



Opportunities in Multiple Sclerosis Care Partner Research: An Interview

Marcia Finlayson, PhD, OT Reg (Ont), OTR; and Kenneth Pakenham, PhD

INTRODUCTION

Guest editor Marcia Finlayson, PhD, OT Reg (Ont), OTR, is a professor in the School of Rehabilitation Therapy at Queen's University in Ontario, Canada. She began her career as a clinical occupational therapist and shifted to a research career focused on generating and sharing knowledge to help people affected by multiple sclerosis (MS) lead healthy, meaningful lives with control over their participation in daily activities, at home and in the community, particularly as they age.

For this special issue on caregiving in MS, she chose to interview Kenneth Pakenham, PhD, emeritus professor of clinical and health psychology at the University of Queensland in Brisbane, Australia. For more than 4 decades, he has investigated the psychological well-being of caregivers, including coping mechanisms and innovative interventions to improve their quality of life. His work is dedicated to applying positive health frameworks to chronic illnesses and to empowering caregivers and individuals with MS.

Together, their expertise illuminates the multifaceted challenges and opportunities in MS caregiving research and understanding.

Read on for an excerpt from the interview, and continue to IJMSC.org to read the full conversation.



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KENNETH PAKENHAM, PHD

MARCIA FINLAYSON: As you think back over your extensive career in caregiving research, particularly in the MS space, where are the biggest gaps in our knowledge? Where could early-career researchers focus?

KENNETH PAKENHAM: I've got 6 knowledge gaps I'd like to take you through. The first is that I don't think we know very much about how MS carers operate in the broader interpersonal context of caregiving that involves the person with MS, the family members, close friends, neighbors, and health care professionals in the broader community. The critical issue here is that most of our research is focused on the caregiver, as if the carer were separate and independent of this crucial interpersonal context in which the caregiver operates. At [the] very minimum, we should be including the person with MS when we conduct research on MS carers. We know caregiving is profoundly interpersonal and that living with a loved one with a degenerative, chronic illness entails an ongoing interactive adjustment for the carer and the person with MS, yet in our psychosocial research, we focus on either the person with MS or the carer as if they were independent of the interactive dyadic processes that are occurring. For these 2 people, the person with MS and the carer, their lives are intertwined in various ways, and to ignore that crucial interactive influence is very, very limiting in terms of research, our understanding, and how we can move forward.

MF: Listening to you summarize and identify this gap that we're not studying, I thought “the family unit,” but it's often more than just the family. I think most of us would acknowledge we depend on our family, but we also depend on our friends, and some of those are closer and some of those are more distal.

KP: I think what you're talking about is beyond dyadic data analysis, but I still think dyadic data analysis is really important because there is that critical element around the person with MS and their primary carer; the mutual influence here is really important. Going beyond that—to your point about understanding the broader network—this can be achieved through our social network data analytic approaches that have been developed and refined particularly over the past decade or so. I

think both dyadic data analytic approaches and social network data analytic approaches will help us understand the role of carers in relation to the person with MS and other people that can assist, and this will inform interventions at the family level, the individual level, and the broader community level.

MF: I totally agree. I think that is such an opportunity moving forward.

KP: The second gap is our lack of understanding of the carer adjustment process. Our focus has been on the function of carers because they play such a critical role economically, socially, etc, in the health care system, but the carer—like the person with MS—has to navigate a process of adjusting to the person's illness and how that affects them in the family. I don't think we really understand a lot about that adjustment process. To some extent, I tried to get at it by investigating the meaning-making that carers go through in their attempt to accommodate this huge change to their lives: A loved one with a degenerative neurological disorder that changes over time, and they have to keep readjusting. I think that's a gap where we could understand a lot more. I think it's a balance: focusing on the function of carers—what they do and how important their role is—but also investigating and understanding how they adjust.

MF: And as part of that adjustment, how do they learn to take on those new roles or activities that they've never had to learn, they've never had to do before? Researchers have described all these functions that caregivers perform, yet we haven't asked how they develop the skills necessary to be able to take on those additional functions.

KP: It is huge. But sometimes we forget the care element of the carer and caregiving. The critical word here is "care." And care implies a motivation to look after, to nurture, to love, to have compassion for. Once triggered, it becomes the powerhouse, the engine. If you care, you can do almost anything. If you care, you'll learn how to administer an injection. If you care, you'll learn how to deal with incontinence. Caring is the critical element. Harnessing that positive, caring drive and related values that the person has is empowering across different care contexts—whether it's because they're in the family and it's more to do with the family context of caring, or whether it's a friend and it's more to do with the friendship context of caring, or whether you're a neighbor and it's more like a next-door neighbor and part of the community notion of caring for someone who is vulnerable.

MF: I think that's a really profound reminder, because we don't think about that or write about that very much. Honestly, I can't think of papers that have specifically addressed that in the MS caregiving literature in the way in which you've just talked about it.

KP: I learned about this through my research on young carers because young carers are not intellectually shaped by the health

care and medical systems. When you care for someone, when you love someone, you don't think of it as anything but caring.

My third knowledge gap is reward. In the review that you and your colleague published, you identified that very few papers over the [past] 29 or 30 years had examined or investigated the positive aspects of caregiving. This is really interesting because, if you think of caregiving, there are costs but there are also rewards. There's incredible fulfillment, there's an enhancement of meaning in life, [and] there can be an enhancement of relationship through caring.

MF: Definitely, and it's often quite intangible. I'm not sure people are always able to articulate what that looks like or how that feels, but it's so important to be able to support people to achieve those rewards fully because it keeps them engaged in caregiving.

KP: This is [what] keeps the engine ticking over, and it produces growth, it produces creativity, it produces clever problem-solving. It produces ingenuity, ways to get around difficult, practical things that pop up because the person has a disability.

The fourth gap is in relation to intervention and, in some ways, I'm sort of paraphrasing the findings from your review, and that's a nice dovetailing of our knowledge. One of the deficits you identified in your review—and for me, this is really important—is the lack of intervention research on carers. To be quite frank, after working in this field for 40-odd years, I started to feel guilty that I had done all this research refining theoretical frameworks around caregiving and developing measurement instruments, and although this research is important and it contributes to science and our understanding of caregiving in MS, all the time there are carers and people with MS struggling with their loss. What am I doing for them? Although my research is producing understanding and advances in scientific knowledge, I nevertheless have a responsibility, an ethical and professional responsibility as a researcher to deliver something tangible that will make a difference to the lives of people with MS and the lives of those caring for people with MS.

I think the importance of intervention research should be highlighted, so I'd like to talk about the way this might move forward. I've developed and published research on a resilience training intervention [REsilience and Activities for every DaY (READY) for MS] over the past 10 years. The focus has been on the person with MS in terms of the delivery of this intervention, but in delivering the group, face-to-face intervention through frontline MS support services, quite often the carer accompanied the person with MS because of disability and practicality issues. What we've found is that having the carer accompany the person with MS to the intervention, anecdotally, they reported greater gains because both were learning a common language about coping strategies and how to better manage the illness and the adjustment process. They had a common language and a common set of skills. Why wouldn't you deliver the same thing to both people?

MF: Even [in] some of the early caregiver intervention work I did, one of the pieces of feedback we received from

caregivers is that they wanted to have the person with MS in some sessions.

KP: And I think that culturally, this is actually more important in some cultural contexts than others. We've delivered and evaluated the [READY for MS] intervention in Italy, Greece, the UK, Australia, and currently it's being translated for delivery in Germany. Anecdotally, in the Mediterranean cultures, the presence of [the] carer—which was often a family member—was seen as really important because of the close community and family ties. I think that intervention is very important and, where possible, it should include at least the dyad and even be extended to other critical people in the network.

MF: You talk about the cultural impact of families [and] what's expected, and I think about my experience in North America [where] families tend to be spread out, and yet they are still providing care, often from a distance. It's more complicated. Do you see potential for dyadic interventions supported by technology to be able to bring families together to receive these dyadic interventions, even if they're not located in the same place?

KP: Yes, definitely. By way of illustration, this resilience training intervention [READY for MS] presents generic resilience building strategies. They're applicable to any person, whether you have a chronic illness or not [and] whether you have a caregiving role or not. The material is suitable for anyone to obtain information, gain understanding, and develop [resilience] skills. In the Greek version [of the intervention], they delivered it as a group program but via real-time video conferencing. The carer wasn't necessarily in another location, [and] sometimes they were all at the computer. Anecdotally, some of the people with MS had their carer with them and were engaging in the material [together]. I think it's entirely feasible to use digital technology for the delivery of interventions that are suitable for carer and person with MS, even if they live separately.

MF: So much potential for the future.

KP: The fifth knowledge gap is around carer diversity. If you think of people with sexual diversity, gender diversity, ethnic/racial diversity, if you think of minority groups like that, they typically have difficulties in accessing with equity health services where they're not stigmatized or discriminated against. This is a serious problem. I'm a sexually diverse person. I identify as a gay man, and I sometimes have difficulties in getting health services where I'm not discriminated against or stigmatized. This is a real problem. If the carer is trying to support a person with MS, the couple may in fact be a same-sex couple, or it might be that the person with MS is heterosexual but the carer identifies differently and, because of this relationship, the person with MS [is] possibly more likely to have difficulties in accessing health care services.

MF: We're going [to] do better in this area. We have to, we have to because we can't leave groups behind. There's too much at stake here for people with MS [and] for families affected by MS.

KP: I agree. Somewhere, somehow, someone needs to voice the truth and the reality that not all people with MS are heterosexual, White, middle-class people, and not all carers have that demographic characteristic. We do have diversity.

The sixth knowledge gap is around young carers. I've done quite a bit of work in this area. I think we know quite a bit about the tasks young carers do. A colleague and I developed a measure that's generic to young carers, but we've used it in studies of offspring of parents with MS [to] identify the tasks that these young people are undertaking. Many of them are undertaking caregiving tasks that are typical of what the adults undertake, and, sometimes, the tasks that these young people are undertaking, you could question whether young people should be undertaking some of the...quite personalized health care tasks. Nevertheless, we do have a reasonable amount of knowledge about the care tasks these young people are undertaking. We also have a reasonable understanding of how these young people experience the process of caregiving in the family. We've identified some of the risks and protective factors that influence the child's adjustment as they are growing up with a parent with MS and having to take on various caregiving roles in the family. And while those knowledge areas can be extended, I think we are at the point where we can start seriously looking at interventions for young carers, for example, interventions that are specifically for the young person and interventions that might be more family focused because of particular needs. A whole family approach may be necessary and appropriate in some contexts, or simply just a young carer-focused intervention. ■

SELECT RESOURCES FROM THE INTERVIEW

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