

Measurement of the quality of life in cancer survivors

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A QOL instrument was developed to measure the specific concerns of long term cancer survivors. The QOL-CS is based on previous versions of the QOL instrument developed by researchers at the City of Hope National Medical Centre (Grant, Padilla, and Ferrell). This instrument was revised over a one year pilot by Hassey-Dow and Ferrell. The revised instrument included 41 items representing the four domains of quality of life incorporating physical, psychological, social, and spiritual well being. The present study was conducted as a mail survey to the membership ($n = 1,200$) of the National Coalition for Cancer Survivorship with 686 subjects responding to the survey. This survey included a Demographic tool, QOL-CS and the FACT-G tool developed by Cella. Psychometric analysis, performed on 686 respondents, included measures of reliability and validity. Two measures of reliability included test-retest and internal consistency. The overall QOL-CS tool test-retest reliability was 0.89 with subscales of Physical $r = 0.88$, Psychological $r = 0.88$, Social $r = 0.81$, and Spiritual, $r = 0.90$. The second measure of reliability was computation of internal consistency using Cronbach's α coefficient as a measure of agreement between items and subscales. Analysis revealed an overall $r = 0.93$. Subscale alphas average ranged from $r = 0.71$ for spiritual well being, $r = 0.77$ for physical, $r = 0.81$ for social, and $r = 0.89$ for psychological. Several measures of validity were used to determine the extent to which the instrument measured the concept of QOL in cancer survivors. The first method of content validity was based on a panel of QOL researchers and nurses with expertise in oncology. The second measure used stepwise multiple regression to determine factors most predictive of overall QOL in cancer survivors. Seventeen variables were found to be statistically significant accounting for 91% of the variance in overall QOL. The fourth measure of validity used Pearson's correlations to estimate the relationships between the subscales of QOL-CS and the subscales of the established FACT-G tool. There was moderate to strong correlation between associated subscales including

QOL-CS physical to FACT physical ($r = 0.74$), QOL-CS Psych to FACT Emotional ($r = 0.65$), QOL Social to FACT Social ($r = 0.44$). The overall QOL-CS correlation with the FACT-G was 0.78. Additional measures of validity included correlations of individual items of the QOL-CS tool, factor analysis, and construct validity discriminating known groups of cancer survivors. Findings demonstrated that the QOL-CS and its subscales adequately measured QOL in this growing population of cancer survivors.

Key words: Cancer survivorship; measurement; quality of life.

Introduction

The quality of life (QOL) among cancer survivors and the means to accurately measure their QOL have commanded increased popularity and attention in the past decade. Several reasons are suggested for this increased attention. First, vastly improved cancer treatment and supportive care have led to extended length of survival for many diseases. Today, over eight million Americans are living with a history of cancer.¹ While much of the information on late effects of treatment were primarily identified in survivors of childhood cancer, clinicians and researchers are beginning to report both intermediate and late treatment effects for many adult cancers.²⁻⁵ In clinical practice, patient education pamphlets, booklets, teaching programmes, and videotapes are currently included in regular discussions among health care providers and patients and their families. Secondly, the emergence of a national forum where cancer survivors have an active voice for their concerns have led to lively debate in the larger political and health policy arenas.⁶ They have participated in evaluation of clinical trials, and have actively advocated for the needs of other cancer survivors. Cancer survivors have also published their first hand experiences with cancer in both the lay and professional literature.^{7,8}

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They have served as a source of inspiration and information for others facing similar circumstances. Taken together, these factors have played a key role in focusing attention to the wider needs and concerns of adult cancer survivors long term.

The purpose of this paper is to report on the psychometric properties of the QOL-CS tool which measures the quality of life of cancer survivors. The goal for future use of the QOL-CS is to evaluate QOL long-term; identify enduring problems in adjustment after treatment; and to identify potential areas for education, counseling, and support.

Review of literature

Quality of life and cancer survivors

The concept of quality of life has particular relevance for long-term cancer survivors. While much of the focus of care during active treatment has been the support of physical and psychological well-being, aspects of social well being (including family, friendship, and work issues) and spiritual well-being most often arise several months to years later. In addition, concerns about late effects of cancer and its treatment on physical and psychological well being take on a vastly different picture with long term cancer survivors. For example, late effects of fatigue, pain, physical decline, sexual and intimacy issues, and cognitive impairments have been identified.⁹⁻¹³ These late effects, while not life threatening, can affect day to day functioning and coping.

Psychologically, cancer survivors may be plagued by the fear associated with cancer recurrence, feelings of uncertainty over their future, loneliness, isolation, anxiety and depression.^{9,14-16} Socially, cancer survivors may often face changes in their family structure and social supports. They may shield their concerns from their family in their desire to not burden them which can often lead to feelings of increased isolation from their usual friendships and supportive networks. Seeking solace and support in cancer support groups have been critical actions to help decrease feelings of loneliness and isolation. Work related fears include the concern over the extent of disclosure, change in work priorities, concern over employee benefits and insurance, discrimination and potential stigma.¹⁸ Few employee programmes are available which address these enormous concerns.

Spiritual and existential concerns most often arise after cancer treatment has been completed.¹⁹⁻²² Spiritual distress of loneliness, despair, grief and

uncertainty over the future have been reported in a few studies.^{19,20,23} Ongoing concerns of day to day living with cancer and its uncertainty have driven many cancer survivors to transcend their experiences. Prayer, meditation, journal writing, enjoyment of nature, altruism and volunteerism are outgrowths of the desire to deepen one's understanding of the cancer experience and its effect on facing one's mortality.²⁴

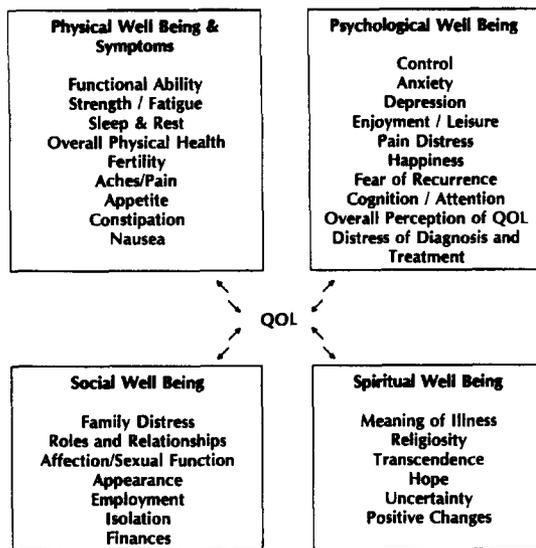
Measurement of QOL of cancer survivors

Measuring QOL among cancer survivors presents a major challenge for several reasons. First, the vast majority of standardized QOL tools focus primarily on acute treatment effects, and often do not contain a longer view of cancer survivorship with specific concerns and needs long term.²⁴ Current standardized QOL tools were developed to evaluate differences in cancer treatment. Much of their use in research has been to measure QOL as an intermediate endpoint in clinical trials.²⁵

Second, QOL tools were first evaluated principally by the health care provider and not the patient. The Karnofsky Scale, with the focus on the physician evaluating patient QOL set the stage for subsequent tool development.²⁶ Proxy measures also have limited applicability, yet, it is now most commonly agreed that subjective evaluation of QOL by patients themselves is the most accurate measure.²⁷ Unfortunately, many items on standardized QOL tools were derived from clinical experience and literature review. Few tools are available which derive content from cancer survivors themselves. In addition, QOL tools have suffered from disproportionate content focusing on the downside of having cancer with few containing elements of positive adjustment. Qualitative methods using interview and focus groups have provided rich content for item development.²⁸ The QOL-CS tool reported in this paper was developed based on interviews with cancer survivors who identified spiritual aspects and positive benefits of surviving cancer.

Theoretical framework

The conceptual framework for the study was based on a model of Quality of Life adapted for cancer survivors. This model is presented in Figure 1. The model originated in the investigators' previous research²⁹⁻³⁵ which identified the domains of quality of life for cancer patients to include Physical Well Being, Psychological Well Being, Social Well Being,

Figure 1. QOL in cancer survivors.

and Spiritual Well Being. While there is not complete agreement of what constitutes the dimensions of QOL in the literature, the domains selected are consistent with predominant views.³⁵ The model presented here was adapted specifically to long term cancer survivors. QOL has an impact on all four QOL domains similar to other investigations, but also includes unique areas of concern.

Methods

Sample

The sample was derived from the mailing list of the National Coalition for Cancer Survivorship (NCCS). The NCCS is a non-profit organization which serves as a peer support group for individuals living with cancer.² A mailed survey to the membership ($n = 1200$) was sent which included the written questionnaires and a cover letter explaining the study and inviting participation. A total of 686 surveys were returned for an overall response rate of 57%.

Instruments

A demographic data tool was used to describe the sample and also to determine characteristics (i.e. length of time since cancer diagnosis) that might influence quality of life. The second instrument was

the Quality of Life—Cancer Survivors Instrument (QOL-CS) which is modelled after several previous instruments by the City of Hope National Medical Centre researchers.¹⁻⁶ This instrument was revised over a one year pilot period based on review of cancer survivorship literature by the investigators and pilot testing (Hassey-Dow and Ferrell). During this pilot testing, in-depth qualitative interviews were conducted with five long-term cancer survivors to determine additional content for this instrument. The instrument was revised so that particular issues of concern to cancer survivors such as distress from treatment, fear of recurrence, fertility issues and other items not reflected in previous QOL versions were included. The instrument included 41 items representing the four domains of quality of life. The tool has evolved over more than fifteen years of QOL research at the City of Hope. In recent years, the spiritual subscale was strengthened and the format was converted from a visual analogue to an ordinal scale.

The third instrument was the FACT-G Tool. The FACT-G was developed by Cella and colleagues.²⁵ It is a 33 item ordinal instrument. The FACT-G tool has been extensively tested and used in oncology research with established concurrent validity with several other QOL instruments, construct validity distinguishing disease stages and factor analysis supporting the five subscales. Cella reports internal consistency by Cronbach's α of $r = 0.89$ Test-retest reliability is 0.92 for the total instrument.²⁵

Procedure

The mailed survey method survey was selected to obtain a large sample with a diversity of cancer diagnosis. The survey was mailed with a cover letter, informed consent form and stamped return address envelope. The mailed survey provided anonymity for respondents.

Data analysis

All data were coded, verified and entered using CRUNCH software. Analysis included descriptive statistics (frequencies, means, standard deviations), and several statistics for assessing psychometric properties. Items within both the QOL-CS Tool and the FACT-G Tool vary in response set, thus all items were transposed for analysis such that the '0' anchor equals 'worst outcome' and the highest anchor equals 'best outcome.'

Results

Demographics

Table 1 presents the demographic data of the sample. The mean age was 49.6 years and 81% of the subjects were female. Predominant religions were Protestant (45%), Catholic (27%) and Jewish (14%). Sixty-three per cent of the sample were married. Forty-nine per cent of the sample were employed full-time and an additional 17% were employed part time. This population was also a predominantly Caucasian sample (94%) and 72% had an undergraduate college degree or above. Sixty-three per cent of the subjects were currently residing with a spouse and 32% had children residing with them. Sixty-eight per cent of this sample had a total family income of \$40,000 or more a year.

The average length of time since cancer diagnosis was 80.4 months. Eighty-three per cent of the patients had undergone surgery, 70% had received chemotherapy, and 51% had received radiation therapy. It is also interesting to note that 11% of the sample had a second or third cancer in addition to their first cancer diagnosis. Seventy-five per cent of the sample had no evidence of disease. Four per cent of the sample were currently receiving treatment for recurrent disease.

Reliability

Two measures of reliability were conducted for the QOL-CS Tool: test-retest and internal consistency. Test-retest reliability is the measure of an instrument's consistency over time. A randomly selected sample of 150 subjects who had completed the initial QOL survey were asked to repeat this survey approximately two weeks later. Of the 150 mailed surveys, 110 responses were received (73%). Of the 110 respondents, only those who had complete data sets on all variables were used for test-retest analysis ($n = 70$). Stability was computed as a correlation between the initial QOL item score and retest score using Pearson's correlation. Table 2 presents the results of the test-retest reliability. The total Physical subscale retest was $r = 0.88$, Psychological Well-Being subscale $r = 0.88$, Social Well-Being $r = 0.81$, and Spiritual Well-Being $r = 0.90$. The overall QOL-CS Tool test/retest reliability was $r = 0.89$. Table 2 also identifies the item to subscale correlation indicating that most of the items were in the range of 0.62–0.85 correlation indicating strong test-retest reliability.

Table 1. Demographic data

	<i>n</i>	%
Age		
$\bar{X} = 49.6$ yrs		
md = 49 yrs		
sd = 12.3 yrs		
Gender		
Male $n = 130$ (19%)		
Female $n = 556$ (81%)		
Level of education		
College degree or above = 72%		
Less than college degree = 28%		
Ethnicity		
Caucasian	94%	
Other	6%	
Religious background		
Protestant	303	(45)
Catholic	179	(27)
Jewish	94	(14)
Other	97	(14)
Marital status		
Married	430	(63)
Never Married	101	(15)
Divorced	85	(12)
Widowed	42	(6)
Living w/ partner	19	(3)
Separated	8	(1)
Other members of household		
Spouse	415	(60)
Child	220	(32)
Alone	152	(22)
Lover	33	(5)
Parent	26	(4)
Friend	10	(1)
Employment status		
Employed full time	335	(49)
Employed part time	116	(17)
Retired	115	(17)
Homemaker	92	(13)
Unemployed through disability	62	(9)
Unemployed and looking for work	19	(3)
Students	29	(4)
Household income		
50,000 or >	342	(55)
40,000–50,000	78	(13)
30,000–40,000	88	(14)
30,000–40,000	88	(14)
Less than 30,000	113	(18)
Cancer type		
Breast CA	294	(43)
Lymphoma	59	(9)
Ovarian	53	(8)
Hodgkins	53	(8)
Cervical	30	(4)
Leukemia	25	(4)
Colon	25	(4)
Other	139	(21)
Months since diagnosis		
$\bar{X} = 80.4$		
md = 58.5		
sd = 73.8		
range = 4–538		
Type of treatment		
Surgery	569	(83)
Chemotherapy	477	(70)
Radiation	349	(51)
Hormone therapy	163	(24)
BMT	47	(7)

The second measure of reliability was computation of internal consistency using Cronbach's α coefficient which measures agreement between items and subscales of the instrument. Analysis revealed an overall $r = 0.93$ indicating strong internal consistency. Subscale alphas range from $r = 0.71$ for Spiritual Well Being, $r = 0.77$ for Physical Well Being, $r = 0.81$ for

Social Well Being, and $r = 0.89$ for Psychological Well Being. Table 3 also presents the individual item to subscale correlation values. Most items indicate strong correlation with the subscale. However, a few items indicate low consistency with the subscale indicating need for further refinement.

Table 2. QOL-CS scale test-retest reliability* ($n=70$)

Items (by subscale)	Item to item correlation value
Physical well being	
Menstrual chg/fertility	0.86
Aches/pain	0.83
Fatigue	0.80
Sleep	0.77
Appetite	0.75
Constipation	0.72
Nausea	0.70
Overall physical	0.51
Total physical subscale	0.88
Psychological Well Being	
Appearance	0.84
Usefulness	0.83
Ca treatment distress	0.82
Fear future tests	0.82
Initial dx distress	0.80
Concentration/memory	0.79
Depression	0.79
Fear recurrent ca	0.79
Happiness	0.78
Fear second ca	0.77
Satisfaction	0.73
Anxiety	0.72
Fear spread ca	0.69
Self concept	0.68
QOL Item	0.68
Control	0.66
Time since tx distress	0.64
Coping	0.61
Total psychological subscale	0.88
Social well being	
Financial burden	0.92
Employment	0.79
Personal relationships	0.74
Home activities	0.73
Feel isolated	0.72
Support/others	0.69
Sexuality	0.67
Family distress	0.66
Total social subscale	0.81
Spiritual well being	
Import relig activ	0.95
Import spiritual activ	0.86
Spiritual change	0.80
Life purpose	0.77
Positive change	0.69
Uncertainty	0.65
Hopefulness	0.64
Total spiritual subscale	0.90
Overall QOL	
Total QOL CS tool	0.89

* Pearson's correlation coefficient

Table 3. Internal consistency*

Items to subscale	Item to subscale correlation value
Physical well being	
Fatigue	0.66
Aches/pain	0.66
Sleep	0.58
Appetite	0.57
Overall physical	0.46
Constipation	0.43
Nausea	0.40
Menstrual chg/fertility	0.18
Total physical subscale to total	0.77
Psychological Well Being	
Anxiety	0.71
Coping	0.69
Depression	0.69
Fear recurrent ca	0.65
Control	0.65
Fear second ca	0.64
Time since tx distress	0.62
Satisfaction	0.60
Fear future tests	0.60
Happiness	0.55
Fear spread ca	0.54
Usefulness	0.52
QOL item	0.49
Concentration/memory	0.44
Self concept	0.41
Ca treatment distress	0.39
Appearance	0.35
Initial dx distress	0.26
Total psychological subscale to total	0.89
Social well being	
Personal relationships	0.67
Feel isolated	0.67
Home activities	0.66
Employment	0.65
Financial burden	0.51
Sexuality	0.47
Support/ others	0.31
Family distress	0.24
Total social subscale to total	0.81
Spiritual well being	
Spiritual change	0.57
Life purpose	0.51
Positive change	0.46
Import relig activ	0.45
Import spiritual activ	0.45
Hopefulness	0.43
Uncertainty	0.15
Total spiritual subscale to total	0.71
Overall QOL	
Total QOL CS Tool	0.93

* Cronbachs α

Table 4. Stepwise multiple regression analysis of selected independent variables with dependent variable QOL total score

Step	Variable	Coeff	Std Err	Model R ²
1	Control	0.05	0.01	0.46
2	Aches/Pain	0.08	0.01	0.61
3	Uncertainty	0.06	0.01	0.69
4	Satisfaction	0.05	0.02	0.74
5	Future	0.09	0.01	0.78
7	Appearance	0.05	0.01	0.81
8	Fatigue	0.07	0.01	0.83
9	Spiritual	0.07	0.01	0.85
10	Finances	0.05	0.01	0.87
11	Family	0.07	0.01	0.88
12	Purpose	0.03	0.01	0.89
13	Self Concept	0.04	0.01	0.90
14	Support	0.05	0.01	0.91

all *p* values < 0.01

Validity

Five measures of validity were used to determine the extent to which the instrument measured the concept of QOL in cancer survivors: content, predictive, concurrent, construct and discriminate. The first method was measurement of content validity. The QOL-CS instrument has evolved over approximately 15 years of research by the investigators at the City of Hope.¹⁻⁶ Further refinement of the QOL-CS instrument was based on review of literature, clinical experience of the investigators, and an initial pilot testing based on a qualitative study using in-depth interviews with five long-term cancer survivors to further define content that might be specific to cancer survivors.²⁸ The initial draft of the QOL-CS was circulated to a panel of quality of life researchers and nurses with expertise in oncology and QOL. Each expert was asked to rate each item as acceptable content and to evaluate the items for clarity. Items were refined based on the content validity estimates and the final version was pilot tested for clarity.

The second measure of predictive validity was examined by use of step-wise multiple regression to determine factors most predictive of overall quality of life among cancer survivors. Independent variables of the regression equation were selected from the items of the QOL-CS tool which could logically be expected to influence overall quality of life. The dependent variable for the analysis was the overall QOL mean score for the total instrument. The results of the regression analysis are included in Table 4. Fourteen variables were included which accounted for 91% of the variance in overall QOL. The variables accounting for the greatest per cent of the variance

were control, aches and pain, uncertainty, satisfaction, future, appearance and fatigue. Control, the chief variable, accounted for 46% of the variance ($r^2 = 0.46$). These results are consistent with our previous research and that of other QOL investigators indicating that many of the predictors of overall QOL are aspects of Psychological Well-Being. In this analysis, however, two physical items of aches and pain and fatigue were also among the top predictors of QOL.

The third measure of validity was tested by Pearson's correlation coefficient to estimate the relationship between the total scale and subscales of the QOL-CS Tool and the FACT-G Tool. This analysis evaluated concurrent validity between the two QOL measures. Table 5 presents the results of this analysis. There was generally moderate to strong correlation between associated scales including QOL-CS Physical to FACT Physical ($r = 0.74$), and QOL-CS Psych to FACT Emotional ($r = 0.65$). There was a moderate association of the QOL-CS Social and FACT Social ($r = 0.44$). The overall QOL-CS correlation with the FACT-G total correlation was $r = 0.78$.

As an additional measure of concurrent validity, Pearson's correlations were also performed on individual items of the QOL-CS Tool. Table 6 presents the correlations based on this analysis. These data are useful in isolating quality of life concepts which are closely related. The table indicates items with correlations of $r > 0.40$ indicating moderate to strong correlation among items.

The fifth measure of validity was accomplished by principal components factor analysis, a form of construct validity used to refine the subscales of the instrument. Table 7 presents the factors identified through this analysis. Factors 1 and 2 include most of the items of Psychological Well-Being and are consistent with our prior research demonstrating it as the predominant factor. Factor 2 captures issues related to the future of the cancer, such as fear of recurrence. Items related to Social Well-Being are captured within Factor 3. Factor 4 includes the major aspects of Physical Well-Being. Spiritual Well-Being is distributed across Factors 5 and 6. Factor 5 includes items measuring religiosity as well as non-religious in nature such as hopefulness, sense of purpose and positive benefits of cancer. One item, nausea, was isolated as a separate factor as this symptom was not a common problem in the cancer survivors group, as generally found during active treatment, and thus, will be eliminated from the QOL-CS instrument. Overall, the investigators are pleased with the results of the factor analysis, particularly considering the early development of this survivorship version and the broad view of QOL encompassing multiple issues

Table 7. Principal component factor analysis (*n* = 686) of QOL-CS

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	Factor 9
Satisf	0.86	Anxiety 0.60	Isolation 0.65	Fatigue 0.48	Religion 0.78	Hopeful 0.59	Self-concept 0.54	Treatment & Distress 0.78	Nausea 0.76
Happiness 0.85		Uncert 0.57	Relatn 0.61	Sleep 0.70	Meditation 0.78	Purpose 0.75	Sexual 0.40		
Overall QOL 0.76		Fear 2nd CA 0.84	Home Activities 0.61	Aches/pain 0.60	Spiritual change 0.85	Positive 0.73	Appear 0.73	Initial dx 0.82	
Control 0.73		Fear Recurr 0.89	Employment 0.76	Appetite 0.38			Fertility 0.72	Family distress 0.43	
Useful 0.70		Fear spread CA 0.82	Finances 0.65	Constipation 0.71					
Coping 0.49		Future 0.82	Time since tx 0.40	Overall physical 0.31					
Support 0.47									
Concentration 0.59									
Depress 0.53									
Variance	5.69	4.49	3.66	2.66	2.12	1.97	1.97	1.83	1.63

Discussion

The QOL-CS instrument extends the previous work of the investigators, as well as contributes to previous work by other QOL researchers. The population of cancer survivors is a growing group with multiple demands on QOL. This study also added to our understanding of the spiritual domain of QOL and to existential concerns of surviving a life threatening illness. The many positive benefits of surviving cancer were also apparent in the findings and provide a critical balance to the negative aspects of surviving cancer. There is continued need for refinement of the QOL-CS instrument such that the unique dimensions of survivorship are appreciated.

A few limitations deserve attention. Similar to other QOL studies, the sample contained few cultural groups. There is great need to examine cultural influences of QOL. The sample consisted of an overwhelmingly limited ethnic diversity of survivors. Particular attention to examining QOL in other cultural groups in the future is paramount. We are currently addressing this issue in our continued QOL research.

The sample was also drawn from the NCCS which conceivably were survivors who were doing well or who were articulate enough to write and share their experiences with the investigators. This area of research, as well as all QOL exploration, must address those individuals who are often neglected and who will require alternate methods to express their stories. It is ironic that little QOL research has been done in the area of cancer survivorship, when in fact the

essence of prolonging life should rest within preserving the quality of those lives. This study serves as a contribution to the quality of lives made possible by advances in cancer treatment.

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