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Editorial

Health-related Quality of Life, Cancer and Health Care

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It is fashionable to talk about quality of life. The increasing interest in the subject reflects the recognition of the need to address the impact of disease and its treatment on the quality of life of the individual. However, unless one understands what is meant by the term 'quality of life' (or health-related quality of life), and the instrument used to measure this phenomenon is valid and reliable, then there is a danger of misinterpretation or worse—misleading information.

The phrase 'quality of life' can be interpreted in several ways depending on the context in which it is used. The use of the term health-related quality of life (HRQL) is helpful in that it focuses on the impact of health on quality of life yet examines issues beyond physical health alone. But what are these issues? It is essential that the investigator is satisfied that any questionnaire measuring HRQL addresses the issues the patient perceives are important in their effect on quality of life. If the questions do not probe the correct areas, then problems, if they exist, will not be identified.

The impact of cancer on the quality of life of an individual has long been recognised with some of the earliest reports of quality of life assessment in adults with cancer [1–3] (in whom survival rates may be very poor). These instruments appropriately concentrated on aspects of health such as anorexia, level of vitality and body image. However, adult survivors of childhood cancer represent a very different population; they are likely to be long-term survivors and they may face unique problems as a result of their treatment, which may impair their quality of life. Examples of the late effects of therapy that are well-recognised are growth impairment (e.g. following cranial irradiation [4]), impairment of cognitive function following cranial irradiation [5], amputation of a limb as therapy for an osteogenic sarcoma, or a ureterostomy or colostomy following pelvic irradiation or extensive surgery (at a very young age) for a soft tissue sarcoma. Other emotional or psychological effects of surviving a life-threatening disease may also be expected. It is therefore surprising that the results of the study of Apajasalo and colleagues (pages 1354–1358) [6] suggest that the quality of life for these survivors is, if anything, better than that of their peers. Several questions are raised by this finding.

It is possible that this is a true reflection of their perceived HRQL and, as the authors discuss, patients who have survived

a life-threatening disorder may have a more positive outlook on life, despite physical difficulties. Another possibility is that there are few survivors of cancer in this particular cohort who have significant adverse sequelae of therapy (more information relating to the treatment received by the cohort and late effects of therapy known to be present in the patients would be helpful). As the authors suggest, it is possible that the 20% of non-respondents are those with significant problems in the long term. A further consideration relates to the measure itself and returns to the question of validity. When using any measure of quality of life, the investigator must be confident that it is sufficiently sensitive. Were the specific issues that could have an impact on the quality of life of an adult survivor of childhood cancer addressed? The validity of a measure for use with a given population should be demonstrated through, for example, the use of focus groups or detailed open-ended questionnaires. It can be supported as in the study of Apajasalo and colleagues [6], by the use of the valuation questionnaire—a measure of how important different health states are to the individual.

It is appropriate that HRQL should now be examined in survivors of childhood cancer. As the survival rates continue to rise [7], and it is anticipated that the majority of survivors will have a full life expectancy, the quality of survival assumes increasing importance. If, as one might expect, aspects of the HRQL of the survivor of childhood cancer are adversely affected, it is important that they are quickly recognised so that appropriate support or intervention can be offered and quality of life optimised. Such information will be of increasing importance as survival rates continue to improve and as differences in survival rates between treatment comparison groups narrow. As physical late effects of therapy have been recognised, modifications of therapy have been made to minimise such late effects. Examples in the U.K. are the omission of cranial irradiation as first-line therapy for acute lymphoblastic leukaemia in standard risk patients in the latest MRC leukaemia trial (UKALL XI), and the use of pre-operative chemotherapy for children with Wilms' tumour (in an attempt to reduce the number of children requiring radiotherapy to the abdomen or flank). Improvement to physical outcome following such changes can be objectively assessed, but subsequent improvement to HRQL can only be assumed until it can be reliably measured and comparisons made. In addition

to physical assessment, one important aim of measures of HRQL, as outcome measures improve, is to obtain information relating to the impact of late effects of therapy as perceived by the patients themselves. It is well-recognised that the expectations of medical staff differ from those of patients [8].

How can measures of HRQL be used to improve health care? On an individual level, if impairment of HRQL is identified appropriate intervention can be provided where resources allow. There has been an increasing awareness of the need to include an assessment of HRQL as one measure of outcome in randomised controlled trials [9]. In this context, the use of a single summary score (or global rating) is of value for comparisons between populations under study, although a profile of HRQL, detailing perceived functioning in different domains, should be included, where possible, to identify specific areas where an increase in support or resources could most effectively be provided.

It is crucial that the instrument used to measure quality of life is brief enough to be acceptable to large numbers of patients, but sensitive enough to identify difficulties they may face. One cannot assume that a general question concerning level of depression or distress will identify the fear of disease relapse, the individuals perceived isolation from their peers, anxiety concerning their future fertility or a poor body image.

It may be too late to question survivors of childhood cancer, as adults, about their quality of life, so it seems appropriate to assess the quality of life of children with cancer earlier than that, in order to optimise outcome. The impact of the malignancy on their quality of life may be expected to change as the child grows and matures. Early recognition of problems, intervention where required and where possible should be attempted, and repeat assessment of their quality of life may identify improvement.

It is not easy to measure quality of life. How can one encompass the enormous number of factors that can have an impact on quality of life using a brief questionnaire, which in

some cases takes fewer than five minutes to complete? Longer questionnaires may be more accurate, but unless they are acceptable and easily completed by the patient then they will be of no practical use except by researchers. A compromise must be reached between a measure that is brief and easy to use and therefore widely acceptable to both patients and physicians, and long, detailed interviews that are likely to elucidate the issues of importance to the patient, but are unlikely to be of practical use, particularly within the clinical setting. What is apparent is that the question of quality of life has now been firmly placed "on the agenda", and there is a general acceptance that it is an important measure of outcome. Doctors, parents and the patients need to be given informed choice, not only about the relative success of therapy, but also the impact such treatment will have on quality of life in the long term.

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