

## Understanding the Quality of Life (QoL) and Quality Adjusted Survival (QAS) in Children, Teens, and Young Adults with Cancer

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**Abstract:** The Quality of Life Group is typically a collection of oncology specialists, psychologists and support workers dedicated to improving the Quality of Life (QoL) of paediatric, adolescent and young adult cancer patients. The Group usually aims at improving patient care by: Identifying areas where patients are suffering, identifying areas where service provision is lacking, direct patients towards appropriate intervention(s), educate health practitioners about the whole needs of the patient, support family and friends so that they can play an active role in patient care, develop and administer interventions that improve QoL and coordinate allied healthcare and community support professionals to build a coherent, patient-focused, support network for patients and their families.

**Keywords:** HRQoL, Quality adjusted survival, Well-being and Q-TWIST analysis.

### 1 Background

The last fifty years has seen a steady increase in survival rates of cancer patients following treatment. The reality of an increased survivor population has resulted in the formation of support groups and NGOs whose patient led focus has forced clinicians to re-examine treatment outcomes.

Typical treatments for cancer such as surgery, radiation or chemotherapy are notoriously damaging to human health and result in a wide range of negative side effects. Cranial radiation for example, is used to treat primary brain tumours and is known to cause an array of cognitive deficits such as memory loss, verbal intelligence decline and slower processing speed (Armstrong *et al*, 2013; Campbell *et al*, 2007). Similar negative outcomes are associated with chemotherapy and surgery for example; resection of a brain tumour can cause comparable neurological impairments seen following insult or degenerative disease.

Given these factors, and the increasing number of survivors, it is unsurprising that there has been a move towards including the quality of life (QoL) of patients both during and post treatment (Tanker and Gotay, 1998).

Quality of life has been defined as an "individuals' perceptions of their position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (The World Health Organization, 1995).

In contrast, the concept of health related quality of life (HRQoL) refers to the impact of health and illness on an individual's QoL.

There are usually four subjective QoL domains: emotional, physical, social and cognitive functioning (Verrisset *al*, 1998). Physical, social and cognitive functioning are considered as a person's psychosocial functioning although the cognitive domain is often substituted for 'school functioning' when working with children/young adults of school age.

In 1996 the American Society of Clinical Oncology suggested that treatment success should be based on two factors, cancer and patient outcomes. Cancer outcomes refer to traditional measures such as response rate, disease progression, toxicity etc. whereas patient outcomes refer to QoL during and post treatment.

The traditional cancer survival endpoints ignore many fundamental aspects of people's lives e.g. emotional and social well-being; recognition of this fact now makes QoL part of good clinical practice. Several health authorities in different countries have acknowledged this in their National Cancer Strategies via stating: "*The goal of specialised care is achievement of the best quality of life for patients and their families with good symptom management during treatment and at end of life*".

Expanding cancer treatment endpoints to include measures of QoL, results in a number of important factors for clinical decision-making. Primarily patients are given informed choice regarding their treatment. It may be that one treatment is preferred over another as a result of QoL being high despite a more negative survival outcome. Similarly, it

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might be that a treatment causes diminished QoL to such an extent that treatment should be discontinued all together (Roila and Cortesi, 2001). Both scenarios are equally valuable to clinicians who run a patient/family centered service, when advising patients of the optimal course of treatment and allow for patients and medical professionals to agree on the best course of action. Quality of life assessments can also guide clinicians in intensity or severity of treatment such as whether to use chemotherapy in conjunction with radiation or to apply continuous or intermittent treatment. Finally, QoL calculations inform medical practitioners about likely cost-utility aspects of different drugs/treatments. This is an important factor in attributing resources at a hospital.

## 2 Paediatric QoL

Regardless of which treatment is provided, all cancer procedures produce great anxiety and distress as well as pain and physical discomfort for a child. Negative effects from treatment start instantaneously and can continue for weeks or even years post treatment cessation. Despite negative consequences, survival rates in paediatric cancer have steadily increased from 58% to 83% between 1975 and 2008 (Siegel 2013). Survival is related to disease manifestation for example, survival from Hodgkin's disease currently stands at 97% whereas the rate is 64% for acute myeloid leukaemia. Similar to adults rates of survival have a corresponding increase in children presenting with a number of post-treatment side effects. It has been estimated that as many as one-third of children who undergo cancer treatment will suffer from a side effect that can be classified as either moderate or severe (Stamet *et al* 2005). Beyond physical issues such as well the documented problems in cardiac function, the endocrine system, or organ toxicity, there is a range of well recognized neurological and cognitive impairments that follow cancer treatment in childhood. These post-treatment sequelae can disrupt normal psychological functioning and significantly reduce a child's day-to-day living experiences. As would be expected, several studies have demonstrated the QoL for children being treated for cancer is poor (Tsai *et al* 2013; Kuhlthauet *al*, 2012; Fortier *et al*, 2013). These studies include patients from several diagnostic groups, ages and treatment stages and report more physical complaints, reduced motor functioning and autonomy, impaired positive emotional functioning (anxiety, depression) and cognitive problems weeks after cancer diagnosis. Whilst all cancer patients need continuous monitoring of their QoL, there is an increased importance in screening paediatric patients for a number of reasons. Firstly, the features of cancer in children are different from those seen in adults (Pritchard-Jones, 2013) (e.g. leukaemia is by far the most common variant found, accounting for one-third of paediatric cancer cases worldwide) and therefore may result in unique symptoms/outcomes. Secondly, and perhaps more importantly, the various developmental stages that occur

throughout childhood make the effects of treatment on QoL especially relevant. This is particularly true for adolescence which, whilst generally being understood as a time of physical health and well-being, the period is also known to be difficult for many teenagers and results in a range of psychosocial issues that are common even during normal development (for example suicide is one of the biggest killers in this age group). Hence, the effects of adding a potentially life threatening disease to this already complicated developmental stage could have greater significance for this age group.

In late adolescence and young adulthood (15-25 years) it is known that cancer survival rates are significantly worse than in younger patients, whilst at the same time, this group has recorded the highest increases in diagnosis (Bleyer, 2001). It is not known if this finding is attributable to disease etiology or social reasons, but one possibility is that younger children have decisions about their disease taken for them by their caregivers whereas young adults, and to a certain extent teens, are able to make choices for themselves. Two possible outcomes of this are that; late adolescents and young adults may not fully understand or accept the severity of the disease that they have (risk behaviour is highest among this group). Alternatively, the diagnosis combined with the developmental stage of the group, could lead to much greater levels of anxiety, fear, depression and alienation leading to poor choices and/or participation in treatment. Both of these possibilities could be monitored by QoL assessments further highlighting the importance of this additional care measure.

## 3 Measuring QoL

There has been extensive research into how to measure QoL. Typically questionnaires are employed however; interviews or diaries can also be used. A number of different instruments have been developed to measure quality of life in children for example: the Child Health Questionnaire (CHQ) (Landgraf *et al*, 1996), or the Children's Quality Of Life Questionnaire (TAPQoL) (Verripset *et al*, 1997). More recently the Pediatric Quality of Life Inventory (PedsQL) has been advanced which consists of a number of features that has made it a popular tool to use. First it combines both a self-report questionnaire as well as a report to be filled out about the child from their caregiver. Perhaps more importantly, it is very rapid to administer with the whole survey taking around ten minutes to complete. The PedsQL also covers ages 2 through to adulthood and has been translated in multiple languages. As such the survey has been used to study QoL in children in health and a wide range of diseases or illness in multiple countries. The validity and reliability of the PedsQL has found to be high after multiple tests and it is recommended for clinical research purposes. Population norms have been established using PedsQL and a large UK cohort has also established a population norm for paediatric cancer

populations (UKALL 2003) (Sung *et al*, 2011).

#### 4 Take Home Message

It is vital for cancer care providers to decode the subjective perception of patients and their families about fulfilling their essential human needs during the disease and its treatment. This decoding opens the eyes of physicians to a blind spot in cancer care that unless seen and dealt with, leaves patients, siblings, parents and extended families to suffer in silence. Cancer health care givers who miss this blind spot will not be able to appreciate their patients complaints about their QoL perception even if stands obvious before their eyes.

The patient's rights to access a high quality health care system dictate that clinicians, allied health professionals and administrators pay a close attention to the QoL issues and do not turn a blind eye into the subject.

The tools to do so are readily available for use and have been validated in several languages.

Employing these simple, non-time consuming tools would possibly reveal that up to 30% of patients are suffering significantly or at risk of suffering (J. Perkins *et al*, 2015) and through an effective communication between the multidisciplinary team simple measures could have a great impact on patients, their families and the wider community.

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