Annotated Bibliography

Source #1:

In this review, Francesco Pagnini summarizes several studies that explored the psychological wellbeing of patients with Amyotrophic Lateral Sclerosis (ALS), as well as the wellbeing of their caregivers. Pagnini’s purpose to this paper is to summarize significant findings about the quality of life (QoL) and psychological well-being in the ALS field. Pagnini defines “quality of life” for the reader, introduces his biopsychosocial approach, and clarifies the faulty assumption that alleviation of pain symptoms will automatically relieve psychological symptoms.

Pagnini separates his paper into several parts (i.e. quality of life, pain, hope and hopelessness, spiritual and existential well-being, depression and anxiety) that apply to both the ALS patients and their caregivers. Summarizing multiple studies from each of these subject areas in depth, Pagnini is able to convey his point and conclusion that many successful studies have been completed and were effective, but that there have been some limitations to each study that need to be tackled and researched more in-depth. For example, there is not any current research that explores what can be done to improve the psychological well-being of ALS patients and caregivers or the efficacy, cost-effectiveness, and advantages or disadvantages of these psychological interventions.

Source #2:


doi:10.1089/acm.2013.0268

In their paper, Francesco Pagnini and colleagues began by discussing that mindfulness meditation has been proven to be an effective technique for reducing stress in chronic diseases. No study has explored the effects of mindfulness meditation on patients with ALS, so Pagnini’s group designed a study to test this. In the paper, they discussed their experiment where they designed a mindfulness meditation program specifically for ALS patients. However, in this paper, the authors do not report the effectiveness of meditation for ALS patients.
Source #3: 

In this paper, Kathrin Boerner and Steven E. Mock discuss the impact of ALS patient suffering on the psychological well-being of the caregiver. The authors point out that the physical impairment of the ALS patient may not be as important for the well-being of the caregiver as the psychological suffering of the ALS patient. There are few studies that examine the impact of patient suffering (physical, psychological, and spiritual) on caregiver well-being. This paper reports the findings of a study with 52 ALS patients and their caregivers. To better understand how patient suffering impacts caregiver well-being, the quality of the relationship between caregiver and patient as well as the degree of compassion from the caregiver was investigated. The findings suggest that important interventions for ALS patients should include how caregivers are affected by the suffering experienced by the patients as well as provide support to improve the quality of relationships between them. The findings support the idea that addressing the needs of the caregiver can benefit not only the caregiver, but also the QoL of ALS patients.

Source #4: 

doi:10.1080/17482960801934148

This study of ALS family caregivers utilizes a qualitative approach to study their needs. A small sample of 19 families participate in two phases of interviews. In the first phase, information was collected about the caregivers’ personal needs since the diagnosis. The second phase, caregivers were asked to rate the importance of the needs from least important to most important. The results indicate that the caregivers’ needs can be described in a 4 stage model. The 4 stages included: Early Coping and Adjustment, Maintenance, Transition to End of Stage, and Coping with Change and Loss. As the disease progresses, more intense demands are placed on the caregivers. The results of this study can help inform health professionals to provide interventions for the families while they care for terminally ill family members. Furthermore, providing these type of interventions can increase the QoL for both patients and caregivers.
Future studies can attempt to address this and understand how these interventions can benefit the QoL.

Source #5:

This study was conducted to determine the correlations between social problem solving, relationship satisfaction, spirituality, and religiousness and quality of life (QoL) and psychological morbidity in caregivers of patients with amyotrophic lateral sclerosis. 75 ALS primary caregivers participated in this study. The strongest correlation reported occurred between the social problem solving skills of the caregiver and the QoL and psychological morbidity. Caregivers’ best QoL and lowest psychological morbidity occurred in those who had a positive problem orientation, approaching problems as opportunities that will have some positive outcome, rather than a negative problem orientation. This correlation has “significant therapeutic implications.” Because these kinds of problem solving skills can be taught, caregivers who are taught to acquire these skills can notably increase their overall QoL and psychological health.

Source #6:

Francesco Tramonti and colleagues conducted a study to examine the correlation between different measures of quality of life, physical status, and mood status in ALS patients. They emphasize the necessity to adopt a wide perspective in order to approach mitigating the burden placed on ALS patients and caregivers. The findings suggest that mood status is more related to physical quality of life than it is to subjective, psychological accounts of quality of life. The authors suggest that further research could be conducted regarding the study of depression in ALS patients and caregivers, as well as the identification of differences in age and gender.

Source #7:
Book chapter 20: Family Caregivers in Amyotrophic Lateral Sclerosis

In this particular chapter, Judith Rabkin and Steven Albert discuss the significant role the ALS caregivers play. Caregivers play a central role in the patient’s quality of life. Rabkin and Albert emphasize that while caregiving can obviously be very burdensome and problematic, there are many rewarding aspects of caregiving as well. Most families are brought closer together through this experience and many caregivers succeed in finding meaning in such a difficult time. Rabkin and Albert assert that caregivers need just as much support as patients do. They need emotional support, as well as practical support, and it is crucial that caregivers maintain a positive mood as often as possible. Some predictors of caregiver wellbeing include maintaining a positive bond, spirituality, an optimistic outlook, and finding a positive meaning in caregiving.

Source #8:

doi:10.1177/0269216312455729

In this 10-year literature review of 59 scholarly articles on family caregiving for families with motor neurone diseases published from January 2000 through April 2011, the authors document the burden experienced by the caregivers. The databases searched as well as the terms used are presented in the article. The section on Caregiver Burden and QOL is most relevant for my research topic. In particular, the authors suggest that caregiver burden may be lessened by providing social support to the caregivers. Family caregivers need a confidant to decrease the levels of isolation experienced by caregivers of ALS patients. Yet, for caregivers who provide prolonged care, seeking and maintaining social support can be challenging due to reduced social contacts with family and friends. Based on the research, the authors suggested interventions to improve QoL for ALS caregivers. Surprisingly, given the evidence on burden and distress experienced by caregivers, there are limited studies on interventions for families caregivers. There are 3 types of interventions that can be provided to family caregivers (1) “providing direct support to family caregivers to meet their practical and emotional needs, (2) providing education to health-care providers in order that they may better meet the emotional needs of family caregivers, and (3) providing interventions that support the existential and spiritual concerns of caregivers”. The most common interventions suggested by the findings included in this review are the interventions that can improve the social support received by family caregivers. Support
interventions can include problem solving strategies and emotional support. In addition, counseling interventions can be used to improve the quality of the relationships between ALS patients and caregivers. The authors conclude that there is a lack of research developing interventions that will improve the experience of caregiving for ALS families and also improve the care of ALS patients.

Source #9:

doi:10.1177/1359105314547244

It is widely accepted that caregiving has been associated with caregiver stress and caregiver burden. Furthermore, the negative consequences of caregiving have been the emphasis of most research in this area. As a result, more recent efforts have been focusing on the positive outcomes of the caregiving experience and the relationship to quality of life. One interesting concept that was explored in this study is the concept of benefit finding. As defined by Brand and colleagues, benefit finding refers to the “process by which people perceive positive growth in areas of relationships and spirituality and find meaning from stressful and traumatic experiences.” Benefit finding was explored in this study of caregivers as a cognitive strategy for coping with distress. Because caregivers experience stress over long time frames, studying benefit finding can help researchers understand the positive effects of the caregiving experience. In addition, interventions to help caregivers can target benefit finding as a coping mechanism for caregivers under stress. Another important concept explored in this study was the concept of social support. In fact, social support is usually perceived as an important indicator of QoL for caregivers.

The purpose of this study was to examine benefit finding as a positive predictor of caregiver QoL. In particular, the researchers hypothesized that benefit finding would be related to QoL by improving the perceived social support. The sample consisted of 84 caregivers in Ireland recruited from caregiver support groups and word of mouth. The disabilities the caregivers were caring for were mental health difficulties (68%) and physical health concerns. The measures included benefit finding (Stress Related Growth Scale), social support (Medical Outcome Study Social Support Scale), and QoL (Adult Carers Quality of Life). The findings support a mediation model. This means that when caregivers reported increased benefit finding, an increase in their perceptions of social support occurred, which led to greater perceived QoL. This is a very interesting finding, and I wonder if this would be true for caregivers of specifically ALS patients who are dealing with issues related to end of life. The findings are consistent with previous research that suggests that social support, especially having someone to talk to about caregiving and getting close emotional support, leads to better QoL for the caregiver. Social
support is one of the main factors that has been found to reduce caregiver stress, which can lead to improved QoL. What is new in this study is that benefit finding was related to increased social support, which in turn improved caregiver QoL. There are some limitations the authors pointed out. First, all the questionnaires were given at one point in time. This makes it difficult to conclude the direction of effects between benefit finding, social support, and QoL. In the future, studies can use a longitudinal design to follow patients and their caregivers over time and determine how increased benefit finding leads to an increase in social support and improvement of QoL. Second, the extent to which the findings can be generalized to other caregiving groups is not clear. The majority of participants in this study were part of a support group. It would be interesting to conduct this study with a wider range of caregivers. In addition, the type of caregivers who care for ALS may be different than the general population studied due to the end of life issues caregivers of ALS patients face. This study contributes significantly in the field of caregiver QoL by studying positive aspects of the caregiving experience. Understanding the positive aspects of caregiving can help clinicians develop interventions to reduce the caregiving burden, feelings of being overwhelmed, and lack of social support. This can be particularly helpful for ALS caregivers who may have a difficult time finding benefits or meaning in the caregiving of terminally ill patients. If improving benefit finding can also improve the perceptions of social support for ALS caregivers, this has the potential to improve the QoL of caregivers significantly as demonstrated in this study.