violence and Abuse Research Initiative was launched to raise awareness of the impact of DVA on people with MS and to develop guidance on the best ways to offer support in MS clinical practice.

DOMESTIC VIOLENCE & ABUSE RESEARCH INITIATIVE

Research Questions

Research Questions (DVA experience of women with MS study)

1. In what ways does DVA manifest in the lives of women with MS?
2. What impact does DVA have on the general health and socio-emotional wellbeing of women with MS?
3. What are the experiences of women with MS of accessing support in relation to DVA through healthcare practitioners and other services?
4. How would women with MS like to be supported by healthcare practitioners and wider DVA services?

Research Questions (Healthcare professional study)

1. How do HCPs view their role in responding to DVA in people living with MS?
2. In what ways do HCPs think that DVA might specifically affect people living with MS?
3. What do HCPs see as the main barriers and facilitators to responding to this issue for people with MS?

Methods

DVA Experience of Women with MS Study
Stage One: Semi-structured interviews

- In-depth semi-structured interviews were conducted with 7 women with MS who have experienced/are experiencing DVA

Stage Two: Co-production workshops

- The second stage of the research utilised an online asynchronous co-production workshop with women with MS who have experienced/are experiencing DVA

Healthcare Professionals Study

- In-depth semi-structured interviews were conducted with 40 HCPs from different professional groups about their views, perceptions and possible experiences of responding to DVA in people living with MS.

Results

DVA Experiences: Coercive control

'he was **forever messaging me, ringing me, finding out where I was, what I was doing, who I was with** and I returned back, and that's when things got really really bad. Like he'd just turn up at my house and he wouldn't leave'

'**I wasn't ever given any money** it would always be if we were somewhere then I might say, oh, you know, I want something, and he might get it, or we might not but there was never sort of oh, well, I'll give you X amount of my salary, so you can do what you want.'

'Another time he was saying that, you know, **I couldn't look after my son because of my disability**.'

' [he] made me think and feel differently about myself and **feel like I was a burden, and I was useless**'.

View of Healthcare Professionals

"I think it's just knowing **what resources are available**, in case there's something that I missed like obviously, we can refer to safeguarding, but **is there something else we can do in the interim**? So, knowing **where to refer, like who to refer to, what support the patient can get**? And, having somebody to maybe go to that can support you through it and **knowing what are the right questions to ask and not the right questions to ask because it's very sensitive**" (MSSN)

"..sometimes p**eople don't realize that what they're going through is different** from the rest of the population. You know, it can be, you know, they that they it's **so such a normal thing. You know they're normalized it** to the point where and **they don't feel that there's another, you know, another potential for their life**" (Neuro OT)

"it's that **continuity** as the one that **potentially knows the patient** and has **built up some trust with them** and is going to have **ongoing responsibility** for their care… **the healthcare teams are more consistent**." (Neurologist)

"I think we get a lot of safeguarding training, but I think we don't get enough on … **what I would try and monitor if I thought the person was being abused** …how they're acting with that person in terms of how they're touching that person, you know, **is their grip a bit harder on their shoulder or just things to make them know that they are there …or will they not leave the room when you want to talk to them**?" (MSSN)

Discussion and Conclusion

DVA Experiences

- Participants had diverse experiences of DVA but all experienced a pattern of coercive and controlling behaviour from their perpetrators
- Coercive controlling behaviour can manifest in a number of ways, but in this study included:
  - Degradation and emotional abuse
    - This included the invalidation of experiences of MS and vicious insults targeting symptoms of MS to degrade
  - Using children to coerce and exert control
  - Isolation
  - Disguising abuse as 'care'

Views of HCPs

- HCPs felt that they were in a prime position to identify and respond to DVA in people living with MS, but expressed the view that some professional groups were better suited to addressing this issue
- HCPs held the view that it was right to ask their MS patients about safety and/or abuse, but differed in their opinions about whether they should ask routinely
- HCPs reported that they needed knowledge about identifying the signs of DVA and the skills to ask sensitively and safely. They felt that interactive, scenario-based learning would help them to discuss and learn from complex cases.
- HCPs valued a multiprofessional approach to DVA response, relying on fellow professionals for both formal and informal support and validation when they suspected DVA.

References

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Supported by The Horne Family Charitable Trust

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