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The impact of newly diagnosed chronic paediatric conditions on parental quality of life

Running head: PARENTAL QUALITY OF LIFE

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ABSTRACT

Objective: Parental functioning and well-being are important aspects of a family's adaptation to chronic paediatric conditions. This study investigates the effects of diagnosis (cancer vs. diabetes/epilepsy) and time since diagnosis on parental quality of life (PQL).

Methods: 122 parents (66 mothers, 56 fathers), whose children were diagnosed and treated for one chronic disease, filled in the *Ulm Quality of Life Inventory for Parents* twice within the first three months after the initial diagnosis. The effects of diagnosis and time (1-2 weeks and 2-3 months after diagnosis) on PQL were analysed separately for mothers and fathers.

Results: Parents of a child with cancer consistently reported lower PQL compared with parents of a child with diabetes/epilepsy. Only the fathers' *well-being* increased significantly within the first three months after the child was diagnosed for a chronic disease. However, in most of the PQL domains there was a persistent impairment within the time-frame of this study. Parents of children with a chronic disease were more satisfied with their family situation than healthy controls. Age of the child was positively correlated with PQL.

Conclusions: A diagnosis of cancer, especially in young children, has a strong negative effect on PQL. Measuring PQL in a preventive approach would help to identify vulnerable parents and to provide psychosocial support in time.

Key words: coping with diagnosis; parents; paediatric chronic conditions; quality of life.

Abbreviations:

PQL Parental Quality of Life

QL Quality of life

ULQIE Ulm Quality of Life Inventory for Parents

Chronic illness in childhood has a substantial impact on the patient's life and on the whole family system. A paediatric illness is defined as a chronic health problem if it lasts over twelve months, affects the child's normal activities, and requires a lot of hospitalisations and/or home health care and/or extensive medical care [1]. From a family perspective, mutual relations between parents and children have to be considered. On the one hand, the health status of the child depends partly on their parents' psychosocial situation, on the other hand parental functioning and well-being is influenced by their child's health status [2]. Psychological distress following a child's diagnosis of severe chronic disease involves risks of long-term psychological and psychosocial problems for parents and families [2-8]. Careful assessment of parental psychosocial status, psychological well-being and functioning is especially useful, because a chronic illness always demands parental participation and adaptation to the new situation [9]. Hence, Cohen found that "managing the illness in the context of total family life was associated with the best medical outcome"[4, p. 157]. Information about parental functioning allows the identification of families with special needs for social support or psychological intervention [10].

In spite of the increasing literature on family aspects of chronic paediatric conditions, the psychological situation of parents of ill children is still underresearched [11-13]. Many psychosocial studies involving families with a chronically ill child neglect to examine the role of fathers within the process of illness adaptation [14]. This may be due to the predominance of mothers in the role of primary caregiver and the presence of mothers within the clinical setting. Fathers usually do not appear as often in a clinical setting and

hence a great effort is required to integrate them into clinical studies. However, from a family systems perspective, fathers have an important role as support person both for their children and for their spouse [15].

There have been different approaches to analysing parental adjustment after a child's diagnosis of a chronic disease and the progression of this adjustment over time. Several studies have investigated psychological disorders or psychiatric symptoms [13;16]. Many parents report high rates of depression or posttraumatic stress symptoms, especially parents of a child with cancer [16]. Others do not present clinical levels of mental disorder and seem to be more resilient to the strain of parenting a chronically ill child. However, the value of a dichotomous category such as mental disorder as an indicator of parental functioning in the context of chronic paediatric conditions is limited. For a more comprehensive description of the parental situation in the context of a chronic paediatric condition, parental quality of life (PQL) was chosen as a focus of the present study, parallel to the health-related QL of the patients themselves. Extending and modifying the definition of quality of life provided by Gill and Feinstein [17], PQL in the case of childhood illness is defined as "a uniquely personal perception, denoting the way individual *parents* feel about the health status *of their child* and/or non-medical aspects of their lives." [17, p. 624, modifications in italics]. This concept captures the broad impact of the disease on the parents' physical, psychological and social well-being or functioning [3]. The construct PQL can be measured psychometrically on a continuum, and it is expected to be sensitive to sub-clinical parental impairments as a consequence of their child's diagnosis. Even in absence of a psychiatric diagnosis such as depression or posttraumatic stress disorder, the level of PQL may vary and be associated with more or less effective coping with the situation. So far, information about PQL has been limited, but its use in research might extend our knowledge on adaptation to chronic childhood illness.

Several issues arising in the literature were addressed in this study. First, disease-specific effects on PQL were investigated. All chronic conditions can be characterised as a persistent, habitual, long-lasting and mostly uncontrollable illness [4], so a non-categorical approach to psychosocial support for chronically ill children and their caregivers is required [18]. Parenting a child with a serious chronic disease compared with parenting a healthy child has been repeatedly linked to elevated parental distress [19]and impaired PQL [20]. However, there are different disease-related stressors, arising from the specific treatment regime such as the number and duration of hospitalisations and the required invasive medical procedures, or from the long-term prognosis of the disease. So far, few studies have compared the impact of different childhood diseases on parents [16;19;21]. Childhood cancer on the one hand, and diabetes mellitus or epilepsy on the other hand are chronic illnesses with different implications for patients and parents. Cancer is a life threatening illness indicating a multitude of adverse medical procedures and treatments such as surgery or chemotherapy, at least in the acute phase of the illness. It is associated with elevated levels of parental distress, compared with diabetes mellitus [19]. Diabetes or epilepsy might be closely linked to problems of compliance or surveillance. Common characteristics of insulin-dependent diabetes mellitus and epilepsy are – in most cases - the absence of acute life-threatening conditions and the need for persistent medical treatment over a long time period. Procedures for controlling the blood sugar level and/or providing regular medication to the child actively involve the parents in the treatment. The corresponding feeling of self-efficacy and the immediate symptom control might help the parents of children with diabetes or epilepsy to maintain a stable emotional and physical state, although in the case of paediatric diabetes, a persistent fear of hypoglycaemia [22] and increasing maternal depression and emotional stress after the first year of the disease [23] have been reported.

Second, changes in PQL within the first three months after diagnosis were examined. Extra-ordinary life stressors such as the diagnosis of a severe chronic disease in one's child may exceed the adaptive ability of the parents and therefore have detrimental effects on PQL in the short term. It might take several months for most parents to utilize their personal resources successfully and develop strategies for coping with the new situation. [24;25]. Additionally, social support may be an effective factor which contributes to the improvement of PQL over time [25]. If the diagnosis of a serious chronic illness constitutes a traumatic event for parents, negative emotional responses have to be taken into account in the short term with a tendency for remission within three to six months, in accordance with the concept of reactive mental disorders (see diagnostic criteria ICD-10 F43.2x or DSM IV 309.x). Therefore PQL is expected to be worse immediately after the diagnosis compared with months after the diagnosis.

The following questions were addressed in this study:

1. What impairment in quality of life is associated with parenting a child which has been diagnosed recently with a serious chronic illness, compared with parenting a healthy child?
2. Do parents of a child with cancer report lower quality of life compared to parents of a child with diabetes or epilepsy?
3. Does time since diagnosis contribute to an improvement of parental quality of life within the first three months post-diagnosis?
4. Are there differences in parental quality of life between mothers and fathers of children diagnosed with a serious chronic illness?

PARTICIPANTS AND METHODS

Participants

A consecutive sample of families with a child newly diagnosed with leukaemia, a solid tumour disease, insulin dependent diabetes mellitus or epilepsy at a German university clinic was asked to participate in the study. In 91 % of the families eligible for the study, at least one parent decided to participate (for details of sample description see table 1). Only nine per cent of the parents declined to participate for different reasons (i.e. no time or not willing to complete the questionnaire), and this proportion was equal in both diagnostic groups. Altogether, 51 parental couples (51 fathers and 51 mothers) and 20 single parents (15 mothers and 5 fathers who were separated from the other parent and were primary caregivers of their child) agreed to participate. No significant differences between participating and non-participating families were found regarding illness factors or socio-demographic aspects. The parents completed self-report questionnaires concerning PQL at 1-2 weeks (T1) and at 2-3 months (T2) after the diagnosis. At T2 the complete sample was able to be reassessed.

To investigate illness-related effects, the study group was divided into two sub-samples (cancer vs. non-cancer). There were no differences between the two main clinical groups in distribution of parental gender, family size or parental education. However, the patients in the oncology group were significantly younger compared with the diabetes/epilepsy group, in concordance with the typical onset age of the diseases. Moreover, the gender distribution within both groups was significantly different with more boys than girls in the oncology group and nearly similar proportions of boys and girls in the diabetes/epilepsy group.

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insert table 1

Procedure

Participants were approached during an inpatient visit or during a visit to the outpatient

unit. A lot of effort was put into the inclusion of fathers in the study. If only one parent from a complete family was present in the hospital, an appointment with the other parent was made at a subsequent visit. Using this procedure it was possible to reach all parental couples that were living together at the time of assessment. If only one parent per family responded, this was always the main caregiver for the child, who did not live together with the other parent in one household. Informed consent was obtained according to the principles of the local ethical committee. The questionnaires were filled in at home and sent back to the university clinic in prestamped envelopes. If parental couples participated, mothers and fathers were instructed to fill in the questionnaires independently of each other.

Measure

The *Ulm Quality of Life Inventory for Parents (ULQIE)* is a 29-item self-report questionnaire, constructed by factor analysis, and developed according to the definition of QL by Gill and Feinstein [17]. The standardization sample consisted of 250 parents with children suffering from cancer, haematological diseases, or insulin dependent diabetes mellitus. The instrument has good psychometric properties: The internal consistency of the total scale is indicated by Cronbach's α of .91, for the subscales between .74 and .88. The external validity for the *ULQIE* total score is substantiated by correlations of .65 with the subscale *psychological well-being* of the Medical Outcome Study *SF-36* [26], .40 with the *SF-36* subscale *emotional functioning*, .53 with the subscale *vitality*, and .50 with the subscale *general health attitude*. Reference data from parents with healthy children (a sample of 24 mothers and 13 fathers from 24 families) are available from a previous study [27]. The rationale, methodology and reliability of the *ULQIE* have been described previously [28].

In the *ULQIE* parents are asked to rate how much they agree with each statement on a series of five-point scales from 1 = "never" to 5 = "always" regarding the past seven days.

The scores of all individual answers of one scale are summed. Scale raw scores are linearly transformed to scales ranging from 0 to 100. Higher scores indicate greater PQL, so the maximum score of 100 would represent optimal PQL. The questionnaire consists of five primary scales and the total scale. The five primary scales are *physical and daily functioning* (7 items, example: "Last week I was able to maintain my usual activities."), *satisfaction with the support from the family (6 items, e.g."*…we could maintain an open communication within our family"), *emotional stability* (4 items, e.g. "… I was hopeful and optimistic"), *self-development* (4 items, e.g. "…I had enough time to meet my friends and acquaintances"), and *well-being* (4 items, e.g. "…I felt burnt out."). The total score is derived by adding the raw scores of all five primary scales and of four additional single items (absence of bodily complaints, pain, nervousness and excitability).

Statistical analyses

Descriptive statistics were calculated for socio-demographic features. Means and standard deviations for PQL scores were calculated for the total study sample and for subgroups of mothers and fathers regarding diagnosis of the child and time since diagnosis. The PQL scores of parents from the clinical samples were compared with the PQL scores of parents with healthy children that had been collected as comparison data in a previous study [27]. Intra-class correlations were determined to analyse the association of maternal and paternal quality of life within couples. Because the mean age and the gender distribution of the children were different in both diagnostic subgroups and both variables had an effect on PQL (for details see the results section), we controlled for these variables in the subsequent analyses. ANOVAs were conducted separately for mothers and fathers with diagnosis (cancer vs. diabetes/epilepsy) as an independent factor and repeatedly assessed different PQL dimensions as dependent measures. The significance level was adjusted for multiple tests by *Bonferroni* corrections to reduce the risk for type 1 errors. *Cohen*'s effect sizes

(*ES*) were determined. All statistical procedures were performed with the software package SYSTAT 10.2®.

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insert figure 1

RESULTS

Parental quality of life in the total study sample

Means and standard deviations for the two subgroups at the two assessment time points and for the healthy comparison sample are presented in table 2a for mothers and in table 2b for fathers. Across all subgroups and across parental gender, the profile of PQL revealed a wide range of responses with *family satisfaction* showing the highest mean value (*mean* = 80.9, *SD* = 15.2). *Physical and daily functioning* had a *mean* value of 61.4 (*SD* = 18.6), *emotional stability* of 54.1 (*SD* = 20.2), and *well-being* of 62.8 (*SD* = 19.3). *Self-development*, compared to other aspects of QL, had a relatively low mean of 40.5 (*SD* = 20.5), and the total score had a mean of 61.9 (*SD* = 13.1). Tables 2a and 2b demonstrate that mothers generally tend to report a lower quality of life compared to fathers.

Comparison with parents of healthy children

Figure 1 demonstrates the PQL profile of parents in both clinical subgroups at T1 compared with a group of 37 parents with healthy children who had previously answered the ULQIE in a study by Terk [27]. Parent's and children's age and children's gender in the comparison group were similarly distributed to the same variables in the study group. *T*-tests revealed significantly lower PQL scores in parents of children with cancer at T1 compared with healthy controls in the dimensions *physical/daily functioning* (t =3.9, $p < .001$), *emotional stability* ($t = 13.9$, $p < .001$), *self-development* ($t = 12.2$, $p < .001$), and *well-being* ($t = 8.3$, $p < .001$), whereas the parents of children with cancer described

significantly more *satisfaction with their family situation* ($t = 3.5$, $p < .001$). Parents of children newly diagnosed with diabetes or epilepsy reported significantly lower PQL at T1 compared with healthy controls in the dimensions *emotional stability* ($t = 9.3$, $p < .001$), *self-development* ($t = 7.5$, $p < .001$), and *well-being* ($t = 6.1$, $p < .001$), and the parents of children with diabetes/epilepsy were also more satisfied with their *family situation* compared with healthy controls ($t = 3.3$, $p = .002$).

Effects of gender and age

Several effects of the child's gender and age on PQL were revealed. *Pearson* correlations demonstrated an effect of the child's age on PQL sum-score (r = .44), with parents of younger children reporting lower PQL. All PQL dimensions were moderately correlated with the child's age (between $r = .33$ and $r = .41$), except *family satisfaction* which was not correlated with patients' age. Moreover, in a two-sample *t*-test a statistical tendency occurred towards an effect of the child's gender on the PQL sumscore with parents of boys reporting a slightly higher QL compared with parents of girls ($t = 1.4$, $p = .18$). On subscale level, this effect was significant for *family satisfaction* ($t = 2.8$, $p = .032$ after *Bonferroni* correction), a statistical trend in the same direction was found for the other four PQL dimensions.

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insert tables 2a and 2b

Correlations within parental couples

For the 51 parental couples in our study sample, intra-class correlations between mothers and fathers at both time points were determined (see table 3). PQL within couples was positively correlated on a moderate to high level in most of the dimensions. A comparison between the first and the second assessment revealed different levels of correlations shortly after the diagnosis and 2-3 months later. At T2, there was more similarity within couples

compared with T1. The association of physical and daily functioning and of emotional stability was greater at T2 compared to T1, whereas the association of self-development was lower at T2.

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insert table 3

Effects of diagnosis and time on maternal quality of life

As demonstrated for subgroups of mothers by diagnosis and time (see table 2a), the distribution of PQL-scores shows considerable between-group variance. The results of the ANOVAs (see table 4a), corrected for children's gender and age, reveal significant effects of diagnosis on maternal quality of life at both assessment time points (overall PQL: F = 7.8, p = .007). Mothers of cancer patients showed consistently lower *physical and daily functioning*, lower *emotional stability*, and lower *self-development* compared with mothers of children with diabetes or epilepsy. *Family satisfaction* and *well-being* are exceptions to this pattern, indicating no significant diagnosis-specific effect. A main effect of assessment time on maternal quality of life can be demonstrated only as a statistical tendency for the domain *family satisfaction* (F = 3.4, p = .070). Post hoc analyses reveal that *family satisfaction* increases between T1 and T2 (see table 2a), extending the elevated level of *family satisfaction* compared with mothers of healthy children that was evident already at T1. The interaction between diagnosis and time showed a statistical trend for *physical and daily functioning*, indicating that mothers of a child with cancer recovered between T1 and T2 in this domain, whereas the mothers of the children with diabetes or epilepsy remained on a similar level. Standardized effect sizes (*ES*) were determined and indicated a moderate main effect of diagnosis on overall maternal QL (*ES* = 0.53) and a small *ES* of time on the maternal QL sumscore (0.36).

Effects of diagnosis and time on paternal quality of life

The same set of analyses as for mothers was performed for fathers. Table 2b demonstrates also considerable variance between subgroups and assessment time-points that were analysed using ANOVAs (see table 4b). However, only one significant main effect of diagnosis was found with respect to *emotional stability*, and on the *well-being* subscale there was a statistical tendency for fathers of children with cancer to report lower scores than fathers of children with diabetes or epilepsy. Moreover, there was a significant main effect of time on paternal *well-being* with an increase between T1 and T2, and a significant interaction effect of diagnosis and time on paternal *emotional stability*, with a considerable increase between T1 and T2 in the diabetes/epilepsy group, whereas fathers of children with cancer stayed on a similar low level at both assessment time points. For fathers, too, the effect size of diagnosis on the QL sumscore was moderate (*ES*=0.58) and the effect size of time since diagnosis on QL was small (*ES*=0.30).

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insert tables 4 a and 4b

DISCUSSION

This study focuses on the impact of a recent diagnosis of childhood cancer or juvenile diabetes/epilepsy on parental quality of life. According to the results of the multidimensional measure, the level of PQL in the case of chronic childhood disease differs depending on which domain of the construct is considered. Compared with parents of healthy children, the parents in the study sample reported low *self-development*, i.e. they have restricted time to be with their partner, with friends or acquaintances, or to develop their personal interests. At the same time, they described considerable restrictions in their *emotional stability* and their general *well-being*, while their *physical/daily functioning* was lower compared with parents of healthy children, with the most prominent findings in the cancer subsample. These results are consistent with the literature on parental distress and

mental disorders in childhood chronic disease [4;13;19;29-31] and extend the previous findings with regard to different aspects of PQL.

As an exception of the general trend of impaired PQL, the parents in our study group were significantly more satisfied with their family situation compared with parents of healthy children. *Family satisfaction* had persistently high values after the child's diagnosis of a chronic disease. As other investigators [32] have proposed before, these results suggest that shortly after the diagnosis, families are more likely to become closer as a result of the illness. Maintaining family cohesion and open communication within the family has been described as an effective and important parental coping style to facilitate adaptation to the new situation with an ill child [8;33]. It is known that parents of a chronically ill child utilize social and emotional support from their families and their partners [7;9;34]. Thus, facing a chronic childhood illness might strengthen family cohesion and decrease family conflict.

Moderate intra-class correlations indicate similarity of PQL within parental couples. Higher correlations at T2 suggest a greater similarity of partners at this time point compared with shortly after the diagnosis. This may be explained by a common effect of the child's medical situation on both parents and by mutual parental support with synchronous effects on individual PQL.

Consistent with our second hypothesis, PQL is determined by the diagnosis of the child. According to the results of the ANOVAs, there is a significant main effect of diagnosis on the sum-score of PQL. This effect is more distinct for mothers than for fathers. Parents of cancer patients report poorer QL than parents of children with diabetes or epilepsy. These differences between the diagnostic groups may be due to high emotional and procedural stress associated with the diagnosis and treatment of cancer [35]. Longer and repeated hospital admissions, potential relapses, long and painful treatment procedures and the life-threatening situation of the cancer patients might be factors that are reflected in this result.

On the other hand, parents of children with diabetes play a more active role in controlling blood sugar level, giving a feeling of self-efficacy [36]. Self-efficacy is known as a resilience factor that promotes mental health, whereas helplessness has been demonstrated to be related to anxiety and depression.

Most of the dimensions of PQL remain quite stable within the first three months post-diagnosis, and therefore our third hypothesis is only partially confirmed. There is a statistical trend toward an increase of maternal *family satisfaction* and an increase of paternal *well-being* within three months after onset of disease, independent of diagnosis type. Symptoms of the autonomous nervous system such as impaired sleep and appetite, which are represented in the *well-being* scale, are known to occur immediately after traumatic events and to decrease spontaneously within several weeks. This effect is in accordance with previous findings [13], and could be partially explained by the improvement of the child's medical situation in the interval between the two assessment time-points. The gender specific pattern may reflect different coping styles of fathers and mothers [37]. As mothers mostly have the role of primary caregiver of the child, they may experience persistent parenting stress with the ill child and may primarily utilize support from their spouse and relatives. Fathers often return to work several weeks after the their child's diagnosis, and therefore they experience a greater distance to the medical field and possibly less disease-specific parenting stress compared to mothers.

The age of the child at the time of diagnosis seems to have a moderator effect on the chronic disease's impact on PQL. Having a younger child is associated with lower PQL, and this finding is consistent with the previously reported higher levels of parenting stress with young children [13]. Developmental aspects are probably responsible for this result. Young children with a chronic disease require more parental presence and support, because they are less able to participate actively in their treatment.

The following limitations of this study should be recognised. First, the study was based on a questionnaire survey and therefore depends on reliability and validity of self-report data. Unfortunately, no data on PQL prior to diagnosis could be gathered because of the study design, and the reference data of a healthy population can provide only an approximate estimation of the baseline level. Second, the sample size was relatively small. Therefore the results should be regarded as preliminary. Third, the clinical relevance of statistically significant differences between subgroups of parents or between assessment time points has to be validated by clinical assessment of the parents in future studies. Although effect sizes allow an interpretation of the comparisons independently of the significance level, it is difficult to determine the minimal clinically significant difference of PQL solely on the basis of self-report data. Moreover, the set of predictors of PQL that was investigated in this study was limited, and other medical and psychosocial variables may contribute to parental functioning. Nonetheless, the results corroborate and extend previous findings linking children's chronic illness and PQL.

CONCLUSIONS

The results of this study validate PQL with chronic paediatric conditions as a construct worthy of further exploration. More research with different diagnoses and with a longer time frame is needed to obtain a more comprehensive description of parental resources and limitations in coping with chronic diseases. Future research should also investigate other psychosocial variables that might predict PQL. It would be interesting to include more social variables to better understand the role of extra-familial social support within the process of adaptation [25].

From a clinical perspective, the *ULQIE* as a diagnostic tool helps to identify vulnerable families and assists health care team members to offer extra support. The results of this study provide further evidence for the fact that parents of children newly diagnosed with a

chronic disease need special attention from the health care team with regard to their personal situation [4;38;39]. Clinicians should be aware of the parents' vulnerability that persists at least during the first three months after diagnosis, and offer them psychosocial support in order to cope with their child's disease if necessary. A cancer diagnosis, especially, can be considered as a risk situation for parents. Providing information on the improved prognosis of paediatric cancer, psychological counselling, and providing professional assistance in child care may contribute to maintaining highest possible level of parental functioning and well-being. Psychosocial support programs and liaison-services in paediatric oncology should be available in the early phase after the hospital admission and diagnosis. Multidimensional measures of PQL should be included in psychosocial intervention studies, both for targeting and evaluating family-centred interventions.

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Table 1: Sample description, divided into the diagnostic subgroups

variable	oncology group (n = 62)	diabetes / epilepsy group (n = 60)
parental gender	33 (53 %) mothers 29 (47 %) fathers	33 (55 %) mothers 27 (45 %) fathers
family composition	50 (81 %) two parent 8 (13 %) single mothers 4 (6 %) single fathers	52 (86 %) two parent 7 (12 %) single mothers 1 (2 %) single father
number of children in family (mean)	mean = 1.16 SD = 0.83	mean = 1.18 SD = 0.92
education of parents	23 (37 %) primary school (9 years) 31 (52 %) secondary school (> 9 ys.) 7 (11 %) university	16 (27 %) primary school 33 (55 %) secondary school 11 (18 %) university
children's age (years)	mean = 6.06 SD = 4.12 range 2.5 – 15	mean = 8.37 SD = 3.62 range 2.5 – 15
children's gender	44 (71 %) male 18 (29 %) female	31 (52 %) male 29 (48 %) female
specific diagnosis	34 (55 %) leukaemia/lymphoma 28 (45 %) tumor	43 (72 %) diabetes 17 (28 %) epilepsy

Table 2a: Descriptive statistics (mean/SD) for **maternal** quality of life (PQL) by diagnosis of child and assessment time (T1: 1-2 weeks postdiagnosis; T2: 2-3 months postdiagnosis), and mean/SD for mothers of healthy children

PQL dimension	Cancer (n = 33)		diabetes/epilepsy (n = 33)		healthy controls (n = 24)
	T1	*T2*	*T1*	*T2*	
physical/daily functioning	51.7 (14.2)	58.8 (18.6)	64.2 (15.4)	65.7 (16.4)	67.0 (19.0)
satisfaction with family	75.9 (14.7)	76.8 (14.9)	80.6 (16.2)	83.7 (14.1)	62.9 (29.4)
emotional stability	47.3 (18.5)	52.8 (21.1)	56.9 (19.6)	63.5 (17.8)	85.3 (13.0)
self-development	24.1 (14.6)	32.8 (17.1)	43.6 (19.0)	46.4 (18.0)	79.7 (15.0)
well-being	54.4 (21.6)	61.6 (16.2)	60.0 (16.1)	69.9 (15.9)	82.8 (16.3)
sum-score	54.8 (10.0)	58.4 (13.1)	62.3 (11.6)	67.0 (11.7)	74.0 (28.6)

Table 2b: Descriptive statistics (mean/SD) for **paternal** quality of life (PQL) by diagnosis of child and assessment time (T1: 1-2 weeks postdiagnosis; T2: 2-3 months postdiagnosis), and mean/SD for fathers of healthy children

PQL dimension	Cancer (n = 29)		diabetes/epilepsy (n = 27)		healthy controls (n = 13)
	T1	*T2*	*T1*	*T2*	
physical/daily functioning	56.9 (18.9)	58.5 (20.0)	65.5 (20.6)	72.0 (19.5)	70.3 (14.5)
satisfaction with family	84.8 (11.2)	86.8 (9.5)	78.2 (19.5)	81.1 (18.1)	60.8 (29.3)
emotional stability	42.5 (17.3)	44.4 (18.2)	56.3 (20.9)	69.4 (14.1)	88.0 (8.1)
self-development	36.4 (19.1)	41.4 (19.6)	48.5 (23.7)	54.4 (17.9)	74.1 (26.1)
well-being	54.1 (20.5)	63.6 (17.0)	67.1 (21.3)	73.6 (18.0)	85.4 (9.8)
sum-score	57.7 (10.6)	60.5 (12.6)	65.0 (16.6)	70.8 (12.0)	79.1 (19.8)

Table 3: Intra-class correlations of parental quality of life within couples (*n*=51)

PQL dimension	**T1**	*T2*
physical/daily functioning	.25	.53
satisfaction with family	.46	.38
emotional stability	.28	.63
self-development	.57	.37
well-being	.61	.58
sum-score	.49	.66

Table 4a: Results of ANOVAs for diagnosis (cancer, diabetes/epilepsy) as independent factor and repeatedly (1-2 weeks and 2-3 months postdiagnosis) measured **maternal** quality of life (PQL) dimensions as dependent variables, corrected for patients' age and gender, significant results ($p < .05$) in bold.

	adjusted means										
PQL dimension	**canc T1**	**canc T2**	**diab T1**	**diab T2**		***main effect: diagnosis***		***main effect: time***		***interaction effect: diagnosis x time***	
					df	***F***	***p***	***F***	***p***	***F***	***p***
physical/daily functioning	51.7	60.3	64.2	64.2	4/62	**5.9**	**.018**	<1	ns	3.9	.052
satisfaction with family	75.7	77.6	80.7	82.8	4/62	2.2	ns	3.4	.070	<1	ns
emotional stability	47.7	53.9	56.5	62.4	4/62	**4.3**	**.042**	<1	ns	<1	ns
self-development	24.4	32.6	43.2	46.5	4/62	**18.1**	**<.001**	<1	ns	1.2	ns
well-being	55.5	63.1	58.9	68.4	4/62	1.8	ns	1.3	ns	<1	ns
sum-score	55.1	59.5	62.0	65.9	4/62	**7.8**	**.007**	2.1	ns	<1	ns

Table 4b: Results of ANOVAs for diagnosis (cancer, diabetes/epilepsy) as independent factor and repeatedly (1-2 weeks and 2-3 months postdiagnosis) measured **paternal** quality of life (PQL) dimensions as dependent variables, corrected for patients' age and gender, significant results ($p < .05$) in bold.

	adjusted means										
PQL dimension	**canc T1**	**canc T2**	**diab T1**	**diab T2**		***main effect: diagnosis***		***main effect: time***		***interaction effect: diagnosis x time***	
					df	***F***	***p***	***F***	***p***	***F***	***p***
physical/daily functioning	60.2	62.0	62.0	68.3	4/52	<1	ns	<1	ns	<1	ns
satisfaction with family	83.0	85.8	80.1	82.1	4/52	<1	ns	<1	ns	<1	ns
emotional stability	44.8	45.4	53.7	68.4	4/52	**14.6**	**<.001**	1.2	ns	**7.0**	**.011**
self-development	39.9	43.7	44.8	51.9	4/52	1.9	ns	<1	ns	<1	ns
well-being	57.0	64.3	64.0	72.9	4/52	3.1	.085	**4.7**	**.036**	<1	ns
sum-score	59.5	61.7	63.1	69.4	4/52	3.0	.089	1.1	ns	1.7	ns

Figure 1: Quality of life profile (*Ulm Quality of Life Inventory for Parents*) of parents in the study sample at T1 (cancer: n=62; diabetes/epilepsy: n = 60) and parents of healthy children (n=37; Terk 2004 [27])