

Health-Related Quality of Life After Treatment of Hodgkin Lymphoma in Young Adults

Kristin Roper, RN, MS, Mary E. Cooley, PhD, RN, FAAN, Kathleen McDermott, RN, BSN, OCN®, and Jacqueline Fawcett, PhD, FAAN

About 9,060 new cases of Hodgkin lymphoma (HL) occurred in 2012 in the United States, with 159,846 people receiving treatment or in remission (Leukemia and Lymphoma Society, 2012). HL affects a disproportionate number of young adults, both men and women. The probability of long-term, disease-free survival is excellent; indeed, individuals with stage I or II HL receiving curative regimens have an estimated five-year survival rate of 90%–95%, which decreases to 60%–80% for those with stage III or IV disease (American Cancer Society, 2010).

An illness such as cancer in young adults has the potential to interrupt the ability to attain expected developmental milestones, such as establishing personal independence, developing intimate relationships with friends and marital partners, and accomplishing career and work goals (Arden-Close, Pacey, & Eiser, 2010; Newton, 2000; Roper, McDermott, Cooley, Daley, & Fawcett, 2009). A serious life-changing event can suddenly alter a young adult's already vulnerable self-esteem and fragile identity, which can have a negative impact on health-related quality of life (HRQOL) (Sidell, 1997; Zebrack, 2000). Therefore, gaining an understanding of the impact of cancer on young adults' HRQOL is important because they may experience a deeper sense of loss than older adults, who have greater life experience and may be more accepting of adverse events (Schroevers, Ranchor, & Sanderman, 2003). This knowledge can serve as a basis for development of evidence-based interventions that are designed to enhance the transition to survivorship, minimize deleterious effects on accomplishing normal developmental tasks, and improve HRQOL.

Conceptual Framework

As seen in Figure 1, this study was guided by the Roy Adaptation Model (RAM) (Roy, Whetsell, & Frederickson, 2009). RAM depicts individuals as biopsychosocial beings who adapt to ever-changing environmental stimuli. Environmental stimuli are categorized as focal, which

Purpose/Objectives: To describe changes in health-related quality of life (HRQOL) and to identify supportive care services used after treatment for Hodgkin lymphoma (HL) in young adults.

Design: A longitudinal, repeated-measures study design was used to test the feasibility of data collection at the conclusion of treatment for HL and at one, three, and six months post-treatment.

Setting: Participants were identified from two large comprehensive cancer centers in New England.

Sample: 40 young adults with newly diagnosed HL were enrolled in the study prior to the completion of chemotherapy or radiation.

Methods: Data were collected by interviews, standardized questionnaires, and medical record reviews.

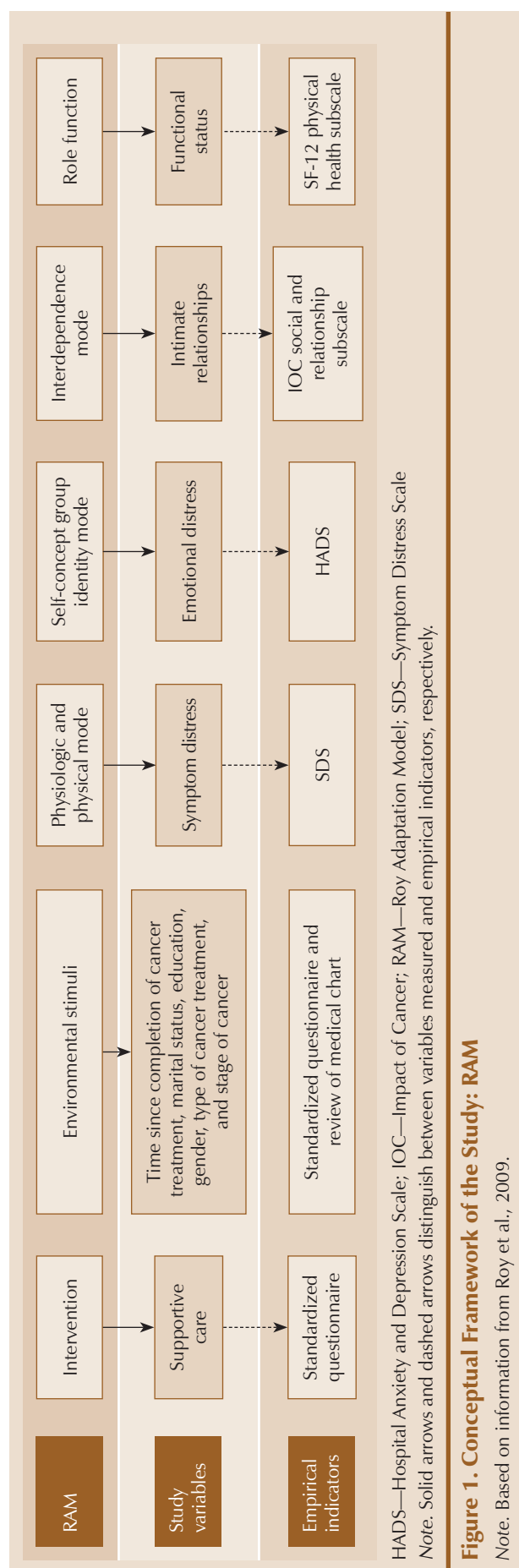
Main Research Variables: HRQOL variables defined as symptom distress, functional status, emotional distress, and intimate relationships; use of specific supportive care services; and baseline demographic and disease-related information.

Findings: Results indicate that symptom distress improved at one month post-treatment and remained low at three and six months. Similarly, functional status improved at one month post-treatment. Only 13% of the sample had significant emotional distress at baseline, and this decreased to 8% over time. Patients placed high value on their intimate relationships (i.e., family and friends or sexual partners). A variety of supportive care services were used after treatment, the most common of which were related to economic issues. However, by six months post-treatment, services shifted toward enhancing nutrition and fitness.

Conclusions: The results from this study suggest that HRQOL in young adults with HL improved one-month post-treatment and that interest in using supportive care services was high.

Implications for Nursing: Facilitating the use of supportive care services at the end of cancer treatment appears to be an important part of helping young adults transition to survivorship.

Knowledge Translation: Supportive care services appear to be a vital component of the transition to survivorship and often change over time from an emphasis on economic issues to enhancing wellness through nutrition and fitness programs.



refers to the stimuli most immediately confronting the person; contextual, which refers to contributing factors in the situation; and residual, which refers to other unknown factors that may influence the situation. When factors making up the residual stimuli become known, they usually are considered contextual stimuli. The individual has coping processes, called regulator and cognator subsystems. The regulator subsystem functions through use of the autonomic nervous system in making physiologic adjustments to the environment, whereas the cognator subsystem controls processes related to perception, learning, judgment, and emotion. Environmental stimuli activate the coping processes. The coping processes act to produce adaptive or ineffective responses. Adaptive responses are those that promote the person's survival, growth, reproduction, and mastery. In contrast, ineffective responses are those that do not promote these goals, thereby signaling a need for intervention. The responses are considered to take place in four biopsychosocial modes. The physiologic mode is concerned with basic needs necessary to maintain the physiologic integrity of the human system. The self-concept mode is concerned with the psychic and spiritual self. The role function mode is concerned with the performance of roles based on the individuals' position within society. The interdependence mode deals with the maintenance of satisfying affectional relationships with significant others. Collectively, the four modes of adaptation comprise HRQOL (Nuamah, Cooley, Fawcett, & McCorkle, 1999). Nurses assess environmental stimuli and individuals' responses to those stimuli in each mode of adaptation and design interventions to maintain or enhance positive responses by managing the environmental stimuli.

The RAM concepts of interest for this study were the focal and contextual stimuli, the four biopsychosocial modes of adaptation, and nursing interventions. Roy et al. (2009) postulated that focal and contextual stimuli influence the response modes. The focal stimulus was time in relation to treatment (completion of active treatment and one, three, and six months post-treatment). The contextual stimuli were represented by demographic (marital status, education, gender) and clinical (stage of disease and type of cancer treatment) characteristics. Biopsychosocial adaptation was represented by four components of HRQOL reflected in the four modes of adaptation. In particular, the physiologic mode was represented by symptom distress, the self-concept mode was represented by emotional distress, the interdependence mode was represented by intimate relationships, and the role function mode was represented by functional status. Supportive care services were identified to determine what nursing interventions might augment existing services.

Literature Review

Although patients look forward to the completion of treatment, feelings of ambivalence and concerns about

recurrent disease often surround the end of active treatment (Arnold, 1999; Brant et al., 2011; Hewitt, Greenfield, & Stovall, 2005). In addition, the end of treatment may seem to be an abrupt conclusion to what patients may regard as a safe environment of monitoring and focused care. Because oncology nurses provide care to patients with HL throughout the treatment period, they are in an ideal position to support patients by addressing survivorship issues systematically prior to the end of active treatment and throughout the transition to surveillance (Ganz & Hahn, 2008; Oeffinger & McCabe, 2006). To date, however, limited data exist to guide evidence-based nursing interventions to facilitate adaptation to living with cancer after completion of treatment (Hewitt et al., 2005).

Only one prospective longitudinal study describing changes in HRQOL in young adults with HL conducted in the United States could be located by the authors. Ganz et al. (2003) compared the HRQOL for those receiving combined modality treatment (CMT) to those who received only radiation before treatment, at six months, and then annually for seven years. Ganz et al. (2003) found that those who received CMT experienced significantly more physical symptoms such as fatigue, poorer QOL, and were more likely to be unemployed at six months compared to those who received radiation therapy alone.

Most studies have been cross-sectional and have examined HRQOL issues among long-term HL survivors, defined as being five years or longer since diagnosis (Adams et al., 2004; Arden-Close et al., 2011; Bloom et al., 1993; Cameron et al., 2001; Fobair et al., 1986; Zabor, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), and/or used samples of patients at mid-life or older. Hjermstad et al. (2006) published the most recent empirical study exploring the QOL of 475 HL survivors. The findings revealed that HL survivors with chronic fatigue experienced significantly lower QOL compared to a general population control.

Symptom distress has been associated with age. Loge, Abrahamsen, Ekeberg, and Kaasa (1999) reported that a statistically significant difference existed between patients with HL who were 60 years of age or older and the general population. The older adult patients had the lowest scores on such physical symptoms as bodily pain, physical functioning, role limitations, and general health. Gil-Fernandez et al. (2003) reported that loss of appetite, problems with diarrhea, and depression were higher in patients with HL who were 45 years or older compared to those who were younger than age 45.

Evidence supporting an increase in emotional distress among HL survivors is mixed. Cella and Tross (1986) reported that survivors did not differ significantly from the general population regarding emotional distress. In fact, many survivors expressed positive outcomes

associated with the cancer experience, such as having a greater appreciation of life and enhanced self-esteem (Cella & Tross, 1986; Yellen, Cella, & Bonomi, 1993). The results of other studies, however, revealed that emotional distress of patients with HL was higher than that of a healthy population and that as many as 50% of patients reported anxiety, depression, or both during the first year after diagnosis and completion of treatment (Devlen, Maguire, Phillips, & Crowther, 1987; Kornblith et al., 1990; Norum & Wist, 1996).

Several researchers have reported disruptions in intimate relationships (i.e., friends and family or sexual partners) among survivors of HL (Cella & Tross, 1986; Fobair et al., 1986; Kornblith et al., 1990). Fobair et al. (1986) identified a moderately high divorce rate (32%), problems with infertility (18%), and less interest in sexual activity (20%) following treatment among 403 HL survivors. Cella and Tross (1986) found significantly lowered intimacy motivation among 60 male HL survivors compared to a healthy control group. Kornblith et al. (1990) noted that 37% of 273 HL survivors reported one or more sexual problems caused by decreased interest, activity, or satisfaction.

Although the majority of HL survivors return to a high level of functional status, changes in social and work-related activities have been noted (Devlen et al., 1987; Fobair et al., 1986; Kornblith et al., 1990; van Tulder, Aaronson, & Bruning, 1994). Devlen et al. (1987) identified a decline and inadequate interest in leisure activities among HL survivors. Difficulties returning to work have been reported by as many as 42% of HL survivors (Fobair et al., 1986). Problems included denial of insurance or other benefits, encouraged to leave work, and being fired, laid off, or demoted (Fobair et al., 1986; Kornblith et al., 1990). Carpenter, Morrow, and Schmale (1989) reported that those patients who had completed treatment more than two years prior to data collection, compared to those who had completed treatment less than two years prior to data collection, experienced greater feelings of abandonment and illness uncertainty, although they appeared better adjusted to career plans as they moved farther away from treatment. Fobair et al. (1986) reported that younger HL survivors (15–34 years) on average had a return of energy within 12 months, although the median time required to resume normal activities was eight months across all ages of the sample (5–65 years).

Supportive care services are services that assist patients and their families in handling the physical, psychological, social, and practical problems that frequently accompany the diagnosis and treatment for cancer (Coluzzi et al., 1995). Limited research exists on the scope of services that are designed specifically for cancer survivors who have completed treatment (Ferrell, Virani, Smith, & Juarez, 2003; Tesauro, Rowland, &

Lustig, 2002). Tesauro et al. (2002) described the type of services available specifically for cancer survivors who have completed treatment from comprehensive cancer centers within the United States. Few researchers have assessed what services are used or needed from the patient's perspective. Gray, Goel, and Fitch (2000) assessed the supportive care services used by women with breast cancer. Of the 731 women with breast cancer, 227 (31%) reported using at least one supportive care service (from a mental health professional, dietitian, or physical therapist), and 249 (34%) indicated that at least one professional service was in place that they would have liked to use but were unable to access. Houts, Yasko, Kahn, Schelzel, and Marconi (1986) surveyed 629 people with cancer to determine their views of unmet psychological, social, or economic needs. Fifty-nine percent of respondents ($n = 371$) indicated at least one unmet need. The most common unmet need was dealing with the emotional aspects of the cancer diagnosis. Younger age, being employed, student status, more advanced stage of cancer, and having received chemotherapy was associated with use of and need for supportive care services (Gray et al., 2000; Houts et al., 1986).

The existing gaps in knowledge about HRQOL after treatment for HL illustrate the need for additional clinical research data to guide evidence-based nursing interventions to facilitate adaptation to living with cancer after completion of treatment for HL. Longitudinal studies designed to examine HRQOL in young adults after completion of treatment for HL are critical to capture changes over time and to direct the timing of clinical interventions (Murdaugh, 1997). This study was designed to extend knowledge by examining changes in HRQOL over time in young HL survivors. The specific aims of the study were to (a) describe changes in adaptation, conceptualized as components of HRQOL of young adult patients with HL at the end of cancer treatment (baseline) and at one, three, and six months post-treatment; and (b) identify supportive care services used at end of treatment (baseline) and at one, three, and six months post-treatment.

Methods

Sample

This study used a longitudinal, repeated measures design. Participants were identified from the Dana-Farber Cancer Institute and Massachusetts General Hospital, both in Boston. To determine sample size, historical data for new consults for patients with HL in 2000 and 2001 were reviewed at the two sites. The authors would have an estimated total of 40–60 potentially eligible patients for 2003. Therefore, the projected accrual goal was 45 patients over one year to ensure

that there would be at least 35 study participants. Data were collected after treatment completion (defined as one week before or one week after the last cancer treatment), and at one, three, and six months post-treatment. Patients were enrolled in the study during a period of one year. The study continued until data were collected from all eligible participants.

Inclusion criteria for patients included English fluency and being 21–40 years of age with newly diagnosed HL (early stages: IA/B, IIA, or IIIA; late stages: IIB, IIIB, or IVA/B). Participants were enrolled in the study prior to the completion of chemotherapy or radiation. Participants were not eligible if they had a prior cancer diagnosis, had recurrent HL, received treatment at another facility, or if they were unable to complete questionnaires because of language barriers or because of major organ or psychiatric disorders precluding the ability to provide informed consent.

Of 126 patients originally screened for the study, 72 patients were ineligible. Twenty-six (33%) were ineligible because of age, 23 (29%) were not newly diagnosed and were receiving a consult for relapsed disease, 20 (25%) were newly diagnosed but were receiving treatment at another facility, and 3 (4%) were non-English speaking or missed screening. Seven (9%) patients were eligible but refused participation. Their stated reasons were that they were too busy, too anxious, or unwilling to participate. Most of those who refused participation were female ($n = 4$), and the mean age of those who refused to participate was 29 years. Of the remaining 47 registered patients, data generating did not begin for seven patients due most frequently to progressive disease that occurred after enrollment.

The sample size for each data collection period was 40 at completion of treatment (baseline; time 1), 38 (95%) at one month (time 2), 37 (93%) at three months (time 3), and 38 (95%) at six months (time 4). Two participants withdrew consent after completing baseline data collection, resulting in an attrition rate of 5%. A cohort of 38 patients completed all data collection, although one participant had missing data at time 3.

Instruments

Demographic and supportive care services data were collected by standardized questionnaires that have been used in previous research (Degner & Sloan, 1992, 1995). Clinical characteristics (cancer stage and type of treatment) were collected by a medical chart review.

Symptom distress was measured by the **Symptom Distress Scale (SDS)**. The SDS is a 13-item self-report questionnaire scored on a five-point Likert scale measuring distress experience relating to the severity of 11 symptoms and the frequency of two symptoms. The SDS asks for symptom scoring on the day the questionnaire is administered and takes about five minutes to

complete. The 11 symptoms include nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, outlook, breathing, and cough. In addition, nausea and pain are reported by frequency separately. A total score is obtained by summing the 13 items; total scores range from 13 (indicating little distress) to 65 (indicating severe symptom distress). Cronbach alpha internal reliability coefficients in newly diagnosed cancers were 0.8 and 0.81, respectively, using SDS (Degner & Sloan, 1992, 1995). Content, construct, and criterion validity also have been reported for SDS with the cancer population (McCorkle, Cooley, & Shea, 2003). Cronbach alphas for the SDS in this study were 0.76, 0.82, 0.84, and 0.81 for baseline, one month, three months, and six months, respectively.

Emotional distress was measured by the **Hospital Anxiety and Depression Scale (HADS)**, which is a 14-item, self-administered measure that can be completed in about 5–10 minutes (Zigmond & Snaith, 1983). The instrument also is reliable for measuring anxiety and depression in survivors in the outpatient setting (Fossa, Dahl, & Loge, 2003; Osborne, Elsworth, & Hopper, 2003; Schofield et al., 2003; Smith, Selby, & Velikova, 2002). A summative score is obtained by adding the items. Cut-scores are available to assist in identification of those who need additional assessment and intervention. Scores range from 0–21 for anxiety and 0–21 for depression. A score of 0–7 for either subscale is in the normal range, a score of 11 or higher indicates probable presence (caseness) of the mood disorder, and a score of 8–10 being suggestive presence of the respective state (Snaith, 2003). HADS was designed specifically to assess these disorders in medically ill patients, including those with cancer, and can be used to monitor changes over time. Its rating system is based on a four-point format and asks how the patient has felt in the past week. The item-to-subscale reliability correlations are reported as being from 0.41–0.76 for the anxiety items and 0.3–0.6 for depression items (Frank-Stromborg & Olsen, 1997). Researchers have reported internal consistency measured by Cronbach coefficient alpha of those with testicular cancer to be 0.85 for HADS–Anxiety and 0.82 for HADS–Depression (Fossa et al., 2003). The Cronbach alpha for the depression subscale of the HADS for the four time points of this study (baseline, one month, three months, and six months) were 0.62, 0.81, 0.82, and 0.85, respectively. The Cronbach alpha for the anxiety subscale of the HADS for the four time points of this study were 0.8, 0.86, 0.76, and 0.82, respectively.

Intimate relationships were measured by two questions on the social and relationship scale of the **Impact of Cancer (IOC)**. The IOC is a 41-item, self-administered measure developed to assess the HRQOL of long-term cancer survivors (Zebrack, Ganz, Benrhaards,

Table 1. Sample Characteristics (N = 40)

Characteristic	\bar{X}	SD	Range
Age (years)	30.9	5.8	21–41
Characteristic	n		
Gender			
Female	24		
Male	16		
Race			
White Non-Hispanic	36		
Other	4		
Marital status			
Never married	15		
Married or living with a partner	25		
Education			
High school or some college	12		
College graduate or advanced degree	28		
Stage of disease			
Early	33		
Late	7		
Treatment			
Chemotherapy only	15		
Radiation only	2		
Chemotherapy and radiation	23		

Petersen, & Abraham, 2006). Time for completion is about 10 minutes. Scoring is on a five-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). This measurement consists of six thematic domains: physical, psychological, existential, social, meaning of cancer, and health worry. Additional items were included for those who were married or in long-term relationships and for those who were employed. Internal consistency reliability coefficients for the subscales ranged from 0.67–0.89 among 193 long-term survivors, including 25% with lymphoma (Zebrack et al., 2006). The revised IOC (version 2) has been developed since the completion of this study following evaluation and refinement of the original scale (Crespi, Ganz, Petersen, Castillo, & Caan, 2008). Two questions from the IOC were recommended as measures of intimate relationships: “I place a higher value on my relationships with family or friends than I did before having had cancer,” and “I feel a special bond with people with cancer” (B.J. Zebrack, personal communication, August 1, 2007).

Functional status was measured by the physical health portion of the **SF-12 Health Survey** (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). Administration time can range from 5–10 minutes. The instrument has eight concepts: physical function, role limitations from physical health problems, bodily pain, general health, vitality, social functioning, role limitations from emotional problems, and mental health. The items of the SF-12, version 2, are aggregated to provide summary measures of physical and mental

health. Scale scores below 50 indicate below-average health status. Norm-based scoring for the population of the United States and for those with chronic illness was available (Ware et al., 2002). Test-retest correlations for physical and mental health were 0.89 and 0.76, respectively.

Procedures

Identification of potential participants was accomplished by reviewing the electronic appointment scheduling system for patients with HL and those who were scheduled for new consults at the first site. Patients were approached after the oncology clinician was notified by a research representative. The research representative provided the patient with a waiver letter and a consent form when it was determined that he or she was eligible for the trial. If the patient agreed to meet with a research representative, the protocol was explained and written informed consent was obtained. Once consent was obtained, arrangements were made for a future telephone interview and the questionnaires were given to the patients as a reference to facilitate the telephone interview. If the patient was undecided about participation in the study, the research representative obtained his or her permission to be contacted at a later date. For those patients enrolled at the second site, the second site principal investigator identified and provided a potential patient with a waiver letter and the informed consent form. A research representative was contacted by the second site principal investigator and arrangements were made to review eligibility, explain the protocol, and obtain consent from the patient.

Approval from the institutional review board was obtained from both sites.

Data Analysis

Descriptive statistics were used for the analyses, including frequencies, means, medians, and standard deviations to describe the sample demographic and clinical characteristics and supportive care services used at each data collection time point by young adults with HL. Descriptive statistics also were used for all scores from the instruments measuring symptom distress, emotional distress, intimate relationships, and functional status at each data collection time point. Nonparametric Friedman tests were used to determine overall differences between means over time, and the Wilcoxon signed rank test was used for the four pairwise comparisons. To protect against error, a Bonferroni correction of 0.0167, based on a desired level of significance of 0.05, was used. Additional analyses were conducted to explore any gender, marital, and type of treatment differences in the components of HRQOL.

Results

Sample Demographics

The final sample consisted of 40 young adult survivors of HL ranging in age from 21–41 years (see Table 1). The participants were primarily female and married. Only 10% of the participants (n = 4) lived with a parent. About 88% (n = 35) of the participants were employed or earning income within the past 12 months; 10% (n = 4) were fully retired from paid employment. Eighty

Table 2. Means and Standard Deviations for Health-Related Quality-of-Life Domains Over Time

Instrument	Score Range	Conclusion of Treatment (N = 40)		Post-Treatment					
				One Month (N = 38)		Three Months (N = 37)		Six Months (N = 38)	
		\bar{X}	SD	\bar{X}	SD	\bar{X}	SD	\bar{X}	SD
Symptom Distress Scale									
Symptoms	13–65	25	6.3	20.1	4.6*	19.7	5.6	19.3	5.1
Hospital Anxiety and Depression Scale									
Anxiety	0–21	5.3	3.7	4.4	3.7	4.1	2.9	4.2	3.5
Depression	0–21	3.5	2.4	2.6	2.9	2.2	2.6	1.8	2.4
Combined	–	8.9	5.1	7	6.1*	6.3	5	6	5.4
Impact of Cancer scale									
Higher value relationships with family and friends	1–5	4	0.8	3.9	1	3.9	1	4.1	0.9
Special bond with people with cancer	1–5	3.6	1	4	0.8**	3.8	0.9	3.7	1
Combined		4	0.8	4	0.7	3.9	0.8	3.9	0.7
SF-12									
Physical	–	43.4	8.3	48.4	7.3*	50.5	8.4	51.3	7

*p < 0.0001; **p < 0.01

Note. Hospital Anxiety and Depression Scale measures emotional distress, Impact of Cancer measures intimate relationships, SF-12 measures functional status, and Symptom Distress Scale measures symptoms.

Note. The variation in sample size is from attrition or missing data at random.

percent ($n = 32$) of the participants had stage I or II HL and 17% ($n = 8$) had stage III or IV. Sixty percent ($n = 19$) of the early-stage participants received single modality treatment.

Symptom Distress

Analyses revealed that distressing and bothersome physical symptoms improved significantly from one to six months following treatment (see Table 2). Overall improvement in symptom distress was evident through significantly lower mean scores at all time points ($p < 0.0001$) compared to baseline. Data were approximately normally distributed at baseline only; therefore, the Wilcoxon signed rank tests were used in lieu of parametric statistics to compare scores at the various time points. Pairwise comparisons revealed significant differences in symptom distress between baseline and as soon as one month ($p < 0.0001$).

Dichotomous groups were created to differentiate those with moderate-to-severe symptom distress, indicated by an SDS score of 25 or higher, from those with low symptom distress, indicated by an SDS score of 24 or lower. Fifty percent ($n = 20$) of the participants reported moderate-to-severe distress at baseline, 11% ($n = 4$) at one month, 16% ($n = 6$) at three months, and 11% ($n = 4$) at six months. For those who reported moderate to severe distress at baseline, 20% ($n = 8$) received CMT and, by six months, 11% ($n = 4$) of the participants who received CMT continued to report moderate-to-severe distress.

Emotional Distress

Examination of emotional distress scores revealed an overall significant difference from end of treatment (baseline) to six months following treatment using the Friedman test ($p < 0.0001$). Pairwise comparisons revealed significant improvements in total HADS depression and anxiety scores from baseline to one month post-treatment ($p = 0.006$). Emotional distress was demonstrated by combined cut off scores at or above moderate (8 or higher) to severe (11 or higher) levels of HADS anxiety and depression scores, respectively. Only 13% ($n = 5$) of the participants had severe anxiety at baseline, which decreased to 8% ($n = 3$) by six months after treatment completion. Although the incidence of severe anxiety decreased to 3% ($n = 1$) at one month, it then increased to 5% ($n = 2$) at three months, and again slightly increased to 8% at six months ($n = 3$). Depression scores improved significantly from baseline to one month ($p = 0.01$), but no significant improvement was noted in anxiety levels ($p = 0.029$) for the same data collection points based on the Bonferroni correction levels of 0.0167. Except for baseline, mean combined scores of anxiety and depression were all within the normal range.

Intimate Relationships

The average mean score for both IOC questions used to measure intimate relationships increased slightly from baseline to six months, although the analysis revealed that the only significant difference in scores ($p = 0.0003$) was from end of treatment (baseline) to one month for the question regarding the special bond with people with cancer.

Functional Status

Functional status significantly improved overall from end of treatment (baseline) to six months using the Friedman test ($p < 0.0001$). Pairwise comparisons revealed a significant increase in scores only from baseline to one month ($p < 0.0001$).

Supportive Care Services

The use of supportive care services declined over time (see Table 3), from 49 inquiries at baseline to 40 inquiries at six months. Sixty-eight percent ($n = 27$) of the participants used one or more services at baseline, but the use of services declined somewhat to 55% ($n = 21$) at six months. Twenty-four participants had questions regarding employee rights, health insurance, disability, and other legal and financial information at baseline, which declined to 16 inquiries at six months. Participation in emotional support groups (14%, $n = 7$) was used as a supportive care service at baseline, including professional and peer counseling. Participation in health behavior programs ($n = 11$, 22%), such as nutrition and exercise programs, were used as a supportive care service at baseline by the participants. Different forms of physical therapy were used at baseline by 14% of participants ($n = 7$), including pain management and physical and alternative therapies. Whereas economic inquiries declined at six months, the use of health behavior programs, particularly fitness programs, increased at six months.

Discussion

The current study was designed to examine changes in adaptation, conceptualized as components of HRQOL in young adults with HL at the end of active treatment (baseline) and at one, three, and six months post-treatment and to identify supportive care services used after treatment. The results of this study reveal that the symptom distress improved as soon as one month after treatment completion. This finding differs from previous studies. In a study of 246 HL survivors, Ganz (2003) reported that SDS scores were significantly worse for all patients with HL at six months and did not return to baseline until one year after treatment. However, Ganz (2003) also found that

Table 3. Frequencies for Supportive Care Services Over Time (N = 40)

Type of Service	Conclusion of Treatment n	Post-Treatment		
		One Month n	Three Months n	Six Months n
Economic inquiries	24	21	13	16
Employee rights	4	3	3	4
Health insurance	9	10	6	6
Legal or financial issues	2	2	1	1
Disability	9	6	3	5
Emotional support	7	6	5	4
Peer counseling	2	2	2	2
Professional counseling	5	4	3	2
Health behaviors	11	12	14	17
Nutrition	4	1	3	5
Fitness	7	11	11	12
Physical therapy	7	3	3	3
Pain management	2	2	2	1
Physical therapy	1	—	—	2
Alternative therapy	4	1	1	—

Note. Participants could report multiple services.

care services and more effective pharmacologic agents—particularly for treatment of chemotherapy-induced nausea and vomiting—which have improved symptom management significantly in the past 20 years (Grunberg et al., 2011; Kris, Tonato, et al., 2011; Kris, Urba, & Schwartzberg, 2011; Sanson-Fisher et al., 2000; Schwartzberg, Grunberg, & Kris, 2011).

The results of the current study indicate that the emotional distress of young adult survivors of HL is not particularly substantial. Mean scores for depression and anxiety were within normal range and improved significantly from baseline to six months. In this study, severe depression was not reported by any of the participants at six months. The findings are consistent with those of other investigators. Loge, Abrahamsen, Ekeberg, Hannisdal, and Kaasa (1997) found that HL survivors younger than age 29 reported less depression than those older than age 50. Kornblith et al. (1998) also reported that HL survivors younger than age 40 had lower levels of depression compared to older HL survivors. Katon (2003) suggested that older adults may experience a

heightened awareness of physical symptoms that can impair HRQOL and can be associated with depressive symptoms.

HL survivors in the current study consistently placed a high value on relationships with family and friends compared to before having cancer. Fletcher et al. (1998) reported that, for those HL survivors who had partners, 191 (39%) believed their relationship was more intense after diagnosis, and only 74 (15%) experienced a worsened relationship or separation. The data imply that HL survivors highly valued their relationships with family and friends at six months after completion of treatment. Findings from previous studies indicate that not only do positive intimate relationships with friends and family contribute to improved coping and adjustment to cancer, but social support from a spouse has been associated with improved survival (Andersen, 1992; Wortman & Dunkel-Schetter, 1979).

Limitations in functional status can range from difficulties in carrying out activities of daily living, such as walking or lifting, to performing activities such as shopping, attending social events, visiting friends, or earning a living. Factors such as older age, physical symptoms, fatigue, and psychological distress significantly predicted disability in a study of 459 HL survivors (Abrahamsen, Loge, Hannisdal, Holte, & Kvaloy, 1998). Consequently, HL survivors were twice as likely to be permanently disabled compared to the general population (Abrahamsen et al., 1998). Contrary to these findings, HL survivors in the current study showed improvement in functional status as soon as

one month post-treatment. Carpenter et al. (1989) reported similar findings in which HL survivors further away from treatment were better adjusted in career plans compared to those who were closer to treatment. In a longitudinal study of 120 HL survivors, Devlen et al. (1987) reported that, for those who did not remain in work during treatment, 24% returned to work within 6–11 months, and an additional 19% returned to work at 12 months or later. As more survivors are able to work during treatment or return to work soon after treatment because of advances in treatment and management of HL, they will be able to maintain financial independence and possibly improve outlook and QOL through work.

The financial obligations of survivors as well as maintaining health insurance coverage also may have an influence on HL survivors' desire to work during treatment or return to work soon after treatment regardless of distressing physical symptoms. Zebrack, Mills, and Weitzman (2007) examined the needs of young adult cancer survivors and reported that 639 respondents (59%) ranked adequate health insurance as their first- or second-most important need, which may be an incentive to return to work before full recovery. Alternatively, other researchers have found that some survivors who experienced a reduction in energy levels or who were less interested in professional work pursuits placed more importance on participating in leisure activities and sport regardless of distressful symptoms (Bloom, Hoppe, Fobair, & Cox, 1988; Joly et al., 1996).

Because the current study focused on young adults with HL, the finding that 50% of inquiries about supportive care services at the end of treatment and one month post-treatment pertained to the socioeconomic burden of cancer is not surprising. Inquiries regarding health insurance increased from end of treatment to one month post-treatment, which may be attributed to increasing concerns regarding out-of-pocket expenses for prescription drugs, inability to work and maintain insurance, and expenses related to copayments for follow-up visits and referrals. Many survivor inquiries at completion of treatment (21%) regarded employee rights, legal and financial issues, and disability. This finding may suggest that survivors are motivated to understand employee rights and protections when continuing or reentering the workforce, possibly for fear of being discriminated against. Treatment often can create lapses in employment and, unless survivors have a safety net or employer support, even a brief illness can be financially and occupationally devastating. Preparing for the worst by inquiring into legal and financial issues may prevent personal bankruptcy. These issues are common for those with chronic illness, including cancer (Himmelstein, Warren, Thorne, & Woolhandler, 2005).

In a study of HL survivors by Jacobs, Ross, Walker, and Stockdale (1983), participants were randomized to one of four groups to determine if psychological and social functioning could be improved through an educational intervention or a peer support group. The education group experienced improvements in anxiety and treatment problems, but the peer support group experienced no significant changes, supporting the argument that professional guidance may be more appropriate (Jacobs et al., 1983). A combination of psychosocial interventions such as stress management, behavioral training, nutritional education, and cognitive therapy are thought to provide longer-lasting benefit and greater emotional support if, most importantly, the psychosocial interventions are planned for 12 weeks or longer (Fawzy, 1999; Rehse & Pukrop, 2003).

In a study of HL survivors who participated in an exercise intervention, a significant reduction in physical, mental, and total fatigue, as well as increased exercise tolerance, was reported (Oldervoll, Kaasa, Knobel, & Loge, 2003). The number of young survivors in the current study doubled in their reported use of services relating to physical fitness activities from baseline to six months post-treatment, which also may have contributed to improved QOL. In a study of 221 cancer survivors who participated in a 12-week community-based exercise program, investigators found improvements in fatigue, insomnia, and physical function as well as being a safe and effective means for improving overall health (Roajotte et al., 2012).

The RAM was a useful guide for the current study in that the concepts of this nursing conceptual model provided a structure for the literature review and led to selection of components of HRQOL that are amenable to nursing assessment and intervention. In addition, the RAM proposition that stimuli influence responses in the four modes of adaptation led to a longitudinal study design and the authors' analyses of changes in the components of HRQOL over time. The finding that some components of HRQOL changed over time provides indirect support of that RAM proposition.

Limitations

Generalization of the current study results is limited by use of a small convenience sample of HL survivors from two major academic medical centers that enroll patients onto clinical trials not offered at other centers. As a consequence, patients seeking treatment are knowledgeable about their disease state and often are of higher socioeconomic status than other patient populations. Socioeconomic factors can be strong predictors of health status, which may account for better health and HRQOL so soon after treatment in this sample of HL survivors. The sample also may have had a greater ability to access supportive care services, such as professional

counseling, exercise and nutrition programs, and physical therapy during treatment, which may have contributed to a quicker recovery after treatment.

Another limitation of the current study is the instrument used to measure intimate relationships. The IOC was refined and evaluated by its developer during the course of this study, which resulted in a significant change to the instrument. As a consequence, the study included only two questions to measure intimate relationships, which may have been invalid and prevented an adequate measurement of the conceptual definition of intimate relationships. Manne and Badr (2008) suggested that, in addition to a dyadic approach in methodology and research design when studying couple adaptation to a cancer diagnosis, a multimethod approach should be implemented using both observational designs and daily diaries that address the needs of patient and partner and enhance communication and understanding of the experience. Understanding the dynamics of intimate relationships in cancer survivors may require the use of a qualitative approach, which may be more informative than a quantitative measure.

Implications for Research

In addition to describing changes in HRQOL over time, the findings of this study may facilitate identification of patient-directed interventions that can promote healthy behaviors and positive lifestyle changes resulting in improved HRQOL. Lifestyle changes, such as attention to diet and increased physical activity, can be initiated during treatment to prevent sedentary behaviors that are common in this population following treatment. Patients with cancer are easily accessible during treatment and lifestyle changes can begin early in the process by providing onsite activities that are convenient, inexpensive, and useful for promoting behavior change, such as nutrition consults and increasing physical activity. Ideally, these services would be covered by insurance. Patients often desire additional knowledge that will improve their physical and psychological well-being. Although onsite patient participation in cancer support programs in an academic medical center can be a challenge for providers because patients often come from long distances and are unable to extend visits for various reasons (e.g., feeling ill, work or family obligations, anxious to return home), opportunities do exist. In addition, many supportive care services were used

at the end of treatment by the study participants, some decreasing and others increasing based on need and appropriate timing. Although not all patients used services, many used more than one service at the same time.

The lack of current research of HRQOL in HL is apparent. The literature review produced articles published as early as the late 1980s through 2006 that investigated physical, psychological, functional, and spiritual domains of HRQOL and may not be relevant today. Side effects from cancer treatment are now treated preemptively with more effective pharmaceuticals, leading to significant improvements in symptom management. This highlights the need for the development of more current, larger, prospective, and longitudinal designs to describe changes in HRQOL in patients with HL.

With regard to policy, the study results provide insight into the economic burden for patients with cancer. Opportunities for accommodation in the workplace as well as legal assistance or opportunities for short-term disability can significantly improve the HRQOL of HL survivors. Occupational health professionals also should be involved in multidisciplinary discussions of needed services. Identifying individual, disease, and work-related factors that will explain the physical and psychological consequences of treatment for both those who continue to work and those who choose not to or are unable to return to work is essential.

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Kristin Roper, RN, MS, is a clinical inquiry specialist at the Phyllis F. Cantor Center, Dana-Farber Cancer Institute; Mary E. Cooley, PhD, RN, FAAN, is a nurse scientist at the Phyllis F. Cantor Center, Dana-Farber Cancer Institute, and an assistant professor in the College of Nursing and Exercise Science at the University of Massachusetts; Kathleen McDermott, RN, BSN, OCN®, is an RN in the lymphoma research program at Dana-Farber Cancer Institute; and Jacqueline Fawcett, PhD, FAAN, is a professor in the College of Nursing and Exercise Science at the University of Massachusetts, all in Boston. The authors take full responsibility for the content of this article. This article was supported in part by an ONS Foundation 2004 Novice Researcher Mentorship Grant, the Dana-Farber Cancer Institute 2004 Friends Grant, and a grant from the National Cancer Institute (#1 U56 CA11863502). Roper can be reached at kroper@partners.org, with copy to editor at ONFEditor@ons.org. (Submitted April 2012. Accepted for publication October 12, 2012.)

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