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Role of a Medical Social Worker in Improving Quality of Life for Patients with Advanced Cancer with a Structured Multidisciplinary Intervention

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ABSTRACT. *Background:* Patients with advanced cancer face multiple challenges to their quality of life (QOL). The goal of this study was to

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investigate the impact of participation in a multidisciplinary intervention, including a social service component, on improving the QOL of patients with advanced cancer undergoing radiation therapy.

Design: A total of 115 participants with newly diagnosed advanced stage cancer, who were receiving radiation therapy, were randomly assigned to either participate in an 8-session structured multidisciplinary intervention or to receive standard care. Each 90-minute session was led by either a psychologist or psychiatrist and co-led with a nurse, physical therapist, chaplain, and/or social worker. The sessions were designed to address the domains that impact QOL: emotional, spiritual, physical, and social domains (support, community resources, financial and legal issues, and advance directives). QOL was assessed, at baseline, 4 (end of treatment), 8 and 27 weeks. The primary endpoint was overall QOL assessed on a 0-100 scale at Week 4.

Results: A total of 115 patients were enrolled from October 2, 2000 to October 28, 2002. Overall QOL at Week 4 averaged 10 points higher in the intervention group than in the control group (80 vs. 70 points, $p = 0.047$) which was an increase of 3% from baseline in the intervention group versus a decrease of 9% in the control group ($p = 0.009$). Of the subscores reflecting patient's opinion regarding their QOL, there was improvement in all social domains which contributed to the overall improvement in QOL. Significant changes from baseline to Week 4 scores were seen in the areas of financial concerns ($p = 0.025$) and legal issues ($p = 0.048$).

Conclusions: A social work component within a structured multidisciplinary intervention results in significant advantages in the social domain of QOL, and contributes to clinically meaningful improvements in the overall QOL for patients with advanced cancer undergoing active medical treatment. Numerous studies have documented the financial burdens and social changes that may occur with the diagnosis of cancer. However, previous research has not examined the role of a social worker in providing financial, social, and legal education, in a structured multidisciplinary intervention, and its direct impact on QOL. Outlined in this paper is the role of the medical social worker in a clinical trial, how education was provided and strategies for future interventions. doi:10.1300/J077v25n04_07 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2007 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. Quality of life, group intervention, advanced cancer, multidisciplinary, education

INTRODUCTION

Quality of life (QOL) is defined as a multidimensional construct that incorporates the five domains of function: physical, mental, psychological, social, and spiritual domains (Aaronson, Meyerowitz, & Bard, 1991; Cella, 1992, 1996; Rummans, Bostwick, & Clark, 2000; Sloan, Cella, Frost et al., 2002; Spilker, 1996). Patients diagnosed with advanced cancer and undergoing cancer treatment face multiple challenges to their QOL. Financial and legal concerns, within the social domain, have been identified by many cancer patients as negatively affecting their QOL. Although cancer patients have frequently identified having these unmet social needs, there is minimal published research available examining how to address and improve these social concerns.

Social concerns impact many adults in our country. For example, a recent poll revealed the high frequency of Americans having concerns about living with chronic medical conditions. Cancer survivorship has become a significant chronic illness in the United States (Short & Mallonee, 2006). Results of the Harris Interactive Survey indicated that “2/3 of Americans who do not have a chronic condition . . . believe they are likely to develop a chronic condition. Many worry that when the time comes they will be unable to afford needed medical care, lose their independence and become a burden to their families” (*Certified Case Management News*, 2001). This worry may be the result of being unaware of what resources are available for medical patients and which services to access either through their health care provider or community resources.

In 1996, John Hancock Mutual Life Insurance and the National Council on the Aging completed a survey of 1,000 adult Americans regarding their financial knowledge and confidence regarding health, finances, and other topics. Cutler (1997) concluded that the lowest levels of financial literacy were in the area of paying for health care and long-term care. Adults were not as well informed as they thought they were, particularly regarding the various options available for financial support. In support of these findings, researchers, through using telephone interview, learned that a medical condition frequently initiated a financially devastating series of events beginning with unexpected high deductibles, copayment requirements and uncovered medical services (Dehn, 2005). Financial concerns can continue after diagnosis and treatment. Of 1,433 cancer survivors interviewed over telephone, 13% of all survivors had quit working for cancer-related reasons within 4 years of diagnosis (Short, Vasey et al., 2005).

Owing to the limited published information regarding how to potentially address these unmet social concerns in cancer populations, investigators can examine the literature regarding patients' lack of knowledge about financial options and the prevalence of financial hardships experienced in the general medical population. In 2001, Oliver and colleagues studied the effects of social support and education on health care costs for patients with fibromyalgia. This study did not reveal differences in health care costs among participants in either of the experimental groups (social support vs. social support and education) or the control group (no intervention). Yet significant decreases in the sub area of helplessness were found for participants in all groups ($p = 0.011$). However, a one-way repeated measure ANCOVA revealed participants in the experimental group that received social support and education showed significantly less helplessness at the one-year assessment than participants in the experimental group that received social support only and the control group ($p < 0.0001$) (Oliver, Cronon, Walen, & Tomita, 2001). This study supports the premise that education can improve QOL by decreasing perceived helplessness, which is frequently experienced by those facing chronic, life threatening medical conditions.

One dominant theme of contemporary medical/legal doctrine is patient autonomy (Basanta, 2002). An advance directive, supported by the Self-Determination Act (Federal Law, 1995; Short & Vargo, 2006), is one way in which an individual may state personal opinions regarding the care of their person prior to an event that would cause them to be unable to direct their care themselves. A study examining end-of-life issues for the elderly concluded that receiving written information and attending meetings with a facilitator, contributed to both the patient and the patient's family having increased knowledge about advance directive planning. The participating patient was less willing to receive life-sustaining treatments than those in the control group who received only the advance directive form (Matulonis, 2004). It is suggested by this study that use of a social worker or nurse to initiate the conversation for providing education on advance directives, may enable the patients and their physicians to continue the dialogue at a meaningful level, thus allowing the application of the advance directive to be more useful (Angelos, 2000).

The Americans with Disabilities Act (ADA) and Family & Medical Leave Act (FMLA) are examples of laws available to support and protect patients and families (Short & Vargo, 2006; United States Department of Health and Human Services, 1993; National Endowment for Financial Education, 2004). The extent of oncology patients' and families'

awareness of these laws is uncertain. A study on long-term breast cancer survivors suggested that healthcare professionals and cancer survivors would benefit from education regarding the positive and negative effects of disclosure, and advocacy against work and insurance discrimination (Stewart et al., 2001).

Thus, education provided by a medical social worker in the areas of financial and legal issues and community resources can potentially decrease feelings of helplessness and correct misguided understandings about options available to cancer patients as resources. Lack of education in these areas can cause unwanted distress, confusion, and potentially poor decision making. Therefore, it is our premise that a social work component within a structured multidisciplinary intervention will contribute to improvement in the overall QOL for patients with advanced cancer under going medical treatment (Cutler, 1997; O'Kane, 2002; Oliver et al., 2001). The purpose of this paper is to present a sub analysis of results from a larger study (Rummans et al., 2006). We will specifically examine the benefits of a multidisciplinary intervention that contains a social work component on overall QOL, social support, financial concerns, and legal issues.

METHODS

Design

A randomized, stratified, two-group, controlled clinical trial was employed to compare the efficacy of a structured multidisciplinary intervention in maintaining overall QOL of patients aged 18 and above with advanced cancer, receiving radiation treatment. Patients were enrolled into the study and then randomly assigned to receive a multidisciplinary intervention for eight sessions or receive standard care which provided access to supportive services, as requested (Rummans, Clark et al., 2002). Randomization was based on a Pocock and Simon balance scheme with three stratification factors: type of malignant disease (brain, head and neck, lung, ovarian, gastrointestinal), other ECOG performance status (0, 1, 2), and age (<50, >50) (Pocock & Simon, 1975). When new persons were entered into the study, the Cancer Center randomization center was notified and they subsequently notified the investigators of assignment to intervention or control group. The primary endpoint was overall QOL measured by a single-item linear analogue scale at the end of the intervention or at 4 weeks, to assess QOL (Spitzer, Dobson, Hall

et al., 1981). The design was reviewed and approved by the Institutional Review Board of the medical center. Details of the methodology regarding this study are described elsewhere (Rummans et al., 2006).

Intervention

The multidisciplinary intervention consisted of 90-minute sessions designed to address the emotional, spiritual, physical, psychological, and social domains of QOL. Structured sessions began with 20 minutes of conditioning exercises conducted by a physical therapist followed by education information, cognitive-behavioral strategies for coping, discussion, and support (caring for a cancer patients' diverse and multidimensional social needs). Each session had a theme focused on one or more of the five domains of QOL and concluded with a 10-20 minute guided relaxation exercise. Topics included goal setting, prioritization, assertiveness, stress management, problem-solving, grief, guilt, hope, rituals, religious beliefs and treatment, death and after life, challenged belief system, meaning and purpose, treatment and treatment side effects, dealing with symptoms, dealing with stress, communication with others, utilizing support systems, dealing with finances, living wills, and planning for medical care when home. Each session was lead by either a psychologist or psychiatrist and depending on the theme, co-led with a nurse, chaplain, and/or social worker.

Social Domain Component of Intervention

The social worker provided structure information in areas of support, community resources, financial, and legal issues (advance directives). The intervention organized this information to be provided in 15 minutes at Sessions 3 and 5. However, the actual estimated time per session was 20-30 minutes. In addition to session content, participants received written materials and we gave contact information for resources at the cancer center and in their home communities. In Session 3, financial information was discussed. Areas reviewed were strategies regarding organization of personal finances, contacts and resources, private and federal disability and insurance (third party, Medicaid, Medicare, High Risk, etc.). Since there was extensive information available on all these topics, a general overview was given and then with participants' guidance, education was given regarding their specific situation. Each session stressed the fact that if one organized and planned from the beginning, in small steps, the task of handling financial affairs is not so overwhelming.

In Session 5, community resources and legal issues (advance directives) were discussed. Encouragement was given for participants to prepare for any travel plans, coordinate local physician care, and locate resources in their hometown. Specific information was given on resources available nationwide that could help them access local services, such as the American Cancer Society, Patient Advocate foundation, and local hospital social workers. The study social worker also discussed areas that the participants may want to consider seeking assistance for such as durable medical equipment, transportation, home health care, and hospice services, and how to access these services. History of legal and procedural development of the advance directive was reviewed. The study social worker discussed the different names that the forms go by in different states and the purposes they have. Questions were answered that clarified different state laws, depending on where participants resided. The term “code status” and language to use in the form were also discussed. It was stressed to the participants that the overall intent of the advance directive is to (1) ensure one’s right to express preferences as a patient even when you cannot communicate, (2) give direction to your loved ones and your physician, (3) designate a spokesperson, and (4) facilitate verbal communication regarding advanced care planning. It was reviewed as well such that it was not a legal requirement to have an advance directive and a person could choose not to complete a form.

Outcome Measures

Spitzer QOL Uniscale and Linear Analogue Self Assessment (LASA) scales were used to measure the primary and secondary outcomes (Bretscher, Rummans, Sloan et al., 1999; Grunberg, Groshen, Steingass et al. 1996; Gudex, Dolan, Kind et al., 1996). Overall QOL was measured by the Spitzer QOL Uniscale and the sub constructs of QOL were assessed by the series of LASA items that have been used in a number of oncology trials (Sloan, Symonds, Vargas-Chanes et al., 2003). The LASAs used in this study consisted of 12 items, each rated on a scale from 0 (as bad as it can be) to 10 (as good as it can be). The items included ratings of overall QOL, plus cognitive, physical, emotional, social, and spiritual well-being. The social dimension included overall social well-being, social support, financial well-being, and legal concerns. Study questionnaires gathered information from participants at Weeks 4, 8, and 27 for further QOL data. The 4 and 8 week times were chosen to provide data at the end of the intervention and the short-term follow-up a month after the intervention. Week 27 was chosen to represent

longer term follow-up. Similar to other investigators our aim was to impact QOL at 6-month follow-up assessments (Manne, Ostroff, Winkel et al., 2005; Nezu, Nezu, Felgoise et al., 2003). Frequency of similar answers was tallied.

Statistical Methods

Raw summative QOL scores from each measure were converted from a 0 to 100-point scale to facilitate comparison. Low scores represent unfavorable responses to the QOL concept and high scores represent favorable responses. A difference of at least 8 points on a scale of 0-100 between groups in QOL, including social domain, would be considered clinically significant (Osoba et al., 1998; Sloan & Dueck, 2004). Descriptive statistics were used to describe the data. Mean differences between arms were tested using Kruskal-Wallis tests at 0.05 significance. Spearman correlation coefficients were used to examine associations between social domains and overall QOL, where a correlation of 0-0.5 is considered a weak relationship, 0.5-0.75 is considered a moderate relation, and 0.75-1.0 is considered a strong relationship (Nunnally & Bernstein, 1996). With a sample size of 50 patients per arm, 80% power was available to detect a difference of 0.55 times the standard deviation, using a two-tailed t-test with a 5% type I error rate (Cohen, 1988).

RESULTS

Of the possible 418 eligible patients, 115 patients were enrolled from October 2, 2000 to October 29, 2002 (57 in the intervention arm and 58 in the control arm). A total of 12 patients were excluded due to study non-adherence (3 canceled due to illness, 6 did not attend at least 5 of the 8 sessions and 3 did not complete both the baseline and Week 4 assessments) resulting in 103 participants. The treatment arms were balanced in terms of patient characteristics including gender, race, and age. The primary tumor distribution was 38% colorectal, 17% head and neck, 15% lung, 12% brain, and 18% other. This was also balanced across arms (Table 1).

Overall QOL at Week 4 averaged 8 points higher in the intervention group than in the control group (72.8 vs. 64.1, $p = 0.047$) which was a mean increase of 3.3 points from baseline in the intervention group and a decrease of 8.9 points in the control group ($p = 0.009$). In addition, changes from baseline to Week 4 were found to be clinically significant

TABLE 1. Baseline Patient Characteristics

	Intervention (N = 49)	Standard Treatment (N = 54)	p-Value
	N (%)	N (%)	
Gender			0.3241
Female	20 (40.8)	17 (31.5)	
Male	29 (59.2)	37 (68.5)	
Race			0.0520
White	49 (100)	50 (92.6)	
Not reported	0 (0)	4 (7.4)	
Age group			0.2997
< 50	7 (14.3)	12 (22.2)	
≥ 50	42 (85.7)	42 (77.8)	
Primary tumor distribution			0.8207
Brain	6 (12.2)	6 (11.1)	
Head and neck	7 (14.3)	11 (20.4)	
Lung	9 (18.4)	6 (11.1)	
GI	18 (36.7)	21 (38.9)	
Other	9 (18.4)	10 (18.5)	

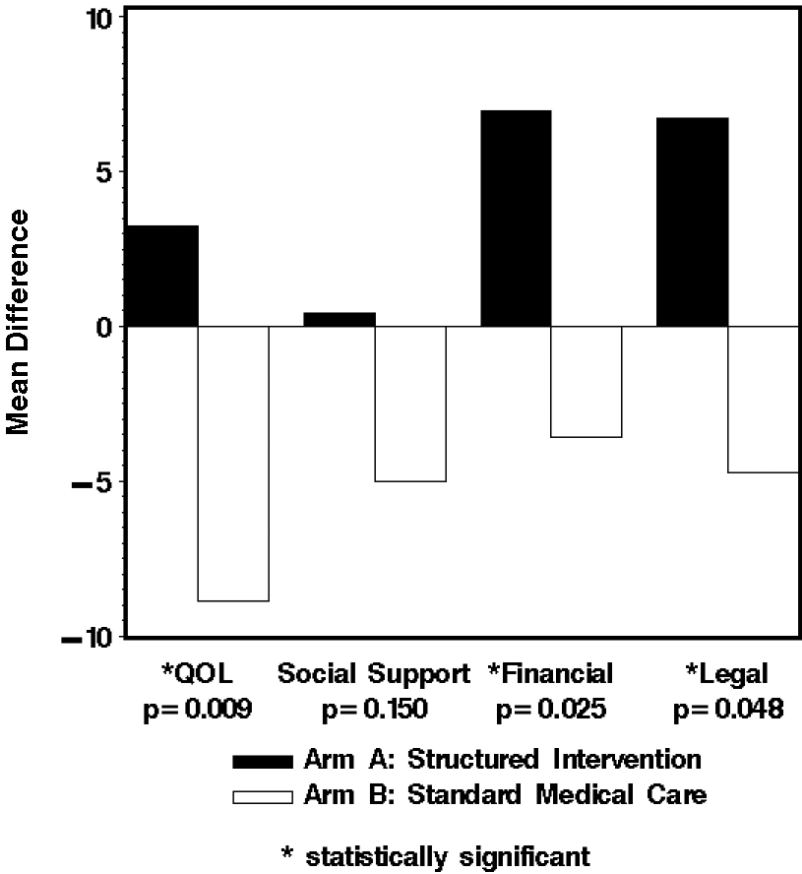
in the social domains of financial concerns ($p = 0.0250$), and legal issues ($p = 0.048$), where again patients in the intervention group improved in mean scores from baseline (7.0 and 6.7 points, respectively) and the control group declined (-3.6 and -4.7 points, respectively; Figure 1).

The correlations of overall QOL with the social constructs of social support, financial concerns, and legal issues were low across all weeks (range of $\rho = 0.17$ - 0.39 ; see Table 2).

DISCUSSION

Our findings are the first published results of a multidisciplinary intervention that provided trained professional staff to address all five domains of QOL. Previous research has not documented the role of social worker providing financial and legal information, and social support, and its direct impact on QOL. This study confirmed that a social work component within a structured multidisciplinary intervention can result in improvement in the social domain, and contribute to clinically meaningful improvements in the overall QOL for patients with advanced cancer undergoing active medical treatment. This is an important finding

FIGURE 1. Changes in Quality of Life from Baseline to Week 4



as numerous sources have documented the financial burdens and social changes that many adults experience following the diagnosis of cancer. In particular, this study has shown that financial and legal issues can be decreased with intervention.

The intervention group benefited to a greater degree than the control group with respect to financial and legal issues and social support. This, however, seems to be independent of overall QOL with the correlation amongst these variables being low. It may be explained by the fact that we are a referral center; therefore, many of our patients have good insurance coverage and come with some knowledge of advance directives.

TABLE 2. Spearman Correlation Coefficients and Probability Between Quality of Life and Social Activity, Social Support, Financial Concerns, and Legal Issues as Measured by the Linear Analogue Self-Assessment (LASA)

	LASA Overall Quality of Life				
	Baseline	Week 4	Week 8	Week 27	Overall
LASA Social Support	0.33 0.0006	0.34 0.0005	0.33 0.0011	0.34 0.0021	0.33 < 0.0001
LASA Financial	0.24 0.0157	0.22 0.0293	0.24 0.0166	0.26 0.0198	0.24 < 0.0001
LASA Legal	0.33 0.0006	0.27 0.0060	0.17 0.1030	0.39 0.0003	0.29 < 0.0001

Also, the presentation of information occurred in the early period of diagnosis. These issues may not have affected the participants until later. It is anticipated that as participants moved further into their diagnosis and treatment there would be an increase in correlation between these variables.

Cancer patients and their families in our society encounter an overwhelming amount of information in relation to their diagnosis, treatment options, and financial concerns. Patients receive information from their providers, their treatment center, their support system, and the internet. Medical personnel are well prepared to address patients' questions regarding their medical status and clinical treatment options, but most are not trained or able to provide guidance about the available resources and support that can assist patients emotionally, financially, and legally. Medical social workers have training and experience to provide tailored guidance in these important areas. This professional guidance can potentially help patients maintain some sense of personal control over their finances, legal matters, and medical decisions allowing them to focus their energies on their treatment and recovery.

Part of the study involved requesting participants' feed back on the intervention. Based on responses, education provided on legal issues (advance directives) was the most universally accepted social worker contribution. This was contrary to the concerns raised during the design phase of this study. Prior to study implementation, our team had anticipated that participants may perceive a discussion about advance directives as "the study team knowing something about their medical status that they had not yet been informed about" or that participants would view advance directives as "a form to be done only when you are dying." Therefore, focus was given on how to present this information in an inoffensive

and positive manner. We believe we were successful in this effort as responses from the participants indicated that discussion about advance directives was beneficial and it was recommended that this be included in future projects.

Less supportive feedback was received regarding the education on financial and community resources. This may be owing to the numerous individual variables involved in identifying that resources are available and pertinent to people. Examples of these variables are age, state of residency, employment, and level of disability. Each of these is a qualifier that affects the financial and community resources that are needed and made available. Participants indicated that this type of information would be helpful. Therefore, while there are difficulties in identifying the best way to provide it in a consistent, structured format, it is a topic to be included.

Limitations

This study does have several limitations, including lack of ethnic and cultural diversity of the participants, cost of the intervention that may make widespread implementation prohibitive for smaller medical facilities, and replication of the study results may be difficult due to the lack of availability of specialty staff in other settings. Another limitation was the lack of evidence that the intervention helped maintain or improve QOL beyond the 27 weeks treatment. The benefit of the intervention may have been limited because this study by design did not involve the caregivers, and given the burden that caregivers encounter, this is an important area.

A limitation perceived by the social worker during this study is that the intervention was delivered in a manner which is different from standard social work clinical practice. This relationship was not personal and interactive as would be the case in individual discussions, where information provided would be based on request or on an understanding of a patient's overall situation. It was instead delivered as part of a structured educational process where personal and sensitive information were provided without any knowledge of the participant's position in dealing with their situation—medically, socially, emotionally, or financially. Social work has not historically been part of research-based interventions and continued exploration of these issues may be beneficial for the expansion and substantiation of the social work profession.

CONCLUSIONS

The results suggest that having a Medical Social Worker as an integrated member of the health care team can be beneficial in terms of improving the QOL of patients with advanced cancer. Having specific topics to review with the patients, such as financial resources, advanced directives, and community resources may be more beneficial than having an open agenda. Using one's clinical experience to guide the selection of topics and strategies to be reviewed may help. Many patients may not be able to identify their unmet needs, or be aware of the range of valuable information that a medical social worker can deliver in a tailored manner.

In sum, our findings demonstrate that it is beneficial to involve a medical social work component in a structured multidisciplinary intervention designed to maintain the QOL of patients with advanced cancer who are receiving radiation treatment. We encourage others to further explore the potential benefits of incorporating a social work component into interventions designed for cancer patients and their caregivers, and to investigate these findings in more diverse samples of cancer patients.

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