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Patient-reported Family Distress Among Long-term Cancer Survivors

KEY WORDS

Long-term survivorship

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Two quality of life studies at the University of Nebraska Medical Center and 3 similar studies in the nursing literature were compared regarding family distress to illness scores as reported by long-term cancer survivors. All studies were cross-sectional mail surveys and used City of Hope National Medical Center questionnaires. Participants represented a broad range of survivorship in terms of diagnosis and length of survival (range of means 3–8 years). Single-item scores were compared among participants regarding the item “How distressing has your illness been for your family?” Significant levels of patient-reported family distress to illness were reported in all 5 studies. Patient survivors may have been able to recall past levels of significant family distress despite prolonged survival or they may have reported significant ongoing family distress as a result of their disease and treatment. Longitudinal assessment of patients’ and families’ quality of life is essential throughout survivorship. Future studies should identify and compare the types distress experienced by patient survivors and families over time and also measure the intensity of their distress. Interventions designed to meet their individual and collective needs, thereby decreasing their distress, are needed to improve quality of life for survivors and families.

■ Literature Review

Cancer and the Family

Research regarding quality of life (QOL) in cancer patients has been reported in the literature over the past several decades

and is considered to be an important clinical outcome in terms of treatment success and survival.¹ Quality of life is defined as an individual’s perception of their current life circumstances² and many of the instruments used to measure QOL are multidimensional, encompassing physical,^{3–8} and emotional and/or psychological well-being domains.^{3–6,8} In addition,

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measures of social well-being,^{3-6,8} family function,⁶ and spirituality^{9,10} have also been incorporated in QOL measures.¹¹

More recently, QOL research has begun to focus on the impact of cancer and treatment on families as well as patients. Family systems theory provides the necessary background to examine the effect of cancer on families.¹² A family can be defined as a social unit with shared beliefs, history, and goals,¹³ and within a family, each member acts individually and also as part of the family unit.¹² An event such as a life-threatening illness in one family member is likely to have serious impact on the other family members.^{12,14} Therefore, the distress experienced by the cancer patient will likely extend to other members of the family as well. The patient's and family's adjustment to the disease has been shown to be interrelated¹⁵ and also has considerable impact on how the disease is managed.¹²

Family members often assume responsibility for providing informal nursing care, medication management, symptom surveillance, and communication with members of the health-care team. Taking on new roles and learning new skills present a physical and psychological challenge for family members who are already dealing with the emotional upheaval of having a loved one with a life-threatening illness. In addition, the illness may represent a financial burden for some families due to expenses not covered by insurance as well as lost opportunity for income due to the caregiving role.^{16,17}

Patients and families often experience disruptions in role functioning and daily patterns of living^{12,18} as they try to reorganize their usual routines, reassign tasks, and compensate in other ways for changes in the patient's physical, psychological, and emotional well-being. Oncology nurses have often observed that a patient's diagnosis of cancer generally results in changes in family function in terms of restructuring or reprioritization. In addition, patients themselves have revealed that the experience of cancer affects their entire family.¹⁹ These role changes are one of the major stressors experienced by family members of cancer patients¹⁸ and often result in decreased QOL for both the patient and his or her family.

Research on the impact of cancer on families often focuses on the time frame immediately surrounding diagnosis and treatment, when patients and families must make many changes in their usual roles and routines to deal with the demands of the disease. Preliminary studies have reported that many aspects of life seem to change as a result of the diagnosis and treatment of cancer, but comparisons of the degree of impact and the timing of the changes experienced by patients and families have been essentially unexplored. Patient and family experiences may be similar or quite different,²⁰⁻²² and their experiences may be out of sync with one another.²¹

When treatment for cancer has ended and recovery has begun, patients and families face the additional challenge of trying to reintegrate their previous roles and responsibilities²³ and adapt to the physical or emotional changes that may have resulted from the diagnosis and treatment of the disease. This may prove difficult for patients and families who are

attempting to move forward with their lives and to reestablish routine family functioning. Exactly how the process of recovery and returning to "normal" occurs for patients and families has not been well described, and research regarding survivorship of families is lacking.¹⁵

In summary, QOL has been accepted as an appropriate outcome for evaluating patients' responses to cancer and cancer treatment. Recent research, although limited, has addressed the impact of cancer and cancer treatment on the family's QOL. However, perceptions of family distress as reported by patients have not been addressed directly and may provide information valuable in planning future studies and interventions for both patients and families.

■ Purpose

The purpose of this article is to review levels of family distress as reported by long-term cancer survivors. In reviewing QOL questionnaires, it was noted that the QOL questionnaires developed at the City of Hope (COH) for bone marrow transplant patients and for cancer survivors included an item on family distress as part of the social well-being dimension. These questionnaires had been used at the University of Nebraska Medical Center (UNMC) in 2 long-term follow-up studies of cancer patients^{24,25} and revealed high family distress as reported by patients. A Pub Med search using the keywords "City of Hope" and "quality of life" revealed 14 references from 1995 through 2002, 2 of which were combined with the 2 UNMC studies and reported in this article along with a separate article regarding a 1997 study utilizing the COH CS instrument.²⁶ The remaining articles identified through Pub Med did not report single-item scores, involved noncancer patient populations, or focused on pain or palliative care, and therefore were not included. The single item identified on both QOL questionnaires was "How distressing has your illness been for your family?" Each of the 2 questionnaires contains this item.

■ Methods

Conceptual Framework of COH QOL Questionnaires

The conceptual framework for the development of these instruments is based on the authors' conceptualization of QOL as multidimensional, including physical, psychological, social, and spiritual well-being domains,^{27,28} which are shown in their model to be interrelated (Figure 1). One of the domains, social well-being, includes aspects of the patient in relation to roles and relationships. This is where the item related to family distress is located. An impact in one domain, such as physical well-being, is likely to impact the other domains as well.⁵

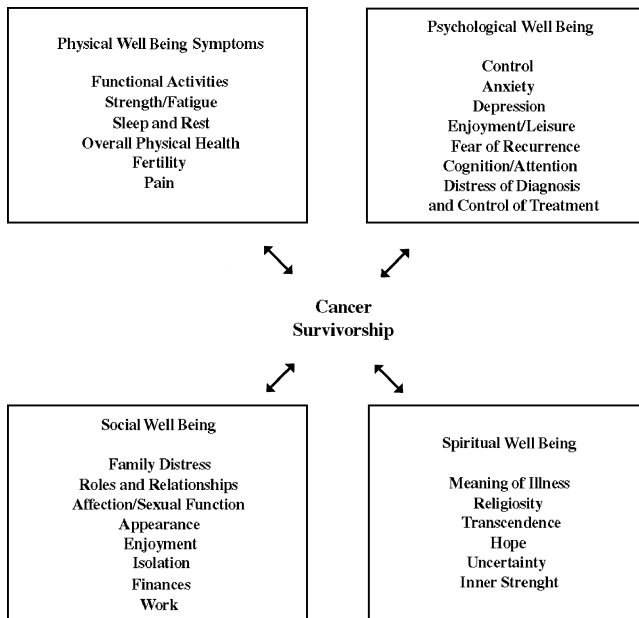


Figure 1 ■ Quality of life model applied to cancer survivors. City of Hope National Medical Center.

City of Hope National Medical Center—Quality of Life in Bone Marrow Transplant Survivors

The COH QOL-BMT (Bone Marrow Transplant) Survivors questionnaire was developed in 1989 and tested from 1990 to 1992 by Grant et al at the COH National Medical Center.

Psychometric analysis of the first version of this instrument demonstrated content validity (.90), test-retest reliability ($r = .71$, $P = .001$), total score internal consistency ($r = .85$, $P = .01$), and subscale alphas of $r = .40$ to $r = .86$ with evaluation by multiple regression analysis, factor analysis, and item correlations.²⁹ Item number 63 from this questionnaire asks patients to rate, “How distressing has your illness been for your family?” on a Likert scale ranging from 0 (*worst possible*) to 10 (*best possible*).

City of Hope National Medical Center—Quality of Life of Patient/Cancer Survivor

The COH QOL-CS (Patient/Cancer) Survivors instrument was developed by Grant et al and was revised for use in survivorship studies by Hassey-Dow and Ferrell. Psychometric analysis revealed overall test-retest reliability was .89 with subscales of physical ($r = .88$), psychological ($r = .88$), social ($r = .81$), and spiritual ($r = .90$). A second measure of reliability, internal consistency, was estimated using Cronbach alpha coefficient, a measure of agreement between items and subscales. This analysis revealed an overall $r = .93$, and subscale alphas ranged from $r = .71$ for spiritual, $r = .77$ for physical, $r = .81$ for social, and $r = .89$ for psychological well being.³⁰ This questionnaire also contains the item “How distressing has your illness been for your family?” in the social concerns subscale, using a Likert scale ranging from 0 (*worst possible*) to 10 (*best possible*).

Table 1 • City of Hope National Medical Center QOL in BMT and CS Item: “How Distressing Has Your Illness Been For Your Family?”

Study	n	Age Mean (Range)	Female	Diagnosis	Treatment Type	Time Since Diagnosis/Treatment, Mean in Months (Range)	Family Distress, Item Score (SD)	Rank, Most Stressful of All Subscale Items
UNMC (Lynch) 2000	218	57 at treatment (18–87)	56%	hematologic, 100% (lymphoma)	transplant and nontransplant	94 (34–218)	4.1 (3.1)	3rd
UNMC (Byar) 1997	56	41 at HSCT (19–59)	54%	hematologic, 95%; breast, 5%	transplant	90 posttransplant (64–152)	3.6 (2.8)	3rd
City of Hope (Ferrell) 1995	687	50	81%	breast, 43%; lymphoma, 17%; ovarian, 8%; other, 32%	transplant and nontransplant	80 (4–538)	3.25 (2.55)	3rd
Dartmouth-Hitchcock (Whedon) 1995	29	35 at transplant (17–51)	55%	hematologic, 76%; breast, 24%	transplant	37 posttransplant (14–76)	2.7 (not reported)	1st
NCCS/Conversations (Ersek) 1997	152	53 (24–75)	100%	ovarian, 100%	nontransplant	60 (3–538)	2.76 (not reported)	3rd

QOL indicates quality of life; BMT, Bone Marrow Transplant; CS, Patient/Cancer Survivor; UNMC, University of Nebraska Medical Center; HSCT, hematopoietic stem cell transplant; NCCS, National Coalition for Cancer Survivorship.

■ Review of Studies

The following studies are reviewed and compared regarding family distress to illness as reported by patients who are long-term cancer survivors (Table 1). All studies were reviewed by their respective Institutional Review Boards and used mailed surveys of recalled data. Three of the studies used the COH QOL-CS version and the 2 remaining studies used the COH QOL-BMT Survivors version.

Study 1

At UNMC, Lynch et al²⁴ conducted a cross-sectional survey of non-Hodgkin's lymphoma (NHL) survivors who had been treated on a Nebraska Lymphoma Study Group (LSG) protocol between 1982 and 1997. The study, "Quality of Life in NHL Survivors," had the following objectives: (1) assessing QOL, medical late effects, and psychosocial function and examining the relationship of patient, disease, and treatment characteristics to QOL in this NHL survivor population and (2) comparing QOL of NHL survivors treated on an LSG protocol to those treated with autologous hematopoietic stem cell transplant (HSCT).

The instruments used in this study included the Medical Outcomes Survey Short Form (MOS SF-36),³¹ the Functional Assessment of Cancer Therapy—General (FACT-G),³² the COH QOL-CS,³⁰ and Demographic questionnaires.²⁹

Eight hundred forty-five patients were identified as potentially eligible for the study, and 50% of these were determined to be ineligible due to lost follow-up, death, inactive physician participation in LSG or refusal to permit patient contact, participation in other QOL studies, or otherwise considered to be a poor candidate. Of the 426 patients who were eligible, 218 (51%) responded. Respondents had a mean age of 57 years (18–87) at the time of treatment and a mean of 94 months poststart of treatment (34–218). Fifty-six percent were women, and 99% were white, non-Hispanic.

The item "How distressing has your illness been for your family?" was the third most stressful item reported overall in the COH QOL-CS questionnaire and the most stressful

item reported in the social concerns subscale (mean = 4.1; SD = 3.1) (Table 2). Only 2 items indicated more distress (lower scores) and were from the psychological well-being subscale. Distress due to initial diagnosis was the lowest score (mean = 2.5; SD = 3.1) and distress due to cancer treatment had a mean score of 3.4 (SD = 3.1).

Study 2

A similarly designed cross-sectional study at UNMC by Byar et al³³ ("QOL Five Years Post-Autologous HSCT") surveyed 5 year or longer survivors of autologous HSCT. The purpose of this study was to examine QOL of long-term transplant survivors; identify demographic, disease, and treatment-related characteristics; determine unmet needs of survivors; evaluate the QOL instruments (MOS SF-36, FACT-BMT,³⁴ and COH QOL-BMT) used in this study; and to provide inception cohort data for the development of future studies.

One hundred ninety-seven patients were eligible for the study and 92 (47%) participated. Participants were randomized to receive the MOS SF-36, FACT-BMT, and COH QOL-BMT; MOS SF-36 and FACT-BMT, or MOS SF-36 and COH QOL-BMT. Fifty-six respondents were randomized to receive the COH QOL-BMT questionnaire and completed it. Participants were transplanted before July 1992 and were a mean of 90 months post-HSCT (64–152). The mean age at HSCT was 41 (19–59). Fifty-four percent were women, and 95% were white, non-Hispanic. Most were transplanted for lymphoma or other hematologic malignancies.

The COH QOL-BMT item, "How distressing has your illness been for your family?" ranked lowest (mean = 3.6; SD = 2.8), indicating greatest distress in the social concerns subscale and also as the third lowest score overall in the questionnaire. Mean scores for other items are found in Table 3. Scale and subscale scores were summarized using means and standard deviations and were compared using the *t* test. No significant difference in patient-reported family distress scores were found in relation to either patient age

❁ **Table 2 • City of Hope National Medical Center—QOL of Patient/Cancer Survivor Social Concerns Subscale**

UNMC "Quality of Life in NHL Survivors" (n = 218)				
No.	Question	Mean	SD	
27	How distressing has your illness been for your family?	4.1	3.1	
28	Is the amount of support you receive from others sufficient to meet your needs?	8.5	2.2	
29	Is your continuing healthcare interfering with your personal relationships?	8.1	2.9	
30	Is your sexuality impacted by your illness?	7.0	3.6	
31	To what degree has your illness and treatment interfered with your employment?	8.2	3.0	
32	To what degree has your illness and treatment interfered with your home activities?	7.4	2.9	
33	How much isolation do you feel is caused by your illness or treatment?	8.3	2.8	
34	How much financial burden have you had as a result of your illness or treatment?	6.9	3.3	
	Total social concerns subscale score	7.3	1.9	

QOL indicates quality of life; UNMC, University of Nebraska Medical Center; NHL, non-Hodgkin's lymphoma. Scale: 0 = worst outcome; 10 = best outcome.

Table 3 • City of Hope National Medical Center—QOL of Bone Marrow Transplant Survivors Social Concerns Subscale

UNMC "Quality of Life Five Years Post-Autologous HSCT" (n = 56)"			
No.	Question	Mean	SD
62	How much financial burden resulted from your illness or treatment?	5.7	3.4
63	How distressing has your illness been for your family?	3.6	2.8
64	Has your illness or treatment interfered with your personal relationships?	6.5	3.5
65	Is the amount of affection you receive sufficient to meet your needs?	8.2	2.2
66	Is the amount of affection you give sufficient to meet your needs?	7.8	2.0
67	Has your illness or treatment interfered with your sexuality?	5.5	3.6
68	Has your illness or treatment interfered with your plans to have children?	5.7	4.6
69	Has your illness or treatment interfered with your employment?	6.3	3.9
70	Has your illness or treatment interfered with your family goals?	6.8	3.6
71	Is the amount of support you receive from others sufficient to meet your needs?	8.2	2.4
72	Has your illness or treatment interfered with your activities at home?	6.6	3.6
73	How much isolation is caused by your illness or treatment?	8.2	2.5
74	Overall social well-being (not calculated)	7.9	1.9
	Total social concerns subscale score	6.7	1.9

QOL indicates quality of life; UNMC, University of Nebraska Medical Center; HSCT, hematopoietic stem cell transplant.

Scale: 0 = worst outcome; 10 = best outcome.

Full range of scores was observed.

or gender. Only initial diagnosis (mean = 1.3; SD = 2.0) and cancer treatment (mean = 2.1; SD = 2.4), items from the psychological well-being subscale, were reported as more stressful overall from the questionnaire.

Study 3

In 1995, a mail survey of the National Coalition for Cancer Survivorship membership (n = 1,200) was conducted at the COH National Medical Center to describe the QOL of long-term cancer survivors.²⁷ Of the 687 (57%) respondents in this study, 43% had breast cancer, 17% had lymphoma, 8% had ovarian cancer, and 32% had other cancers. Respondents had a mean age of 49.6 years, and were a mean of 80 months postdiagnosis of cancer, 94% were white and 81% were women. Utilizing the COH QOL-CS questionnaire, the score for family distress was 3.25 (SD = 2.55), the lowest of the social concerns subscale items (range 5.78–7.91) and the third most stressful item reported on the questionnaire after the psychological subscale items of distress of the initial diagnosis (mean = 1.58; SD = 2.39) and treatment distress (mean = 2.52; SD = 2.60).^{28,35}

Study 4

Findings from a 1995 cross-sectional study by Whedon et al of 29 autologous BMT survivors from Dartmouth-Hitchcock Medical Center, who were a mean of 37 months (range 14–76) posttransplant for hematologic malignancy (76%) or breast cancer, also indicated high levels of patient-reported family distress.³⁶ The purpose of this study was to describe the QOL of 1 year or greater survivors of autologous BMT and to evaluate the validity and reliability of the COH QOL-BMT instrument in this population. Respondents had a

mean age of 35 years at the time of transplant (range 17–51), were predominantly women (55%), and all were white. In this study, family distress to illness was the lowest single item reported in all subscales (mean 2.7).

Study 5

Similar findings were reported by Ersek et al²⁶ from a combined study (n = 152) of ovarian cancer survivors (mean 60 months postdiagnosis) that included a subset of the National Coalition for Cancer Survivorship study respondents and an ovarian cancer networking group called *Conversations* and that utilized the COH QOL-CS questionnaire. The mean age of respondents was 53 years and 94% were white. The group mean score for the family distress item was 2.76, the lowest score in the social concerns subscale and the third lowest item reported overall on the questionnaire. Only initial diagnosis distress and cancer treatment distress scores were lower, 1.25 and 1.98, respectively.²⁶

Summary of Studies

These 5 studies provided similar summaries of family distress as perceived by cancer survivors. Participants in these studies were long-term cancer survivors (range of means 3–8 years postdiagnosis and treatment), who received either standard therapy and/or transplant. The mean age of respondents in these studies was 35 to 57 with a range of 17 to 87 reported for 4 of the studies (Table 1). In 1 study, family distress was lowest and in the other 4 studies it was the third lowest item. In these 4 studies, only distress associated with diagnosis and treatment was identified as more stressful.

■ Discussion

Although comparison of a single-item from a multi-item, multiscale questionnaire must be interpreted with caution, results of the single item reported in these 5 studies provide important preliminary information regarding high levels of patient-reported family distress to illness and may indicate the need for more long-term assessment of survivor and family distress, which has been previously reported.³⁷ In their study of terminally ill cancer patients, Chochinov et al³⁸ determined that a single-item assessment of depression provided reliable and accurate screening for depression.

In the studies reviewed here, patient survivors are perceiving high levels of family distress as a result of their illness. Only initial diagnosis and treatment were perceived as more stressful. These findings may indicate that the level of family distress in the past was so significant that patient survivors were able to recall the experience despite having survived several to many years, or they may have reported significant *ongoing* family distress as a result of their cancer.

The implications of these findings for patient survivors include the need for improved communication and ongoing discussion with patients and family members regarding the issues they remembered as stressful for their families. By identifying the issues and concerns that are recalled from the cancer experience, healthcare professionals can provide appropriate counseling and referral, which will allow patient survivors and families to gain perspective regarding the impact of cancer on their lives.

Although these studies provide evidence of the patients' perception of family distress, there is no indication regarding the families' perception of their distress which may differ from the patients'. The implication of this finding for family survivors includes the need for research to identify the type and the timing of the challenges faced by families and to measure their perceived levels of distress over time. Answers to these questions are important in considering the type of recommendations and interventions offered to patient survivors and families that will address their ongoing concerns and assist them in managing the more subtle or latent changes they may be experiencing.

■ Limitations of Study Comparisons

The results for 3 of the 5 studies compared here were reported using only published data, therefore, a thorough review and report of findings was not possible regarding these studies in this article. In addition, the results of one of the studies conducted at UNMC have only been presented in abstract form to date.

The findings reported in these studies represent the perception of distress as reported by patients only and further research is needed to clarify the families' perception of distress caused by the illness and treatment.

All 5 studies represent diverse patient populations in terms of type of cancer (ie, breast, lymphoma, leukemia, ovarian,

and other cancers) and inherent differences in diagnosis and treatment, which included transplant and nontransplant regimens, making comparisons among these patients difficult. Patients treated with multiple regimens and/or transplant are more likely to be at risk for the development of late and long-term effects³⁹ due to increased exposure to treatment-related toxicities, making it difficult to compare the impact of transplant versus nontransplant treatment regimens on physical, psychosocial, and family aspects of QOL.

Participants in these studies represent adults only and are primarily white, which limits the ability to generalize findings to other age or ethnic groups.

Implications of other clinical characteristics, such as length of survivorship, relapse status, number of relapses, and current treatment, should be addressed in other studies.

■ Implications for Nursing

The use of the 4-dimensional model, which includes social and family well-being, provided consistency across the 5 studies in looking at the single item regarding family distress.

As healthcare providers, oncology nurses have the opportunity to observe and interact with patients as well as their families over the course of the disease, treatment, and long-term survivorship. This unique perspective allows nurses to assess both the patient and their family and to provide assistance in identifying their individual and collective needs. The needs and concerns of both the patient and the family must be clearly identified to provide appropriate and timely interventions. Nurses are often the frontline resource for education and referral of patients and families and must continually reassess the needs of both. In order to carry out these responsibilities, nurses need access to current community support programs and to social worker/counseling support. Assessment of patients' and families' needs is critical during all phases of disease and treatment, including the period of recovery and long-term survivorship.

■ Future Studies

Previous research has indicated that the QOL of cancer patients and their families is interrelated (Figure 2), and patients have reported high levels of family distress resulting from their disease and treatment. Future studies should be developed to identify and compare the types of distress experienced by patient survivors and families and to measure the intensity of distress they report. Future studies should also be designed to include assessment of both family and patient QOL before treatment and at the same time intervals posttreatment, using similar measures, to determine whether they are experiencing distress at similar times throughout the course of disease and survivorship. Specifically, longitudinal studies are needed to monitor cancer patients⁴⁰ and their families throughout the disease trajectory,⁴¹ especially in

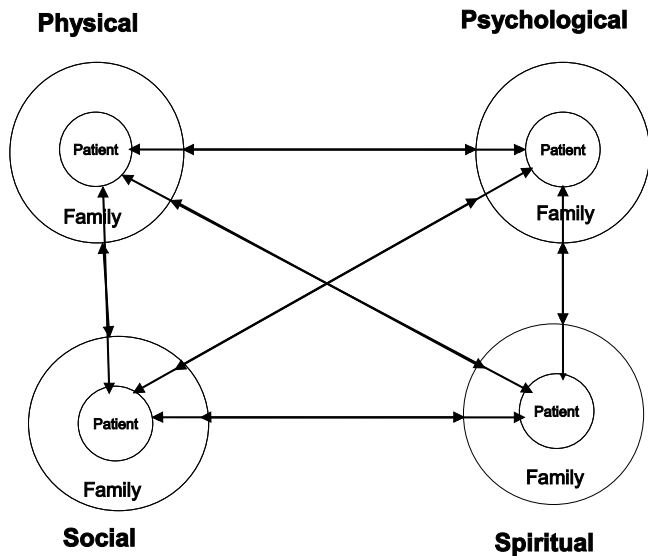


Figure 2 ■ Patient and family quality of life. Adapted from Ferrell, Grant, & Dow, 2001. City of Hope National Medical Center.

recovery.⁴² The goal of these studies should include identifying the specific needs of patient survivors and families, such as communication, education, counseling, and caregiving, throughout the continuum of illness, recovery, and survivorship. Longitudinal studies, which will require ongoing nursing assessment, will provide important information regarding patient survivor and family interventions. These interventions may need to change over time to reflect the stages and transitions experienced as a result of the disease.⁴³ Patient survivors and families who are experiencing similar stressors should be monitored to determine whether these stressors may intensify or resolve over time.

The inclusion of patient and family QOL measures, specifically those aimed at identifying the type, intensity, and timing of the stressors experienced by patients and families, will provide nurses and other healthcare professionals with important information regarding the specific educational and support interventions that may be needed. In addition, information on the timing of these interventions is needed to provide patient survivors and their families with optimal care during the course of the disease and treatment and throughout the period of survivorship.

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