

Parents of children with cancer: integrative review of questionnaires to assess their quality of life

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Abstract

Objectives: To identify the existence of instruments to assess the quality of life of parents of children with cancer and to gather the most common effects that occur in them.

Methods: Integrative review study of literature on the Quality of Life Parents of children with cancer, to search the database on the website of Virtual Health Library, which houses the MEDLINE and LILACS selecting articles from 2012 to 2016.

Results: Sixty-one publications were found after processing the exclusion, only seven of them met the pre-established inclusion criteria. Most of the 7 studies that composed this review 4 were in the English language and 3 in Portuguese and used the following questionnaires: Family Symptom Inventory, Whoqol-Bref and the Zarit Scale, Shirom-Melamed Burnout Questionnaire, Families Scale Scores, Depression Anxiety And Stress Scales, Impact of Event Scale-Revised, Satisfaction with Social Scale, and Burden Assessment Scale, Whoqol-Bref and SERVQUAL Questionnaire, Caregiver Burden Scale, and QV by the SF-36 and General Comfort Questionnaire (GCQ).

Conclusion: We think that studies should be developed about the physical and emotional status of caregivers of children with cancer, as they interfere in the recovery of these children. And family caregivers also suffer from the overload of care needed for cancer treatment. The results obtained through research can base the construction of plans of care also directed to family caregivers.

Keywords: Caregivers, Child, Nursing, Quality of life, Surveys and Questionnaires, Neoplasms

I. Introduction

The word cancer comes from the Latin word “crab”, possibly by obstinacy by which it adheres to any part. Academically is called “neoplasm”, that is new formation. Studies pointed out that the diagnostics of cancer directly influence the well-being and the quality of life of the patients, especially in the family context, recreation and personal suffering [1].

The possibility of presence of any disease in any family member already brings anxiety, doubts and preoccupations to all members that lives with the same. When the disease is confirmed, and mainly when is a chronic disease, like cancer, the mutual suffering between the patient and the family is potentialized because this disease so feared by the population, is a real stigma, bringing with it psychological factors which tend to enhance the aforementioned suffering [2,3].

Most of the time, the patient is the one who gets the attention from several professional areas during his treatment, meanwhile the parents are seen as those who provide support during the process of caring, letting go unnoticed there emotional and physical needs, that is, they go through painful moments too, of anxiety, doubts and anguish, but also by a break in their daily lives and they need support as well to strengthen their energies to convey to their loved one a quality care [2].

During the impact of the diagnosis of the disease and the treatment, even the suffering, is the main caregiver, the guardian, who has the responsibility to care his loved one, take important decisions, execute the daily activities, to fight against the difficulties to execute the care. Regarding the care provided, the parents fully assume this role, which consequently, can lead to great wear and tear on them. They tend to be emotionally destructive, although they avoid lettings their own feelings show to save the sick, but seek emotional support on the family, in the team and other companions [4].

The biopsychosocial changes that occur in parents of children with cancer will determine different placements that will require different care. Thus, evaluation parameters will have to be specific to contemplate at different stages with different needs of parents [3].

Therefore, it raises the problem that it is necessary in the daily practice of nursing the use of an efficient instrument to evaluate the quality of life of the parents of children with cancer, enabling them to raise their reactions and analyze their influence or interference in the treatment of the child, aiming at a plan of nursing care for parents too.

Given the relevance of the theme, there was an interest in developing a integrative review of the literature, with the objectives of identifying the existence of instruments to assess the quality of the life of parents of children with cancer and to gather what are the most common effects that occur in them under treatment.

II. Methodology

An integrative review of literature was developed through the search of health database in the English, Portuguese and Spanish languages. The database was the Portal of the Virtual Library, which houses MEDLINE and LILACS. The descriptors used were “Family”, “Caregivers”, “Child”, “Minors”, “Adolescent”, “Medical Oncology”, “Pediatrics”, “Nursing”, “Neoplasm”, “Surveys and Questionnaires”, “Quality of Life”. The inclusion criteria of the article selected in the review were as follows: that they deal with the quality of life of parents or caregivers of children with cancer; Quality of life of caregivers of cancer patients; Questionnaires or scales that assess the overload and the quality of life of caregivers of cancer patients; Publications from 2012 to 2016, texts that were available online in English, Portuguese and Spanish. Exclusion criteria were: restricted access; references of studies that did not deal with the proposed theme; references from studies that appeared repeatedly in the database; language other than those proposed.

In the month of September 2016, the search was initiated by the databases and using the descriptors mentioned above, crossing them. Finally, the filters inserted: period = 2012 to 2016 and language = English, Portuguese and Spanish. Regarding the duplicity of the studies, found in more than one database used in the research, it was verified the need to exclude the copies, with only one version to be analyzed.

III. Results

There were 61 references in the databases searched. After the selection through the titles, there were 34 references left. After processing the deletion, only 7 had met the pre-established criteria. Most of the 7 studies that composed this review 4 were in English and 3 in Brazilian Portuguese. In the last ten years, health professionals who have followed and treated children with cancer have been observing that the diagnosis and treatment of cancer in children seriously shakes the emotional state of the parents and this interferes negatively with the care given to them [2].

In general, the most frequent positive and negative effects (table 1) occurring in the parents of children with cancer, from diagnosis to hospitalization, are presented hereafter. There are more negative than positive effects.

Table 1. Frequent positive and negative effects occurring in the parents

Positive effects	Negative effects
<ul style="list-style-type: none"> ● Tranquility ● Inner Strength ● Respect ● Hope ● Acceptance 	<ul style="list-style-type: none"> ● Insecurity/pressure ● Confusion/intrusion ● Apathy ● Uneasiness/despair ● Restructuring/Overprotection ● Reduction of affectivity ● Marital separations ● Abandonment of the home ● Abandonment of the children ● Anguish ● Impatience/distrust ● Little tolerance of the child's requests ● Little tolerance of child suffering ● Guilt ● Panic in the hospital environment ● Conspiracy of silence ● Denial / alternative treatments ● Rage ● Bargain ● depression ● Somatization (Insomnia, nausea, vomiting, gastritis, hyporexia, fatigue)

The main causes of these effects are described next (table 2).

Table 2. Main causes of negative effects on parents of children with cancer

<ul style="list-style-type: none"> • Difficulty of accepting your child's illness • Difficulty of acceptance of your hospitalized child • Lack of knowledge about the disease and its prognosis • Child is always considered very fragile and with high possibilities and longevity • Personal routines and independence were halted • Less willingness to care for the child in a different environment • Having to take care of the child • Interruption in family routine
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The literature review evidenced different instruments for evaluating the quality of life and overload of caregivers of cancer patients, the synthesis of which is shown in table 3.

Table 3. Synthesis of the references

References	Questionnaires	Synthesis of results
Karlson C.W. <i>et al</i> , 2015, J Pediatr Hematol Oncol.	Family Symptom Inventory	The authors created and tested a brief road map for psychological and other symptoms such as pain and sleep disorders called Family Symptom Inventory (FSI). He concluded that the FSI proved to be valid and have good internal reliability for psychosocial screening, which may lead to improved quality of care in children with hematologic cancer.
Samky F. O. A. <i>et al</i> , 2014, Psicologia: Ciência e Profissão.	Whoqol-Bref and Zarit Scale	Family members were assessed using the Whoqol-Bref questionnaire and the Zarit Scale, which showed that caregivers feel overwhelmed, but the overload is camouflaged as they do not feel comfortable disclosing their feelings and feelings of guilt that are considered inadmissible.
Lindahl N.A <i>et al</i> , 2014, Pediatr Transplantation	Shirom–Melamed Burnout Questionnaire	An instrument called the Shirom-Melamed Burnout Questionnaire was used for parents. Burnout between fathers and mothers was associated with severity with children's health problems. This situation has decreased after transplantation, but parents need to be monitored and receive psychological support for well-being.
Shortman R.I <i>et al</i> , 2012, Child: care, health and development	Families Scale Scores	One study evaluated parents of children who had brain tumors through the Families Scale Scores scale. They concluded that families of children with this diagnosis experience a high negative impact which makes it difficult to cope with stress. For this reason they need help and support
Teixeira R.J <i>et al</i> , 2012, Psycho- Oncology	Depression Anxiety and Stress Scales, Impact of Event Scale— Revised, Satisfaction with Social Support Scale, and Burden Assessment Scale.	The study used 4 instruments to assess depression, stress and overload. It has been found that social support can be a mediator in the relationship between psychological imbalance and the caregiver's overload.
Saijjaid H <i>et al</i> , 2013, Global Journal of Health Science	Whoqol-Bref and SERVQUAL Questionnaire	The authors assessed the quality of life of family caregivers through WHOqol-Bref and the SERVQUAL Questionnaire. They found that providing high-quality services to patients is one way to promote quality of life and caregiver satisfaction.
Rubira E.A <i>et al</i> , 2012, Acta Paul Enferm	Caregiver Burden Scale and SF-36	Used on the Caregiver Burden Scale and SF 36 scale to assess overload and quality of life. They found several domains in quality of life, which puts in danger the quality of care provided to children and cause mismatches in the health of the caregiver.

After reviewing the literature, it was noticed that only two instruments for assessing the quality of life and burden of family caregivers are translated and validated in the Brazilian Portuguese, the Whoqol-Bref and the SF-36.

IV. Conclusion

We think that studies should be developed about the physical and emotional status of caregivers of children with cancer, as they interfere in the recovery of these children. And family caregivers also suffer from the overload of care needed for cancer treatment. The results obtained through research can base the construction of plans of care also directed to family caregivers.

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