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TITLE

Bereaved parents' quality of life: resilience and professional support

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ABSTRACT

Objectives: The study aimed to compare the quality of life (QoL) among cancer-bereaved parents with a control group and explore how resilience and support from healthcare professionals associated with QoL of parents 2-8 years after the loss of a child to cancer.

Methods: This nationwide, cross-sectional survey was administered among parents (n= 161) who lost their child to cancer between 2009 and 2014, compared to a matched control parent group (n= 77). A study-specific questionnaire, Resilience Scale for Adults (six factors: “Perception of self,” “Planned future,” “Social competence,” “Structured style,” “Family cohesion” and “Social resources”) and a single-item measure of parents’ QoL were included for the study.

Results: There was a lower QoL in both bereaved parents (mean= 5.1) compared with the control parents (mean= 5.8), $p < 0.001$. Two resilience factors, “Perception of self” (OR = 1.8, $p = .004$) and “Planned future” (OR = 2.05, $p < 0.001$), and given sufficient information during the child’s last month (OR = 2.63, $p = 0.003$) were positively associated with long-term QoL in cancer-bereaved parents.

Conclusion: The findings indicate lower QoL among both fathers and mothers 2-8 years after losing a child to cancer. The study also highlights the positive role of resilience and the importance of informational support on long-term QoL in cancer-bereaved parents. Bereavement support should be tailored for supporting individual needs.

Keywords: Bereavement, Bereaved Families, Childhood Cancer, Quality of life, Resilience Factors

KEY MESSAGES

What was already known?

Bereaved parents have low short-term QoL.

Social support and resilience are important factors.

What are the new findings?

Bereaved parents have lower long-term QoL than the control group.

Better informational support and resilience are associated with higher QoL.

What is their significance?

a. Clinical: Improving resilience is helpful for long-term QoL in bereaved parents.

b. Research: Support should be tailored for individual needs.

INTRODUCTION

The loss of a child considerably changes parents' lives and may cause an identity crisis with a loss of meaning in life.¹ The bereavement process is associated with higher risks of poor quality of life (QoL), depression, anxiety, and prolonged grief in cancer-bereaved parents.² QoL is often defined as the concept that incorporates physical functioning, mental status, and a person's ability to engage in social activities.³ Previous research has mainly investigated QoL in cancer survivors, patients with cancer, and their caregivers.⁴ Lower short-term QoL has been found in bereaved family members of patients with cancer compared with controls.⁵ However, there has been little research investigating QoL among cancer-bereaved parents in a long-term perspective compared with control parents.⁷

Although it is important to reduce risk factors during stressful life events, it is also essential to focus on factors such as resilience that can protect individuals' QoL and increase the likelihood of positive outcomes.⁸ The growing interest in resilience and its impact on QoL is primarily motivated by identifying which protective factors and mechanisms promote healthy adjustment after exposure to significant life stressors.⁹ *Resilience* refers to "a dynamic process encompassing positive adaptation within the context of significant adversity".¹⁰ Resilience was found to be an important moderator of pain and stress, supporting a protective effect of resilience.¹¹ However, to our knowledge, the protective role of resilience on long-term QoL is unclear among cancer-bereaved parents.

In general, both positive and negative circumstances regarding end-of-life and follow-up care influences parents' ability to return to everyday life and resume their routines.¹² "Social support" is an important resilience factor that can protect and prevent adverse outcomes in the face of difficulty.^{13 14} When a child becomes ill with cancer, social resources of parents also extend to include healthcare professionals. Availability and support from healthcare professionals greatly affect both patient care and families' coping.¹⁵ Moreover, research

indicates that support from healthcare professionals can influence cohesion, safety, and QoL of families.^{12 15} Informational support (having a dialogue) is one of five categories of supportive interactions with healthcare professionals linked with emotional consequences.¹⁶ Parental bereavement outcomes can be affected by information's adequacy and how healthcare professionals provide information during the child's illness and after the loss.¹⁷ Bereavement outcome and its related factors are critical issues in assessing palliative care services. However, it is unclear how given information and support during illness and following loss would be associated with long-term QoL in cancer-bereaved parents. Therefore, the present study was designed to assess long-term QoL among cancer-bereaved parents compared with a control group. The study also aimed to explore associations between resilience and support from healthcare professionals with the QoL of parents 2-8 years after losing a child to cancer. It was hypothesized that cancer-bereaved parents would show lower long-term QoL compared to control parents. Moreover, bereaved parents with higher resilience and support from healthcare professionals would report higher QoL.

METHODS

Design

Information was obtained through a self-reported survey. This cross-sectional study was approved by the Regional Committees for Medical and Health Research Ethics (2014/1997/REK Midt) and conducted following the Declaration of Helsinki. All participants signed a written informed consent before participation. The data were collected from July to October 2017.

Participants and Procedure

This nationwide survey was conducted among Norwegian parents who lost their child to cancer 2-8 years earlier, between January 2009 and December 2014. We identified a total of 246 children/young adults who died of cancer before the age of 24 in that period via the Norwegian Cancer Registry. Their parents ($N= 473$) were identified through the Norwegian National Registry. Inclusion criteria were speaking and writing Norwegian and having an identifiable address. An invitation letter with a written consent form was mailed to all those parents. One reminder was also sent approximately three weeks after the first invitation. Only those parents who returned the consent form received a hard copy of the questionnaire with a prepaid envelope with the returning address by mail. Mothers and fathers received the questionnaire separately, allowing them to answer independently.

In addition, 492 parents of children without cancer were identified through the National Population Registry as a control group, matched with the bereaved group regarding the child's age, gender, and place of birth. The control parents were invited the same way as the bereaved group.

Assessment instruments

A self-report study-specific questionnaire for cancer-bereaved parents was used in this study.¹⁸ The questionnaire covers items regarding periods of the child's illness, the time after the child's death, the parents' current life situation, and sociodemographic factors. This questionnaire was already translated and validated.¹⁹ The questionnaire for the control group consisted of sociodemographic questions, QoL and RSA.

Quality of Life

A single-item question was used to assess global QoL: "How would you assess your QoL during the past month?". The response options were measured on a 7-point visual digital

scale, ranging from 1, “worst possible QoL” to 7, “best possible QoL,” and the respondent was asked to circle the most appropriate value.⁷ This single-item has previously been used to assess QoL,^{7 20} and its construct validity was also confirmed.²¹

Resilience

Resilience Scale for Adults (RSA) was used to measure healthy adaptation after being exposed to stressful life events.¹⁴ RSA is a 33-item self-report scale; each item is rated on a 7-point scale, and the overall sum score ranges from 33 to 231. A higher score indicates a higher level of resilience.²² The RSA comprises six factors covering *intrapersonal* and *interpersonal* protective resources (Table 1). Previous studies have reported RSA as a reliable and valid instrument to measure different aspects of resilience in various populations.²²

<Table 1 about here>

Table 1. The Resilience Scale for Adults (RSA) with its factors.

	Subscale	Definition
Intrapersonal resources	<i>Perception of self</i>	It consists of 6 items regarding self-confidence, the ability to solve problems, and trust in the decisions made.
	<i>Planned future</i>	It entails 4 items regarding a person’s view of whether they have an optimistic view of the future.
	<i>Social competence</i>	It consists of 6 items and includes statements regarding flexibility, friendships, and how individuals see themselves in social settings.
	<i>Structured style</i>	It consists of 4 items regarding whether the individual is good at planning their time or has clear goals for the future
Interpersonal resources	<i>Family cohesion</i>	It contains 6 items, including statements about supportiveness and views of what is important in life among the family members

	<i>Social resources</i>	It has 7 items concerning the individual's perception of support in their life and who can help in difficult times.
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Support from healthcare professionals

In this study, healthcare professionals were those who provide healthcare treatment and advice based on formal training and experience, such as medical doctors, nurses, and psychologists. Two study-specific items were included to measure support from healthcare professionals.¹⁸ One item was “Did you receive any support from healthcare professionals to handle your feelings and the situation in general during your child’s illness period?” with four response options: “No, not at all,” “Yes, some,” “Yes, enough,” and “Yes, very much.” The item was dichotomized into poor (0) or good support (1) for regression analysis.

The second item was “Did you receive little or no support from healthcare professionals after their child’s death, and whether the absence of support still affected your life today.” There were five response options: “Not relevant, not experienced,” “Does not affect me at all today,” “Affects me a little today,” “Affects me moderately today,” and “Affects me a lot today.” The response options were reversed before statistical analysis, where a higher score indicated greater perceived support from healthcare professionals. Then, this item was dichotomized into no support/negative effect (0) or good support (1) for regression analysis.

Information from healthcare professionals

The information given by healthcare professionals to parents was measured with two study-specific items.¹⁸ The first item asked: “How much information did you receive from healthcare professionals during the last month of your child’s life about the progression of the disease?” Three response options were: “No information,” “A little,” and “Sufficient.” This

item was dichotomized into no/little information (0) or sufficient information (1) for regression analysis.

The second item asked: “Was the message of your child’s incurable cancer prognosis given respectfully?” Four response options were “Not relevant, I never received that information,” “Not at all,” “To a certain degree,” and “To a great extent.” This question was dichotomized into no/little information (0) or sufficient information (1) for regression analysis.

Statistical analysis

All statistical analyses were performed using SPSS (Version 27). Initially, descriptive analyses of the variables were conducted. Sociodemographic variables were compared between the groups using independent sample t-test for continuous variables and Chi-square or Fisher’s exact test for categorical variables. Since the QoL score was ordinal and skewed, non-parametric tests were used. Mann-Whitney U test was used to compare QoL between the groups also between the genders within each group. Spearman correlation analysis was run to investigate associations between QoL and independent variables. Due to the ordinal nature of the QoL score (dependent variable), ordinal logistic regression with Proportional Odds (PO) model was chosen to estimate proportional odds ratios for independent variables. The PO model is the most common form of ordinal logistic regression in the literature and it is also named as the cumulative logit model.²³ First, the association between each independent variable (i.e., resilience factors, support items) and QoL was explored using univariate ordinal logistic regression. Then, significant factors were put into a model and analyzed using multivariable ordinal logistic regression and the PO model. Due to the number of comparisons, a nominal significance level of 0.01 was chosen to reduce the risk of false-positive results.

RESULTS

Out of 473 invited bereaved parents, 10 parents were excluded after informing us that their child did not die primarily to cancer, 177 individuals did not respond to the invitation, 45 individuals declined to participate, and 11 individuals had a wrong address. We received 230 consent forms; however, 58 individuals did not return the questionnaire, and 11 individuals withdrew their consent; two gave no reason, and nine stated that the questionnaire was emotionally too difficult to answer. Finally, 161 parents returned the completed questionnaire (response rate: 34.9 %). Of 492 control parents, 84 declined to participate, 15 had wrong addresses, and 309 did not respond to the invitation letter. Finally, 77 individuals had returned the completed questionnaires (response rate: 16.1%).

Table 2 presents the sociodemographic characteristics of the participants. Altogether, participants mainly were females (60%) and employed (91%) and had university educations (67%) (Table 2). No significant differences were found between the demographic variables except that; the bereaved mothers were older than the control mothers ($p = 0.01$), and more bereaved fathers lived in a small town ($p = 0.01$) than the control fathers. All resilience factors were significantly lower in the bereaved group compared with the control group ($p < 0.05$).

<Table 2 about here>

Table 2. Characteristics of the cancer-bereaved (n= 161) and control parents (n= 77).

	Bereaved group <i>n</i> (%)	Control group <i>n</i> (%)	<i>p</i>-value
Age (years) ^a	54.4 (7.6)	51.8 (7.9)	0.012
Children number ^a	2.6 (0.9)	2.6 (0.7)	0.910
Region of residence			0.046
Countryside	32 (19.9%)	16 (20.8%)	
Small town	38 (23.6%)	22 (28.6%)	
Town	58 (36%)	15 (19.5%)	
Big city	32 (19.9%)	24 (31.2%)	

Gender			0.980
Men	63 (39.1%)	30 (39.0%)	
Women	98 (60.9%)	47 (61.0%)	
Place of birth			0.045
Norway	148 (93.7%)	66 (85.7%)	
Another country	10 (6.3%)	11 (14.3%)	
Marital status			0.793
Married/living together with the child's other parent	132 (70.2%)	62 (80.5%)	
Married/living together with another person	16 (9.9%)	7 (9.1%)	
Living alone. but have a partner	13 (8.1%)	3 (3.9%)	
Single	19 (11.8%)	5 (6.5%)	
Education			0.242
Primary and lower secondary school	6 (3.8%)	2 (2.6%)	
High school	24 (15.1%)	7 (9.2%)	
Technical college	32 (20.1%)	11 (14.5%)	
College/university (3 years)	45 (28.3%)	20 (26.3%)	
College/university (4 years or more)	52 (32.7%)	36 (47.4%)	
Work situation			0.532
Work	137 (89.5%)	72 (93.5%)	
Studies	1 (0.7%)	0 (0.0%)	
Unemployed	1 (0.7%)	1 (1.3%)	
On sick leave/receiving disability benefit	11 (7.2%)	3 (3.9%)	
Housewife	4 (2.7%)	1 (1.3%)	
Time since loss (years) ^a	6.4 (1.5)	-	
Loss of a boy	73 (45.1%)	-	
Loss of a girl	89 (54.9%)	-	

Note. a: These values are shown as mean (standard deviation).

Quality of life

Figure 1 demonstrates the QoL scores in each group. Mean QoL values were 5.2 and 5.0 for males and females in the bereaved group, while 5.9 and 5.7 for males and females in the control group. Mann-Whitney U Test revealed significantly lower QoL in the bereaved parents (Mean= 5.1, median= 5, $n= 161$) compared with the control parents (Mean= 5.8, median= 6, $n= 77$), $z= -4.67$, $p < 0.001$. However, there were no significant gender differences in the QoL score in the bereaved group ($z= -1.11$, $p= 0.27$) or the control group ($z= -0.68$, $p= 0.50$) (Figure 1).

<Figure 1 about here>

Correlation analysis

Spearman correlation analysis showed that all resilience factors positively correlated with QoL in both groups ($p < 0.001$), except for “Structured style” in the control group (Table 3).

Table 4 displays the Spearman correlation coefficients between QoL and support items.

Accordingly, only received information about the progression during the last month was positively associated with QoL in the bereaved parents ($p < 0.001$).

<Table 3 about here>

<Table 4 about here>

Table 3. Descriptive values, Spearman correlation coefficients (rho) between the quality of life and resilience factors in cancer-bereaved and control parents.

		Mean (SD)	QoL (rho)	1	2	3	4	5	6
1. Perception of self	<i>Bereaved</i>	5.1 (1.2)	.58**						
	<i>Control</i>	5.6 (1.0)	.51**						
2. Planned future	<i>Bereaved</i>	4.9 (1.4)	.58**	.68**					
	<i>Control</i>	5.8 (1.0)	.61**	.79**					
3. Social competence	<i>Bereaved</i>	4.7 (1.2)	.35**	.51**	.35**				
	<i>Control</i>	5.2 (1.0)	.39**	.40**	.45**				
4. Family cohesion	<i>Bereaved</i>	5.4 (1.2)	.40**	.28**	.30**	.42**			
	<i>Control</i>	5.7 (1.1)	.51**	.63**	.72**	.47**			
5. Social resources	<i>Bereaved</i>	5.6 (1.0)	.44**	.43**	.40**	.55**	.79**		
	<i>Control</i>	6.1 (0.8)	.49**	.52**	.63**	.47**	.79**		
6. Structured style	<i>Bereaved</i>	4.9 (1.0)	.47**	.46**	.53**	.23*	.27**	.29**	
	<i>Control</i>	5.4 (1.0)	.15	.30*	.29	.15	.17	.21	
Total RSA	<i>Bereaved</i>	5.1 (0.9)	.61**	.78**	.77**	.70**	.69**	.79**	.62**
	<i>Control</i>	5.6 (0.7)	.61**	.82**	.87**	.67**	.85**	.79**	.38*

Note. M: mean; SD: standard deviation; QoL: Quality of life; *: $p < 0.01$, **: $p < 0.001$

Table 4. Descriptive values and Spearman correlation coefficients (rho) between the quality of life and support variables in cancer-bereaved parents.

	Median (Mode)	QoL	Support during illness	Support after death	Information given during the last month
Support during illness	2 (2)	.20			
Support after death	3 (5)	.15	.33*		
Information given during the last month	3 (3)	.26*	.27*	.18	
Incurability information given respectfully	3 (4)	.09	.18	.11	.14

Note. M: Mean; SD: Standard deviation. QoL: Quality of life.

* = $p < .01$

Regression analysis

Table 5 presents the variables associating with long-term QoL in the bereaved parents.

Among the support items, only one item (information about the progression of the illness during the last month) was significantly associated with the QoL (unadjusted OR 2.61, $p = 0.001$). All unadjusted ORs were significant for the resilience factors ($p < 0.001$) except for “Structured style.” The assumptions for logistic regression were investigated, indicating that the model fits the data well. Significant factors were put into a model and analyzed using multivariable ordinal logistic regression. The ordinal logistic regression on the significant variables (i.e., information about the progression of the illness during the last month, perception of self, planned future, social competence, family cohesion, and social resources) showed that parents who received sufficient information about the progression of the illness during the last month of their child had a better QoL 2-8 years later (OR = 2.63, $p = 0.003$). Only two of the six resilience factors were positively associated long-term QoL, namely “Perception of self” (OR = 1.8, $p = .004$), “Planned future” (OR = 2.05, $p < 0.001$). The

model significantly predicted the QoL score in the bereaved (Pseudo R²: 52 %, $p < 0.001$).

Details including parameter estimates and test of parallel lines are presented in a supplemental Table.

<Table 5 about here>

Table 5. Summary of ordinal logistic regression analysis predicting QoL in the cancer-bereaved group.

	Unadjusted OR (95% CI)	<i>p</i>-value	Adjusted OR (95% CI)	<i>p</i>-value
Age	1.03 (0.99 , 1.07)	0.095		
Gender (females)	0.73 (0.41 , 1.29)	0.278		
Time since loss	1.06 (0.88 , 1.27)	0.538		
Support during illness (code= 1) ^a	2.18 (1.20 , 3.98)	0.011		
Support after death (code= 1) ^a	1.78 (0.99 , 3.19)	0.053		
Information given during the last month (code= 1) ^a	2.61 (1.46 , 4.67)	0.001	2.63 (1.39 , 4.97)	0.003
Incurability information given respectfully (code= 1) ^a	1.48 (0.76 , 2.89)	0.245		
Perception of self	3.20 (2.34 , 4.37)	<0.001	1.8 (1.21 , 2.68)	0.004
Planned future	2.98 (2.25 , 3.93)	<0.001	2.05 (1.47 , 2.85)	<0.001
Social competence	1.93 (1.48 , 2.50)	<0.001	1.12 (0.80 , 1.57)	0.504
Family cohesion	1.90 (1.47 , 2.48)	<0.001	1.26 (0.83 , 1.93)	0.280
Social resources	2.58 (1.89 , 3.53)	<0.001	1.23 (0.72 , 2.09)	0.449
Structured style	1.74 (1.28 , 2.37)	0.249		
			$\chi^2_{(6)} 108.03, p < 0.001,$ Pseudo R ² : 52 %	

Note. Predefined reference group was score 7 for QoL.

^a [Code=0, no/little support/information from healthcare professionals]: Reference outcome .

OR: Odds ratio; 95% CI: 95% confidence interval.

DISCUSSION

To our knowledge, this is the first nationwide study that has assessed long-term QOL and the importance of resilience and support from healthcare professionals in cancer-bereaved parents compared with a matched control group.

Long-term QoL

In agreement with the first hypothesis, the findings revealed significantly lower QOL among the bereaved parents than the matched control group. This result supports prior observations of lower QoL in bereaved parents than control parents several years after their loss.^{7 24}

Previous studies have shown lower short-term QOL in bereaved family members of patients with cancer than that of the general population.^{5 6} This finding indicates that bereaved parents are vulnerable, even 2-8 years after the loss, which supports the notion that bereavement outcomes after the loss of a child are intense and long-lasting.⁷ Therefore, both bereaved fathers and mothers are vulnerable to be affected, and this should be investigated further.^{24 25}

Parents of children with cancer need longitudinal, interdisciplinary, and multifaceted support during the child's treatment, end of life, and following the child's death, continuing for as long as parents benefit.^{26 27} Parents should be offered various interventions for supporting different needs.²⁸ However, the optimal timing and ideal components of bereavement support are not well-defined, and future RCTs should explore proper timing and interventions.²⁸

No significant differences were found between the genders in either group in the present study, consistent with some previous studies.²⁹ Similarly, we found no evidence of gender differences on QoL in bereaved parents who lost their children due to different death causes.²⁵ However, some studies found a higher risk for lower QOL in female bereaved family members.^{5 29} These conflicting results may have resulted from the various instruments

used to measure QoL in bereaved groups. QoL is a complex, multifaceted concept and its lack of consensual definitions is because QOL is a multidisciplinary term.³⁰ Thus, research with multiple approaches may be necessary to capture the QoL concept.³⁰

Resilience and QoL

Bereavement outcome depends on both interpersonal and intrapersonal protective resources.³¹ However, the findings revealed that only two resilience factors (perception of self and planned future) were significantly associated with a higher QoL in the bereaved parents. The results indicate that intrapersonal resources are more important than interpersonal resources to protect the bereaved parents from highly stressful experiences in a long-term perspective. Accordingly, the second hypothesis was partly confirmed as only two resilience factors were significantly associated with QoL. Similarly, one study showed that among resilience factors, perception of self and planned future were associated with long-term psychological distress in cancer-bereaved parents.⁸ Planned future means that an individual has a positive outlook on own future and the ability to plan ahead and make clear goals. Perception of self includes self-confidence and the ability to solve problems.²² Hence, parents with a well “Planned future” and positive “Perception of self” may have greater capacity and confidence in recovering and establishing a new life.⁸ The bereaved parents may benefit from interventions commonly used in practice such as psychotherapy, support groups, and professional counseling.

Support and QoL

Only 36% of the bereaved parents experienced enough/very much support from healthcare professionals during their child’s period of illness. However, in the questionnaire, healthcare professional was a general term, including all professions, and did not specify which

healthcare professionals these parents received support from. Higher support from healthcare professionals during the illness period was associated with better long-term QoL in the bereaved parents; however, the effect disappeared when controlled for other significant factors. Previous studies have defined support from healthcare professionals as emotional and practical support,³² close relationships, physical and emotional availability, and a common understanding between physicians and parents.³³ End-of-life support in palliative care can facilitate the grief process and enhance resilience and well-being in the bereavement period.¹⁶ Thus, support from healthcare professionals should be available during the illness period as it may reduce the adverse effects of having an incurably ill child.

In the present study, 36% of the parents reported insufficient support from healthcare professionals after their child's death moderately/greatly affected them at the time of the survey. This item was also associated with a lower long-term QoL among cancer-bereaved parents. The finding is similar to other studies where cancer-bereaved parents missed contact with the healthcare team that treated their child.³⁴ The follow-up received from their home community after the loss was also inadequate.²⁷ Support should focus on parents' intrapersonal resources; for example, individual therapy can strengthen the intrapersonal traits of bereaved parents.³⁵ Although existing guidelines highlight the importance of communication between children's parents and the healthcare team for end-of-life decisions,³⁶ the present study indicates a lack of regular contact from the healthcare professionals following parents' bereavement. Thus, healthcare professionals should enhance compassionate connection (i.e., reassurance and empathy) and guidance to patients and their families in end-of-life care.³⁷ It is crucial to acknowledge that personalized plans are essential for bereavement support to meet their needs at the right time.

Informational support and QoL

The second hypothesis was partly confirmed: bereaved parents with higher informational support from healthcare professionals reported better QoL. An interesting finding was that sufficient information about the progression of the illness during the child's last month was associated with higher long-term QoL in the bereaved parents (Table 4). Only 53% of the bereaved parents received sufficient information from the healthcare professionals during the last month. The primary goal of therapy is recovery,^{1-22 24-29 31-40} but when there is no realistic chance for a cure, one study showed that only 49% of the parents learned that their child had no chance for cure from a discussion with the medical team.⁴⁰ This finding supports previous studies suggesting the importance of honest and sensitive communication that empowers decision-making and prepares parents.³⁹ Pediatric advance care planning (pACP) is increasingly recognized as a way to improve care at the end of life. Lotz et al. (2017) emphasized the need for improving communication with families for good pACP to elicit realistic hopes and make meaningful plans, following the principle "hope for the best, prepare for the worst."^{38 39} A qualitative study also concluded that anticipatory mourning allows parents to begin grief and make choices before a loved one's death.⁴¹ Therefore, bereaved parents appear to benefit from the sensitive conversations during their child's end-of-life care, particularly the last month.

Although 78% of the parents stated that the information about their child's incurable cancer was given respectfully by the healthcare professionals, this factor was not significantly associated with long-term QoL among the bereaved parents. In contrast to this finding, previous studies showed that parents value physicians approaching them empathically and compassionately.¹⁷ Bereaved family members may benefit from receiving information about prognosis and the end-of-life period in a direct, honest way.³⁷ Furthermore, healthcare professionals are a great resource in helping parents plan ahead, make clear goals, and strengthen their perception of themselves.

Strengths and limitations

The main strength of the present study was the nationwide sample for both bereaved and control parents. Although matching the bereaved group to a control group for several characteristics is a strength, there may be large residual confounding for unmeasured covariates. Also, low response rates may have led to a greater covariate imbalance between the bereaved parents and control groups. Two main reasons for the low response rate were: some bereaved parents felt that answering questions regarding the deceased child was emotionally very hard, also, we were not allowed to call participants following the Ethical Committee's decision. The response rate was very low in the control group compared with the bereaved group. Another limitation was using a single-item question to measure QoL, which results in a less discerning measure of different aspects of QoL. Also, in the questionnaire, healthcare professionals were a general term, not identifying which healthcare professionals were in focus. Future prospective longitudinal studies are needed to examine the interaction between QoL, protective factors, and support over time. RCTs are required to examine effectiveness of interventions to improve outcomes for bereaved families.

CONCLUSION

The present study indicates lower QoL among bereaved parents 2-8 years after losing a child to cancer than matched control parents, with no evidence of gender effect. The findings emphasize the positive role of resilience (particularly "Perception of self" and "Planned future") for better long-term QoL in cancer-bereaved parents. It also seems that information about illness progression during the last month may positively influence the long-term QoL of bereaved parents. Thus, healthcare professionals should have honest and emphatic conversations with parents of children with cancer and promote parents' resources.

Considering previous research and this study, some bereaved parents struggle to adjust to their new life; thus, multidisciplinary supportive interventions should be available and offered to those in need during the bereavement period. Some needs may also be addressed by social (non-professional) support in the community. The support should be tailored for supporting individual needs.

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DECLARATIONS

Contributors: HKV and MEBE designed the study. HKV collected the data. All authors were involved in data interpretation. OR performed statistical analyses and wrote the original draft. HKV, AEW, OH, TR, UK, BL, and MEBE performed critical revisions of the manuscript. All authors read and approved the final version of this manuscript.

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References

1. Polita NB, de Montigny F, Neris RR, et al. The Experiences of Bereaved Parents After the Loss of a Child to Cancer: A Qualitative Metasynthesis. *J Pediatr Oncol Nurs* 2020;37(6):444-57. doi: 10.1177/1043454220944059 [published Online First: 2020/07/28]
2. Rosenberg AR, Baker KS, Syrjala K, et al. Systematic review of psychosocial morbidities among bereaved parents of children with cancer. *Pediatr Blood Cancer* 2012;58(4):503-12. doi: 10.1002/pbc.23386 [published Online First: 2011/11/01]
3. Post M. Definitions of quality of life: what has happened and how to move on. *Topics in spinal cord injury rehabilitation* 2014;20(3):167-80.
4. Neris RR, Nascimento LC, Leite A, et al. The experience of health-related quality of life in extended and permanent cancer survivors: A qualitative systematic review. *Psychooncology* 2020;29(10):1474-85. doi: 10.1002/pon.5472 [published Online First: 2020/07/14]
5. Song JI, Shin DW, Choi JY, et al. Quality of life and mental health in the bereaved family members of patients with terminal cancer. *Psychooncology* 2012;21(11):1158-66. doi: 10.1002/pon.2027 [published Online First: 2011/08/09]
6. Kim Y, Given BA. Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 2008;112(11 Suppl):2556-68. doi: 10.1002/cncr.23449 [published Online First: 2008/04/23]
7. Kreicbergs U, Valdimarsdottir U, Onelov E, et al. Anxiety and depression in parents 4-9 years after the loss of a child owing to a malignancy: a population-based follow-up. *Psychol Med* 2004;34(8):1431-41. doi: 10.1017/s0033291704002740 [published Online First: 2005/02/24]
8. Rasouli O, Aarseth Bo M, Reinfjell T, et al. Protective and risk factors associated with psychological distress in cancer-bereaved parents: A cross-sectional study. *Eur J Oncol Nurs* 2021;51:101929. doi: 10.1016/j.ejon.2021.101929 [published Online First: 2021/03/14]
9. Windle G. What is resilience? A review and concept analysis. *Reviews in clinical gerontology* 2011;21(2):152-69.
10. Luthar SS, Cicchetti D, Becker B. The construct of resilience: a critical evaluation and guidelines for future work. *Child Dev* 2000;71(3):543-62. doi: 10.1111/1467-8624.00164 [published Online First: 2000/08/23]
11. Friborg O, Hjemdal O, Rosenvinge JH, et al. Resilience as a moderator of pain and stress. *J Psychosom Res* 2006;61(2):213-9. doi: 10.1016/j.jpsychores.2005.12.007 [published Online First: 2006/08/02]
12. Behrman RE, Field MJ. When children die: Improving palliative and end-of-life care for children and their families: National Academies Press 2003.
13. Werner EE. Risk, resilience, and recovery: Perspectives from the Kauai Longitudinal Study. *Development and Psychopathology* 2009;5(4):503-15. doi: 10.1017/s095457940000612x
14. Friborg O, Hjemdal O, Rosenvinge JH, et al. A new rating scale for adult resilience: what are the central protective resources behind healthy adjustment? *Int J Methods Psychiatr Res* 2003;12(2):65-76. doi: 10.1002/mpr.143 [published Online First: 2003/06/28]
15. Hansen MIT, Haugen DF, Sigurdardottir KR, et al. Factors affecting quality of end-of-life hospital care - a qualitative analysis of free text comments from the i-CODE survey in Norway. *BMC Palliat Care* 2020;19(1):98. doi: 10.1186/s12904-020-00609-x [published Online First: 2020/07/09]
16. Lundberg T, Olsson M, Furst CJ. The perspectives of bereaved family members on their experiences of support in palliative care. *Int J Palliat Nurs* 2013;19(6):282-8. doi: 10.12968/ijpn.2013.19.6.282 [published Online First: 2013/10/25]
17. Bright KL, Huff MB, Hollon K. A broken heart--the physician's role: bereaved parents' perceptions of interactions with physicians. *Clin Pediatr (Phila)* 2009;48(4):376-82. doi: 10.1177/0009922808327055 [published Online First: 2008/11/22]

18. Kreicbergs U, Valdimarsdóttir U, Steineck G, et al. A population-based nationwide study of parents' perceptions of a questionnaire on their child's death due to cancer. *Lancet* 2004;364(9436):787-89. doi: 10.1016/s0140-6736(04)16939-0
19. Vegsund H-K, Rannestad T, Reinfjell T, et al. Translation and linguistic validation of a swedish study-specific questionnaire for use among Norwegian parents who lost a child to cancer. *Social Sciences* 2018;7(10):187.
20. Thulin H, Kreicbergs U, Wijkstrom H, et al. Sleep disturbances decrease self-assessed quality of life in individuals who have undergone cystectomy. *J Urol* 2010;184(1):198-202. doi: 10.1016/j.juro.2010.03.009 [published Online First: 2010/05/19]
21. Parkin D, Rice N, Jacoby A, et al. Use of a visual analogue scale in a daily patient diary: modelling cross-sectional time-series data on health-related quality of life. *Soc Sci Med* 2004;59(2):351-60. doi: 10.1016/j.socscimed.2003.10.015 [published Online First: 2004/04/28]
22. Hjemdal O, Friborg O, Stiles TC, et al. Resilience predicting psychiatric symptoms: a prospective study of protective factors and their role in adjustment to stressful life events. *Clinical Psychology & Psychotherapy* 2006;13(3):194-201. doi: 10.1002/cpp.488
23. Osborne JW. Regression & linear modeling: Best practices and modern methods: Sage Publications 2016.
24. Dumont E, Bourque CJ, Duval M, et al. A Portrait of Self-Reported Health and Distress in Parents Whose Child Died of Cancer. *Omega (Westport)* 2020;30222820959943. doi: 10.1177/0030222820959943 [published Online First: 2020/09/22]
25. Song J, Floyd FJ, Seltzer MM, et al. Long-term Effects of Child Death on Parents' Health Related Quality of Life: A Dyadic Analysis. *Fam Relat* 2010;59(3):269-82. doi: 10.1111/j.1741-3729.2010.00601.x [published Online First: 2010/08/03]
26. Snaman JM, Kaye EC, Levine DR, et al. Empowering Bereaved Parents Through the Development of a Comprehensive Bereavement Program. *J Pain Symptom Manage* 2017;53(4):767-75. doi: 10.1016/j.jpainsymman.2016.10.359 [published Online First: 2017/01/04]
27. Kreicbergs UC, Lannen P, Onelov E, et al. Parental grief after losing a child to cancer: impact of professional and social support on long-term outcomes. *J Clin Oncol* 2007;25(22):3307-12. doi: 10.1200/JCO.2006.10.0743 [published Online First: 2007/08/01]
28. Kochen EM, Jenken F, Boelen PA, et al. When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with grief-and loss theories. *BMC palliative care* 2020;19(1):1-22.
29. Brazil K, Bedard M, Willison K. Correlates of health status for family caregivers in bereavement. *J Palliat Med* 2002;5(6):849-55. doi: 10.1089/10966210260499032 [published Online First: 2003/04/11]
30. Haas BK. A Multidisciplinary Concept Analysis of Quality of Life. *Western Journal of Nursing Research* 1999;21(6):728-42. doi: 10.1177/01939459922044153
31. Stroebe M, Schut H, Stroebe W. Health outcomes of bereavement. *Lancet* 2007;370(9603):1960-73. doi: 10.1016/S0140-6736(07)61816-9 [published Online First: 2007/12/11]
32. Sarajärvi A, Haapamäki ML, Paavilainen E. Emotional and informational support for families during their child's illness. *International nursing review* 2006;53(3):205-10.
33. Snaman JM, Kaye EC, Torres C, et al. Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys. *Cancer* 2016;122(17):2757-65. doi: 10.1002/cncr.30087 [published Online First: 2016/06/01]
34. Lichtenthal WG, Corner GW, Sweeney CR, et al. Mental Health Services for Parents Who Lost a Child to Cancer: If We Build Them, Will They Come? *J Clin Oncol* 2015;33(20):2246-53. doi: 10.1200/JCO.2014.59.0406 [published Online First: 2015/06/03]
35. Rogers CH, Floyd FJ, Seltzer MM, et al. Long-term effects of the death of a child on parents' adjustment in midlife. *J Fam Psychol* 2008;22(2):203-11. doi: 10.1037/0893-3200.22.2.203 [published Online First: 2008/04/16]

36. Hechler T, Blankenburg M, Friedrichsdorf SJ, et al. Parents' perspective on symptoms, quality of life, characteristics of death and end-of-life decisions for children dying from cancer. *Klin Padiatr* 2008;220(3):166-74. doi: 10.1055/s-2008-1065347 [published Online First: 2008/05/15]
37. Morris SE, Nayak MM, Block SD. Insights from Bereaved Family Members about End-of-Life Care and Bereavement. *J Palliat Med* 2020;23(8):1030-37. doi: 10.1089/jpm.2019.0467 [published Online First: 2020/02/11]
38. Kamihara J, Nyborn JA, Olcese ME, et al. Parental hope for children with advanced cancer. *Pediatrics* 2015;135(5):868-74. doi: 10.1542/peds.2014-2855 [published Online First: 2015/04/08]
39. Lotz JD, Daxer M, Jox RJ, et al. "Hope for the best, prepare for the worst": A qualitative interview study on parents' needs and fears in pediatric advance care planning. *Palliat Med* 2017;31(8):764-71. doi: 10.1177/0269216316679913 [published Online First: 2016/11/25]
40. Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 2000;284(19):2469-75. doi: 10.1001/jama.284.19.2469 [published Online First: 2000/11/14]
41. Rini A, Loriz L. Anticipatory mourning in parents with a child who dies while hospitalized. *J Pediatr Nurs* 2007;22(4):272-82.

Figure Legend

Figure 1. Quality of life scores for each gender in the bereaved and control groups.

