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Ready or Not: Planning for Health Declines in Couples with Advanced Multiple Sclerosis

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Abstract

This study explored how couples living with advanced multiple sclerosis (MS) approach planning for health changes together. A qualitative descriptive approach was used, with multiple in-depth interviews. Ten couples were interviewed, consisting of 10 participants with advanced MS and their 10 respective spouses. Interviews were transcribed verbatim and analyzed for themes related to dyad decision making. Particular focus was paid to how or if couples planned for worsening health, including advance care planning (ACP). Characteristics of couples that had made plans for worsening health included: a desire to make decisions ahead of time, work in a healthcare field and a life-threatening health event for the care giving partner. Characteristics of couples that had not discussed plans for worsening health included: diminished quality of communication between partners and hoping for a cure. Findings suggest that providers may need to assess quality of communication between partners, as strained communication may negatively affect the process of informed health care decision making.

Introduction

Multiple Sclerosis (MS) is a chronic degenerative demyelinating disease of the central nervous system (CNS). Approximately 400,000 people are living with MS in the United States. MS is characterized by a variable and often unpredictable disease course. Affected individuals experience progressive loss of physical function including but not limited to symptoms such as fatigue, balance problems, pain, and incontinence, as well as emotional and psychological challenges such as depression, memory disturbances and decreased decisional capacity (Vazirinejad, Lilley & Ward, 2008).

The care giving tasks that become necessary as the disease progresses are commonly performed by a spouse or life partner. Individuals may live 50 plus years post diagnosis and over the long disease course, MS becomes a shared experience involving the individual with the diagnosis and their care giving partner (Schwartz & Kraft, 1999; Courts, Newton & McNeal, 2005). The many daily decisions of managing care often take place as negotiations within the context of the relationship between partners (Boeije, Duijnste & Gryphonck,

2003). There is growing recognition that couple communication about illness-related issues influences these health care decisions (Arden-Close et al, 2010).

Some of the most important illness-related decisions a couple living with MS face involve planning for long term care and end of life decisions, but little is known about how these couples negotiate these discussions and how healthcare providers can aid them during this process. A small body of research describes how care providers can assist patients living with MS in making health care decisions related to palliative and end of life care (Campbell, Jones & Merrills, 2010; Brandis et al, 2008) but no literature explores how couples with MS make health care decisions together. This study addresses this gap in the literature.

The literature emphasizes the need for exploration of the topic, as little research has described the experience of couples living with advanced MS. This secondary analysis focuses on the experiences of couples living with advanced MS. This population that may be in need of additional support as they near the disease stage that may necessitate ACP and other important health care decisions related to end of life preferences. Sadly, there are reports both from providers and patients living with MS that end of life conversations are not happening (Edmonds et al, 2007; Kumpfel et al, 2007). An additional desired outcome of this study is to contribute to the discussion among care providers of how couples can be assisted during these discussions.

Methods

This study employed a qualitative descriptive approach (Sandelowski, 2000; Sandelowski, 2010), attempting to capture a narrative from couples living with advanced neurological illness. The original study included participant dyads with one partner living with either Parkinson's disease or Multiple Sclerosis and examined unmet needs, concerns, and end of life preferences. This article reports findings related to those couples living with advanced MS and focuses specifically on their planning for health care changes. The target population of couples living with advanced MS was chosen because of the challenges faced by these individuals (Campbell, Jones & Merrills, 2010) along with the preponderance of research on individuals and couples living in the first years after diagnosis of MS and comparative lack of literature on couples living with MS near the end of life. Dependence on mobility aids was used to attempt to identify more disabled participants who might therefore be living with more advanced MS (Buchanan et al, 2009). Couples with one member diagnosed with MS were identified through local support groups and one neurology practice and invited to contact the researchers. Possible participants were screened for being dependent on mobility aids to walk distances less than 25 feet, being wheelchair or bed bound, long term partnered relationship and/or marriage and a diagnosis of MS. Exclusion criteria included being able to walk with minimal mobility aids (cane/no mobility aids) and memory loss that would result in an inability to answer questions or participate in an interview.

Participants were interviewed in their home using a semi-structured interview guide. General information was gathered for demographic description and the couples were interviewed separately. The semi-structured interviews explored themes related to the hardest parts of day to day living, daily routines, communication with medical professionals, needs and stresses, plans for the future as well as hopes and fears. Interviews were recorded and transcribed verbatim. A second, joint couple interview was conducted one week to one month later. Ten couples were interviewed, resulting in 20 participants total and 30 total interviews. Review of the individual interviews by both investigators prior to the second interview allowed for further exploration of topics and yielded rich qualitative data. Each interview lasted 30–90 minutes. Transcripts were reviewed for themes throughout data collection and after its completion. An eclectic approach allowed for simultaneous collection

of qualitative data and development of research questions. A deductive phase where transcripts were reviewed for content related to research questions was followed by an inductive phase where content areas were reviewed for themes, compared and contrasted.

Advanced care planning (ACP) emerged as a theme early in the data collection. Later the themes of moving or assisted living, getting help in the home and worsening health were merged with ACP to make a Planning Ahead theme. Themes were tested for credibility by a comparison to accounts of MS dyads in the research literature. An audit trail was maintained. Emerging themes were reviewed by the second author and assessed for their presence in the transcripts given the same data, perspective and context. Results were compared to similar findings in the literature and alternate explanations were considered.

Sample

Mean years diagnosed for the sample was 21 years. All the participants with MS required assistive devices, such as rolling walkers, wheelchairs or scooters. Seven of the 10 self-identified as chairbound, one identified as homebound. The mean age of the care giving spouse was 60. Mean age of the spouse with MS was 58. Seven of the participants with MS were women, three were men. All of the participants identified as white. Mean income fell roughly at \$40,000–50,000.

Results

The couples living with advanced MS were aware of the potential for declining health in the affected partner. They hoped that the MS would not get any worse but feared abilities and function of the partner with MS would be lost in the coming years. However, this awareness did not necessarily culminate in discussions about what they might want this future to look like.

When couples planned for changes in health, they described several different kinds of activities that helped them prepare for the future. These included writing advance directives or living wills, communicating with loved ones about their plans for the future, planning to move to a more supportive living environment and receiving home health services. This is congruent with the literature on advance care planning, which describes couples getting ready for future health changes with a diverse spectrum of behaviors not limited to end of life preferences, but encompassing more general changes in healthcare needs and living arrangements (Fried et al, 2009).

Couples described a dynamic process between partners when asked about planning for the future. The partner with MS was the main decision-maker about their healthcare needs, but the care giving spouse was vital during the decision making process. The care giving spouse kept up with details of health care decisions and foresaw future needs. They discussed and in some cases debated healthcare decisions with their partner. All the spouses offered emotional support and companionship to their spouse with MS. As in other literature describing living with MS, the planning for what life might be like with more advanced MS was a family affair (VanderLinden et al, 2008; Leidstrom, Isaksson & Ahlstrom, 2010).

When planning ahead was considered as a theme, three categories emerged out of the ten couples interviewed; those who had planned for health declines including advance directives (Making Decisions Up Front), those who had planned for health declines but had not talked explicitly about their own preferences (On The To-Do List), and those who had not talked about plans for health declines (Hoping For A Cure).

Making Decisions Up Front: Couples with advance directives

Three couples had written advance directives or living wills, communicated end of life wishes to their loved ones and made plans for living with more assistance. These couples felt confident in their understanding of each others' wishes and had a sense that they were planning together for the future. They all described needing or wanting to make these decisions ahead of time.

One participant with MS related her desire to write living wills to her experience during her parents' end of life care, saying it is easier to make decisions ahead of time rather than have to stop interventions once they have been started. Another couple said that their relationship as a gay couple made it necessary for them to set down their wishes in black and white to avoid having family members make those health decisions instead of their spouse; "so before anything happened at all, we automatically went out and did the POAs. We did everything 100% right up front." (Care giving spouse). The third couple attributed their planning to the spouse with MS's plan-ahead personal style. She described this personal style as she talked about her interest in assisted living;

It was nothing specific at the beginning. I knew it was a chronic illness, progressive illness so I just knew it would be nice to be aware of what's out there (assisted living) in case it was going to be needed. I think what it amounts to is I call myself more proactive because that's the way I've always been almost all of my life. I would look towards the future and try to get ready for things like that. If I was going to college I'd better make good grades in high school, this type of thing. So I've just always been oriented that way." (Spouse with MS).

These descriptions highlight the desire of the spouse with MS to make decisions before changes in their health occurred. They were differently motivated (by family experience, because of being a gay couple, because of personal style), but in each case, they made clear that they desired to do their advance care planning "up front."

There were two other notable similarities among these couples. First, all three of the partners with MS had worked in a hospital; as a nurse, chemist and social worker. One of these attributed her willingness to engage in ACP to her experience in a healthcare environment. Of the twenty total participants in the study, four had worked in a hospital environment. Three of these were individuals living with MS, these three individuals constituted this "Making Decisions Up Front" category. The one other participant was a care giving spouse who was very interested in ACP, but her spouse with MS resisted her attempts to discuss it. Among those interviewed in this study, the participants with healthcare experience were also the participants discussing questions of advanced care planning with their spouse.

Second, all three of the care giving spouses had experienced life-threatening illnesses themselves. Five of the ten couples had lived through life-threatening illness of the care giving spouse. Almost all of the couples in the study had experienced an acute exacerbation of the spouse with MS. These experiences were labeled during thematic analysis as "close calls." Living through a time of acute illness deeply impacted all the couples, often they expressed their gratitude for making it this far. However, a close call on the part of the spouse with MS did not seem to have much bearing on the couple's discussion of ACP. Couples from all three levels of preparation (Making Decisions Up Front, On The To-Do List, and Hoping For A Cure) had lived through close calls of the spouse with MS. However, the five couples that had lived through close calls of the care giving spouse had talked about what they might do if the MS spouse's health worsened, though not all of them had gone so far as to complete advance directives. It is unclear why there was this difference in the response to acute illness in the care giving spouse versus the spouse with MS.

On The To-Do List: Couples planning for a decline in health without advance directives

Four couples had done some planning about living arrangements or healthcare changes, but had not written advance directives. The care giving spouse had heard their partner with MS talk about worsening health, such as talking about friends that had died or been acutely ill, but they had not necessarily had a frank discussion related to their own healthcare preferences. These four couples variously expressed a readiness to make these decisions, but had not yet taken the action of decision-making. They described ACP as being “on the to-do list.”

These couples were heterogeneous in their feelings of whether or not they had planned for the future together. Some felt prepared, some did not. One partner would express that their wishes were known while their spouse wasn't so sure they would know what to do if the time came for decisions such as keeping their spouse on a ventilator. The one thread that ran through all these interviews was that of choice. Care giving spouses wanted to support the ability of the spouse with MS to choose. Likewise, the spouse with MS didn't want to feel that others were arbitrarily making choices for them. As one participant put it, “the time is coming that they're going to have to put me somewhere, but I want something I can choose on my own.” (Spouse with MS). Her spouse agreed and even though they had not engaged in ACP, he was interested in starting it; “that discussion is while her mind is still sharp and she knows what she wants and knows that I would do exactly what she wants to the best of my ability.” (care giving spouse). This theme of supporting the self-efficacy of the spouse with MS was repeated through this group. They were ready to begin discussing ACP, but it just hadn't happened yet.

Hoping For A Cure: Couples without a plan for a decline in health

There were also couples that had no advanced directive or living will written, had not communicated their wishes to loved ones and had not planned yet for a decline in health, including more supportive living arrangements. Three of the ten couples were in this category. In their own private thoughts, they had reflected on what might be coming as the MS progressed, but they avoided entertaining those thoughts and they had difficulty discussing feelings about the future with each other. The care giving spouse had a sense that the partner with MS didn't want to talk about moving or changing things. These couples said they were “hoping for a cure.”

Couples in this category all experienced some level of difficulty communicating. This was described as part of the relationship and not something new to this stage of their marriage. It seemed to be part of how the partners conducted themselves. As one spouse with MS put it, “I don't talk a lot” (couple 3). These spouses with MS were especially seen as not being complainers.

The other side of not complaining, though, was the concern these care giving spouses had that their spouse with MS was struggling to make sense of their changing health and perhaps suffering in silence. They hesitated to ask questions of their partner, feeling that would be too pushy. Instead, they hoped that their partner would one day be ready to talk about their feelings and hopes for the future. One husband described that constant waiting and watching as the hardest part of his relationship with his wife. These spouses wondered if planning for worsening health might contribute to their partner's depression, such as the concern voiced by one care giving wife;

“I've thought about those things [ACP]. I haven't really expressed them a lot. I haven't expressed them I think out of the fear. What is he going to say? I know how easily he gets depressed. I don't like to rock the boat.” (care giving spouse).

While difficulty communicating was not something isolated to this category, their difficulties communicating were significant. The care giving spouses expressed communication as either a need (i.e. it was absent in the relationship) or the hardest part of their relationship. While their communication style had not changed from previous years, in the context of living with advanced MS, old styles of relating to one another seemed to hinder the ability of these couples to have some of the meaningful discussions necessary when planning for changes in health.

These couples also expressed a hope for a cure for MS in their lifetimes. Four of the ten couples expressed that they were waiting or hoping for a cure and three of them fell into this category. The fourth couple did not qualify for the Hoping For A Cure category as they had discussed living options in case her MS worsened including nursing homes, though not ACP. It is worth noting that when a cure was hoped for—sometimes by the care giving spouse, sometimes by the affected spouse—it was only hoped for explicitly by one partner. The other partner remained silent on the subject, or in several cases, remarked in their private interview that their spouse didn't understand MS or was in denial.

It is important to point out that these couples are not negligent or willfully ignoring their situation. They had rebuilt their homes to accommodate the needs of the affected spouse. They were aware of the progressive nature of MS and thought about what the future may bring. These couples adapted successfully to changes in the past and seemed to be applying that strategy to their admittedly uncertain future. As one husband put it, “farther out, I think that's going to be a challenge. I think I see a challenge. I could plan on it but it probably wouldn't work out. You can plan for disaster all you want.” (care giving spouse, couple 10). He saw change in the future, but had not discussed it with his wife nor planned for the changes; he could catastrophize, but preferred to focus on today.

While his assertion is true—that you cannot plan for every disaster successfully—the key point for healthcare professionals is that these couples still worry about the future, even if they take no action on it. This lack of self-efficacy has been associated with negative health outcomes for the partner with MS, as well as relational strain (Fraser & Polito, 2007; Wollin et al, 2009; Schwartz & Kraft, 1999). Supporting couples as they adapt to role changes and helping couples avoid relational strain is a stated research agenda item in the field of MS research (Gulick 1998; Kraft et al, 2008). These couples living with advanced MS that are not planning for changes in the affected partner's health may require aid from their healthcare team to spark discussion between partners about the future. Focus could be made on the ways ACP sustains the self-efficacy of the spouse with MS and how ACP can ease the unaddressed fears of the care giving spouse. However, none of these benefits will be realized if health care providers are not first willing to assess families with MS for their readiness to plan for the future and then willing to talk about what kinds of changes in health these couples might reasonably expect.

Discussion

The experiences of these ten couples show that couples affected by MS are aware that a decline in health is approaching. However being aware does not mean they are planning for those changes. In fact, the couples that had planned most fully for declines in the health of the spouse with MS were uniquely composed of a motivated and healthcare savvy spouse with MS, and a care giving spouse that had survived a life-threatening health event of their own. These couples felt confident in knowing each other's wishes despite an uncertain future and were ready to make alternate living arrangements when their healthcare needs necessitated it.

Couples that have not completed ACP may be ready to begin. These couples may require focused assessment to identify their readiness to engage in ACP as it may not be immediately obvious that they are interested in discussing this often delicate subject. Conversely, couples may have one partner that is convinced that enough planning has been done, but this may not be the case. Participants in this study that had not written an advance directive were sometimes sure they were in agreement about plans for declines in health and ACP, but their spouse was not similarly convinced. These couples may be in a good position to learn more about each other's desires for the future, if discussion is not squelched by the mistaken belief that they already know what each other wants.

Couples that have neither advance directives nor plans for more assistive living arrangements may be experiencing difficulty communicating or untreated depression of the spouse with MS. Depression is the most commonly diagnosed psychiatric disorder of people living with MS (Wallin et al, 2006), so this is of concern to those working with these couples living with MS. Additionally, depression and communication have been shown to be mutually influencing in MS dyads; with untreated depression negatively affecting communication and poor communication contributing to depression among the partners (Schwarz & Kraft, 1999).

In this study, the couples Hoping For A Cure were concerned about the future and what it may bring in health changes, but not talking together. A recent study described couples living with MS, how they related to one another and the quality of their communication. The researchers noted that a large part of the relational strain observed in the couples involved the loss of self-worth and a feeling of being out of control for the partner with MS (Starks et al, 2010). It is worth consideration that one of the common motivators for participants in this study to engage in any kind of planning for worsening health was a desire to preserve or enhance the self-efficacy of the spouse with MS. Participants with MS wanted to be able to decide for themselves. Care giving spouses wanted to make sure their partner had the opportunity to make independent decisions. For these individuals, discussing the unpredictable future could be a positive and affirming behavior. Further research is necessary to demonstrate that individuals with MS experiencing difficulty communicating with their partner could regain a sense of control through discussing ACP and plans for changes in their health.

A limitation of the study is the small sample size (n=20) which limits the transferability of this study, as does the homogeneity of the sample by ethnicity. However, the sample was diverse in age (range 42 – 75) and the couple types were diverse, including a non-cohabiting long term committed couple, married couples and a gay couple.

Conclusions

Supporting MS couples as they adapt to role changes and helping couples avoid relational strain is a stated MS research agenda item (Gulick 1996; Kraft et al, 2008). Couples living with advanced MS may require aid from their healthcare team to plan for the future. Focus could be made on the ways ACP sustains the self-efficacy of the spouse with MS. Additionally, providers may need to acknowledge communication between couples as a dimension of wellness necessary for informed health care decisions. The lived experience of these couples affirms that planning for changes in health are made in the context of the relationship.

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