

QUALITY OF LIFE OF CANCER CHILDREN CAREGIVERS

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Current Situation

Oncology is one of the fields experiencing the fastest development in the last few years. New treatment methods brought about bigger chances of survival¹ for cancer patients and cancer became a chronic disease. On the other hand, cancer is still a disease with severe impact on the patient as well as his/her family and close friends. The number of survivors and people with cancer symptoms under control is increasing and therefore the research in their quality of life gains more and more importance as well. Current research is dealing with the question: “What kind of life is dignified and worth and to what extent can a patient’s health status predominate over one’s subjective well-being in a situation of a fatal illness. In other words, nowadays the question of quality of life arises aside quantity of life and success of treatment.

Children cancer is a relatively rare condition, however, as much as 7-10% of children suffer for some kind of chronic illness (Řičan, 1995: 79). Cancer is unique because of the depth and seriousness of its impact on the ill child and its family. The quality of life of ill children is considerable compromised due to pain arising from the illness itself as well as aggressive treatment procedures, loss of energy and possibilities to enjoy common everyday activities, inability to maintain contact with peers in education and social sphere and in older children also with fear of future.

Cancer does not affect the particular person (in our case a child) in isolation, but the whole family. Behaviour and role patterns are disturbed by the illness and family members have to cope with a new and demanding situation and in many cases change their social roles or even leave some of them and take up new ones.

Research outcomes support the evidence that the success of treatment is to a large extent (up to 20%, University Hospital Brno, 2006) influenced by one’s family, it means its preparedness and ability to cope with stressful situations, cooperate with doctors and nurses, make decisions about future treatment and offer physical and

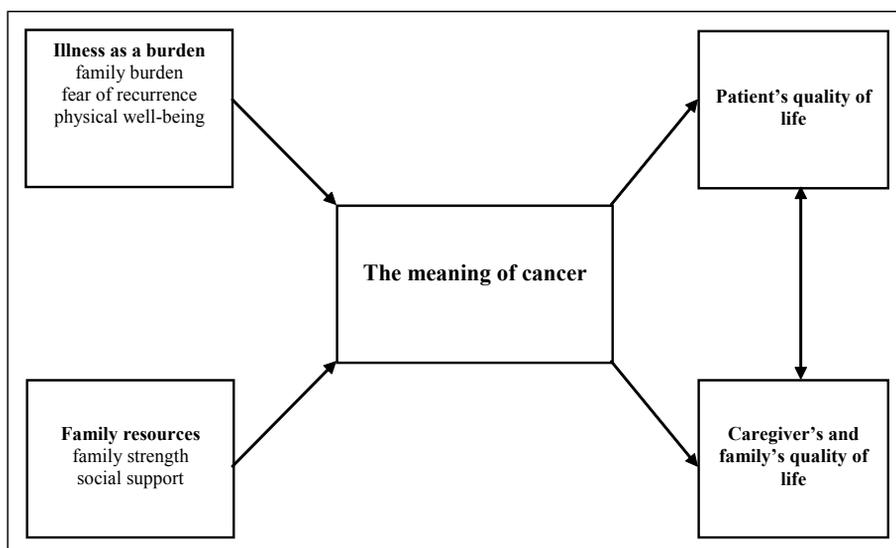
¹ The prognosis of children cancer has improved tremendously (up to 75% of disease-free survival in five years after treatment) in the last few years (Cancer Research UK, 2004, Available at: <<http://info.cancerresearchuk.org>>).

emotional support to its child². Quality of life of a family influences overall well-being and treatment of its child.

Factors Influencing Quality of Life of Caregivers and Families

Northouse et al. (2006) created a “*family survivorship model*” based on evaluation of the impacts of cancer on family. There are three variables included in the model: fear from recurrence of the illness, family burden, physical well-being (especially important for the patient). Other factors identified as important for coping with cancer are: family strength, social support and meaning of the illness.

The family-survivorship model of a cancer patient (pict. 1) shows interconnectedness of its parts and its influence on the overall quality of life of the whole family.



Pict. 1: Family-survivorship model of cancer patients by Northouse et al. (2006)

When talking about quality of life, we have to mention one very important factor – shortening of hospital stays and the preference of out-patient and home care. Patients are released to home care as soon as possible. This approach is convenient from economic point of view as well as for the patient him/herself (especially when talking about a child),

² This fact has been reflected by professional in western countries as well. An approach called Family-Centred Care has been put into practice in the United Kingdom and the USA. This approach puts family in the centre of all decision making and discussions. It is not only medical personnel who are taking care of the child and its parents. There is a wide range of non-medical services offered. Their aim is to help parents and children with problems arisen due to the illness and thus enhance their subjective quality of life. The offer of non-medical services has been improving and widening in the last few years. Nowadays, we can take advantage of services of psychologist, social worker, special education teacher, counselling workers and therapists from NGOs and an offer of supporting services (such as accommodation in hospital).

who is cared for in known and pleasant environment. In the case of cancer patients, home care might mean long months of bed rest. The caregiver burden thus persists and becomes his/her new lifestyle. The result of this new trend is rising importance of informal caregivers who are responsible for a patient's care in home care.

Most frequently mothers are forced to change their lifestyle considerably because they accompany the ill child during hospital as well as home care. Fathers usually continue working and take care of the household and healthy children in mother's absence. In comparison with mothers, the fathers' life more resembles the normal one (before the illness). However, they also are affected by the disease and should not stay out of professionals' focus. Therefore, the current interest of scientists focuses not only on quality of life of the ill child but also quality of life of persons who take care of it or keep close contact, so called primary caregivers.

Lim et al. (2004) made an analysis of 19 studies focused on particular aspects of cancer caregiver's quality of life. Based on this analysis they published the following list of areas most influenced by cancer:

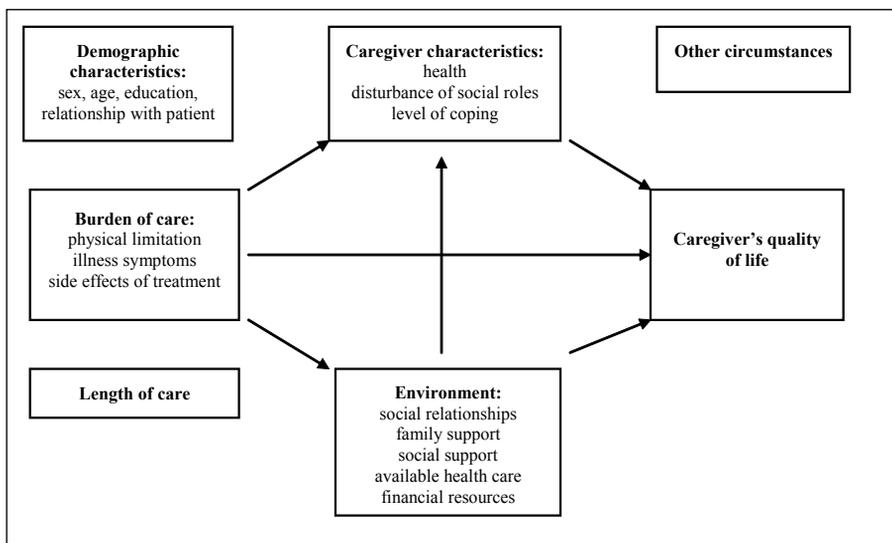
- Ill person characteristics – functional state, age, sex, psychological well-being, type of cancer, pain, symptoms (seriousness of illness)
- Caregiver characteristics – age, sex, physical state, monthly income, QOL at the beginning of treatment, education, health care, psychological well-being, anger, anxiety
- Primary burden – objective context, demands on caregiver, seriousness of illness, length of care giving, recurrence, caregivers overburden, degree of patient's dependence, intensity of care
- Secondary burden – subjective context, care giving demands, role change, responsibility, caregiver's experience, disruption of lifestyle
- Evaluation of burden – evaluation of situation, feeling of control, difference in understanding of situation (patient and caregiver)
- Coping strategies
- Social support – quality and appropriateness of social support, social network and social life, family life (quality of relationships), loneliness, family resources (psychological, social, interpersonal, material), formal support

This overview offers all dimensions mentioned by different authors. Every model of quality of life assigns different level of importance to particular dimensions. It could be supplied with the point of view of professional distinguishing between quality of life in curative and palliative care.

Model of Quality of Life in Cancer Children

Different aspects and factors influencing caregivers' quality of life were taken into account in the model of caregiver quality of life created by White et al. (2004) (pict. 2). Their study focused on caregivers of stroke patients; however, the basic dimensions can be applied to the situation of cancer children caregivers as well. The basic dimensions are the same for both, there are differences only in specific impacts of illness and relationship with the patient.

The model of White et al. adopted for the specific situation of cancer children caregivers can be found below.



Pict. 2: Concept of quality of life of cancer children caregivers

This model clearly shows multidimensional character of caregiver quality of life as well as interconnectedness of particular dimensions of caregiver's social role and his/her quality of life. This concept has a great complexity; therefore, it is not possible to narrow a measurement to measuring of a single dimension (Mayo, 2002).

The concept of caregiver quality of life has the major dimensions identical with general public, however, their importance and sub-dimensions will differ.

We will use Weinitzer et al. model of quality of life used in generic questionnaire SF-36 to demonstrate the specific aspects of cancer caregivers. Dimensions identified by SF-36 are as follows: physical functioning and social roles, physical pain, overall health, vitality, social relationship (functioning in society), emotional well-being, spirituality.

Among the *physical aspects* of QOL we can include tiredness, sleep problems, loss of appetite and need to rest. The most important form *psychological aspects* are emotional burden, stress, fear for the patient, nervousness, anger, feeling of destruction and depression (Kornbith et al., 1994), confusion, lack of information about the situation, feeling of hopelessness (Vađurová, 2007). In the study of patients after bone marrow transplantation Boyle et al. mentions the following *social relationship* aspects: family support, change of responsibility distribution in the family, persistent, long-term demands on care. *Spirituality* is according to Matthews et al. (2004) the most highly rated dimension in cancer survivor caregivers. This dimension includes spiritual well-being, feeling of spiritual support, utility, hope, feeling of sense and overall satisfaction with life. This dimension is important also to parents of cancer children in active treatment (Vađurová, 2007).

Measuring Quality of Life of Cancer Caregivers

Measuring quality of life in medicine, e.g. Alzheimer disease has a long tradition and a number of tools has been developed. However, this is not true for cancer caregivers; there are only a few measurement tools, for example:

- Quality of Life Tool (QoL Tool)
- Caregive Quality-of-Life Index (CQoL-Index)
- Caregiver Quality of Life Index-Cancer (CQOLC)³
- Care-related quality of life instrument (CarerQol Instrument)
- Scale of Quality of Life of Caregivers (SQLC).

Caregiver Quality-of-Life Index (CQoL-Index)

CQoL-Index has been developed by McMillainem and Mahonem (Deeken et al., 2003). it is a simple tool evaluation caregiver's quality of life in four dimensions: physical, psychological, social and financial. A visual-analogue scale from 0 to 100 is used for an answer indication.

One disadvantage of this tool is low inter-correlation and low sensitivity to change in time (Decken et al., 2002: 947).

Quality of Life Tool (QoL Tool)

A 20-item questionnaire QOL Tool was developed by Ferrel et al. in 1995. It also uses a visual-analogue scale from 0 to 100 for answer indication. In comparison with CQoL Index this tool is more detailed as all four measured dimensions (physical, psychological, social and spiritual) contain further sub-dimensions. Ferrel et al. focused on the impact of cancer patient pain on caregiver quality of life. The disadvantage of this questionnaire is its narrow focus on the pain experience (Decken et al., 2002: 947).

Caregiver Quality of Life Index-Cancer (CQOLC)

One of the most widely used tool is CQOLC by Weinitzer et al. (1997). It is a self-evaluation questionnaire. Every item is evaluated by a respondent on a Likert scale from 0 (not at all) to 10 (absolutely). The overall score is given by the total value of individual items. The highest score possible is 140, higher score means better quality of life (Rhee, 2005).

Care-related quality of life instrument (CarerQol Instrument)

Care-related quality of life instrument (CarerQol Instrument) is one of the newest tools for measurement of quality of life. It was developed by Brouwer et al. in 2006. The questionnaire focuses on quality of life of informal caregivers. The authors evaluate care giving from economic point of view and state that informal caregivers very often leave their jobs and care giving is thus economically demanding. Despite this fact, economists do not satisfactorily consider care giving as a financial burden and a reason for special allowance. therefore, the authors attempted to develop a tool to measure economic impact of certain treatment methods.

³ Decken et al. used abbreviation CQoL-Canc, more widely used is CQOLC, used by the author himself (M. A. Weitzner).

Quality of Life of Cancer Children Caregivers

The following information is based on a research carried out by the author in 2007.

Nowadays, there is no standardized and widely used tool for measuring quality of life of caregivers of cancer children in active treatment or finished treatment. The questionnaires usually focus on caregivers as such⁴, caregivers of adult cancer patients⁵ or caregivers of terminally ill children or adults⁶.

For the purposes of this research, we modified the already existing questionnaires to suit our specific situation and aims of our research.

The basis of our questionnaire is formed by variables influencing caregiver quality of life created by White et al. (2004):

- burden of care – physical, psychological, emotional situation of caregiver, length of care
- caregiver characteristics – sex, age, education
- environment variables – social support, economic situation.

These variables are to a large degree identical with dimensions of QOL identified in generic questionnaire SF-36. This questionnaire is used for a wide range of respondents and numerous foreign researches use it for measuring caregiver quality of life⁷ as well. The dimensions of SF-36 are mentioned above. The dimension “physical pain” has been omitted as it is not relevant when not measuring a patient’s QOL. On the other hand, we have added the dimension “economic situation”, this is being emphasised by contemporary studies⁸ and also introductory demographic information (based on White et al., see above). The situation of cancer children caregivers is very variable and depends on the treatment and health status. Therefore, items measuring psychological and emotional well-being ask about situation in the last 4 weeks⁹.

The use of a set of questions from foreign researches allows a partial comparison with results of foreign researches. However, this questionnaire was also supplied with original questions to develop a questionnaire that is relevant for our cultural background, specific situation and research goals.

The questionnaire measured subjective quality of life of cancer children caregivers in active treatment and shortly after the end of the treatment. Among the most important factors belong a respondent’s characteristics. The average respondent of the research was a woman aged 25-36, having two children, with secondary school education and living in a village. The child would be treated for the period of 7 to 12 months.

⁴ CarerQOL instrument (Brouwer et al., 2006), Caregiver Activity Survey, Caregiver Quality-of-Life Index (CQoL-Index), Scale of Quality of Life of Caregivers (SQLC), etc.

⁵ Caregiver Quality of Life Index-Cancer (CQOLC) (Weitzer et al., 1997)

⁶ QOLLI-F (Cohen et. al)

⁷ Patti et al., Caregiver quality of life in multiple sclerosis: a multicentre Italian study, 2007, Jönsson et al., Determinants of Quality of Life in Stroke Survivors and Their Informal Caregivers, etc.

⁸ Glozman (2004), White et al. (2004)

⁹ The questionnaire SF-36 usually uses the scope of one month (University of Wollongong: review SF-36, 2004). A time frame was employed also by Cohen et al. in their questionnaire QOLLI-F for caregivers of terminally ill patients. With respect to this specific situation, the time frame was set on 48 hours.

Seven dimensions of quality of life in a 14-item questionnaire were evaluated. The particular dimensions reached different summary score (scale 1-5, 1=max.; overall health – 3; vitality – 3; emotional well-being – 3,6; physical functioning and social roles – 3,3; social relationships – 2,9; spirituality – 3,4; economic situation – 3,1). The total score of cancer children caregiver quality of life reached 3,18 (median = 3,16; scale 1 – 5; 1 = max.). When expressed verbally it means considerably good quality of life. The outcome of our research corresponds with the research of Dutch team of Brouwer et al. (2006, CarerQoL-VAS) who came to the score 5,7 (median= 6; scale 0-10).

Therefore, we can state that the *overall quality of life of cancer children caregivers in our research is not considerably compromised the illness. However, individual dimensions are affected to different extends.*

Discussion

Cancer caregiver quality of life is a concept that is slowly becoming more central to professionals working with cancer children and their families. At present, there is no standardized and widely used tool for measuring QOL of cancer children caregivers in active treatment respecting their specificity. Quality of life and evaluation of its particular dimensions offers a very precise picture about caregivers' needs, the appropriateness, coverage and quality of services for them.