# Assessment of the impact of cancer on work, recreation, home management and sleep using a general health status measure

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## Summary

A general health status measure (the UK Sickness Impact Profile) was used to assess health-related quality of life in 212 cancer patients [143 women, mean (SD – standard deviation) age 55.3 (11.7) years] compared to 105 age-sex matched control subjects [71 women, mean (SD) age 54.7 (12.2) years]. The four main areas of impairment in the cancer patient group were work, recreation and pastimes, home management and sleep and rest. The majority of patients were unable to work or working shorter hours due to their disease. A diagnosis of cancer was likewise found to have a major impact on active leisure pursuits and led to reduced participation in social and community activities. Patients had particular problems in carrying out household chores and maintenance or repair work in the house. Many patients had difficulty sleeping at night and tended to sleep during the day or rest for much of the day.

The majority of studies of quality of life in oncology patients concentrate upon alterations in symptoms, such measures would fail to detect impairment in the aspects described above. Greater attention should be directed towards addressing issues such as changes in employment status and the need for help in the home to improve the overall care of cancer patients.

## Introduction

Cancer is the second leading cause of death and causes more lost years of life than any other disease in Britain[1]. In the treatment of cancer the majority of patients will not be cured and, therefore, assessment of the impact of cancer and its treatment on quality of life are being increasingly recognized as an important part of the overall assessment of outcome[2]. The diagnosis of cancer may have a wide ranging impact on an individual's lifestyle and quality of life, both positively and negatively[3-6]. This contributes to the difficulty in designing a measure or instrument to assess health-related quality of life in cancer patients. Many measures concentrate upon physical impairment and are purely functional status assessments[7,8]. However, this approach is incompatible with the World Health Organization[9] definition that 'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. The Medical Research Council's Cancer Therapy Committee working party on quality of life reviewed the existing measures for patients with cancer[10] and recommended that the ideal measure

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should cover: symptoms due to cancer; adverse effects of treatment; physical functioning; social interaction; psychological adjustment; sexual functioning and body image. The purpose of the present study was to evaluate the impairment in health-related quality of life in cancer patients as assessed using a general health status measure, the United Kingdom Sickness Impact Profile (UKSIP)[11].

## Description of the UK Sickness Impact Profile

The UKSIP consists of 136 items of daily living which are aggregated into 12 categories. In addition to calculation of an overall score, these categories can be combined to form a physical dimension, a psychosocial dimension and five independent categories, including sleep and rest, eating, home management, recreation and pastimes and work[12]. The categories in the physical dimension are ambulation, body care and movement and mobility. The four categories of the psychosocial dimension are social interaction, communication, alertness behaviour and emotional behaviour. The UKSIP can be self or interviewer administered. The rater is asked to consider each of the items and mark it as applicable to them if it is related to their health. It takes 15-20 min to complete. The items for inclusion were identified from reports from individual patients, health care staff, relatives and healthy individuals. They were based on the assumption that sickness is defined as the individuals' perception of health. Items were weighted by a panel of judges according to severity of dysfunction. A high score reflects a high level of dysfunction. Test-retest reliability and validity have been established using different interviewers and techniques and with different patient groups.

## Methods

### Patient selection

Patients were recruited from a population attending the Imperial Cancer Research Fund, Oncology Unit at the Churchill Hospital in Oxford. Patients were considered eligible for entry into the study provided they had received at least one cycle or course of treatment or a minimum of 1 month of therapy where taken on a continuous basis, for example tamoxifen. Patients under 18 years and those patients who were unable to complete the UKSIP for themselves were excluded from the study. In the outpatient clinic patients were interviewed by a clinical pharmacist prior to their medical consultation to identify any drug related problems[13]. Patients were asked whether they would participate in the study and complete the UKSIP. Written instructions regarding completion were provided on the cover page of the UKSIP. Patients were instructed to complete the global rating

of their overall health status on the cover page and subsequently to read each of the 136 UKSIP statements and mark those which they considered were applicable to them and related to their health. Specifically they were told to consider the effect the disease was having on their quality of life on the day of completion of the questionnaire.

*Control subject selection*
To distinguish between the effect of cancer and the effect of age and sex on health-related quality of life, a group of age-sex matched control subjects was recruited on a 2 : 1 test : control ratio. Since the majority of the cancer patients were recruited from within the Oxfordshire area, to eliminate bias introduced by socio-economic variables due to geographical location, the control subjects were also selected from this same area. Six general practitioner practices in the Oxfordshire area were approached regarding access to their patient lists and information. The purpose of the study and the reason for their being identified was explained. Four practices responded positively and introductory meetings to explain in more detail the nature of the study were set up. Two practices declined as they were already involved in other studies of this type. Subsequently control subjects were identified from the practice lists by a practice manager who was independent of the study. The cancer patients were grouped in 5-year age ranges, for example 30-34 years, to simplify the matching process. The practice manager was asked to select randomly patients who belonged to a particular age range and were of the required sex by entering these two parameters into the practice computer. Exclusion criteria included individuals who had been diagnosed or were under investigation for any type of malignancy and those who were severely mentally or physically disabled requiring social services support or were wheel chair bound. These criteria were imposed to avoid any impact in the control subjects due to cancer and also to exclude individuals who were severely disabled due to a non cancer diagnosis. Selected individuals were then mailed a UKSIP with an explanatory covering letter asking them to complete the questionnaire and to return it to the investigator in a prepaid addressed envelope at their earliest convenience. Each UKSIP was coded such that it could be identified on return, which was necessary for follow up. The respondents were asked not to identify themselves on the form to maintain confidentiality. Whilst this method of administration of the questionnaire differed from that of the cancer patients, it ensured an independent, randomly selected population, which could not have been achieved by recruiting individuals from the hospital outpatient area or from the workplace. Importantly, the method of completion of the UKSIPs was the same in the cancer patients and control subjects as they completed the questionnaires at home and either returned them

by hand or by mail. Time and resources available for the study did not allow for identified control subjects to be visited at home.

*Pilot study*
A pilot study was conducted using 20 cancer patients to identify any problems associated with administration of the questionnaire. During the pilot study patients were given the UKSIP to complete whilst waiting for their medical consultation. This proved to be impractical since this time was subject to constant interruption. Therefore, for the main study patients were allowed to take the UKSIP home and to complete it the same day and return it at their next clinic appointment having clearly stated the date of completion.

*Data analysis*
Data from all returned UKSIPs was checked for completeness. A computer program was used to process and analyse the data using a Statistical Package for Social Scientists (SPSS). The difference between the scores for control subjects and cancer patients for all the UKSIP categories were compared using a Mann-Whitney statistical test.

**Results**
*Patients*
Two hundred and sixteen patients with cancer were approached. Of these four failed to return their completed questionnaires, leaving 212 individuals recruited. No patients refused to participate. Sixty-eight per cent were women. The mean (SD) age was 55.3 (11.7) years. The primary sites of the malignant disease in decreasing order were: breast (48%); gastro-intestinal (15%); renal (13%); lung (10%); ovary (6%); other (8%). Patients from 52 different occupations representing all socioeconomic classes were recruited.

*Control subjects*
One hundred and thirty-five control subjects were mailed a UKSIP of which 111 (82%) were ultimately returned. Of these, the first 105 returned were analysed, 71 (67.6%) being from women. These respondents provided the age-sex profile which was required for the subject group. Six of the questionnaires were returned too late to be included in the analysis. The mean age of the group was 54.7 (12.2) years. A statistically significant difference ($P < 0.01$, Mann-Whitney) was found between the UKSIP scores for the cancer patients and control subjects in all of the categories of the UKSIP. The areas of greatest impact in the cancer patients when compared to the age-sex matched control subjects were found to be in the independent categories of work, recreation and pastimes, home management, and sleep and rest (Table 1). The areas of impairment within these categories are presented in detail in Table 2. No significant difference ($P > 0.05$) was found in any UKSIP categories between socio-economic classes.

*Table 1. UK Sickness Impact Profile scores for cancer patients (n=212) and control subjects (n=105)*

| Category | Cancer patients | | | | | Control subjects | | | | | Mann-Whitney 95% Confidence intervals | P |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Median | Q1 | Q3 | Mean | SD | Median | Q1 | Q3 | | |
| Work | 34.4 | 32.8 | 18.1 | 0.0 | 70.1 | 1.3 | 7.3 | 0.0 | 0.0 | 0.0 | 9.820, 12.021 | 0.01 |
| Leisure | 17.4 | 17.8 | 10.2 | 0.0 | 29.9 | 3.4 | 10.7 | 0.0 | 0.0 | 0.0 | 8.079, 13.170 | 0.01 |
| Home care | 15.8 | 15.4 | 13.2 | 0.0 | 23.7 | 3.0 | 10.5 | 0.0 | 0.0 | 0.0 | 9.708, 60.387 | 0.01 |
| Sleep | 13.4 | 12.3 | 12.0 | 9.8 | 21.4 | 3.2 | 6.6 | 0.0 | 0.0 | 0.0 | 8.529, 13.979 | 0.01 |

SD=Standard deviation

*Table 2. Frequency of positive responses to UK Sickness Impact Profile statements in control subjects (n=105) and cancer patients (n=212) which relate to the categories of work, recreation and pastimes, home management and sleep and rest*

| Statement | Control subjects | | Cancer patients | |
|---|---|---|---|---|
| | Frequency | (%) | Frequency | (%) |
| **Work category** | | | | |
| I am not working at all | 1 | (1.0) | 96 | (45.3) |
| I am doing part of my job at home | 0 | — | 2 | (0.9) |
| I am not getting as much work done as usual | 1 | (1.0) | 10 | (4.7) |
| I often get irritable with my workmates | 0 | — | 2 | (0.9) |
| I am working shorter hours | 4 | (3.8) | 27 | (12.7) |
| I am only doing light work | 2 | (2.9) | 17 | (8.0) |
| I only work for short periods of time and rest often | 0 | — | 2 | (0.9) |
| I work at my usual job but with some changes | 0 | — | 6 | (2.8) |
| I do not do my job as carefully and as accurately as usual | 0 | — | 2 | (0.9) |
| **Recreation and pastimes category** | | | | |
| I spend shorter periods of time on my hobbies and recreation | 5 | (4.8) | 72 | (34.0) |
| I am going out to enjoy myself less often | 12 | (11.4) | 66 | (31.1) |
| I am cutting down on some of my inactive pastimes | 6 | (5.7) | 22 | (10.4) |
| I am not doing any of my usual inactive pastimes | 0 | — | 3 | (1.4) |
| I am doing more inactive pastimes in place of my usual activities | 1 | (1.0) | 41 | (19.3) |
| I am taking part in fewer community activities | 2 | (1.9) | 32 | (15.1) |
| I am cutting down on some of my usual physical activities and more active pastimes | 4 | (3.8) | 58 | (27.4) |
| I am not doing any of my usual physical recreation or more active pastimes | 3 | (2.9) | 41 | (19.3) |
| **Home management category** | | | | |
| I only do housework for short periods and rest often | 4 | (3.8) | 43 | (20.3) |
| I am doing less of the household chores than I would normally do | 7 | (6.7) | 85 | (40.1) |
| I am not doing any of the household chores that I would normally do | 2 | (1.9) | 16 | (17.5) |
| I am not doing any of the repair and maintenance work I would usually do | 4 | (3.8) | 65 | (30.7) |
| I am not doing any of the shopping I would usually do | 3 | (2.9) | 30 | (14.2) |
| I am not doing any of the cleaning I would usually do | 2 | (1.9) | 26 | (12.3) |
| I have difficulty using my hands | 2 | (1.9) | 3 | (1.4) |
| I am not doing any of the clothes washing I would normally do | 1 | (1.0) | 23 | (10.8) |
| I am not doing heavy work around the house | 9 | (8.6) | 92 | (43.4) |
| I have given up taking care of business and personal affairs, eg banking, paying bills | 2 | (1.9) | 9 | (4.2) |
| **Sleep and rest category** | | | | |
| I spend much of the day lying down | 0 | — | 13 | (6.1) |
| I sit for much of the day | 7 | (6.7) | 60 | (28.3) |
| I am sleeping/dozing most of the time | 1 | (1.0) | 7 | (3.3) |
| I lie down more often during the day to rest | 1 | (1.0) | 29 | (13.7) |
| I sit around half asleep | 0 | — | 4 | (1.9) |
| I sleep less at night | 16 | (15.2) | 84 | (39.6) |
| I sleep or doze more during the day | 3 | (2.8) | 37 | (17.5) |

*Analysis of UKSIP categories of work, leisure, home management and sleep and rest*

**Work:** The major problems identified in the cancer group were that patients were: not working at all (n=96, 45%); working shorter hours due to their health status (n=27, 13%); or doing only light work (n=17, 8%). Work patterns were particularly affected in patients within 6 months of their first diagnosis and the last 4 months of life. Patients in manual labour were most affected but this did not reach statistical significance. Forty-two per cent of patients had retired early due to their health.

*Recreation and pastimes:* Some patients with cancer (n=41, 19%) were found to have altered their leisure activities to more inactive pastimes. Seventy-two (34%) patients stated that they spent less time on their hobbies and recreation. Patients also reported that they were going out less often (n=66, 31%) and taking part in fewer community activities (n=32, 15%). Men were more affected in their social interactions than women. Patients who survived 4 months or less from the time of completing the UKSIP were most affected.

*Home management:* Patients with cancer reported problems in managing their homes especially in having

their usual ability to do household chores (n=85, 40%) and maintenance or repair work in the home (n=65, 31%). In particular, they did not have the capacity to perform heavy work around the home (n=92, 43%). The ability to manage the home markedly deteriorated within the last few months of life.

*Sleep and rest:* Cancer patients reported that they sat around for most of the day (n=60, 28%) and dozed more during the day than usual (n=37, 18%). Patients reported that they slept less at night (n=84, 40%). Patients who had a survival time of 7-9 months were most affected.

**Discussion**

In the present study the health-related quality of life of 212 cancer patients was assessed using the UKSIP and compared with 105 age-sex matched control subjects. It is important to match for age and sex as some of the responses to the UKSIP may be affected by these variables which would falsely elevate the impairment of health status attributed to cancer[14,15]. Furthermore, others have reported that quality of life in cancer patients is more significantly affected in men than women particularly in aspects related to

work, physical and social activities[16]. However, in this study all UKSIP categories except those related to social interaction were equally affected in both sexes and across all age groups.

The UKSIP category of work was the most significantly affected aspect of the cancer patients life. Two-thirds of the group were not working at all or were working shorter hours as a result of their disease. Only one of the control subjects was not working due to their health. The issue of correlating work and cancer with quality of life has received relatively little attention[17] and clearly is an area requiring further assessment. In some cases patients are physically able to work between treatments but repeated clinic appointments and hospital visits jeopardize their job security. Where possible interim visits and laboratory assessment should be managed by the patient's general practitioner to reduce the number of lost working days. There is some evidence that there is job discrimination towards both patients with active malignant disease and those with a past history of malignancy[18]. There are also significant financial implications associated with loss of employment which may contribute to increased stress and anxiety for the patient. In some cases, patients may elect to discontinue working in order to spend their remaining lifetime pursuing other activities.

Leisure activities were greatly affected in cancer patients when compared to the control subjects. All aspects of this category were affected, particularly the time spent on active pastimes and participation in social and community activities. Sutcliffe and Holmes[19] also found that work and leisure activities are key areas affected in patients with cancer receiving outpatient radiotherapy.

Management of the home was the third most affected aspect in the study. Three-quarters of the cancer patients had significant impairment. Where problems were reported in the control subjects these were confined to elderly (>60 years old) women. The importance of being able to continue to run the home in the maintenance of self esteem has also been noted[20]. Guadagnoli and Mor[21] reported that 90% of cancer patients receiving outpatient therapy required help with home management.

Sleep and rest was disturbed in three-quarters of the cancer patients. Many patients stated that they sat for much of the day or lay down for a rest during the day. This probably influenced their lack of ability to sleep at night. Problems with sleep were unrelated to age or sex in the patient group in contrast to the control subjects where it was primarily a problem in the elderly. This finding that sleep and rest is a major concern of cancer patients has also been reported by others[22,23]. Alteration in sleep pattern may be due to a variety of causes including general debility, anxiety over the future, pain which may wake the patient from sleep or prevent sleep or 'cat naps' during the day which may in some cases be related to drug therapy.

It is unlikely that differences between the patient and control groups were due to causes other than cancer. However, this may need to be addressed in the future by matching the control subject population not only to age and sex but also employment status, financial status, family support and concurrent illness. The effect of survival time or time from diagnosis on quality of life did not reach statistical significance. Others have noted that whilst both these parameters are commonly used end points in assessing oncology patient outcomes they are not necessarily good predictors of a patient's quality of life at different points in the disease trajectory[19,24].

In conclusion, all of the aspects of quality of life assessed by the UKSIP were significantly affected in cancer patients when compared to the group of age-sex matched control subjects. The use of simpler methods of assessment which concentrate on functional status or symptoms alone would fail to assess these areas. Equally it must be recognized that a general health status measure such as the UKSIP, would not be suitable for use in isolation as it does not provide any information relating to specific symptoms. Greater attention should be directed towards addressing aspects such as changes in employment status and the need for help in the home to improve the overall care of cancer patients.

Future studies should be directed towards prospectively incorporating a general health status assessment at suitable intervals during the course of treatment supplemented with shorter functional status or symptomatic assessments at more frequent intervals. This would reduce the burden for the patient of completing a lengthy instrument and yet provide useful information.

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