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Health satisfaction and family impact of parents of children with cancer: a descriptive cross-sectional study

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Author contribution

The study was designed by TL & EAG. EAG and JS collected and analysed the data. EAG and TL wrote the manuscript and made critical revisions for important intellectual content. This manuscript was prepared following STROBE guidelines.

Ethical approval

Approval was secured from the Research Ethics Committee of the University of Jordan and from the hospital (Ref: 100/2014-2015).

ABSTRACT

Background: The impact on parents of coping with a child who has cancer can be both severe and multifarious. Considerable distress persists throughout the treatment phase, persisting even after completion of treatment with heightened anxiety and stress associated with thoughts of recurrence or relapse.

Aim: The purpose was to investigate the links between parents' satisfaction with the healthcare offered to their child with cancer and the impact on families of caring for such a child (including their health-related quality of life) in a Middle-Eastern country.

Study Design: A descriptive, correlational, cross sectional design was adopted. Arabic versions of parent-completed, validated instruments were completed by 113 parents whose child had cancer.

Results: Family relationship was found to be the best functioning domain, and Daily activities was seen to be the poorest. In general, parents expressed satisfaction with their child's healthcare, but inadequate attention had been paid to their emotional needs. Cases in which children were reported to exhibit more emotional and behavioural problems correlated with greater negative impact on the family and disrupted family functioning.

Discussion: Parental quality of life was more severely affected than family quality of life. This results from mothers taking up most of the caregiver burden, and the impact on mothers was significantly greater than that on fathers. Children were protected from stress and anxiety by their mother. This burden on mothers resulted in deficits in emotional, social and physical functioning.

Practice and policy Implications: Nurses and other health professionals should redress the balance between family-centred care strategies and child-centred approaches. Effort is needed to provide psychological support to parents by ensuring adequate preparation of staff, especially nurses, to recognise need and provide support in a therapeutic environment. Support may be needed for years after the diagnosis. This is a health professional role that may currently be neglected, and for which training is essential.

Keywords: Cancer Care, Children and Young People, Family Health, Health Policy, Mental Health, Nursing Therapeutics, Quality of Life, Quantitative Methods

INTRODUCTION

The Common Parental Response to Having a Child with Cancer

The international literature considers a wide variety of aspects of parental responses to a child having cancer (1). Parents can show remarkable psychological resilience, (2) though a notable exception to this is relapse or recurrence of the cancer (3). Evidence from the Netherlands (4), the UK (5,6), Sweden (7), the USA (8) and Japan (9) indicates that most parents show more stress, increased anxiety and reduced health-related quality of life (HRQOL) than population norms.

Features of Parental Stress

Klassen et al. (10) found Canadian parents to have poorer HRQOL outcomes in all aspects of physical health and most facets of psychosocial wellbeing. Others found poor parental HRQOL to be related to increased stress and deteriorating mental health. Parents also experienced reduced intensity of social support, worse health behaviour, worse family functioning, and greater stress than parents who did not face the same challenge (8). American parents experienced considerable worsening of diet and nutrition, lowered physical activity, and curtailed social pleasure. Lone parents fared worst of all, suffering poorer relationships with friends and with the child's siblings (11). The impact may be experienced as posttraumatic stress, clinical depression and marital or partner discord (1,12).

A Swedish study (13) recognised a key role for children's oncology nurses to identify parents who are at risk of losing social support and to intervene to reframe a positive response to the current circumstances. However, others found little convincing research evidence of the effectiveness of nursing intervention with this population (14).

Time Profile of HRQOL and Stress

The profile of reduced HRQOL and stress may not be linear, with US parents experiencing improvement, decline and stability over time in family cohesion (15). A timeline of parental quality of life is seen (10), with most psychological distress at the point of diagnosis. Significant distress remains during treatment (1,16), correlating positively with the intensity of treatment (3) and especially chemotherapy (17). A review in Australia noted that completion of treatment can provoke intensified parental anxiety and additional stress as parents lose the security of the treatment regime and fear recurrence or relapse. Fear of recurrence was also linked to persistent fatigue in parents (18). A study in the Netherlands identified that significantly increased psychological distress may be experienced as long as five years after completion of treatment (2).

Aggravating and Protective Factors

High-level family functioning before diagnosis was seen in an American study to correlate with less parental stress during treatment. Parents displayed more adaptive than maladaptive coping strategies (19). Caring for a child with posterior fossa syndrome exerts particular physical and psychological burdens on the caregiver, with long-term reduction in parental HRQOL (20). A Canadian study found financial difficulties to be a major concern, persisting for years, and reducing maternal HRQOL (21). This was confirmed in an Italian study (22), noting that most calculations of financial cost are gross under-estimates. If financial difficulties are prolonged then intense psychological distress may result (20). The child's behaviour and care-giving demands also reduce parental physical and mental health (4, 23). Knowledge of the cancer decreased the stress experienced by Malaysian mothers (17), while better parental health habits (sleeping and diet) were protective in Canadian mothers (10). Optimism correlated with better satisfaction with life, anxiety, depression and perceptions of health for British parents (6). Reducing stress and the psychological burden ameliorates the impact on parental physical and mental health (8, 23).

Gender Differences in Response

Research from Brazil concluded that women suffered more than men from stress, anxiety and social distress (1). However, a study in Jordan recognised that mothers of children with cancer suffered significantly more from stress than other mothers, but fathers, while certainly reacting to the revelation of the diagnosis, were also impacted by their wife's stress (24).

Overall, much is known about the problems of parental responses to a child having cancer, yet only two studies reported in this review address the impact of health care interventions on parental wellbeing. The study that we report here investigated the links between parents' satisfaction with the healthcare offered to their child and the impact on families of caring for such a child.

METHODS

Design:

A descriptive cross-sectional design was adopted. Arabic versions of parent-completed, validated instruments were completed during 2016 by Jordanian parents who had a child with cancer.

Participants:

All eligible families over a six months period were invited to participate. There is no peak period for cancer referral. A total of 113 parents completed the questionnaires, and there was no missing data. Only three declined the invitation. The inclusion criteria were Jordanian parents of a child with any diagnosis of cancer and who spoke Arabic, resided in the same house with the child, and had prime responsibility for the child's care. The vast majority of residents with children in Jordan who are treated for cancer are Jordanian nationals and speak Arabic. Parents were excluded if their child had terminal cancer so as to avoid imposing an additional psychological burden on the family. By "terminal" we meant when the child was actively dying as

identified in the Red traffic light category of the Spectrum of Palliative Care Needs. (25) It is clear that the voice of these parents was not represented, and we intend to address this in further research with an amended design. Children were on a spectrum from early after diagnosis to approaching completion of treatment and entering follow-up care. This was to ensure that the experiences which might change along this journey would be included.

Setting:

The hospital in which the study took place is the main centre for cancer care in Jordan. One paediatric ward and its associated (but separately located) outpatient clinic were the sites for recruitment and data collection. Patients receive most of their active treatment on the ward, but continue treatment through the outpatient clinic. Many of the same staff of the healthcare team are seen in both settings.

Measures:

The PedsQL Family Impact Scale

This thirty-six item parent-reported module measures parent functioning (physical, emotional, social, cognitive, worry, communication) and family functioning of daily activities and relationships. Reliability of $\alpha=0.97$ was reported for the original scale (26). It is based on a five-point 0-4 Likert scale. Once reverse-scored, items are transformed in a linear manner to a 0–100 scale in which reduced negative impact (better functioning) is represented by higher scores. A Parent HRQOL Summary Score and a Family Functioning Summary Score can be calculated. A well-used formula was adopted of scores of less than 66 as indicating reduced quality of life, and 50 or less as indicating seriously impaired quality of life (27).

The PedsQL Healthcare Satisfaction Hematology/Oncology Module

This parent-report module of twenty-five questions is focused on satisfaction in six subscales of General Satisfaction, Information, Inclusion of Family, Communication, Technical Skills, and

Emotional Needs. A Total satisfaction score is also calculated. Varni et al. (28) reported good internal consistency: Cronbach's alpha of 0.57 to 0.78. The basis is a five-point scale (0-4), transformed to a 0-100 scale, but without reverse-scoring. Higher scores indicate more satisfaction.

The Strengths And Difficulties Questionnaire (SDQ)

This tool measures emotional and behavioural problems in children 3-16 years as perceived by parents or teachers (29). The Cronbach coefficient for the total scale is 0.73. Twenty-five items are arranged into five subscales each of five items: emotional symptoms, conduct problems, hyperactivity–inattention, peer problems, and prosocial behavior. With the exception of prosocial behavior, higher scores relate to more impaired psychological wellbeing. Each subscale has a range of scores 0-10, with Total Difficulties Score range of 0-40 (excluding the Prosocial Behavior Scale). The total and subscales scores are categorized as normal, borderline, and abnormal. The Arabic version of this questionnaire has been shown to be valid and reliable (30,31).

Translation and piloting

Translation and psychometric testing of the original PedsQL Family Impact Scale has been reported previously by the authors (32). The PedsQL Healthcare Satisfaction Hematology/Oncology module was translated into Arabic by the researchers with permission from Mapi Trust. Optimal accuracy in the translated version of the instrument was achieved through adoption of published guidelines.(33) Two experts in family mental health checked the revised questionnaire to establish face validity, considering individual items and the whole instrument for relevance, appropriateness and comprehensive attention to cardinal elements. No problems were identified. Piloting of both instruments together was undertaken with ten parents who lived with a child with cancer. No issues were discovered with the questionnaires or the administration process.

Statistical Methods

Descriptive statistical analysis was applied to demographic data and the make-up of the sample. IBM SPSS Statistics (version 21: IBM Corporation, Armonk; NY, USA) was used to perform statistical analyses. Bivariate correlation analysis was undertaken. Associations between the variables of family impact, parents' satisfaction with healthcare, and emotional and behavioural problems in children were investigated using the Pearson product-moment correlation coefficient. T-test was selected to calculate the effect of gender on family impact and parental satisfaction with healthcare. The level of statistical significant was considered to be $p \leq 0.05$. To verify the assumptions of normality before the application of t-test, descriptive tables and the Kolmogorov-Smirnov test were completed.

Ethical approval and data collection

Approval was secured from the Research Ethics Committee of the University of Jordan and from the hospital (Ref: 100/2014-2015). Parents were approached by a senior nurse involved in their care to elicit permission to be contacted by the researchers. Informed consent was addressed through printed information sheets, verbal explanations, and signed consent forms. The voluntary basis of participation was emphasized, together with the right to withdraw from the study without needing to provide a reason. Confidentiality and secure management of data was assured, and no personally identifying data was included in the questionnaires. Study numbers were substituted for names. Participants had the choice to complete the questionnaires at the point of recruitment or at a later date, though all opted to complete them immediately. The study was conducted in private in out-patient clinics and a hospital ward in Amman, Jordan.

RESULTS

Demographic characteristics of parents

A total of 113 parents completed the instruments. Mean parental age was 39 years (SD=7.0) ranging from 24 to 56 years. There were more women (n=82, 72.6%) than men (n=31, 27.4%). The majority was Muslim (n=107, 95%) with a Christian minority (n=6, 5%). For most parents, the highest level of education completed was secondary school (50.9%). Twenty-six per cent worked full-time, 4% were in part-time employment, 10% had retired, and 58.7% described themselves as housewives.

Demographic characteristics of children

The youngest child was 5 years old and the eldest 18 (mean=10.17 years, SD=3.4years). There were 30 girls and 40 boys. A range of cancer diagnoses was represented: leukemia (n=34, 46%), lymphoma (n=4, 5.7%), other cancers (n=32, 48.3%). This spectrum of diagnoses was present in the cases recruited both from the ward and from the follow-up clinic. However, as would be expected, the children receiving active treatment on the ward were more acutely ill than those attending the follow-up clinic. The latter had problems more with side-effects (as well as ongoing treatment).

Family Impact

Family relationship functioning was found to be the best functioning domain, and Daily activities was seen to be the poorest functioning. See Table1. Three of seven subscales showed reduced HRQOL (score <66), and four showed seriously reduced HRQOL (score <50). Quality of life was seriously impaired in Physical functioning, Emotional functioning, Worry and Daily activities. All other subscales showed reduced HRQOL other than Family relationships. The Total impact score demonstrated reduced HRQOL, with the Parent summary score exerting the most impact on this. **(Insert Table 1 here)**

Parental satisfaction

There was moderate satisfaction with the healthcare offered to children (total scale mean=71.7; SD=16.8). Satisfaction with Technical skills (for example, how quickly staff respond to the child's nausea and pain) was the highest ranked scale. Emotional needs was the lowest ranked and demonstrated moderately reduced satisfaction. See Table 2. **(Insert Table 2 here)**

Emotional and behavioural problems

The mean Total strengths and difficulties score on the SDQ was 17.2 (SD=5.8). Pro-social and Emotional problems subscales were ranked the highest means. The Peer problems subscale was ranked the lowest. Tentative banding of normal, borderline abnormal, and abnormal have been suggested (<http://www.copmi.net.au/images/pdf/Research/sdq-english-uk-self-scoring.pdf>). According to this, all subscale mean scores fell within the normal banding other than Conduct problems which was borderline abnormal. The mean Total strengths and difficulties score was also borderline abnormal. The mean Prosocial score was normal. However, population norms for some countries (though none in the Middle East) are available from the SDQ website (<http://www.sdqinfo.org/g0.html>), all of which (Prosocial score excepted) show norms much below the mean scores of Jordanian children with cancer. This indicates that Jordanian children demonstrated more problems than the norms established in other countries. This is detailed in Table 2.

Correlations between PedsQL Family Impact scale, PedsQL Healthcare Satisfaction Hematology/Oncology scale and the Strengths and Difficulties Questionnaire

There were negative relationships between total SDQ score and the total PedsQL Family Impact scale and all of its subscales ($p \leq 0.05$). Cases in which children were reported to exhibit more emotional and behavioural problems were linked to more frequently reported negative impact on the family and disrupted family functioning. See Table 3. **(Insert Table 3 here)**

Pearson correlation was used to determine the relationship between family impact and healthcare satisfaction. There were positive significant correlations between the Social functioning subscale of the PedsQL Family Impact scale and the PedsQL Family Healthcare Satisfaction Hematology/Oncology General satisfaction subscale ($r=.229$, $p=0.016$), Information subscale ($r=.209$, $p=0.027$), Inclusion of family subscale ($r=.219$, $p=0.021$), Technical skills subscale ($r=.282$, $p=0.003$) and Total satisfaction score ($r=.189$, $p=0.046$). With the exception of Emotional needs and Communication, parents were more satisfied in all aspects of healthcare satisfaction if they reported better social functioning.

Moreover, there was a positive correlation between the Communication subscale of the PedsQL Family Impact scale and the Information ($r=.305$, $p=0.001$), Inclusion of family ($r=.329$, $p=0.0001$), and Communication ($r=.307$, $p=0.001$) subscales as well as the Total satisfaction score of the PedsQL Healthcare Satisfaction Hematology/Oncology scale ($r=.311$, $p=0.001$). In addition, the Family Impact scale Worry subscale correlated positively with the Inclusion of family subscale ($r=.275$, $p=0.003$), Technical skills subscale ($r=.196$, $p=0.041$) and the Total satisfaction score ($r=.209$, $p=0.028$). There was a positive correlation between the Family Impact scale Daily activities subscale and the Healthcare Satisfaction Inclusion subscale ($r=.190$, $p=0.046$).

Parental gender

The effect of parental gender on the total scores of all three instruments was established with a two-tail t-test. There was a statistically significant difference in Total impact score in the PedsQL Family Impact scale between mothers and fathers ($t(110)=-2.356$, $p=0.020$). Mothers' functioning was more adversely affected than fathers' functioning. However, there was no statistically significant difference between mothers and fathers in Total satisfaction score ($t(110)=1.881$, $p=0.06$), and no statistically significant difference in Total SDQ score between mothers and fathers ($t(110)=.569$, $p=0.571$).

DISCUSSION

Limitations

While children were on a spectrum from early after diagnosis to approaching completion of treatment and entering follow-up care, the sample was insufficient for us to calculate the relative impact at these points. We sampled continuously over a six months' time period rather than selectively, and while cancer diagnosis shows no seasonal variation, there was the potential for selection bias. Moreover, the instruments reported here rely on parent-reported data about child behaviour rather than child self-reported or observational data. More mothers than fathers formed the sample, and while it was an achievement to include fathers at all, this gender bias has to be taken into account when discussing parental responses. The limitations of the sample meant that we were also unable to discriminate the potential impact of the type of cancer and severity of illness when analysing the data from the instruments.

Bornstein (34) among others emphasises the culturally-bound nature of parenting, with significant commonality and differences not only within countries but also across world regions. Jordanian fathers may have more involvement in childcare than is the case in other Middle Eastern countries, but the predominance of the care burden falling on mothers is a commonality across the region. We detected differential responses between mothers and fathers in the Family Impact scale, but not in other aspects. Further research would be required to make a more emphatic claim about this.

The usefulness of the instruments

The paucity of studies in the Middle East makes interpretation of scores difficult. Work to establish population norms in the country and the region would be worthwhile. In this study, and in others, mean scores were found to be considerably worse than the population norms that are available (that is, higher SDQ score indicating more problems, and lower HRQOL scores showing greater deficit in HRQOL). Clinically relevant cut-offs have been declared for various

populations and age groups, though largely in US populations (27, 35, 36). The general suggestion of considering scores of less than 66 as indicating reduced HRQOL, and scores of 50 or less as indicating seriously impaired HRQOL seems to work well and is at least not an over-estimate.

Impact on parents

The impact on parents was significant. All aspects other than family relationships were adversely affected, showing as impaired or seriously impaired HRQOL. Similar conclusions have been drawn by researchers in North America (8,10), Europe (4-7), and the Far East (9). It was not possible to establish whether positive family relationships existed before the diagnosis of cancer, so the protective nature of this (19) could not be explored. Parental HRQOL was more severely affected than family HRQOL. This could relate directly to the caregiver burden falling mostly on mothers (who formed the majority in this study). This fits explicitly with research from Brazil (1) though also less explicitly in most other studies in the field, some of which were directed purposefully only at mothers in Iran (37,38). The total impact score for mothers was significantly worse than that for fathers, and mothers' functioning was more adversely affected. This conforms previous research in Jordan (24). The reduced quality of life scores for women are perhaps not surprising in a society in which formal and informal caring is generally held to be the "work of women" rather than men.

Satisfaction with healthcare

Generally, parents were satisfied with the healthcare that was experienced, though less so regarding emotional needs. This central aspect of nursing care may be overlooked as other aspects of care demand priority attention. In areas of communication, emotional care and general satisfaction some level of dissatisfaction was linked to significant reduction in HRQOL. This points again to the need for better psychological or emotional care of parents, supported by better communication with them, as also found by Kearney et al (39). Financial problems

aggravate the need for support (20,22,40). Norberg and Boman (13) highlight the close, extended contact maintained by nurses with families, and urge better training of nurses to be able to identify such problems and intervene effectively.

Reported child-centred factors were important to parental HRQOL, as also found in Canada (4), and in the US (23). Negative impact on parental HRQOL was associated with worse scores in emotional problems, conduct problems and hyperactivity as well as the Total score in the SDQ. Every aspect of parent and family impact was associated negatively with these factors in the reports of the child's response. This indicates that while children may be protected by their parents from the worry and anxiety associated with diagnosis and treatment, the burden is shifted to parents and manifested in physical, emotional and social functioning deficits. This reinforces previous findings (37,38).

IMPLICATIONS FOR NURSING AND HEALTH POLICY

National policy movement is needed to mandate the provision of emotional support for parents; action which will necessarily include both training for professionals to recognise and intervene when necessary, and provision for the necessary therapeutic environment and infrastructure.

While culturally unsurprising, perhaps, the particular caring burden on mothers indicates a need for nurses, particularly, to act to provide appropriate support for parents (especially mothers), preferably in an anticipatory manner, and almost certainly for some years after the diagnosis (which will require a broader multi-professional approach). This has policy and resource implications. There is ongoing debate in the profession in Ireland, Sweden, Australia and the UK about the relative merits of family-centred care and child-centred care (41,42,43), but perhaps redressing the balance between these is required to ensure that parents are enabled by nurses and psychological therapists to be well enough to provide care for the child.

Since ameliorating the psychological and emotional burden suffered by parents can be expected to improve their physical and mental health (6, 8, 23) - at least for British and US parents, and since parental health and wellbeing is intimately linked to better outcomes for the child, then such an investment should be seen as a central aspect of the local care plan and of central health policy by national governments.

The additional carer burden must be met by action to provide psychological support nationally, while the nursing response to individual families must be extended beyond the treatment phase. Where cancer treatment is focussed in the capital, community nurses and psychological services must be made available in all parts of the country in the years after treatment. This is a significant demand, with substantial training requirements, expectations of provision in localities, and requirements for changes in attitude to follow-up cancer care and support of parents.

CONCLUSION

The impact on Jordanian parents in this study of coping with a child who had cancer could be severe and varied in nature. The domains of physical, emotional, social and cognitive functioning were all seriously affected, daily activities were disrupted, and worry was felt strongly. Parents' emotional needs were not met adequately. These are clearly nursing care issues, so nursing practice needs to change to address the deficits. There are likely to be training issues involved. There is an obvious role for counselling and other professional psychological support. Child-centred factors increased the caring burden in both physical and emotional aspects, indeed in all domains of family impact. The instruments that were used were effective in identifying overall HRQOL and impact as well as clarifying which domains were linked. The availability of population norms would strengthen the clinical application of these results, while additional qualitative data might help to interpret the results more fully.

The outcomes of this study should prompt policy initiatives to develop clinical protocols for routine assessment by nurses and other professionals of parents' healthcare satisfaction, HRQOL and perceptions of family impact as a result of the diagnosis of childhood cancer. Those responsible for professional education for health professionals must ensure the inclusion of training to provide support (especially emotional) for parents in these circumstances. Both need to account for ongoing parental support needs in the follow-up years after active treatment. Nurses should expect to form a central part of this support.

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Table 1: Means and Standard Deviations of The PedsQL Family Impact Scale (n=113)

Scale	Number of items	Mean	SD
Physical Functioning	6	45.5	24.1
Emotional Functioning	5	47.8	24.1
Social Functioning	4	54.3	26.5
Cognitive Functioning	5	52.0	29.4
Communication	3	51.9	28
Worry	5	48.2	26.6
Daily Activities	3	38.5	28
Family Relationships	5	70.4	24.7
Parent HRQOL Summary	20	49.2	20.9
Family Summary	8	58.7	22.0
Total Impact Score	36	52.1	18.6

Table 2 Means and Standard Deviations of the PedsQL Healthcare Satisfaction Hematology/Oncology Module and of the SDQ Parent Report (n=113)

PedsQL Healthcare Satisfaction Hematology/Oncology Module		
Scale	Mean	SD
Information	71.5	22.1
Inclusion of family	70.0	22.2
Technical skills	75.1	18.4
Communication	70.0	23.6
Emotional needs	64.9	26.3
General satisfaction	80.8	16.2
Total satisfaction	71.7	16.8
SDQ Parent Report		
Scale	Mean	SD
Emotion problems	5.2	2.3
Conduct problems	3.9	1.6
Hyperactivity	4.8	2.2
Peer problems	3.11	1.6
Prosocial	6.8	2.2
Total Strengths and Difficulty	17.2	5.8

Table 3: Relationship between PedsQL Family Impact scale and SDQ (n=113)

Scale	Emotional problems	Conduct problems	Hyperactivity	Peer problems	Prosocial	Total Strengths and Difficulties
Physical Functioning	-.418**	-.338**	-.192*	-.310**	-.051	-.443**
Emotional Functioning	-.325**	-.311**	-.197*	-.158	-.022	-.357**
Social Functioning	-.203*	-.275**	-.271**	-.183	.190	-.326*
Cognitive Functioning	-.276**	-.240*	-.267**	-.134	-.070	-.302**
Communication	-.250*	-.189	-.149	-.030	-.136	-.230**
Worry	-.372**	-.394**	-.233*	-.191	.001	-.406**
Family Summary	-.411**	-.412**	-.284**	-.160	.088	-.479**
Daily Activities	-.297**	-.278**	-.251**	-.190	.051	-.376**
Family Relationships	-.397**	-.419**	-.240*	-.107	.089	-.450**
Parent HRQOL Summary	-.383**	-.376**	-.274**	-.232*	.004	-.443**
Total Impact Score	-.452**	-.444**	-.316**	-.229*	.007	-.517**

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).