

Quality of life and hope in elderly people with cancer

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ABSTRACT

The aim of this study was to describe the characteristics in Quality of Life (QoL) and hope in elderly people newly diagnosed with cancer, and to compare the results for those who survived six months after diagnosis with those who did not. The design of the study was a quantitative study including drop-out analysis. Data were collected prospectively from a group of 101 older people with cancer. The core questionnaire EORTC QLQ-C30 was used to measure QoL and Nowotny's Hope Scale (NHS) was employed to measure hope. Participants who died within six months of diagnosis had significantly lower QoL and had more complaints about symptoms compared to those who survived. However, hope did not differ significantly between those who died and those who survived. Despite lower QoL score among those who died they were able to deal with their difficult situation and maintain hope in late life. This capacity seems to be an important component of hope in the elderly; thus it is essential to strengthen hope.

Keywords: Hope; Quality of Life; Elderly People with Cancer; Palliative Care; Survivors

1. BACKGROUND

The improvement and maintenance of QoL are a major goal of cancer care for older people, especially under conditions of limited improvement of survival and at the price of significant complications [1]. From a study comparing QoL in elderly people with and without cancer it was found that the former group had lower (poorer) scores in QoL and more symptom complaints [2]. This issue is particularly relevant to the elderly person with cancer, who may have a limited life expectancy compared to younger to younger people and increased risk of complications from their treatment [1].

People newly diagnosed with cancer are in an especially vulnerable and unknown situation in which the diagnosis can threaten hope and make the future uncertain. Hope may be particularly important for people diagnosed with a life-threatening illness [3], such as cancer. Few studies describe the concept of hope in people who are elderly and have cancer [4-5]. A qualitative study identified loss of hope as threatening for an elderly person with cancer, because it represented the finiteness of life [6]. According to Nowotny [7] the aspect of life expectancy may not necessarily be important because seriously ill people speculate less on cure or extra life span and more on what is possible and realistic in the situation. This is in line with Benzein [3] who identified hope in healthy people as a process linked to meaning in life. Therefore, hope is a notion that not only contains the number of years left to live, but also the *meaning* of life, which is in line with the findings of Nowotny [7]. This issue may be important for the elderly person with cancer due to limited life expectancy, regardless of the outcome of the disease trajectory.

Few studies report on QoL and hope for cancer patients and for older people in general. In a follow-up study a low level of hope was identified as a predictor for decreased QoL in elderly people with cancer six months after diagnosis [8]. Rustoen and Hanestad (1998) observed in an intervention study (age range 26 - 78; n = 96 newly diagnosed cancer patients) that hope scores in 'the hope group' were significantly improved two weeks after the intervention compared to the scores in the two control groups. In another study hope was identified as an important resource for cancer patients having an impact on their QoL [9]. According to Rustoen and Hanestad [10], one significant important issue in employing the concepts of 'hope' and QoL is that they can be seen as two separate ones. However, although they are dependent on one another, the relationship is not simple [9]. Earlier intervention studies have identified a strong positive relation between hope and QoL, and suggest that both improve

following intervention [10-12]. Thus, hope may buffer against decreased QoL and so be regarded as a personal resource. QoL is often assumed to be an important outcome variable within health care in regard to disease trajectory, treatment and the ability to manage daily living with a diagnosis of cancer. Hope, however, appears little investigated as an important outcome variable in health care.

In palliative care, where patients have to live with uncertainty due to their illness and due to the length of life they may expect, hope is one of the most important issues [13]. The concept of palliative care is above all based on the idea of reinforcing factors that improve QoL and decreasing the impact of factors that may reduce it [14]. However, there is a lack of knowledge about elderly people with cancer, especially in relation to those in the advanced stages. Nevertheless, it may be important to explore QoL and hope in the elderly with cancer to gain insights about how they may be better able to manage their situation and to give them high quality care at the end of life. Thus, the aim of this study was to describe the characteristics in QoL and hope in elderly people newly diagnosed with cancer, and to compare the results for those who survived six months after diagnosis with those who did not.

2. METHOD

2.1. Design

A prospective, follow-up study with the overall aim to examine elderly persons newly diagnosed with cancer was conducted [15]. A dropout analysis was performed and results from this analysis will be presented in this paper with focus on the difference in QoL and hope between those elderly people newly diagnosed with cancer who survived for six months after the diagnosis and those who did not.

2.2. Sample Selection

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Among 142 patients (aged 65 + years) referred to the Department of Oncology in the Capital Region. Inclusion criteria for the study were having a diagnosis of breast cancer, lung cancer, gynecological cancer or colorectal cancer, and undergoing treatment and / or receiv-

ing supportive hospital care for the cancer. Eligible patients were invited to participate by letter and subsequently contacted via telephone by the first author (BAE), when their willingness to participate and full understanding of their rights concerning participation and non-participation were confirmed. In total, 101 newly diagnosed with cancer, met inclusion criteria for the study and agreed to participate. In total, 41 refused to participate for reasons of to general frailty ($n = 13$), cognitive dysfunction ($n = 3$), next of kin not wanting the patient to contribute ($n = 10$) or for unspecified reasons ($n = 15$). The 101 people in the study group consisted of 74 women and 27 men. In total, 26 of the 101 participants (17 women, 9 men) died within six months of diagnosis (labeled 'died') while 75 survived (labeled 'survivors') at least six months.

2.3. Instruments

A questionnaire was developed for the follow - up study addressing socio-demographic data, and QoL and hope [15]. Quality of life (QoL) was used as a health-related quality of life measurement and was measured using the EORTC QLQ-C30 (version 3), referred to below as QLQ-C30 [16]. The instrument is cancer specific, multi-dimensional, applicable in different cultures [17-18], and has been translated into several languages, including Danish. The QLQ consists of three subscales: the global health status/QoL, functional scale and symptoms scale including 30 items. The response format for all subscales consists of a 4-point Likert scale format ranging from one to four "not at all", "a little", "quite a bit" and "very much" [19]. QLQ-C30 was scored in accordance with the methodology developed by QLQ-C30 ranging from 0 to 100 [19]. The internal consistencies of the instruments were calculated using Cronbach's Alpha (0.70 - 0.90). The reliability analysis for QLQ-C in this study was α 0.76 - 0.97, except for emotional function α 0.61 and cognitive function α 0.43.

Nowotny's Hope Scale (NHS) was used to measure hope. The instrument consists of 29 questions covering six dimensions, and provides detailed information on different aspects of hope. It is specifically developed to measure hope in individuals suffering a crisis such as a diagnosis of cancer. The response format scores consist of a 4-point Likert format ranging from one to four "strongly agree", "agree", "disagree" to "strongly disagree" [20]. NHS was translated from English into Danish according to internationally accepted guidelines [21] and was transformed to scores ranging from 29 to 116 according to Nowotny [20]. A score from 29 - 50 indicates "hopelessness", 51 - 72 "low hope", 73 - 94 "moderately hopeful" and 95 - 116 "hopeful" [22]. In this study the reliability analysis ranged from α 0.74 - 0.88,

except for the item “comes from within” (α 0.20).

2.4. Data Collection

Data reported in this paper are all from the drop-out analysis from the prospective follow-up study (baseline measurement) after having identified those, who were lost to follow-up six months after. Structured interviews, based on the questionnaire developed for the follow-up study, were conducted by the first author two to four weeks after the diagnosis. All data were therefore self-reported by participants, except for age, sex, and type of cancer, which were collected from the referral list of the oncology clinic.

2.5. Ethical Approval

The Danish Data Protection Agency was informed of the database. The study protocol was sent to the Copenhagen County Ethical Committee which found formal approval unnecessary. Prior to enrolment, each participant received oral and written information about the aim of the study, and it was emphasized that participation was voluntary and would not in any way affect their treatment. All participants were informed about procedures for ensuring confidentiality and anonymity.

2.6. Analysis

Descriptive statistical analyses were performed on all variables. The measures are described using median and Interquartile Range (IQR). Data were further analyzed for differences between those who died and those who

survived. In addition, all variables were regarded as non-normally distributed; hence non-parametric statistics methods were applied. For differences between two independent groups (age groups and years at school) Kruskal-Wallis one-way analysis of variance was used for analyzing ordinal scale data (**Table 1**). Analysis was performed to explore differences between those who died ($n = 26$) and those who survived ($n = 75$) within the six-month period. Mann Whitney U-test was used to analyze differences in the nominal and categorical level of data at baseline between the two groups. Tests with p -values < 0.05 were regarded as statistically significant. Statistical analyses were carried out with SPSS 11.5 for Windows®.

3. RESULTS

3.1. Socio—Demographic Data

The median age of the study group was 74.74 (IQR 8.75) (**Table 1**). Those who died ($n = 26$) had a median age of 73.90 (IQR 9.88). Sex distribution was 65.4% women and 34.6% men. Those who survived ($n = 75$) had a median age of 75.49 (IQR 8.7). Sex distribution was 76% women and 24% men. For further information, see **Tables 1** and **2**. There were no statistically significant differences in the distribution by age, sex, type of accommodation, number of years at school, latest occupation, no income other than retirement pension and financial circumstances between those who survived and those who died.

Table 1. Demographic characteristics %.

Variable	(n = 26)	Survivors (n = 75)	Total (n = 101)	P-Value ¹
Age, Median (IQR)	73.90 (9.88)	75.49 (8.7)	74.74 (8.75)	0.284 ^{2&3}
Sex %				0.294
Women	65.4	76	73.3	
Men	34.6	24	26.7	
Diagnosis (= n)				
Breast cancer	1	23	24	
Gynecological cancer	5	20	25	
Lung Cancer	6	19	25	
Colo-rectal cancer	14	13	27	
Total	26	75	101	
Marital Status %				0.193
Married	61.5	46.7	50.5	
Not married (includes divorced, widowed, separated and single)	38.5	53.3	49.5	
Type of accommodation (%)				0.321
Apartment	53.8	56	44.6	
House / farm	42.3	41.3	52.5	
Sheltered house	3.8	2.7	3.0	
Years at school, Median (IQR)	8.00 (3.00)	9.00 (3.00)	8.00 (3.00)	0.091
Last profession/occupation %				0.641
Housewife or blue collar	53.8	27.3	46.5	
Employee or public servant	30.8	42.7	33.7	
Self-employed	15.4	16	19.8	

¹Mann-Whitney test; ^{2&3} Kruskal Wallis test.

3.2. Quality of Life

Participants who died had an overall lower QoL than those who survived ($P = 0.018$). They had lower scores in functional scale ($P = 0.006$), lower physical function ($P = 0.003$) and lower role function measured on the subscale role function ($P = 0.003$). Moreover, in the symptom scale ($P = 0.026$), they had a higher score, indicating more problems and complaints. Those who died reported significantly more frequent fatigue than those who survived ($P = 0.007$) as well as more dyspnea ($P = 0.025$) (**Table 3**).

3.3. Hope

No significant difference was found in the level of hope between those who died and those who survived. However, in the subscale 'comes from within' a total score was median 11.00 and a significant difference was identified between the two groups ($P = 0.005$) (**Table 4**). Those who died and those who survived. However, in the subscale 'comes from within' a total score was median 11.00 and a significant difference was identified between the two groups ($P = 0.005$) (**Table 4**).

Table 2. Economic situation, Receiving help and in contact with health care system.

Variable	Died (n = 26)	Survivors (n = 75)	Total (n = 101)	P-value ¹
Economic situation				
Other income than retirement pension	25.7	24.0	27.7	0.581
Reduced economic ability activity due to cancer	7.7	14.7	12.9	0.360
In contact with health care system				
Hospitalized within the last six months	88.5	94.7	93.1	0.285
In contact with general practitioner (GP)	80.8	84	83.2	0.706
In contact with home help service	38.5	26.7	29.7	0.259
In contact with home nurse	26.9	22.7	23.8	0.662
Receiving help				
Need more help	75.9	73.0	75.8	0.268
Having children	96.2	88	90.1	0.233
Getting help from children	65.4	59.1	61.5	0.428
Having grandchildren	88.5	84	85.1	0.583
Getting help from grandchildren	34.6	19	24.4	0.056

¹Mann-Whitney Test.

Table 3. Quality of life-comparison for those who died within the first six months and those who survived.

Variable	Died (n = 26)	Survivors (n = 75)	In total (n = 101)	P-value ¹
Global health status / QOL (QL) ²	50.00 (50.00)	75.00 (33.33)	66.67 (33.33)	0.018
Functional scales ³	63.33 (37.78)	77.78 (22.22)	77.78 (25.56)	0.006
Physical function (PF)	46.67 (50.00)	73.68 (33.33)	73.33 (40.00)	0.003
Role function (RF)	66.67 (87.50)	100.00 (33.33)	66.67 (66.67)	0.003
Emotional function (EF)	66.67 (43.75)	75.00 (41.67)	75.00 (41.67)	0.345
Cognitive function (CF)	83.33 (16.67)	83.33 (33.33)	83.33 (16.67)	0.789
Social function (SF)	100.00 (33.33)	100.00 (0.00)	100.00 (00.00)	0.069
Symptom scales ⁴	28.21 (17.95)	20.51 (26.51)	23.08 (20.51)	0.026
Fatigue (FA)	66.67 (44.44)	33.33 (38.89)	44.44 (44.44)	0.007
Nausea & vomiting (NV)	0.00 (33.33)	0.00 (16.67)	0.00 (16.67)	0.903
Pain (PA)	33.33 (50.00)	16.67 (33.33)	16.67 (33.33)	0.086
Single items ⁵				
Dyspnoea (DY)	33.33 (66.67)	0.00 (33.33)	0.00 (66.67)	0.025
Insomnia (SL)	33.33 (41.67)	0.00 (66.67)	0.00 (66.67)	0.626
Appetite loss (AP)	33.33 (66.67)	0.00 (33.33)	0.00 (33.33)	0.086
Constipation (CO)	0.00 (33.33)	0.00 (33.33)	0.00 (33.33)	0.844
Diarrhoea (DI)	0.00 (0.00)	0.00 (33.33)	0.00 (33.33)	0.293
Financial difficulties (FI)	0.00 (0.00)	0.00 (0.00)	0.00 (00.00)	0.108

¹Man n-Whitney test; ²Higher scores indicate higher health related quality of life.; ³Higher score indicate higher function; ⁴Lower scores indicate fewer problems ⁵ Lower scores indicate fewer problems.

Table 4. Nowotny's Hope scale-those who died within the first six months and those who survived.

Variable	Died (n = 26)	Survivors (n = 75)	Total (n = 101)	P-value ¹
Nowotny's Hope scale ²	85.00 (16.25)	86.00 (14.00)	85.00 (14.50)	0.929
Confidence	14.50 (6.00)	25.00 (5.00)	25.00 (5.00)	0.861
Related to others	18.00 (4.50)	17.00 (5.00)	18.00 (5.00)	0.810
Future is possible	14.50 (5.00)	13.00 (5.00)	14.00 (5.00)	0.800
Spiritual beliefs	7.00 (6.00)	5.00 (5.00)	5.00 (5.00)	0.224
Active involvement	14.00 (4.00)	14.00 (4.00)	14.00 (4.00)	0.901
Comes from within	10.00 (1.25)	11.00 (1.00)	11.00 (1.00)	0.005

¹Mann-Whitney Test; ²Higher scores indicate more hope.

4. METHODOLOGICAL CONSIDERATIONS

Collecting data through personal, structured interviews may have strengthened the result of the study in more than one respect. Such interviews ensured that all questions in the schedule were answered, with no gaps in the data. Another advantage was that emotive and sensitive questions could be asked and misunderstandings checked immediately. The interviewers were also able to sense if some questions were particularly difficult for participants to handle. Nowotny's Hope Scale questions were posed towards the end of the interview. It could be argued that, during the interview, participants were taken through all aspects of a difficult life situation, and, from a rational point of view, this may have negatively influenced hope-scores. Equally, the participants may have experienced the interview situation as valuable and meaningful, which may have influenced hope-scores positively.

No study like this one has been carried out before so it can be regarded as a valuable pilot. It should be stressed that 26 patients in the sample died within the first six months from the follow-up study. Although statistically taken into account this small number suggests the need to conduct a similar but larger study focusing on hope and QoL in elderly patients with advanced cancer. The relationship between hope and QoL should be the key especially when each group is studied independently with focus on survival and palliative care.

5. DISCUSSION

The 75 elderly cancer patients who survived the first six months after diagnosis were in good condition according to QoL, physical functioning and incidence of symptoms at the time of diagnosis as opposed to those who did not. Those who died had, as expected, significantly lower QoL and more complaints. However, the level of hope did not differ significantly between the two groups (except from the subscale 'comes from within'). As expected, those who died were at a significantly lower level of functioning capability than those who survived.

Though, it is noteworthy that the same level of hope was reported by both groups. Different aspects of this finding will be discussed below.

Despite a lower QoL score among those who died (and despite the seriousness of their situation), they were equally able to deal with their difficult situation and to maintain hope in late life as newly diagnosed with cancer. The theoretical approach to hope in this study was not only related to the future but also to new goals and strategies in life, and / or feelings of safety and comfort [22]. The importance of hope and meaning, and how to maintain and measure hope, has been of interest within cancer care [10,20,23-25]. However, consensus on a common definition has not been reached [9]. Hope has been defined as a catalyst that assists individuals to cope successfully with life's challenges and transitions, and which facilitates continued functioning during chronic illness and other significant losses [26-28]. This is especially important for elderly people who are challenged with the task of maintaining hope in the face of loss [12]. Defining hope in relation to achievement, success, and control is problematic for the elderly who may perhaps already have experienced loss of their spouse and friends, moving away from the family home, and / or reduction in physical capacity [27-29]. In clinical practice, it is often stated that health care professionals should not take away hope from people suffering from cancer; especially those with advanced cancer. Assuming that hope is a catalyst that assists people to handle successfully changes in life, and that it is an inner power or resource, it should be independent of experienced losses and may be based in a person's ability to maintain hope *perse*, despite losses and difficulties.

In the current study QoL was measured by EORTC, a health related QoL instrument where a person's perceptions of health status and aspects of life are considered in relation to expectations of normal living [30]. EORTC cover aspects such as general health, physical functioning, physical symptoms, emotional functioning and cognitive function [31]. Although the global QoL seemed to

be equal and without significant difference in the two groups we investigated, the result underlines the need for recognition of QoL by health care professionals immediately on diagnosis in order to counteract the serious reduction in QoL that could occur in the early stages of cancer in the elderly.

The entire sample scored “moderately hopeful” in accordance with the methodology developed by Nowotny (1989). According to Rustoen [24], hope can be regarded as a component in the individual’s ability to cope with stress in a life-threatening situation. Interpretation of the results of this study, however, requires caution for at least two reasons. Firstly, the relation between QoL and hope is uncertain [24]. Secondly, the reliability of the subscale ‘comes from within’ was low ($\alpha = 0.30$). Findings from a qualitative study, however, confirm that the existential dimension of hope in elderly people newly diagnosed with cancer is essential (Esbensen, 2004). In the current study, such people had suddenly to face the possibility that they might die within a short time-frame. Despite the diagnosis of cancer in old age, advanced cancer and a need for palliative care, those who died obviously managed to maintain hope at the same level as those who survived the first six months after diagnosis. This may be interpreted in the light of the core of the SOC model (The model of Selective Optimization with Compensation) according to which, to some extent, the elderly were able to strengthen their belief in handling difficulties and to set up new goals despite an uncertain future [32]. However, it has been suggested that the meaning of hope for palliative patients is the hope for others, not suffering and a peaceful death. This reflects a discourse of hope that is framed by QoL, not life or death [5,29].

Based on this study we suggest that patients adapt to their situation and appreciate every day in the face of a potentially limited life expectancy. We also suggest that other issues normally neglected in life become important when one is diagnosed with a life-threatening disease. Morse and Doberneck [33] pointed out from a qualitative study of four participant groups (patients undergoing heart transplant, spinal cord-injured patients, breast cancer survivors, and breastfeeding mothers intending to continue nursing while employed) that the degree of threat experienced by a person as opposed to feeling safe can motivate and strengthen hope. This may also have been the situation for the 26 people in the sample who died within the first six months; their ability to mobilize their own resources despite the cancer may have helped to maintain hope.

6. RELEVANCE TO CLINICAL PRACTICE

This study has implications for care and support in the field of cancer care in the elderly. A group of elderly

people had suddenly to face the possibility that they might die within a short time-Despite the diagnosis of cancer and the need for palliative care, those who died obviously managed to maintain hope at the same level as those who survived the first six months after diagnosis. Assuming that hope is a catalyst that assists people to cope successfully with changes in life, and that it is an inner power or resource, it should be independent of experienced losses. Instead, hope may be based in a person’s ability to maintain it perse, despite losses and difficulties, and the clinical implications are therefore to support hope in the individual patient.

Despite limited life expectation some patients were able to adapt to their changed situation. It might be that other matters become more important with a potentially life-threatening disease. Health-care professionals may play a significant role in identifying elderly people with cancer who are unable to mobilise their own resources to maintain a moderate level of QoL. In addition, those patients who have difficulty in adapting to the new situation, and therefore at risk of experiencing reduced QoL and hope need specific intervention.

7. CONCLUSIONS

Those who died within the first six months had lower QoL and more complaints than those who survived. A significant difference was identified in Global QoL, in physical and role function. However, no significant difference was identified in the total level of hope between the two groups. Hope may be based in a person’s ability to maintain hope per se which underlines the necessity for health care professionals continuously to recognize the situation of the elderly individual with cancer in order to counteract the reduction in QoL that may occur and to support their hope.

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