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SUMMARY OF RESEARCH

Summary of Research: Caregiver Involvement in MS: Duty or Disruption?

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ABSTRACT

This Summary of Research summarizes a previously published discussion between people with multiple sclerosis (PwMS) and their caregivers and healthcare professionals (HCPs) about how to include caregivers in consultations and decisions about multiple sclerosis (MS) care. The aim of the discussion was to help HCPs to understand differences in these relationships so they can adapt the style of consultations to support everyone.

Keywords: Caregivers; Family; Multiple sclerosis; Shared decision-making

Key Summary Points

This is a Summary of Research Article, covering a commentary entitled "Caregiver involvement in MS: duty or disruption?".

Multiple sclerosis (MS) impacts family members and loved ones, as well as the person with MS.

Family members are often involved directly in the care of the person with MS, so it is important to involve them in care decisions.

A group of healthcare professionals (HCPs), people with MS (PwMS), and their caregivers discussed the pros and cons of including caregivers in consultations and in making decisions about MS care. They discussed different ways to improve communication between HCPs and PwMS, and how to provide support for the caregivers too.

As every person with MS has a different relationship with their caregivers, it is important for HCPs to adapt their care approach to suit individual needs.

Possible ways to do this include meeting PwMS and caregivers separately, as well as together, to make sure they each feel like they have been heard and their needs have been met.

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INTRODUCTION

- This Summary of Research Article, overviewing a commentary entitled “Caregiver involvement in MS: duty or disruption?”, summarises a discussion between people with multiple sclerosis (PwMS), their caregivers, and healthcare professionals (HCPs) about how to include caregivers in consultations and decisions about multiple sclerosis (MS) care [1].
- When a person is diagnosed with MS, the family lifestyle may change, with some family members taking on a caregiver role.
- The role of caregivers is very important, especially if the person with MS experiences cognitive impairment.
- Every person within an MS/caregiver relationship is different, and each person with MS will require something different from their caregiver.
- Therefore, it is important for HCPs to understand these different relationships and how much each person with MS wants their caregiver to be involved in consultations or making decisions about their MS care.
- However, it can be difficult for HCPs to adapt to these different relationships and involve caregivers while also ensuring the needs of PwMS are being met.
- A group of HCPs, PwMS, and caregivers discussed the pros and cons of involving caregivers in consultations and decision-making. They also discussed how HCPs can adapt their consultations according to how much PwMS want their caregivers involved, while making sure that caregivers are also supported.

WHO TOOK PART IN THE DISCUSSION?

The discussion consisted of:

- A panel of two neurologists and two PwMS.
- An audience of HCPs, PwMS, and their caregivers.

WHAT WERE THE RESULTS OF THE DISCUSSION?

Involving caregivers in consultations and decisions about care can benefit PwMS, but it can also cause issues:

Benefits of including caregivers in consultations and shared decision-making in MS care

- Caregivers can provide emotional support to PwMS during consultations, helping to keep them calm, open, and honest.
- Caregivers see PwMS every day so may provide additional insight into changes in symptoms that PwMS themselves might not be aware of.
- Since caregivers do not experience symptoms themselves, they may be more focused on the practical and social issues of MS, such as employment decisions or home adjustments. Caregivers can help PwMS discuss these issues with their HCP and get the support they need.
- PwMS may want their partners with them during consultations to discuss topics such as pregnancy or family planning.
- PwMS experiencing emotional, neuropsychiatric, or cognitive symptoms may need caregivers to help them communicate with HCPs during consultations.
- Having caregivers with them can help PwMS to recall and understand the large amount of information they are told during consultations. Receiving the same information also minimizes the potential for conflict.
- In cases where there are cultural or language barriers between the person with MS and their HCP, a caregiver may help to bridge this gap by translating or clarifying information.
- Caregivers can help to motivate PwMS to adhere to treatment, maintain activities of daily living, or stick to lifestyle changes, such as increased exercise, stopping smoking, reducing alcohol intake, and changing their diet.
- Caregivers can help PwMS to make decisions about their care by helping them to accept their diagnosis and start treatment as early as possible, providing a more impartial point of view, and practical support.

Potential issues with including caregivers in consultations and shared decision-making in MS care

- Including caregivers in consultations may be more time-consuming and leave less time for HCPs to tell PwMS important information.
- Caregivers may need different information from consultations compared with PwMS, making it difficult for HCPs to know what to prioritize.
- Some PwMS may find it hard to be open and honest with their HCP in front of their caregiver,

especially when talking about embarrassing topics such as sexual dysfunction or bladder and bowel issues.

- Some PwMS might wish to maintain a separation between their condition and home life, and shield their family members from the burden of care, which is not possible if they are included in consultations.
- Changing relationships or tension at home may lead to poor communication during consultations.
  - As children with MS become teenagers, they may wish to have more independence and may find having their caregiver in consultations overbearing.
- Caregivers may have strong opinions that are different to those PwMS, making it difficult for PwMS to make decisions or feel heard.
- The culture or religion of a person with MS and their caregiver may affect how they make decisions.
- If caregivers are too involved, it may make it difficult for PwMS to take responsibility for managing their MS or learning more about their condition.

Improving communication between HCPs and PwMS

- It is helpful for HCPs to be aware that the opinions of family members and the dynamics of individual families will have both good and bad impacts on PwMS, in and out of medical settings.
- It would be beneficial for HCPs to consider that every person with MS is unique and will have different needs. HCPs could then adapt their approach to care so that it suits individual PwMS and their caregivers.
- For PwMS who want their caregivers to be included in consultations, it is important they are still given the opportunity for private conversations with their HCPs.
  - One approach could be for caregivers to be present for half of the consultation, and for PwMS to be on their own with their HCPs for the second half of the consultation; this would be a good idea for teenagers with MS, as they could have some independence, but their caregivers aren’t completely excluded.
  - This would also be important to encourage discussions around sensitive topics.

Providing support for caregivers and families of PwMS

- It is important to balance the needs of PwMS with the needs of their caregivers or families:
  - Caregivers and families need information and support, but consultations should be focused on the person with MS. Additional support for caregivers could be given separately from the consultation with the person with MS, for example using internet resources, support groups, in-clinic training days, and MS nurses or social workers.
  - This would reduce the burden on the person with MS and give family members more time to voice their concerns.
  - If this information and support is given separately, then it would be beneficial if it is consistent with the information provided to PwMS and is culturally sensitive.
- HCPs could give suggestions for organizations, charities, and other sources of reliable information that PwMS and their families could use.

WHAT WERE THE MAIN CONCLUSIONS OF THE DISCUSSION?

- Involving caregivers in consultations and shared decision-making in MS care can benefit PwMS, but it can also cause issues.
- It would be helpful for HCPs to establish the dynamic between the person with MS and their caregiver, and then adapt their approach to suit individual preferences.
- Possible ways to do this include consulting PwMS and caregivers separately, while ensuring that the information provided is consistent and sensitive.

ARE THERE ANY PLANS FOR FURTHER STUDIES ON THIS TOPIC?

Further studies in the future would give us a greater understanding about:

- Family members’ opinions about the care of PwMS, and how this might impact PwMS’s attitudes toward treatment.
- How treatment impacts the lives of PwMS and their families, including romantic relationships.

- The relationships between HCPs, PwMS, and their caregivers.

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