Program Preferences to Reduce Stress in Caregivers of Patients With Brain Tumors

Jonas J. Swartz, BA, and Stephen T. Keir, DrPH, MPH

Providing care for patients with cancer places caregivers at risk for experiencing elevated levels of stress. Caregivers of patients with brain tumors may be at increased risk because of the multifaceted needs of this patient population. As such, the authors sought to determine caregiver preferences toward various types of stress-reduction programs for a population of stressed caregivers. This information provides valuable insight for researchers designing studies to address the experiences of stressed caregivers.

At a Glance

✦ In the study, most participants reported experiencing elevated levels of stress because of caregiver responsibilities.

✦ Overall, caregivers were most interested in programs such as exercise, massage, and coping skills training to reduce stress.

✦ Reducing stress associated with caregiving stands to improve the physical health and emotional well-being of caregivers.

Caregivers of patients with brain tumors are called upon to provide physical and emotional support to patients with cancer, who have a disease trajectory that may include functional, cognitive, and neuropsychological sequelae. Most often, caregivers are family members who help loved ones with activities of daily living, such as managing finances, accompanying patients to appointments, administering medications, and providing emotional support. Providing care for a family member with cancer places a caregiver at risk for experiencing caregiver burden (Goodfellow, 2003). In addition, meeting the multifaceted needs of patients with brain tumors, a particularly vulnerable cancer population, places caregivers at increased risk for elevated levels of psychological stress (Keir et al., 2006). This article describes stress-reduction programs of interest for caregivers. The authors hope that the information will help healthcare researchers and professionals to design effective stress-reduction intervention programs for caregivers of patients with brain tumors. To better address the issue, the article links data concerning caregiver stress with caregiver preferences for programs to reduce stress using Sherwood et al.’s (2004) conceptual model regarding caregiver stress.

Stress and Caregiving

Looking at the factors associated with stress in the cancer caregiver population is not a new field of research. Studies have documented that age, educational level, and ability to participate in valued activities play a role in caregivers’ levels of emotional stress (Burns, Tanner, Preece, & Cameron, 1981; Goldstein et al., 2004; Sansoni, Vellone, & Piras, 2004). In addition, caring for patients with dementia and problems with cognition also has been reported to increase stress (Covinsky et al., 2005).

The stress associated with caregiving has been shown to negatively affect caregiver health. Previous studies have indicated that being a caregiver is linked to negative psychological and physiologic health consequences. Psychological disorders reported include panic disorder, major depressive disorder, post-traumatic stress disorder, and generalized anxiety disorder (Sansoni et al., 2004; Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005; Winslow, 2003). Physiologically, caregivers have been reported to experience high incidences of respiratory infections, hypertension, eating disorders, and poor health habits, as well as reduction in immune function (Baron, Cutrona, Hicklin, Russell, & Lubaroff, 1990; Carter & Chang, 2000; Chentsova-Dutton et al., 2000; Mittelman, Roth, Haley, & Zarit, 2004).

Brain tumors, regardless of grade, can be responsible for physical and psychological changes in patients. The changes result from the disease and treatment and depend on the...
location and size of the brain tumor. Symptoms can include headaches, fatigue, and seizures. Patients with brain tumors also may have changes in vision, hearing, smell, speech, motor ability, strength, coordination, balance, memory, and learning ability (Lovel, 2004). Other changes in mood and cognitive impairment may include depression, dementia, anxiety, aggression, memory impairment, and attention impairment (Litofsky et al., 2004; Pelletier, Verhoef, Khatri, & Hagen, 2002). The diverse symptomatology corresponds to the complexity of demands on and potential stressors for caregivers of patients with brain tumors.

Sherwood et al. (2004) developed a conceptual model to help healthcare providers recognize sources of stress for caregivers of patients with brain tumors. The model proposes that caregivers respond physically and emotionally to patients’ tumors and neurologic status. Many patients with brain tumors have often-changing combinations of physical, cognitive, and neurologic manifestations of the disease. Caregivers use internal resources such as physical and emotional health and external resources such as social support and home healthcare providers to help fulfill the care demands of patients. Finally, providing care elicits emotional and physical responses from caregivers. The feedback loop changes constantly with the changing status of the patient (Sherwood et al.). Building on Sherwood et al.’s model, the current study looked at different types of stress-reduction programs that would develop internal resources for caregivers.

Caregiver Stress and Stress-Reduction Programs

Research studies undertaken at the Tug McGraw Research Center (TMRC) in the Preston Robert Tisch Brain Tumor Center at Duke University in Durham, NC, have shown that a high percentage (72%) of the caregiver population report elevated levels of stress. Several characteristics were correlated with higher levels of perceived stress. Men reported more stress than women. Caregivers of patients with low-grade tumors were more stressed than caregivers of patients with high-grade tumors. Caregivers who had attained higher levels of education (college and advanced degrees) experienced and reported more stress. Younger caregivers of patients with low-grade tumors also experienced and reported more stress (Keir et al., 2006).

Prior research conducted at the TMRC indicated that the vast majority (81%) of caregivers wanted to learn about stress-reduction techniques and programs and believed in their potential efficacy (87%). Caregivers also indicated that participating in stress-reduction programs was feasible, as 70% of the sample could find time to participate in a program for a period of 30 minutes at least twice a week. In addition, caregivers preferred to participate in programs at home (90%), either alone (37%) or with the patient for whom they were providing care (28%) (Keir et al., 2006). The data clearly indicate that caregivers are interested in and believe that they are able to participate in some form of stress-reduction program.

Table 1 outlines demographic characteristics of the sample in the current study. In addition to assessing the stress levels of caregivers, the researchers asked them to indicate on a list of stress-reduction techniques whether they were participating in any such programs or activities currently. If participants responded “yes,” they were asked to rate their experiences (“negative,” “neutral,” or “positive”). The research questionnaire and list focused on three broad types of stress-reduction techniques.

- Body-focused techniques (e.g., deep soft-belly breathing, qi gong, tai chi, yoga, progressive muscle relaxation, massage, exercise)
- Mind-body techniques (e.g., meditation, guided imagery, biofeedback)
- Skill-building techniques (e.g., coping skills training)

The stress-reduction techniques included in the study were selected by a panel of clinicians and researchers who believed that the techniques could be undertaken safely or modified to fit the needs of the general caregiver population; the techniques had been shown to reduce stress in other populations. Programs that make use of massage have been shown not only to reduce stress, anxiety, fatigue, and perceived burden in caregivers of patients with cancer but also to increase immune function (Goodfellow, 2003; Rexilius, Mundy, Erickson Megel, & Agrawal, 2002). Exercise training, including muscle strength, cardiovascular fitness, relaxation, body awareness,
and massage, have demonstrated reductions in stress and have helped to mitigate stress and reduce effects of caregiver burden across heterogeneous groups of caregivers of patients with cancer (Molloy et al., 2006). Interventions involving meditation and yoga have been found to be useful in improving physical and emotional functioning and may improve affect, coping, physical well-being, and stress management for familial caregivers (Waelde, Thompson, & Gallagher-Thompson, 2004). The therapeutic benefits of tai chi, including stress reduction, have been explored in a number of populations, including patients with cancer and caregivers (Kuramoto, 2006; Mansky et al., 2006). Relaxation techniques, such as progressive muscle relaxation and deep soft-belly breathing, have been shown to help patients with cancer and other populations with stress, anxiety, and depression (Decker, Cline-Elsen, & Gallagher, 1992). Guided imagery has been shown to reduce stress and anxiety in patients waiting for basic medical treatments, such as intramuscular injection (Toth et al., 2007).

Mindfulness-based stress-reduction programs, such as meditation, were proven to reduce stress by 32% in caregivers of children with chronic conditions (Minor, Carlson, Mackenzie, Zernicke, & Jones, 2006). They also have been shown to improve quality of life, mood, and symptoms associated with stress in outpatients with prostate or breast cancer (Antoni et al., 2006; Carlson, Speca, Patel, & Goodyear, 2004). Coping skills training has been effective in reducing stress levels and increasing quality of life in familial caregivers of hospice patients with advanced cancer (McMillan et al., 2006). Biofeedback techniques have been used to help caregivers understand more about themselves and to allow them to better understand how to control and regulate stress response (Webster, 1997).

To design targeted stress-reduction programs for caregivers of patients with brain tumors, the researchers looked at the preferences for certain stress-reduction and made recommendations concerning stress-reduction interventions they would most likely find interesting. Table 2 identifies caregiver preferences for certain stress-reduction programs. The table provides preference information based on overall interest, gender, stress status, and tumor grade. Overall, male participants ranked exercise, massage, meditation, and deep soft-belly breathing as preferred interventions to reduce stress; female participants preferred exercise, massage, coping skills training, and progressive muscle relaxation. The findings suggest that elevated levels of stress increase caregivers’ desire to take part in stress-reduction programs. Forty-five percent of stressed male caregivers reported interest in participating in a stress-reduction program compared to 38% of the total male caregiver population. Stressed male caregivers reported being most interested in massage (69%), meditation (69%), exercise (63%), and progressive muscle relaxation (50%). Fifty-one percent of stressed female caregivers reported interest in participating in a stress-reduction program as compared to 46% of the total female caregiver population. The effect of education on program preferences could only be ascertained for female participants because of insufficient numbers in groups of male caregivers. Stressed female caregivers ranked exercise (78%), massage (70%), coping skills training (63%), and progressive muscle relaxation (59%) as preferred methods of stress reduction.

Stressed women providing care for patients with grade I or II (low-grade) tumors reported more interest in participating in 8 of 11 programs presented to them in the study, suggesting that caregivers of patients with low-grade tumors may be more likely to take part in stress-reduction programs. In general, patients with low-grade tumors live more independent lives and require less care than their counterparts with high-grade tumors, which may allow the caregivers more freedom to participate in activities outside of their caregiver role. In terms of educational background, women with college degrees were often twice as likely to want to participate in stress-reduction programs as compared to women with high school education (see Table 3). Female caregivers of patients with low-grade tumors were most interested in participating in programs that involved exercise (88%), coping skills training (75%), and guided imagery (75%) to reduce stress.

### Table 2. Intervention Preferences: Overall Interest and Interest by Gender, Stress Status, and Tumor Grade

<table>
<thead>
<tr>
<th>INTERVENTION</th>
<th>OVERALL (N = 60)</th>
<th>BY GENDER</th>
<th></th>
<th>BY STRESS STATUS</th>
<th></th>
<th>BY TUMOR GRADE (I OR II)</th>
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<th>BY TUMOR GRADE (III OR IV)</th>
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<tr>
<td></td>
<td>n %</td>
<td>MEN (N = 20)</td>
<td>WOMEN (N = 40)</td>
<td>MEN (N = 16)</td>
<td>WOMEN (N = 27)</td>
<td>MEN (N = 1)</td>
<td>WOMEN (N = 8)</td>
<td>MEN (N = 15)</td>
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<tr>
<td>Exercise</td>
<td>44 73</td>
<td>14 70</td>
<td>30 75</td>
<td>10 63</td>
<td>21 78</td>
<td>– –</td>
<td>7 89</td>
<td>9 60</td>
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<tr>
<td>Massage</td>
<td>40 66</td>
<td>14 70</td>
<td>26 65</td>
<td>11 69</td>
<td>19 70</td>
<td>– –</td>
<td>5 63</td>
<td>11 73</td>
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<tr>
<td>Coping skills training</td>
<td>30 50</td>
<td>7 35</td>
<td>23 58</td>
<td>6 38</td>
<td>17 63</td>
<td>– –</td>
<td>6 75</td>
<td>6 40</td>
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<tr>
<td>Progressive muscle relaxation</td>
<td>29 48</td>
<td>9 45</td>
<td>20 50</td>
<td>8 50</td>
<td>16 59</td>
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<td>4 27</td>
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<tr>
<td>Deep soft-belly breathing</td>
<td>28 47</td>
<td>10 50</td>
<td>18 45</td>
<td>4 25</td>
<td>13 48</td>
<td>– –</td>
<td>3 38</td>
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<tr>
<td>Meditation</td>
<td>28 47</td>
<td>11 55</td>
<td>17 43</td>
<td>11 69</td>
<td>14 52</td>
<td>– –</td>
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<td>8 53</td>
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<tr>
<td>Yoga</td>
<td>25 42</td>
<td>6 30</td>
<td>19 48</td>
<td>6 38</td>
<td>14 52</td>
<td>– –</td>
<td>5 63</td>
<td>11 73</td>
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<tr>
<td>Guided imagery</td>
<td>22 37</td>
<td>7 35</td>
<td>15 38</td>
<td>7 44</td>
<td>12 44</td>
<td>– –</td>
<td>6 75</td>
<td>7 47</td>
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<tr>
<td>Biofeedback</td>
<td>18 30</td>
<td>6 30</td>
<td>12 30</td>
<td>6 38</td>
<td>10 37</td>
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<td>Tai chi</td>
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<td>4 25</td>
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<td>– –</td>
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<td>Qi quoung</td>
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Conclusion

The results of the study are encouraging. Although caregivers of patients are indeed stressed, they want information to reduce stress and believe that stress-reduction programs and interventions can help. Furthermore, the authors believe that the programs caregivers preferred could be modified safely to the health status of most caregivers. Caregivers preferred to receive information and follow-up via readily available, inexpensive forms of communication, such as e-mail and postal correspondence.

The information from the study can be applied using Sherwood et al.’s (2004) conceptual model for caregivers of patients with brain tumors. Because studies have shown that caregivers do, in fact, demonstrate emotional responses to stress, healthcare providers can intervene to suggest or facilitate external resources to help them deal with stress. Specifically, caregivers may welcome information about exercise and massage for stress reduction. Stress reduction, if effective, could improve the physical health and emotional well-being of caregivers. This, in turn, would make caregivers better equipped to make difficult decisions for loved ones with brain tumors.

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References


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