

Multiple sclerosis

Caregiver involvement may improve patient care and treatment

Multiple sclerosis (MS) is a disease with unpredictable progression, causing huge distress to the entire family of people living with the disease. Professor Jürg Kesselring at the Department of Neurology & Neurorehabilitation, Kliniken Valens in Switzerland, reviews the discussions he and other internationally acclaimed neurologists participated in regarding caregiver involvement in doctor consultations for people with MS. Although such an approach may prove beneficial in multiple ways, it is also necessary to protect patient privacy. Future efforts will aim to develop personalised approaches, to ensure family involvement in consultations is conducted efficiently and to help improve the patient's quality of life.

Multiple sclerosis (MS) is a complex condition with variable symptoms according to the extent of nerve damage and the type of nerves affected. Characterised by consecutive relapses and various physical, cognitive, and emotional symptoms, it is a disease with variable progression affecting the whole family of people living with MS.

Studies on other chronic conditions, such as heart disease or diabetes, have shown that when family members participate in the consultations, patients gain a better understanding of their condition and are more inclined to follow their doctor's advice. To provide a holistic approach, it is crucial to understand the dynamics between the patient and their caregivers or family members and to include them in the management of MS.

At the annual meeting of the European Charcot Foundation in Baveno, Italy, in November 2019, people with MS joined an international group of expert neurologists, led by Professor Kesselring of Kliniken Valens in Switzerland. The group discussed family involvement in consultations and decision-making for the shared care of MS patients. The panel of physicians suggested a number of reasons why caregiver involvement during MS care is helpful. In certain

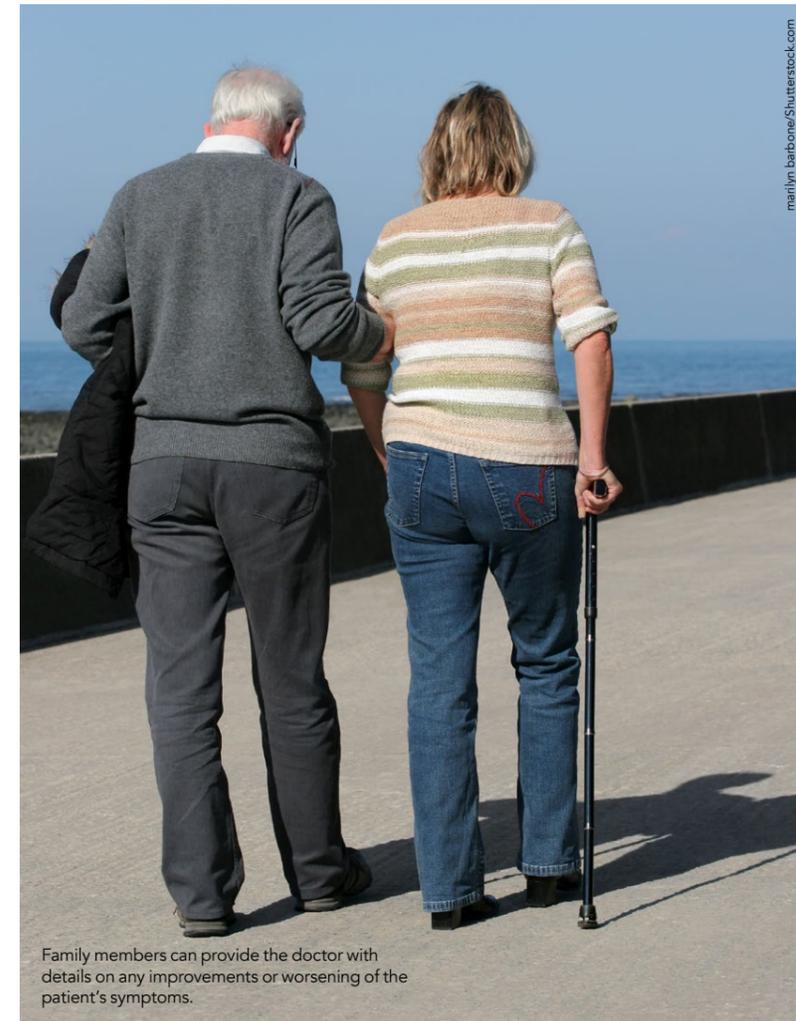
situations, it is of absolute necessity to have family participation, such as in cases of MS during pregnancy or for adolescent MS.

BENEFITS OF SHARED CONSULTATIONS

Shared care can help overcome miscommunication between the patient and healthcare professional and therefore simplify decision-making. Cognitive impairment is an early symptom of MS that can lead to miscommunication and worsen the patient's adherence to health advice. The active involvement of a family member can improve engagement, help regain common understanding, and facilitate informed consent for care management. Family members may also assist by offering emotional support, helping the patient to be in a more open and honest emotional state while in consultation, thus facilitating communication and the process of shared decision-making.

A common issue with MS patients is poor adherence to treatment. Several factors may cause this behaviour, including extended periods of remission, the inability to predict how the disease will progress, the lack of specific information on the causes or treatments for MS, the fear of medical procedures, side effects, as well as cognitive deficits and psychological problems. A family member may offer support either by directly helping the patient to overcome some of these issues or by bringing the issues forward to be managed by the healthcare team.

Moreover, as family members participate in the patient's everyday life, they can provide information and details of the symptoms or of any improvement or worsening of symptoms. Such contribution is particularly important



Family members can provide the doctor with details on any improvements or worsening of the patient's symptoms.

marilyn_barbore/Shutterstock.com

practical or social issues that arise as a consequence of the disease and which affect the whole family. These may be decisions related to employment, family planning, or home adjustments.

CHALLENGES OF SHARED CONSULTATION

Aside from the benefits, the joint presence of the patient and family members in consultations can be challenging because of potentially opposing priorities and any privacy concerns the patient might have. Practical issues may also arise, such as time pressure for the healthcare professional. Indeed, family involvement in medical appointments can increase time pressure and prevent the healthcare professional from covering essential topics within the given time frame.

Sharing can be difficult for a patient who wishes to separate their condition from their home life as much as possible, in an effort to relieve family members of the stress and difficulties of care. A shared consultation may also cause disturbance, as it can bring home the reality of MS or may otherwise inhibit the patient from opening up out of embarrassment or due to over-reliance on a caregiver with an overbearing attitude.

Indeed, overbearing involvement by family members may prevent patients from gaining independence to take the necessary responsibility for the management of MS. This is particularly true for adolescent patients, where the involvement of families in consultations and decision-making should be constructive and not undermine the adolescent's autonomy. Importantly, the consultation style should be modified according to the teenager's maturity,

Shared care can help overcome miscommunication between patient and healthcare professional and therefore simplify decision-making.

because emotional dysfunction, anxiety, and depression experienced by the patient may result in misleading impressions of their condition.

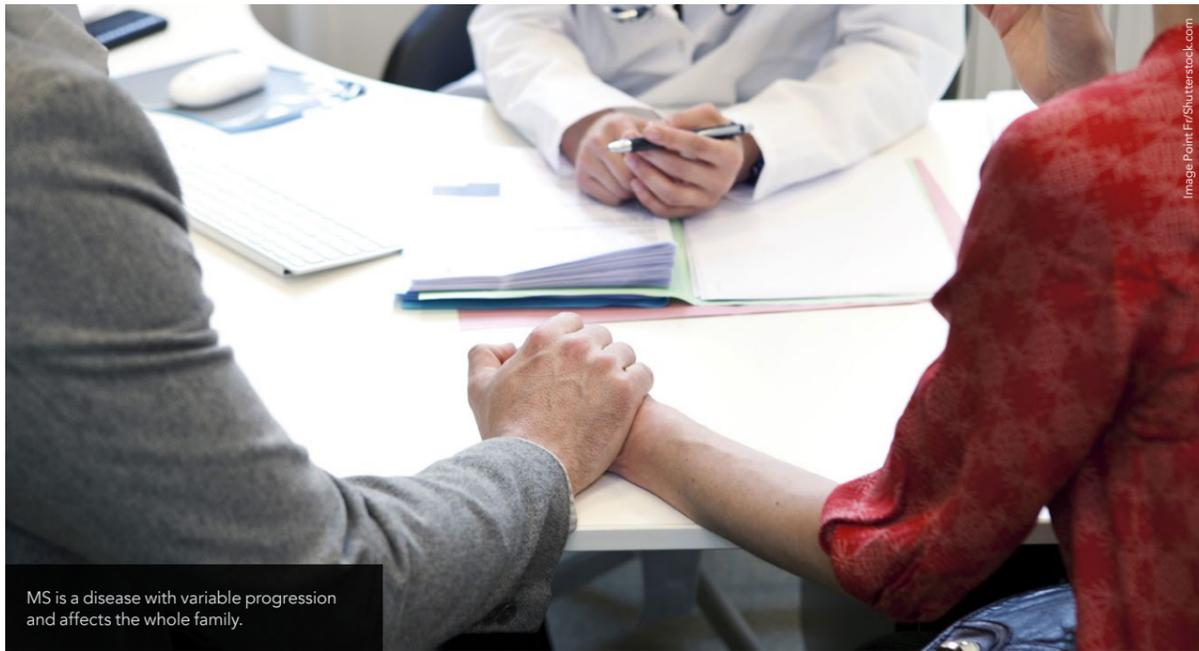
Another benefit of family members attending appointments would be to more efficiently tackle and solve various

Families can also have valuable input in helping the MS patient to accept their diagnosis and overcome 'analysis paralysis' or overthinking, which may lead to delays in care decisions. With MS in particular, it is very important to start treatment as early as possible, and family members/caregivers can not only assist in rational decision-making but also offer relief to patients by providing them with practical support.



It's important to understand the dynamics between the patients and their family members and caregivers.

asirin_pamaji/Shutterstock.com



MS is a disease with variable progression and affects the whole family.

also taking into consideration the shift in family dynamics.

There are certain aspects of MS that may be particularly uncomfortable for patients to discuss in the presence of their caregivers. Men with MS may encounter erectile or ejaculatory problems, and women with MS may develop vaginal dryness leading to sexual dysfunction and reduced libido for both partners. It is understandable that the caregiver's presence may discourage patients from openly discussing these or other common and

potentially embarrassing problems, such as bladder and bowel dysfunction.

OVERCOMING OBSTACLES IN SHARED COMMUNICATION
Although there is no single solution that fits every case and each MS patient

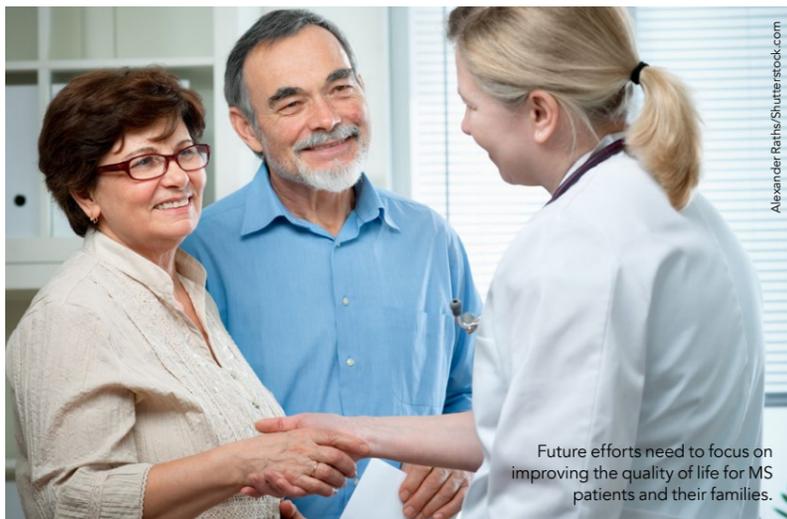
To address the patient's need for privacy, one option would be for the healthcare professional to see the patient on their own for half the consultation.

is unique with particular needs, it is conceivable that there is a pressing need

overall to optimise communication within MS families and enhance support. To address the patient's need for privacy, one option would be for the healthcare professional to see the patient on their own for half the consultation. Caregivers can join the consultation for the second half. Moreover, inclusion in peer support groups and attendance of in-clinic training or access to MS nurses can serve as

other sources of tailored information for family members, thus avoiding direct involvement in consultations.

Future efforts need to focus on improving the quality of life for MS patients and their families. One direction is to develop interventions to improve the psychological state of MS patients and their caregivers. Also, guidelines advising for shared consultations in patient care will need to align with the increasing diversity of cultural backgrounds and family structures that now exist. Ultimately, the level and form of involvement should be dictated by the patient's best interest. To achieve this, the healthcare professional will have to individualise consultations, taking into consideration the patient's personal circumstances and family situation.



Future efforts need to focus on improving the quality of life for MS patients and their families.



Behind the Research

Professor Jürg Kesselring

E: juerg.kesselring@bluewin.ch T: +41 79 502 5755 W: www.kliniken-valens.ch

Research Objectives

Professor Kesselring, together with other internationally acclaimed neurologists, discusses the family's involvement in the provision of care needs for people with MS.

Detail

Address

Prof Jürg Kesselring FRCP
Department of Neurology & Neurorehabilitation
Kliniken Valens, CH 7317 Valens, Switzerland

Biography

Jürg Kesselring is Emeritus Head of the departments Neurology & Neurorehabilitation and Physical Medicine & Rehabilitation at Kliniken Valens, Switzerland. He is also Professor of Clinical Neurology at the University of Bern, member of the International Committee of the Red Cross (ICRC), Honorary President of the Swiss Multiple Sclerosis Society, and Fellow at the Royal College of Physicians in London. He has published over 250 original publications (impact factor > 400), 15 books, and 52 book chapters.

Funding

- Merck KGaA

Collaborators

- Members of 'MS in the 21st Century', an international steering group of healthcare professionals and people living with MS (msinthe21stcentury.com): Alexey Boyko, Alice Laroni, Trishna Bharadia, Pieter van Galen, and Nektaria Alexandri

References

Kesselring, J, et al, (2022) Caregiver involvement in MS: duty or disruption? *Neurol Ther* 11, 9–20. doi.org/10.1007/s40120-021-00299-4

Personal Response

Do modern healthcare systems allow the development of individual approaches for MS consultation?

Unfortunately, healthcare systems do not always nor everywhere allow the development of individual approaches. A lot has been achieved but much more is necessary!

What is the most difficult aspect of MS that can hinder caretaker involvement in consultations?

The attitudes of persons with MS, their relatives, and often also of caregivers can hinder their involvement in consultations. Improvements are always possible and still need a lot of effort.

