

Key Points

1. Most research on the impact of chronic illness on partners focuses on caregivers and the elderly; however some of the conclusions are likely valid for diseases such as CM/SM
2. Research has shown that often a chronic disease has a larger impact on the quality of life of the partner than the patient
3. Partners may suffer from depression, exhaustion, impaired social life, and physical and emotional distress; economic hardships are also common
4. Characteristics of the partner, characteristics of the patient, and the specifics of the situation all influence the impact on the partner
5. Some partner/caregivers actually report positive aspects to the situation, such as a new meaning to life and a closer relationship with the patient

Sources

www.searchforcare.com

Source (Fig1 &2): Rees J, O'Boyle C, MacDonagh R. Quality of life: impact of chronic illness on the partner. *J R Soc Med.* 2001 Nov;94(11):563-6.

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How Chronic Illness Affects Partners

[Ed. Note: Over the course of the last year, several readers have requested more information on how Chiari and syringomyelia affect not just the patient, but their spouses and families in general. In response, we are launching a series called Family Impact. Given the limited research on CM/SM, there is not much directly written about how these conditions impact family life; however, much can be learned from research into the impact of chronic diseases in general and specific diseases - like MS, which are similar to Chiari and syringomyelia - in particular. Since the topic is new to many people, we will not limit ourselves to recently published research, and like the source for this article, will reach back to provide information that is relevant and useful.]

Although the impact of pain and disease on a patient's quality of life is an area of active and ongoing research, less attention has been paid to how a chronic disease affects the partner of the person afflicted. Some insights, however, can be gleaned from research into caregivers of chronically ill people. It is reasonable to assume that many partners become a caregiver to some degree, whether it is taking on extra chores around the house, assisting with medical issues directly, or going to work to make up for lost income.

With this in mind, Dr. Jonathan Rees and colleagues published a review of how chronic illness impacts a partner's quality of life in the November, 2001 issue of the *Journal of the Royal Society of Medicine*. In highlighting the importance of this topic, Rees points out that studies have suggested that many partners/caregivers actually report a lower quality of life than the patients themselves.

Research focused on the care of the elderly has clearly shown that caregiving has a serious impact on quality of life. In various studies, caregivers have been shown to suffer from increased stress, anxiety, depression, decreased social life, and even worsening physical health. A study by Kornblith found that the wives of prostate cancer patients reported greater psychological distress than their husbands. A study by Weitzenkamp showed that the spouses of spinal cord injured persons had higher levels of depression than the patients themselves. The burden of care is not just psychological either. Research has shown that the added stress and anxiety can lead to loss of appetite, disrupted sleep, and a generally lower level of overall health.

Rees points out that partners/caregivers are faced with many challenges and difficulties (see Figure 1). These include everything from extreme financial difficulties, to dealing with the changed relationship with their spouse, to the physical toll the added burden can bring. In addition to the extra work that a partner may be doing, the psychological stress of worrying about the future and whether their loved one is hurting and in pain can be difficult to handle. Adding to the problem is a sense of social isolation that overcomes many partners. Even if they have the time and energy to go to social functions - such as a neighborhood gathering - they may not want to go alone. This can lead to withdrawal and social isolation, increased feelings of having to do everything themselves and adding to the psychological burden.

Research has shown that a number of factors influence the impact a chronic illness has on a partner, including factors involving the caregiver, the patient, and the situation itself. Some research has shown that women suffer more of an impact than men, and younger women in particular. Also caregivers who live alone with their partners and families with lower incomes are especially susceptible to the burden of a chronic illness.

In looking at the patient, somewhat surprisingly, it is not clear if there is a link between the severity of the illness and the impact it has on the partner. Some research has found such a link, while other research has reported the opposite. There is also research suggesting that the mental health of the patient may be more important than their physical health in predicting how much of an impact it will have on the partner.

It appears that the type of care required also influences the impact on the partner. Extra, impersonal chores, such as shopping, are often perceived as less of a burden than if the care required is personal in nature, such as feeding or bathing. In addition, restrictions brought on by the situation, such as needing to be home most of the time, can increase the negative impact on the partner.

Given all the negatives discussed so far, it may be hard to believe, but many partner/caregivers actually report positive aspects their situation. Some people report finding a new meaning to life and an increase in self-worth and self-esteem. In addition, some people report that they feel closer to their spouses as a result of the situation and that the situation has made them a more caring person in general.

Anecdotally, this publication once posed the question whether anything positive came out of anyone's experience with Chiari or SM. While some people emphatically stated NO, many people reported that their experience had changed their views on life, changed their priorities, changed their relationships, and changed how they interact with people, all for the better.

Rees concludes his review by recommending that doctors and clinicians recognize the burden that is placed on partners and caregivers (see Figure 2) and respond accordingly. Given that the burden can adversely affect not only the partner's psychological, but physical health as well, Rees recommends that doctors assess the partner's needs separate from the patient's and should encourage partners to express their concerns and points of view freely.

<u>Figure 1</u> <u>Potential Partner/Caregiver Problems</u>	<u>Figure 2</u> <u>What Doctors Can Do To Help Partners/Caregivers</u>	<u>Figure 3</u> <u>Signs Of Caregiver Burnout</u>
<ul style="list-style-type: none"> • Fear of the future • Anxiety and depression • Worsening relationship with partner • Reduced or absent sex life • Fatigue, lack of sleep • Social withdrawal - unable to attend social functions, don't want to do things alone • Financial difficulties - lack of income, increased medical costs 	<ul style="list-style-type: none"> • Recognize the burden placed on partners and offer appropriate support • Encourage partners to be present during appointments • Address partner concerns in addition to patient concerns • Assess the partner/caregiver's needs separately from the patient • Provide information on support to the partner 	<ul style="list-style-type: none"> • Withdrawing from friends and family • No longer participating in activities you enjoy • Feeling helpless and hopeless frequently • Loss of appetite • Altered sleep patterns • Getting sick more often • Fantasizing about escape • Feeling you want to hurt yourself or the person you are caring for

Clearly, the burden of a chronic illness falls not just on a patient, but on their family as well. Even if someone is able to mostly care for themselves, a spouse may have to take on extra duties around the house or with the kids, or even work extra hours to make enough money. Beyond this, both patient and partner must adjust to what has happened and how it will affect their life going forward.

Although not addressed in the review by Rees, caregiver burnout is a recognized phenomenon and caregivers should be aware of the signs (see Figure 3). Anyone feeling too much stress or anxiety should seek out help or talk with their doctor.

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