

# “I don't think they know enough about it”: Women with Multiple Sclerosis and Domestic Violence and Abuse

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## Background: Disability, MS, and Domestic Violence and Abuse

### Disability and DVA

- Disabled people are more likely than non-disabled people to experience a variety of forms of violence throughout their lives including domestic violence and abuse (DVA).
- As seen in Figure 1. in the year ending March 2022 10.3% of disabled people in England and Wales had experienced DVA compared to 4% of non-disabled people
- Disabled people experience **unique forms of DVA**<sup>1,2</sup>
  - Impairment specific abuse
  - Abuse by carers (paid and informal)
  - Abuse by partner carers
- Research has **homogenised disabled people** meaning very little is known about how experiences of DVA and support may vary by impairment type.

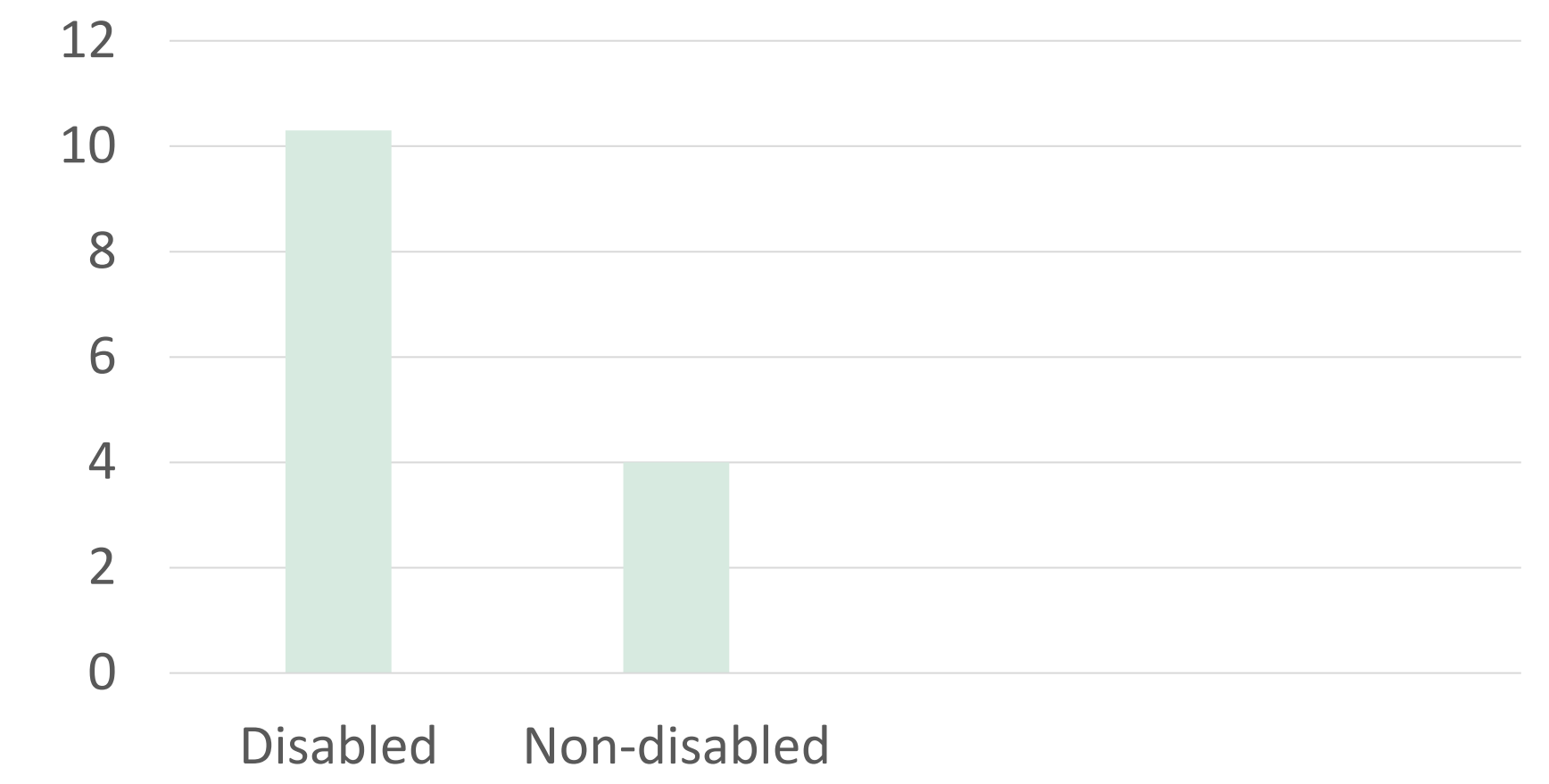


Figure 1. Percentage of adults aged 16 years and over, by disability, who experienced DVA in England and Wales, year ending March 2022 (Office for National Statistics - Crime Survey for England and Wales)

### MS and DVA

- Research suggests that the impairments pwMS experience increase their risk of being abused by carers, family members, and partners/spouses<sup>3,4</sup>
- Social factors including **social isolation** and **unemployment** have been highlighted as increasing risk<sup>4</sup>
- Physical abuse, economic abuse, sexual abuse, and psychological abuse have all been found<sup>4,5</sup>
- Lower education level, financial dependency, neurological impairment, and sexual dysfunction connected to experiencing DVA

## Research Questions and Knowledge Gap

### Knowledge Gap

- Available literature has so far failed to consider in-depth the experiences of women with multiple sclerosis and the causes of DVA beyond the individual's impairment.

### Research Questions

- What are the experiences of women with MS of accessing support in relation to DVA through healthcare practitioners and other services?
  - What barriers do women with MS encounter when seeking help?
  - What enables successful access to support?
- How would women with MS like to be supported by healthcare practitioners and wider DVA services?

### Wider Research Project

- This research has been undertaken alongside research considering the views of HCPs to create a toolkit to inform practice as part of the MS & DVA initiative in the UK

## Methods

### Stage One: Semi-structured interviews

- In-depth semi-structured interviews conducted with 7 women with MS who have experienced/are experiencing DVA
- The interviews consider their experiences of DVA as a woman with MS with a particular focus on how they would like to be supported, including what facilitates good access to support and who they would like to be supported by.

### 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
- Will discuss the non-sensitive findings from the interview stage and will then utilise **creative methods in the form of mind-mapping** to explore the women's ideas regarding what support they want from healthcare practitioners and from DVA services.

### DVA Experiences: Coercive control

'Then the words **started to get a bit more aggressive**. So if it would be like, "Well, you're going to piss yourself." "If you come with me, there's no toilet so you're going to piss yourself. It's going to be awful", so immediately it starts putting tiny doubts in your mind to think actually, you know, am I gonna be okay?'

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

'And then it progresses to resentment, I think, in their mind where they just resent you for everything, and then they start **blaming you, and then they start gaslighting you**'

### Experiences of support from healthcare practitioners

'even with my MS team they know about it and they've never offered any kind of support in regards to the DV side of it it's just kind of like just get on with it'

'She said "I'd like to see you in three days time, would that be alright with you?" and then it was like a weeks time would that be alright with you? **Carried on following me up until I was smiling.**' (GP)

'people like the **consultants and the people at the hospital don't ask**. The GP did and I thought well I said that I used to be but I'm not now and I thought it is just that GP's have to ask that question but I think that it's really really good that they do because of the connection between your health and being abused.'

## 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 as shown in *Figure 2* 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'

### Healthcare Practitioner's (HCPs) Role

- Some women reported very positive interactions with HCPs which reduced isolation, ensured their needs were met, and most importantly believed them.
- Others expressed not viewing HCPs as a first point of contact discussing not knowing what support HCPs can provide.
- Most women view HCPs as being able to play an important role in their support journey, particularly as empathetic people to speak to and direct them to support
- The participants identified **the need for more holistic wrap-around support which takes into consideration all the challenging life factors they are experiencing**. To ensure victim-survivors feel supported and not isolated meaningful interactions with professionals are fundamental.

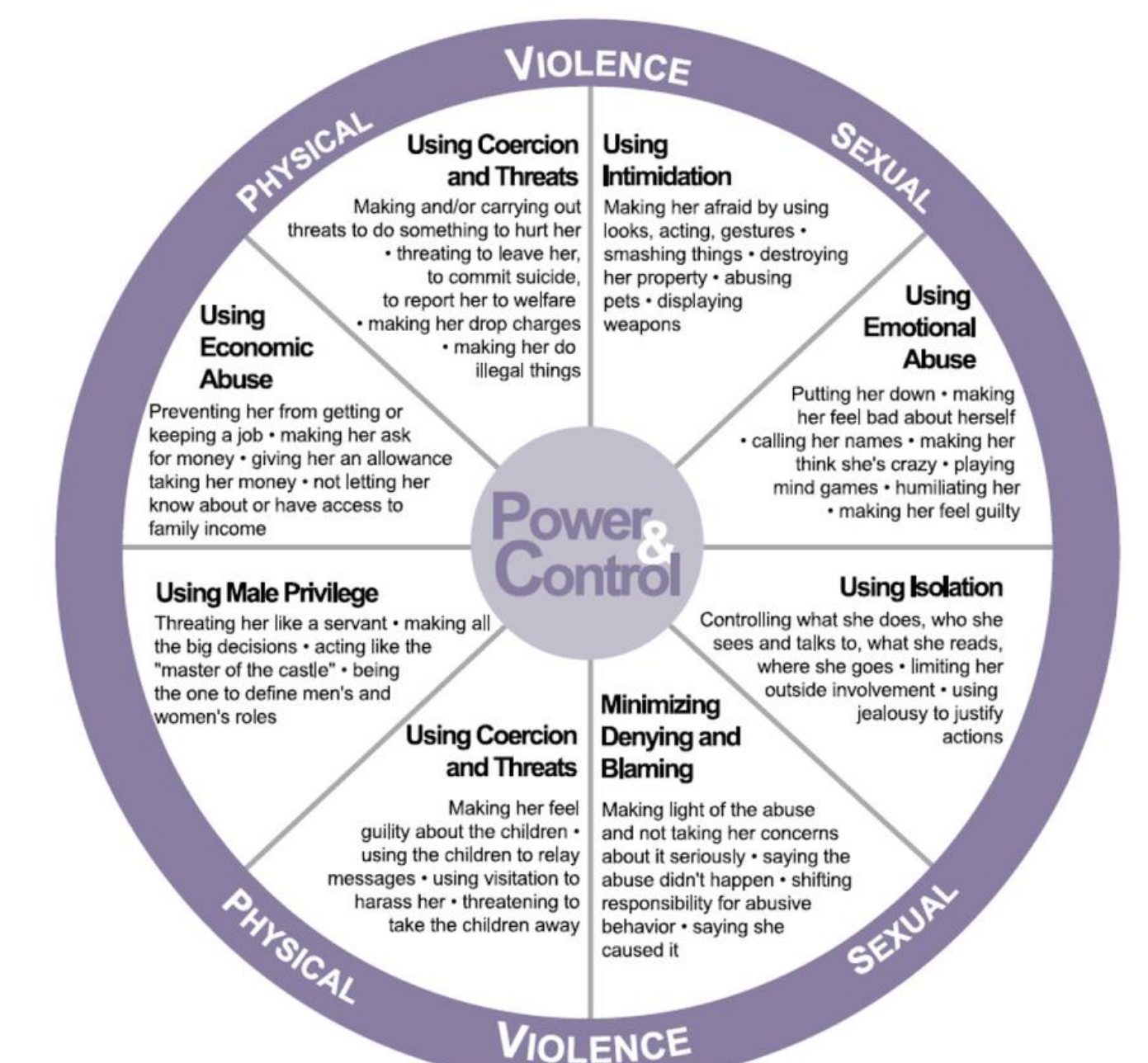


Figure 2. The Power & control wheel

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