

Good communication with healthcare providers helped patients with multiple sclerosis to cope and adapt

Thorne S, Con A, McGuinness L, *et al.* Health care communication issues in multiple sclerosis: an interpretive description. *Qual Health Res* 2004;14:5–22.

Q How do people with multiple sclerosis (MS) describe and explain helpful and unhelpful communications in their health care?

DESIGN

Interpretive descriptive study.

SETTING

A city in western Canada.

PARTICIPANTS

12 Euro-Canadians (83% women) who were 33–54 years of age, had been diagnosed with MS ≥ 5 years ago, and were seeking healthcare services to help them live with their disease. 7 were unemployed because of their chronic condition, 3 were employed, 1 was on leave of absence, and 1 was a student. 6 had been professionals (3 healthcare professionals).

METHODS

Participants were interviewed face to face for 1–2 hours. Interviews were audiotaped verbatim, and transcripts were coded for conceptual themes. A focus group interview with 8 participants was used to validate, clarify, and refine findings. 3 healthcare professionals who cared for people with MS participated in validation interviews to confirm that the logic of the participants' perspectives would have credibility with a health professional audience.

MAIN FINDINGS

Participants emphasised that communication with healthcare providers affected both their experiences of health care and their ability to manage their illness on a daily basis. 3 themes emerged. (1) *Managing fear*. Fear was a prominent theme related to uncertainty at various stages (ie, during appearance of symptoms, awaiting diagnosis, and diagnosis). Communication within healthcare encounters either increased or decreased fear. Pre-diagnosis fear related to troubling and intermittent symptoms and awaiting test results. The dismissal or minimisation of symptoms by healthcare professionals led to anger, fear, and loss of confidence that continued long after diagnosis. Fears associated with awaiting test results related to the importance health professionals placed on these results. If test results did not support a diagnosis, participants perceived that their symptoms were again under scrutiny. Participants experienced fear and uncertainty when follow up communication was initiated only if test results were positive for MS. Diagnosis led to a quest for information, difficulty in knowing which questions to ask, and fear about the future. When healthcare professionals gave only essential and simplistic information, fear and frustration escalated. Participants wanted timely, direct, and non-paternalistic information about MS. Participants' fear was increased if they perceived that physicians evaded or avoided discussing MS. (2) *Taking charge*. Participants increasingly realised the need to take full responsibility for managing the personal and clinical aspects of MS. They felt alone in learning about MS, but recognition of the limitations of healthcare providers was important for taking charge. Healthcare professionals who acknowledged the limitations of science, but saw their role as being supportive and facilitative, were helpful. Interactions with healthcare providers either empowered or isolated participants. Receiving inaccurate or outdated information, being given an overly optimistic picture, or having information withheld from them was

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problematic, whereas acknowledgement of participants' expertise and supportive, understanding communications were encouraging. (3) *Crafting a life*. Once fear and learning how to take charge were managed, participants focused on incorporating MS into their personal, family, and work lives. This phase was characterised by participants changing their expectations of their bodies, of what medical science could provide, and of the kind of life they wanted to live. Participants wanted healthcare professionals to recognise that MS was only one part of their lives. They learnt to manage troubling symptoms, cope with unpredictability, and recognise the limitations of healthcare providers. They valued being respected as competent and knowledgeable partners in healthcare decision making.

CONCLUSIONS

People with multiple sclerosis found that effective healthcare communication and support helped them to manage their disease. Poor communication, too little information, and minimisation of their disease hindered adaptation.

Commentary

In the study by Thorne *et al*, 12 people with MS shared their perceptions of healthcare professionals' communication patterns across the trajectory of chronic illness. They identified 3 transition points of the MS trajectory and described the different communication styles required to optimise successful adaptation in each phase. In *managing fear*, health professionals helped patients to obtain and interpret information and resources. During the *taking charge* phase, health professionals had to relinquish control and work to empower patients to manage their MS. Finally, in *crafting a life*, the health professional's role was to support and champion patients through a complex integration process.

Thorne *et al* suggest major differences in the communication patterns of health professionals in chronic and acute care management models. Chronic illness requires lifelong management over the course of a changing illness. As the prevalence of chronic illness increases, health professionals must be prepared to expand their knowledge of communication theories and strategies that reflect the special needs of people with chronic illness.

Besides acute and chronic illness, 3 other variables that may influence helpful communications between healthcare providers and people with MS are age, gender, and ethnicity. MS is a disease with an onset in young adulthood. Study participants were 33–54 years of age. The developmental milestones that shape the desired communications patterns in young to middle age are different from those of older populations. In this study, 83% of participants were women. Would a comparable group of men describe desirable communication patterns differently? Some literature supports different styles of communication based on gender.¹ Finally, all study participants were of Euro-Canadian ethnicity. How might ethnicity influence desired communications with health professionals throughout the chronic illness trajectory? Further research is needed to answer these and other questions to improve communication strategies in chronic illness.

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1 Fanelli S. Gender differences in the presentation and responsiveness of disease. *Adv Nurse Pract* 2004;12:59–62.



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