

## **Opportunities in Multiple Sclerosis Care Partner Research: An Interview**

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

The following is the complete transcript from an interview conducted on August 22, 2023 between Marcia Finlayson, PhD, OT Reg (Ont), OTRD; and Kenneth Pakenham, PhD. A selection from the interview and a featured resources list were published in the November/December 2023 issue of the *International Journal of Multiple Sclerosis Care*. The complete transcript made via Otter.ai and edited for clarity and content follows.

Guest editor Marcia Finlayson, PhD, OT Reg (Ont), OTR, is a professor of rehabilitation therapy at Queen's University in Ontario, Canada. She began her career as an occupational therapist, and this interest developed into a career in teaching and research focused on self-management programs and rehabilitation services for those affected by multiple sclerosis (MS) and their caregivers. Her expertise encompasses areas such as fall prevention, fatigue management, and optimizing health-related services.

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, the expertise of Drs Finlayson and Pakenham illuminates the multifaceted challenges and opportunities in MS caregiving research and understanding.

**Marcia Finlayson:** How did you get interested in studying MS caregiving?

**Kenneth Pakenham:** Thirty years ago, a long time ago, when I was completing my PhD, I experienced neurological symptoms and at that point, I was diagnosed with probable MS. They gave me up to 10 years before they would be able to confirm whether this was an MS trajectory

or not, so I started to get interested in [the] medical and psychosocial aspects of MS, including caregiving. The caregiving element came in because I was very much aware of the effects of my neurological symptoms on my then wife and my child and that lived experience of seeing the interactive effects of my physical symptoms and my family consolidated my experience and findings through my PhD research that I was just finishing. My PhD was on HIV/AIDS. I did the first statewide needs assessment of people affected by HIV and AIDS in Australia in the late 1980s and through that research, I was very aware of the social context of illness, and in particular, family networks, friendship networks, and how they are affected by the illness, and how they in turn could support or have various impacts on the person with the illness. So that's how it all got started. I feel really, really strongly about the social context of illness and caregiving is a really important element of that social context, that lived experience. It's my clinical experience, and it's my research experience.

**MF:** It's the perfect combination. As you think back over MS caregiving research since you got involved, where do you think we are? Where are the most important gains? Where are the biggest gaps?

**KP:** In terms of gains, we certainly have a better understanding of the caregiving work that MS carers undertake. The specification of the tasks that caregivers undertake, we've got better understanding in that area. I think that MS carer research has demarked a greater recognition and respect for the work that MS carers do. I think we've got a better understanding of white heterosexual partners in MS dyads. And I think one of the gaps is that we know very little about the other carers who have different demographics. I think the other gain is that there's been a shift away from a focus on [the] negative burden that carers experience and there's been a move towards insights into the protective factors that enhance adjustment to caregiving over the long haul, such as meaning making, sense of coherence, mindfulness, acceptance. I think that shift from almost getting stuck in trying to understand caregiver burden, the move away from that into understanding what actually facilitates, enhances the caregiving experience and adjustment to caregiving has been a really, really important shift.

**MF:** Yes, and it seems to me that that shift is still quite new. I would attribute that shift to a lot of the work that you've done and I sure hope that that continues because when you look at the literature as a whole, there's still a lot of literature on burden and I think we need to understand how to support people in a positive way.

**KP:** I get really, really disappointed; my heart sinks every time I see a new [carer burden] paper come out. This is 2023. Another paper, another paper, another paper on caregiver burden. Caregiver burden, we don't understand it; it's a messy construct. There's no clear agreement on what it is. For example, the measures of carer burden include coping strategies, resources, tasks, and distress. And where has it gotten us? Thirty years of studying caregiver burden. Where has it gotten us?

**MF:** Now, the shift to the more positive, I think, gives us more potential for interventions that can really support people.

**KP:** For me, it gives a direction forward. It gives us a sense of malleable factors that we can target to enhance meaningful lives for caregivers and the person with MS.

**MF:** That's great. Are there other things you think about as big gaps?

**KP:** I've actually got 6 knowledge gaps that 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 was separate and independent of this crucial interpersonal context in which the caregiver operates. At a very minimum, we should be including the person with MS when we conduct research on MS carers. We know that 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 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:** What are some of the methods you think would help us get past that? Because that's some pretty complex dyadic research and it seems to me that that really calls for multidisciplinary research teams that would go past a typical MS research team.

**KP:** Not necessarily. I can give you some examples. But I just wanted to pick up on how important this point is because in the review that you and your colleague published in 2021 on MS carers, you show that less than half of the MS carer studies that you reviewed incorporated characteristics of the person with MS. You didn't mention this, but I suspect even fewer, if any at all, included data from both the person with MS and the carer. I think this is one of the most critical gaps. But to your point about how we approach this and do we need multidisciplinary teams, etc, not necessarily. I'd like to illustrate this with the research that I've done as an independent, and in most cases, solo researcher initially, and then later, in collaboration with others who had more experience in dyadic data analytic approaches. My first study focusing on dyads was in 1998, and I showed that coping strategies of each partner in the MS dyad influenced adjustment at the individual and collective dyadic levels. In subsequent studies, I showed that the use of 2 highly protective mental health factors, mindfulness and acceptance, influenced adjustment at the individual and dyadic levels.

**MF:** I remember those papers!

**KP:** These couples, they live together, they're connected. There's one with MS, there's one without MS, and the one without MS is typically doing a lot of the family caregiving and picking up a lot of the work around the house, etc. Then we looked at how their mindfulness and acceptance strategies interacted and shaped adjustment within the relationship, the carer-care recipient relationship, but also at the individual level. Then, in a longitudinal study, again with couples, we found that one partner's relationship satisfaction, at the initial assessment, predicted the other person's relationship satisfaction 12 months later. And then in my work on meaning

making, I showed how that benefit finding and sense making in each person within a dyad, the carer and the person with MS, was correlated with the other person's meaning making and some of the themes that were in benefit finding and sense making were similar between the 2 partners in the relationship. In addition, each person's meaning making influenced the other person's adjustment.

**MF:** Listening to you summarize all of this and identifying this gap that we're not studying...I'm going to [call it] the family unit, but often it's more than just the family. You referred to the review that my colleague and I published last year; the thing that was really striking to me during that work is that we don't look at the other people that are part of an overall support system. I think most of us would acknowledge [that] 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. We just didn't see that at all in the 120 research papers we included in that review.

**KP:** I agree and it's a serious gap. I think that 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. But 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 at a broader community level.

**MF:** It would be nice to have more options than just individual level interventions, for certain.

**KP:** I'd like to give an example of how important this is at an intervention level. I'm going to just briefly summarize a study that I and colleagues conducted where we compared 2 types of interventions, 1 that focused on the caregiver and the person with HIV, so it was dyadic focused. The other intervention approach just focused on the carer, but we also collected data from the care recipient. And we also had a waitlist control. So, a total of 3 groups: a waitlist control and 2

active intervention groups, 1 that focused on the dyad, and 1 that focused on the carer. Across all 3 groups, we collect[ed] data on the person with HIV and the carer. What we found is at post intervention and 4-month follow-up, carers and the care recipient in the dyadic intervention improved across a range of psychosocial outcomes, significantly more than the person with HIV and the carer in the carer-focused group and then, of course, in relation to the waitlist control. For me, that illustrates the importance of not separating something that is, in fact, a social unit.

**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 adjust or navigate a process of adjusting to the person's illness and how that affects them in the family. I think we don't really understand a lot about that adjustment process. To some extent, I tried to get at it through 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, which changes over time, and they have to keep readjusting. I think that's another knowledge gap that we could understand a lot more about. I think it's having balance on focusing on the function of carers, what they do and how important their role is, but also investigating and understanding how they adjust.

**MF:** The thing that makes me think about is, 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? As you know from the work you've done, and some of the work that others and I have done, we 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. In addition to the psychological and psychosocial adjustment, it's a huge amount of change for a person over time, and it's constantly changing.

**KP:** It is huge. But you know, 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 has more to do with the family context of caring, or whether it's a friend and it has 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 that 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 system. When you care for someone, when you love someone, you don't think of it as anything but caring. You know, these young people don't talk about tasks or things that they do. They just frame it within the context of caring for a parent or other family member. That's very beautiful. [A] highly motivational way of framing and understanding caregiving is to highlight the care element.

My third knowledge gap is reward. In the review that you and your colleague published, you identified that very few papers over the 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 or burden, but there are also rewards. There's incredible fulfillment, there's an enhancement of meaning in life, there can be an enhancement of relationship, etc, through caring.

**MF:** Definitely, and it's often, I think, quite intangible. I'm not sure that 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, right? Because it keeps them going to care.

**KP:** This is [what] keeps the engine turning 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.

Another lived experience anecdote here. Just recently I visited one of my nieces, who has a partner who has been diagnosed with a serious degenerative neurological disorder. I saw the care in caregiving in action as she talked about how doing things for her partner is her way of caring for him, is her way of showing that she cares for him—she loves him, wants to be connected to him. I think that's central to caregiving.

So, I think that the focus on the rewards, the motivational factors, the protective factors around caregiving will better inform the development of intervention supports for carers and the person with MS than a focus on burden. I think it's the way forward.

The fourth gap is in relation to intervention and, in some ways, I'm sort of paraphrasing the findings from your review and, well, that's a nice dovetailing of our knowledge. One of the other deficits or gaps 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 30 odd years I actually 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, and 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 [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 had to accompany the person with MS in attending the intervention, because of disability and practicality issues. What we've found is that having the carer accompany the person with MS and attend the intervention, anecdotally they reported greater gains because both were receiving 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 that I did, one of the pieces of feedback that we received from caregivers is that they wanted to have the person with MS in some sessions. They said, "You know, it would be very helpful to have a couple of sessions on our own, but when I'm practicing some things, I'd actually like to have them here so that we can work through it together." I think it's very consistent. My experience is very consistent with what you're talking about.

**KP:** And I think that culturally, this is actually more important in some cultural contexts than others. We've delivered and evaluated the 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:** It strikes me, you talk about the cultural impact or influence with families together or what's expected, but I think about my experience in North America, families tend to be spread out, and yet, you're still caregiving, 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 somehow to receive these dyadic interventions, even if they're not located in the same place?

**KP:** Yes, definitely. So just by way of illustration, this resilience training intervention [READY for MS] presents generic resilience building strategies. Now, they're applicable to any person, whether you have a chronic illness or not, whether you have a caregiving role or not. The material is suitable for anyone to obtain information, gain understanding, and develop skills. We delivered the program initially in group[s] face-to-face and carers would attend, but we've also developed an online version. The online version was delivered through a website of a frontline

service provider to people with MS in Australia and New Zealand. It was initially delivered to people with MS, but in the qualitative data that we obtained, many people with MS said that they shared the material and the program with family members or carers who benefited from it as well. When you're sitting in the room, and you're at the computer, and the person with MS invites someone in the household—"Oh, have a look at this, and have you done this?"—a conversation and interaction around that material ensues. In the Greek project, they delivered it as a group program via real-time video conferencing. Anecdotally, some of the people with MS had their carer with them and [they] were engaging with the material [as well]. 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. And, as you pointed out in your review, we know very little about MS carers who are not White, middle class, heterosexual partners of the person with MS. If you think of, for example, people with sexual diversity, gender diversity, ethnic/racial diversity, if you think of minority groups like that, they typically have difficulties in equitably accessing health services where they're not stigmatized or discriminated against. And 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:** I think there's so much we need to know and learn in this whole area. I don't know what the discussions are in Australia around diversity, inclusion, equity. You know, every country looks at it a little differently. Here we call it "EDI," equity, diversity, inclusion, and add an "a" sometimes for accessibility. But we have a lot to improve upon in this area because there are a lot of people who just aren't being seen because they're not being included in the research and we're not even asking them what their issues are.

**KP:** I think it's really interesting because as I said, I've been working in the MS field for 30 years and I'm visibly identified as sexually diverse and sometimes even gender fluid, so it's been interesting working in the MS field because it's just not talked about. And I haven't felt comfortable about talking about it because I'm juggling the extent to which I will be respected, because I have to collaborate with people on the ground, with people with MS, with carers, with health care providers, with funders, with researchers. I don't want to jeopardize collaborative opportunities and my work by the possibility that something about me might negatively impact such opportunities.

**MF:** I have to say that that makes me feel just so sad and then I'm going to say I would be honored to collaborate with you any time, Ken. Honestly, your early work is one of the things that has inspired me to keep this caregiving thread in my research for all this time. 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, for families affected by MS.

**KP:** Thank you very much. I agree. There needs to be 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. And it's just quiet. It's silent.

**MF:** Yes, crickets.

**KP:** The fact that you identify this as an area for future research in your review also highlights the point, and I think we need to keep highlighting that.

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 that young carers do. I and a colleague 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 sort of 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 them, in some cases, quite personalized health care tasks. But nevertheless, we do have a reasonable amount of knowledge about the care tasks these young people are undertaking. We also have a reasonable understanding through our research of how these young people experience the process of caregiving in the family and 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 that 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 also interventions that might be more family focused because of particular needs. A whole family approach may be necessary and appropriate in some contexts as well, or just simply a young-carer-focused intervention.

**MF:** As you were talking there, one of the things that struck me was that in some areas of health care you specifically hear about family-centered care. I'm not sure I have ever seen that language in the MS literature. It may be out there. I think it goes back to your earlier conversation about the dyad, the social interactivity, and understanding the unit.

**KP:** I think similarly. I haven't read, heard about, or had conversations about family-centered care and this is interesting, because if you think of the typical demographic of people with MS, often younger, often at the point of entering longer-term relationships, thinking about having children, or having children. This is like the parenting phase of life and so many people with MS are in that family [and] parenting phase of life. And yet, we know very little about the needs around parenting and kids managing parents with a severe disability. I think that's another knowledge gap for us to explore.

**MF:** Those are some big gaps. We need to start recruiting more people to start doing work in this area. I know there are people who are starting to do work in the area, or have always had it as an undercurrent in some of their work, but there's certainly a lot of work to be done still.

**KP:** Yes, yes, I agree.

**MF:** Is there something in particular from your work that you'd really like to see pushed forward? Or when you think about the gaps you've identified, is there one that stands out in particular?

**KP:** Well, 3 stand out. The 3 areas are the dyadic and network analytic approaches to carers and their interpersonal context. The other is the development of interventions or supports for carers, but across the lifespan, understanding caring as a lifespan phenomenon rather than just adults needing support. And then the third is work on parenting in MS and the supports that families require.

Going [back] to the point about technology. One of your questions was around technology and virtual care. I think that the growth of online and digital resources can greatly benefit carers, particularly young carers who are really familiar with digital technology and they like it and they're comfortable with it, and they're really skilled at using it. But I think that online and digital resources can be great assets for carers. And one of the reasons for this is that in my experience, and this may be part of the reason why there's not so many studies of MS carers, it's quite difficult to recruit carers into research and of course, it's completely understandable because they're often at this busy family stage of life. There are kids, school, extracurricular activities, parenting, career development, work, and on top of that, there is the navigation around the disability, and MS symptoms, and so on. So, it's just really hard for carers to find the time to devote to our research or interventions. Digital resources enable easier and quicker access for carers. They're time-poor, typically, and I think that online digital resources overcome that barrier.

**MF:** I think one of the challenges also in terms of recruiting caregivers, depending on where you are, is they're just very geographically dispersed and so bringing people together is challenging. Certainly, using virtual connections and familiarity with video conferencing, it's just ubiquitous now. People are familiar with it. I think it gives us a lot of potential to do interventions, even in this kind of format like we're doing here today on Zoom or other sort of similar formats. People can find their connections and create those social networks.

**KP:** Yes, the real-time video conferencing delivery of the resilience training program [READY for MS] in Greece is going so well. [The team] has deliver[ed] the program to almost 40 people with MS through real-time video conferencing, and that form of delivery has been really well received by the people, but there is a caveat to all of this. In the Australian pilot study where we evaluated the online delivery of the resilience training program, we had fairly low levels of engagement, (measured by the number of sessions people engaged in and the amount of time they stayed in sessions). I suspect that part of the low engagement on the back of COVID is due to digital overload, particularly in health care. This was delivered to people with MS, so in the health care context, during COVID, 3 years of everything being virtual or digital.... I've been reading about this in the literature to try to understand digital overload and burden. They call it digital burnout. I think that's a [case for] caution around how we use it, and people still really like to have contact other people face-to-face wherever possible.

**MF:** The greater use of video conferencing has opened doors, and now we have to understand how to use it well, when to use it, when not to use it, and how to really support people to be engaged in these formats because it's not going to be for everybody.

**KP:** I think in reflecting on the online program, there was no health care professional engagement or support, so the person was completely self-directed and autonomous. I think different options need to be available for people who have different needs in that regard, as you say.

**MF:** Any final wise words from all your experience in this area of work, in this area of research?

**KP:** Well, I think there are a couple of points. I think the care element of caregiving should never be forgotten and, that is soft, but powerful. It's complex because it's intra- and inter-personal. I don't think we should neglect or forget that critical element of the word, but also of the phenomena. If we keep that in mind, it will remind us [to use] an interpersonal approach in our research, whether it's dyadic or network or even if we just collect data from the 2 people involved. It will also help to guide us in relation to our supports and our interventions. There is a

person caring, and there is someone being cared for and even the person that has been cared for cares for the carer. It's very beautiful.

**MF:** That is a lovely place to end.