*Title:* Design of an individualised questionnaire to measure the impact of cancer on quality of life: the Cancer Dependent Quality of Life Questionnaire (CancerDQoL).

*Running title:* Cancer Dependent Quality of Life (CancerDQoL).

*Author names:* Amy Garden a, Michelle D. Taylor a, b, Jonathan Davidson a, Charlie J. Gilbride b, Clare Bradley b

*Author institutional affiliations:* a Psychology Department, Royal Holloway, University of London, Egham, Surrey, TW20 0EX, UK; b Health Psychology Research Ltd., 188 High Street, Egham, Surrey, TW20 9ED, UK.

*Corresponding author:* Dr Michelle D. Taylor, Health Psychology Research Ltd., 188 High Street, Egham, Surrey, TW20 9ED, UK. Email: [mt@healthpsychologyresearch.com](mailto:mt@healthpsychologyresearch.com).

CB is the academic lead on questionnaire design, development and linguistic validation and copyright holder for the Cancer-Dependent Quality of Life (CancerDQoL) questionnaire.

*Access to CancerDQoL:* please visit [www.healthpsychologyresearch.com](http://www.healthpsychologyresearch.com).

*Keywords:* Adults, Cancer, Individual differences, Measurement, Oncology, Quality of Life (QoL), Questionnaire design

**Abstract**

*Objective:* To design an individualised questionnaire to measure the impact of cancer on quality of life (QoL), which is needed to capture the effects of cancer treatments on QoL as opposed to health status and functioning, measured by existing commonly used questionnaires.

*Methods:* Design of the Cancer-Dependent Quality of Life (CancerDQoL) questionnaire based on the Audit of Diabetes Dependent QoL questionnaire and related –DQoLs for other conditions. Sharing a common template –DQoL questionnaires specify life domains and respondents rate personally applicable items for impact of their condition and importance for their QoL. Item selection, face validity and content validity were established through clinician and patient ratings of the importance and relevance of 60 domains from the –DQoL item library, and semi-structured interviews with 25 English-speaking participants with a range of cancers attending a cancer centre in Zimbabwe (age range: 25-78 years; 16 women, 9 men). Ten interviews were subsequently conducted with UK English-speaking participants with a range of cancers attending Maggie’s Centres in London and Dundee (age range 40-76; 5 women, 5 men) to adapt the instrument for UK use.

*Results*: The first draft of the CancerDQoL contained 26 domain-specific items from the -DQoL Item Library. Participants required no new items. Mean domain scores from 25 Zimbabwean patients indicated that cancer negatively impact on all domains of QoL included, with the exception of ‘having children’. Mean weighted impact scores were greatest for ‘health’, ‘physical capability’, ‘enjoyment of food and drink’ and ‘dependency’. ‘Having children’ and ‘feelings about past medical care/self-care’ had the least mean weighted impact. UK interviews led to further refinement of the questionnaire and confirmed that no new items were required. One item, ‘weight’, was removed because this domain was considered a physical symptom rather than an aspect of life.

*Conclusions:* Face and content validity of the individualised CancerDQoL is established for an adult sample of English-speaking cancer patients in Zimbabwe and confirmed in an adaptation following UK interviews. Large-scale data collection with the CancerDQoL has now been completed in the UK to enable psychometric evaluation.

*Abbreviations*: CancerDQoL- Cancer Dependent Quality of Life; HS- health status; HRQoL-health related quality of life; FS- functional status; SEIQoL- Schedule for the Evaluation of Individual Quality of Life; AWI - average weighted impact; WI - weighted impact

**Background**

Globally, cancer was responsible for an estimated 9.6 million deaths in 2018 and the global cancer burden has risen to 18.1 million (1). Living with cancer, and its treatment, can have a profound impact on a person’s quality of life (QoL). Measures which are capable of accurately assessing the impact of cancer and its treatment are important for choosing between different treatments and for identifying individuals who may need more support.

The importance of measuring QoL among individuals with long-term health conditions is widely recognised (2, 3). Access to personalised care, including needs assessment, a care plan and health and well-being information and support is part of NHS England’s long-term plan radically to improve care and support for people living with cancer (4). The new ‘quality of life metric’ introduced in 2019 will use questionnaires to track and respond to the long-term impact of cancer after a person’s cancer treatment ends (4). NHS England estimated that in the UK approximately 7000 more people were surviving cancer after NHS treatment in 2019 compared with seven years previously (4).

There have been several reviews in the literature of the impact of different cancers on QoL (5-9). However, comparing results across studies has been complicated by the different measurement tools used to assess QoL. Generic measures of health status and function such as the EuroQoL five dimensions (EQ-5D**; 10**) and the Short-Form 36-item questionnaire (SF-36; 11) have been commonly used to assess what is referred to as ‘health-related QoL’ among cancer patients in a number of studies (12-16). These generic measures are assumed to have the advantage of enabling comparison across different diseases, however, the selection of items is better suited for some conditions than others (17) and these tools are less suitable for capturing the domains of life which may be impacted by a specific disease type. For example, in diabetes, the individualised diabetes-specific QoL measure, the Audit of Diabetes Dependent Quality of Life (ADDQoL; 18), shows that dietary freedom is the aspect of life most impacted by diabetes and important for QoL. Yet, neither the EQ-5D nor the SF-36 measure this domain. Instead they focus on symptoms and functioning, which observers view as important rather than aspects of life rated as important and relevant to the individual’s QoL (19). Although often related there is a need to distinguish health status from QoL. Health status and functional status are often used interchangeably to refer to health-related QoL (HRQoL) (19), which is also often referred to as representing a person’s general QoL throughout the literature. However, a person might view their health status as ‘good’ because their treatment is effective, while viewing their general overall QoL as ‘poor’ because of the impact of the condition and its treatment on their QoL (20). To differentiate QoL that has been affected by a specific medical condition, Mitchell and Bradley (2004) have used the term “condition-specific quality of life” (21). QoL that is specifically impacted by cancer would be referred to as “cancer-specific (or cancer-dependent) quality of life.”

The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – C30 [EORTC QLQ-C30; 22] and the Functional Assessment of Cancer Therapy [FACT; 23] are two cancer-specific patient-reported outcome measures which have been widely used in the literature. A limitation of these measures is that they do not allow the person to indicate the extent to which domains of life are personally relevant or important. The EORTC questionnaire contains 30 items. The first seven items ask about physical capabilities such as walking, or carrying heavy bags; mobility; need for assistance with self-care (i.e. eating, dressing, washing, using the toilet); and ability to work or carry out household jobs. This is followed by a series of physical and cognitive symptoms including dyspnoea, pain, fatigue, sleep disturbance, weakness, loss of appetite, nausea and vomiting, constipation, diarrhoea, tension, worry, irritability, depression and memory. The remaining items measure interference with family life and social activities, and the perceived impact of the condition and its treatment on financial difficulties. There is also a global health and quality of life scale. At least 18 of the EORTC QLQ-C30 questionnaire items are asking specifically about symptoms rather than domains of quality of life. Such measures may be useful to clinicians in that they provide an indication of disease severity or functional limitations, but they do not provide information about the areas of life which are most relevant and important to the individual.

It is recognised within the literature that an individualised approach to measurement of quality of life is preferable over the use of standard questionnaires. The Schedule for the Evaluation of Individual QoL (SEIQoL) was developed by McGee and colleagues in the early 1990s and recognises the value in assessing the individual’s own view of their QoL (24). The SEIQoL is a face-to-face interview measure which requires patients to nominate the five most important domains for their QoL. The relative importance of each domain is calculated statistically by comparing an overall rating of QoL with the current status of each of these (24). The philosophy underpinning the SEIQoL has been used in the design and development of individualised condition-specific measures starting with the Audit of Diabetes Dependent Quality of Life (ADDQoL) questionnaire (18) for people with diabetes. An Average Weighted Impact (AWI) score is obtained by multiplying the impact of particular domains of life by ratings of the importance of those domains of life for QoL and taking the average of the resulting Weighted Impact (WI) scores for all applicable domains of life. The WI score, for specific domains of life, can be used to compare different aspects of life that are affected more or less by a condition. Similarly, the AWI score provides an overall picture of the impact of a condition on a person’s QoL that can be tracked over time and compared between groups with the same and different conditions (which have a -DQoL measure available) (25). The ADDQoL has been used as a template for the design of several other –DQoL questionnaire measures including those for retinopathy, HIV, macular degeneration, hypothyroidism and other hormonal deficiencies, renal problems, aortic aneurysms, Parkinson’s disease and dementia (26-33). The development of these condition-specific measures has led to an Item Library that can be used to create new draft questionnaires based on the same questionnaire template. The aim of the present study was to select relevant QoL domains, from the pre-existing -DQoL Item Library, and establish if interviewees required any additional items to be included in the design of a new questionnaire to measure cancer-dependent QoL among individuals with different types and stages of cancer.

**Methods**

CancerDQoL Questionnaire Design

The design of the CancerDQoL was based on the Audit of Diabetes-Dependent Quality of Life (ADDQoL) (18,34) and successive adaptations of the ADDQoL for people with other long-term conditions (26-33). Domains of life from the Item Library collected following validation of previous -DQoL questionnaires were modified for people with cancer, e.g. ‘If I did not have diabetes (cancer), my family life would be’. This minimises the work needed during linguistic validation as the optimal wording and structure of the items has already been established with other patient groups: the ADDQoL alone has been linguistically validated in more than 84 languages. Life domain items that were not likely to be impacted for most people with cancer were omitted from the early draft but could be added in if patients perceived a need for them. Symptom items (i.e. ‘Energy’, ‘Bodily discomfort’, ‘Depression’, ‘Anxiety’, ‘Sleep’, ‘Stamina’ and ‘Physical discomfort’) were excluded because the CancerDQoL is not intended to be a symptom measure.

The initial list of potential CancerDQoL items covered 60 life domains. Each of the 60 life domain items was rated for relevance to cancer, importance, and wording by two consultant oncologists in the UK, and one English-speaking cancer patient from Zimbabwe. Items from the Item Library, which both the oncologists and the patient rated as ‘highly important’, were retained. The following six core items (items that occur in all -DQoL measures) were also retained: ‘Holidays’, ‘Family / relatives’, ‘Friends / social life’, ‘Appearance’, ‘Confidence’ and ‘Motivation’. The resulting draft of the CancerDQoL contained 26 domain-specific items including the six core items, leisure activities, work, ability to do things physically, close personal relationships, sex life, having children, finances, feelings about the future, health, dependency on others, past medical care and/or self care, spiritual or religious aspects, cognitive function (e.g. memory and concentration), other’s reactions (e.g. fuss and worry), time taken to do things, getting out and about, weight, the need to conceal things, freedom to eat and drink, and enjoyment of meals.

All of the quality of life domains are introduced by a statement with five response options, e.g. If I did *not* have cancer, my working life would be…. *very much better, much better, a little better, the same, worse* (Impact rating: scored from -3 to +1). Respondents then rate how important that domain is to their quality of life on a 4-point scale from *very important* to *not at all important* (importance rating: scored from 3 to 0). A weighted impact (WI) score is calculated by multiplying the domain’s impact rating by the corresponding importance rating. Weighted domain impact scores range from -9 to +3 representing the maximum negative to maximum positive impact of cancer on the domain. The WI score, for specific domains of life, can be used to compare different aspects of life that are affected more or less by a condition. Similarly, the Average Weighted Impact (or AWI) score can be calculated to provide an overall picture of the impact of a condition on a person’s QoL, that can be tracked over time, and compared between groups with the same and different conditions (which have a -DQoL measure available) (25). The AWI score is calculated by multiplying the impact of particular domains of life by ratings of the importance of those domains for QoL, and taking the average of the resulting WI scores for all applicable domains of life.

Similar to other -DQoL measures the CancerDQoL is individualised. It takes into account the relevance of each aspect of life for the individual by giving respondents the opportunity to indicate where particular domains (e.g. work, sex life) are not applicable. There is a free comments section at the end of the questionnaire where respondents can describe other ways in which cancer, and its’ treatment, affect their quality of life. This allows for the addition of further domains to the questionnaire in the future as part of the continuing development of the measure.

Alternative phrasings of items 14 (‘If I did not have cancer, I would need to depend on others.’), 19 (‘If I did not have cancer, my feelings about past medical care and/or self-care would be’), and 21 (‘If I did not have cancer, the speed with which I could do things would be.’) were included at the end of the first draft of the questionnaire and tested for preferred wording following feedback obtained from the two clinicians and the patient who completed the initial item ratings. The substitute choices were: ‘If I did not have cancer, I would be able to do things for myself.’, ‘If I did not have cancer, my feelings about past medical care and/ or self-care (e.g. anger or regret) would be’, and ‘If I did not have cancer, the time it takes me to do things would be’.

In addition to the life domain items, the CancerDQoL contains three items providing an overview of the respondent’s general QoL, an overview of the impact of cancer on QoL, and an overview of perceived general health. Question I: Present QoL (‘In general, my quality of life is’) asks people to rate their present QoL on a 7-point Likert scale from excellent to extremely bad (scored +3 to -3). Question II: Cancer-specific QoL (‘If I did not have cancer, my quality of life would be’) asks people to rate what their QoL would be if they did not have cancer, on a 5-point scale from very much better to worse (scored -3 to +1), providing an overview measure of perceived impact of cancer on quality of life. Question III: Present health status (‘In general, my health is’) asks people to rate their current perceived health status on a 7-point scale from excellent to extremely bad (scored +3 to -3).

Participants

The demographic and clinical characteristics of the Zimbabwean and UK samples are shown in Table 1.

*Zimbabwean sample*

The sample in Zimbabwe consisted of volunteer patients who spoke English as a first language, and who were recruited from Oncocare; an outpatient cancer treatment clinic in Harare, Zimbabwe. There were 9 men and 16 women with a range of different primary cancer types including breast, bone, lung, cervical, colon, prostate, blood, skin and liver. Participants ranged from 25 to 78 years of age. Time since diagnosis ranged from 1 to 13 years. The majority of participants were invited to take part when they attended the treatment clinic during a three week data-collection period in April 2018 (n=21). Four participants were recruited via a mailing list advertising the study. Participants on the mailing list were sent a flyer about the study, which included the researcher’s contact details. All participants were aged 18 or older and were currently undergoing cancer treatment. People with a diagnosed severe and enduring mental health problem, and people with a brain injury or severe cognitive impairment were not included.

*UK sample*

Ten participants (5 men and 5 women) were subsequently recruited from Maggie’s Centres in London and Dundee to adapt the questionnaire for UK use. The participants ages ranged from 40 to 76 years and they had a range of different cancer diagnoses including breast, prostate, lung and myeloma. Time since diagnosis ranged from 8 months to 5 and a half years.

Interviews

Semi-structured interviews were conducted with all of the participants. The interview schedule was modelled on previous -DQoL questionnaire development work, specifically the HIVDQoL (35) and tailored to be cancer-specific. Audio recordings and written notes were made during each interview to allow subsequent transcription. Each interview lasted approximately one hour. Interviews started with open questions about the effects of cancer on QoL, and experiences of treatment. Patients were asked: “If you woke up tomorrow to find that you no longer had cancer, how would that affect your quality of life?”. Additional questions were asked to gather information about symptoms of cancer, and any complications and/or side effects of cancer and its treatment on QoL. These questions were asked to gather spontaneous mentions of domains of life which are impacted by cancer. Interviewees then completed and commented on the draft CancerDQoL questionnaire. Participants were asked to ‘think aloud’ making comments and suggestions for potential changes to the questionnaire. Following the interviews the Questionnaire Design Team met to review the interview responses. Draft items were modified and removed as necessary until no further changes were needed.

**Results**

*Zimbabwean sample*

Responses to each item were examined to explore the range of response options and to rank items in terms of perceived importance to quality of life and perceived impact of cancer. Mean ratings of importance and impact for each item and WI scores were calculated (Table 2).

Mean domain scores from the 25 Zimbabwean patients indicated that cancer had a negative impact on all of the 26 domains of life included in the CancerDQoL, with the exception of ‘Having children’, which had an overall mean impact score of 0. Table 2 shows the mean impact scores for each domain in descending order of impact. The mean importance ratings are also shown along with the position of each domain in order of weighted impact. The most severely impacted domains were ‘health’. ‘sex life’, ‘time taken to do things’ and ‘dependency on others’. The least impacted domains were ‘having children, ‘spiritual/religious aspects’ and ‘feelings about past medical care/self-care’. The impact rankings of the domains were changed in most cases after the impact ratings were weighted by importance except for ‘health’, ‘dependency on others’ and ‘having children’, which remained as the first, fourth and least impacted domains respectively. The full range of impact ratings were used in 22 of the 26 domains and the full range of importance ratings were used in 15 of the 26 domains (Table 2). A positive impact of cancer was indicated by single participants on three domains: ‘finances’, ‘need to conceal’ and ‘spiritual/religious aspects’. The mean weighted impact scores are shown in Figure 1. Mean WI scores were greatest for ‘health’, ‘physical ability’, ‘enjoyment of food and drink’ and ‘dependency’. ‘Having children’ and ‘feelings about past medical care/self care’ had the lowest mean WI scores (Figure 1).

Spearman’s rho correlation coefficient’s between impact and importance scores ranged from -0.609 (Enjoyment of food and drink) to 0.192 (Weight). Most correlations were negative indicating that greater negative impact was correlated with greater importance for quality of life, but correlations were only statistically significant for ‘Health’ and the two items concerned with food and drink i.e. ‘Enjoyment of food’ and ‘Freedom to eat and drink’ (Table 3).

Responses to the two overview items measuring general quality of life and cancer-specific quality of life showed that present QoL was either ‘very good’ or ‘good’ for the majority of participants (70%), followed by ‘neither good nor bad’ (17%). Despite this the majority of participants (60%) rated the overall impact of cancer as negative, i.e. that their QoL would be ‘very much better’ or ‘much better’ if they did not have cancer. Twenty two percent of participants reported that their QoL would be ‘the same’ if they did not have cancer. Four percent of participants indicated that their QoL would be ‘worse’ if they did not have cancer. Seventy eight percent of participants indicated that their present general health was ‘excellent’, ‘very good’ or ‘good’.

The not-applicable option (NA) was provided for 9 of the 25 life domain items. The frequency of use of NA options ranged from 0%, where ‘Holidays’ were applicable to all participants, to 52% for ‘Need to conceal’, indicating that just over half the participants did not feel the need to conceal things.

Spearman’s rho correlation coefficients were examined between the two QoL overview items (‘In general, my quality of life is’ and ‘If I did not have cancer, my quality of life would be’), the general health overview item (‘In general, my health is’) and the average weighted impact score (AWI). Significant correlations were found between the cancer-specific QoL overview item and the average weighted impact score (rho (23) =0.574, *p*<0.01), and between the cancer-specific QoL overview item and the general health status item (rho (23) = 0.527, *p* <0.05). Cancer-specific quality of life was positively correlated with general health status (rho (23) = 0.425, p<0.05) indicating that better cancer-specific quality of life is associated with better self-reported general health status.

Following the interviews with the 25 Zimbabwean participants, a meeting to review the interview responses was held by the Questionnaire Design Team, including the authors and two linguists experienced in linguistic validation of existing –DQoL measures for other conditions to conduct translatability assessments on any new items or modifications proposed, and chaired by one of the authors (CB). The following decisions and modifications to the CancerDQoL were made:

* The wording of the introductory phrase of each domain-specific item was changed from ‘If I did not have cancer’ to ‘Without cancer’ following comments from some participants that repeated use of the longer phrase ‘If I did not have cancer...’, placed continual emphasis on the word ‘cancer’. The simplified shorter phrase leads without pause into the rest of the sentence, without the same emphasis on the word ‘cancer’. It will also make future translation of the questionnaire easier.
* The item ‘Having children or more children’ was not applicable to almost half of the participants (*n*=12) and only two participants indicated that the item was important to them. The item was originally designed for the HIVDQoL and appeared to be less relevant to people with cancer in the present study. However, the item was retained for further testing in a UK sample.
* A few participants questioned the need for a response option indicating a positive impact of cancer. However, positive effects of cancer on quality of life were described by a small number of participants. For example, one participant said: *“I think that cancer has brought me closer to God”*, and another reported a positive impact on family relationships: *“The family unit is more cohesive now...especially our children”.* The decision to have one level of positive impact for the life domain items and the cancer-specific overview items was therefore supported.

*UK Sample*

The 10 interviews which took place with participants attending Maggie’s centres in London or Dundee were used to adapt the CancerDQoL for UK use, and to check the acceptability of the modifications made following the interviews with participants in Zimbabwe. Two further design team meetings took place after the 7th and 10th UK interviews. These resulted in the following modifications:

* One item, ‘weight’, was removed because this domain was considered a physical symptom more appropriate for a symptom questionnaire. It was felt that QoL aspects of this item are already captured by 'physical appearance' and 'physical ability' domains.
* The 'cancer-specific health' (‘Without cancer my health would be’) item was moved to the end of the questionnaire and considered as a cancer-specific health overview item alongside the general health item (‘In general, my health is’) to mirror the QoL overview items and separate the health items from the quality of life items.
* Completion instructions were updated to reflect both the acute and/or chronic nature of cancer as well as the emphasis on treatment and side effects as factors to consider when completing the questionnaire.
* The majority of the participants preference was for the wording, “Without cancer” rather than “If I did not have cancer” at the start of each domain-specific item, and no participants had difficulty in item comprehension thus the “Without cancer” prefix was retained.

The interviews with UK participants confirmed that the CancerDQoL is suitable for use with a UK sample and no new items were needed.

**Discussion**

This study has taken the first step towards the development of an individualised condition-specific measure of the impact of cancer on QoL using the same template and method used in the design of -DQoLs for other conditions (25). The CancerDQoL enables individuals to rate only the domains that are relevant to them and consider both the impact of the condition on each relevant life domain and the importance of each domain for their quality of life.

The findings illustrate that cancer has a substantial negative impact on quality of life. There was also evidence of altered rankings of the life domain items resulting from weighting the impact ratings by the importance ratings. This shows that weighting by importance does, as expected from previous work on other -DQoL measures, refine the measure (26-33). It has been argued in the literature that it is tautologous to assign importance weightings in a QoL measure, which consists of domains that have already been selected based on their perceived importance (36). Nevertheless, the full range of importance scores was used in the present study for 16 of the 26 domains suggesting that domains that were very important to some were not at all important to others. ‘Family life’ moved up to rank seven (from rank 15), once it had been weighted for importance, showing that relatively small impact ratings can be magnified considerably by the importance of the domain to the individual. Therefore, it is argued that, use of a weighted impact score provides a more accurate representation of individuals’ perceptions of the impact of cancer on their quality of life, and reflects individual differences in the perceived importance of each domain for QoL.

The CancerDQoL has the potential to provide clinicians with a more holistic view of the impact of cancer on an individual’s QoL. At a group or service level, treatments and support mechanisms which are focused on targeting domains of life which are most impacted by cancer, without considering importance, may result in less than optimal use of resources. Basing decisions about care on impact ratings alone may lead to organisations inappropriately giving more attention to issues which are impacted by cancer but are not necessarily the main priorities for patients.

The design of the CancerDQoL ensures it is condition-specific. The initial selection of items from the -DQoL Item Library based on consultant oncologist and patient ratings was confirmed in subsequent interviews with people living with cancer. Interview participants were asked to consider specifically the impact of cancer on these domains and to provide feedback on any additional domains they thought were needed. There were no new items generated from the CancerDQoL interviews revealing how flexible and adaptable the items in the Item Library are across multiple conditions (25). In support of Joyce (1994) (20), the general overview items showed that although the majority of patients stated that their QoL would be ‘very much better’ or ‘much better’ without cancer, they also reported that their present quality of life was either ‘very good’ or ‘good’, and that in general their health was either ‘very good’ or ‘good’.

The CancerDQoL is likely to be more sensitive to change than generic measures of QoL. It is also more likely to differentiate between the impact of cancer and its treatment and the impact of unrelated comorbidities. In previous research, Woodcock et al., (2001) found that the ADDQoL differentiated between complications of diabetes and unrelated comorbidities whereas the generic SF-36 health status measure did not (37).

A larger study has now been completed to evaluate the psychometric properties of the CancerDQoL in the UK. Future research is expected to compare CancerDQoL findings from different countries, including the UK, and across different age groups and nationalities. The item ‘Having children or more children’ was not relevant to the majority of participants in the present study. However, it is possible that this item will be more relevant among younger samples. Conducting the research in Zimbabwe resulted in the inclusion of a large number of ethnic minority groups suggesting that the measure is relevant to people from different cultural backgrounds. It will be important to determine in a larger sample, where subgroup analysis is justified, whether the CancerDQoL is equally suitable across a broad range of cancer types, and with people at different stages of treatment and undergoing different forms of cancer treatment.

This study has demonstrated that items selected from the –DQoL item library to create a new –DQoL for people with cancer had good face and content validity in English-speaking cancer patients in Zimbabwe, and this was confirmed in an adaptation following UK interviews. The CancerDQoL was acceptable for use with adults with a range of different cancers.

*Acknowledgements*

The authors thank the Medical Research Council of Zimbabwe for approval to conduct this study (MRCZ/B/1457). The authors are grateful to Dr. K Naik, Chairman of the Board, Oncocare, Zimbabwe and Jackson Kanhenga, Head of Corporate Affairs, Bains Imaging Group, Zimbabwe, for granting permission to carry out the research at Oncocare. The authors thank Portia Bashiri-Chuma, Clinic Manager, Oncocare, Zimbabwe, for support in recruiting participants. The authors extend their gratitude to the patients who participated and Dr. Ndoro and Dr. Tsikai for consultation on items for inclusion in the questionnaire. We recognise Health Psychology Research (HPR) Ltd. for supporting this study and in providing the expertise of Mrs Alison Wilson, Mrs Janet Bayfield and Dr Anita Smarendache.

*Conflict of interest statement:*

C.B. is a director and majority shareholder of Health Psychology Research Ltd., which licenses her questionnaires for others to use and charges licence fees to commercial companies, paying royalties to C.B. on these occasions. C.B. via Royal Holloway receives research grants from GSK/ViiV for design, development and use of measures for people with HIV and from Medtronic for design and development of measures for people with varicose veins. Co-authors A.G. and M.D.T. have no conflicts of interest to declare.

*Author contributions*

A.G recruited the participants, collected and analysed the data. A.G. and M.D.T. wrote the manuscript. M.D.T. and C.B. advised on the design, recruitment and data analyses. C.B. is the academic lead on questionnaire design, development and linguistic validation and copyright holder for the CancerDQoL. All authors reviewed and edited the manuscript.

**References**

1. Union for International Cancer Control (UICC). Annual report 2018. June 2019. Available from: <https://www.uicc.org/resources/2018-annual-report>

2. Edgar A, Bowling A.: 1997, Measuring health; a review of quality of life measurement scales (2nd Edition). Med Health Care Philos 1998; 1:181-182

3. McKenna SP. Measuring patient-reported outcomes: moving beyond misplaced common sense to hard science. BMC Medicine 2011; 9:86

4. NHS. The NHS long-term plan. 2019. Available from: <https://www.longtermplan.nhs.uk/>

5. Pickard AS, Wilke CT, Lin H-W, Lloyd A. Health utilities using the EQ-5D in studies of cancer. PharmacoEconomics 2007; 25:365-384.

6. Taarnhǿj GA, Johansen G, Pappot H. Quality of life in bladder cancer patients receiving medical oncological treatment; a systematic review of the literature. Health and Quality of Life Outcomes 2019; 17: 20.

7. Dunn J, Lynch B, Aitken J, Leggett B, Pakenham K, Newman B. Quality of life and colorectal cancer: A review 2003; 27:41-53.

8. Montazeri A. Health-related quality of life in breast cancer patients: a bibliographic review of the literature from 1974 to 2007. Journal of Experimental & Clinical Cancer Research 2008; 27:32.

9. Reich M, Lesur A. Perdrizet-Chevallier C. Depression, quality of life and breast cancer: a review of the literature. Breast Cancer Research and Treatment 2008; 110: 9-17.

10. EuroQol. A new facility for the measurement of health-related quality of life. Health Policy 1990; 16(3):199-208.

11. Ware J, Sherbourne C. The MOS 36-ltem Short-Form Health Survey (SF-36). *Medical Care* 1992; *30*(6): 473-483.

12. Conner-Spady BL, Cumming C, Nabholtz JM, Jacobs P, Stewart D. A longitudinal prospective study of health-related quality of life in breast cancer patients following high-dose chemotherapy with autologous blood stem cell transplantation. Bone Marrow Transplant 2005; 36: 251-259.

13. Hamashima C. Long-term quality of life of postoperative rectal cancer patients. Journal of Gastroenterol Hepatol 2002; 17(5):571-576.

14. Cheville AL, Almoza M, Courmier JN, Basford JR. A prospective cohort study defining utilities using time trade-offs and the EuroQoL-5D to assess the impact of cancer-related lymphedema. Cancer 2010; 116(15):3722-3731.

15. Bunevicius A. Reliability and validity of the SF-36 Health Survey Questionnaire in patients with brain tumours: a cross-sectional study. Health and Quality of Life Outcomes 2017; 15:92.

16. Reulen RC, Zeegers MP, Jenkinson C, Lancashire ER, Winter DL, Jenney ME, Hawkins MM. The use of the SF-36 questionnaire in adult survivors of childhood cancer: evaluation of data quality, score reliability, and scaling assumptions. Health Qual Life Outcomes 2006; 4:77.

17. Mitchell J, Bradley C. Quality of life in age-related macular degeneration: a review of the literature. Health and Quality of Life Outcomes 2006; 4:97.

18. Bradley C, Todd C, Gorton T, Symonds E, Martin A, Plowright R. The development of an individualized questionnaire measure of perceived impact of diabetes on quality of life: the ADDQoL. *Quality of Life Research* 1999; *8*:79-91.

19. Bradley C. Importance of differentiating health status from quality of life. *The Lancet 2001; 357*(9249):7-8.

20. Joyce CRB. Requirements for the assessment of individual quality of life. In: McGee HM and Bradley C (Eds.) *Quality of life Following Renal Failure: Psychological Challenges Accompanying High Technology Medicine*. Chur, Switzerland; Harwood, 1994; 43-54.

21. Mitchell J, Bradley C. Design of an Individualised Measure of the Impact of Macular Disease on Quality of Life (the MacDQoL). *Quality of Life Research* 2004; *13*(6):1163-1175.

22. Aaronson N, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez N. et al. The European Organization for Research and Treatment of Cancer QLQ-C30: A Quality-of-Life Instrument for Use in International Clinical Trials in Oncology. *JNCI Journal of The National Cancer Institute* 1993; *85*(5):365-376.

23. Cella D, Tulsky D, Gray G, Sarafian B, Linn E, Bonomi A. et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of Clinical Oncology* 1993; *11*(3):570-579.

24. McGee H, O'Boyle C, Hickey A, O'Malley K, Joyce C. Assessing the quality of life of the individual: the SEIQoL with a healthy and a gastroenterology unit population. *Psychological Medicine* 1991; *21*(03):749.

25. Bradley C, Romaine J, Gibbons A. Individualised, condition specific measures of quality of life, designed using a common template and item bank, facilitate cross-condition comparisons. *Quality of Life Research* 2018; 27(Suppl 1):S155.

26. Bradley C. Design of a renal-dependent individualised quality of life questionnaire: RDQoL. *Advances In Peritoneal Dialysis* 1997;*13*:116-120.

27. Gibbons A, Bayfield J, Wilson A, Bradley C. Design of the individualised Memory Dependent Quality of Life (MemoryDQoL) and the Memory Treatment Satisfaction Questionnaire (MemoryTSQ) for people with dementia using existing -DQoL and -TSQ templates and libraries. *Value in Health* 2019; 22(Suppl 3):S758.

28. Gibbons A, Bayfield J, Wilson A, Bradley C. Design of the individualised Parkinson’s Dependent Quality of Life (Parkinson’sDQoL) and the Parkinson’s Treatment Satisfaction Questionnaire (Parkinson’sTSQ) using templates and item libraries from existing -DQoL and -TSQ measures for other conditions. Value in Health 2019; 22(Suppl 3):S758-759.

29. Brose L, Bradley C. Psychometric Development of the Individualized Retinopathy-Dependent Quality of Life Questionnaire (RetDQoL). *Value in Health* 2010; *13*(1): 119-127.

30. McMillan C, Bradley C, Gibney J, Russell-Jones D, Sönksen P. Preliminary development of the new individualized HDQoL questionnaire measuring quality of life in adult hypopituitarism. *Journal of Evaluation In Clinical Practice* 2006; *12*(5):501-514.

31. McMillan C, Bradley C, Razvi S, Weaver J. Evaluation of New Measures of the Impact of Hypothyroidism on Quality of Life and Symptoms: The ThyDQoL and ThySRQ. *Value in Health* 2008;*11*(2):285-294.

32. Mitchell J, Bradley C. Design of an Individualised Measure of the Impact of Macular Disease on Quality of Life (the MacDQoL). *Quality of Life Research* 2004; *13*(6):1163-1175.

33. Peach G, Romaine J, Wilson A, Holt P, Thompson M, Hinchliffe R, Bradley C. Design of new patient-reported outcome measures to assess quality of life, symptoms and treatment satisfaction in patients with abdominal aortic aneurysm. *British Journal of Surgery* 2016; *103*(8):1003-1011.

34. Wee H, Tan C, Goh S, Li S. Usefulness of the Audit of Diabetes-Dependent Quality-of-Life (ADDQoL) Questionnaire in Patients with Diabetes in a Multi-Ethnic Asian Country. *Pharmacoeconomics* 2006;*24*(7): 673-682.

35. Romaine J, Murray M, Bradley C. Psychometric evaluation of a new individualised condition-specific quality of life questionnaire for people with HIV (HIVDQoL). *Journal of International AIDS Society* 2016; *19*(100).

36. Trauer T, Mackinnon A. Why are we weighting? The role of importance ratings in quality of life measurement. *Quality of Life Research* 2001; *10*(7).

37. Woodcock AJ, Julious SA, Kinmonth AL, Campbell MJ; Diabetes Care From Diagnosis Group. Problems with the performance of the SF-36 among people with type 2 diabetes in general practice. *Quality of Life Research* 2001; 10(8):661-70.

Table 1: Demographic and clinical characteristics of the Zimbabwean (n=25) and UK (n=10) samples

Zimbabwean Sample UK Sample

Characteristic N (%) Mean (range) N (%) Mean (range)

Age (years) 51.00 (25-78) 59.22 (40-76)

Gender

Male 9 (36) 5 (50)

Female 16 (64) 5 (50)

Ethnicity

White 10 (40) 9 (90)

Chinese 1 (10)

Asian or Asian British 1 (10)

Black 12 (48)

Mixed race 3 (12)

First language

English 13 (52) 10 (100)

English and Shona 12 (48) 0 (0)

Cancer type

Breast 9 (36) 5 (50)

Bone marrow 5 (20)

Lung 4 (16) 1 (10)

Cervical 4 (20)

Colon 2 (8)

Prostate 2 (8) 3 (30)

Blood 1 (4)

Skin 1 (4)

Liver 1 (4)

Myeloma 0 (0) 1 (10)

Cancer treatment

Chemotherapy 21 (84) 6 (60)

Radiotherapy 10 (40) 7 (70)

Natural alternative 1 (4) 0 (0)

Hormone therapy 0 (0) 7 (70)

Surgery 0 (0) 3 (30)

Stem cell transplant 0 (0) 1 (10)

Time since first 38.0 (1-156) 32.90 (8-68)

cancer diagnosis (months)

*Note*: Participants who spoke English and Shona were bilingual. Each type of cancer and cancer treatment has been accounted for separately when a participant has more than one diagnosis or had more than one treatment.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Position in order of mean impact rating | *n* (max 25) | NA response  (% of responses) | | Mean impact rating (*SD*) | Range of possible impact scores = -3 to +1. | | | Mean importance rating (*SD*) | | Range of possible importance scores = 3 to 0. | | | | Range of possible WI Scores = -9 to +3. |
|  |  |  |  | | Min. | Max. |  | | | | Min. | | Max. | Position in order of WI Score. | | |
| Health | 23 |  | -2.26 (0.86) | | -3 | 0 | | | 2.65 (0.78) | | 0 | 3 | | 1 | |
| Sex life | 20 | 13.04 | -2.10 (1.07) | | -3 | 0 | | | 1.95 (1.05) | | 0 | 3 | | 6 | |
| Time taken to do things | 23 |  | -2.09 (1.08) | | -3 | 0 | | | 1.96 (1.02) | | 0 | 3 | | 5 | |
| Dependency | 19 | 21.74 | -2.05 (1.03) | | -3 | 0 | | | 2.00 (1.08) | | 0 | 3 | | 4 | |
| Physical ability | 23 |  | -1.91 (0.95) | | -3 | 0 | | | 2.35 (0.78) | | 0 | 3 | | 2 | |
| Fuss or worry | 22 | 4.35 | -1.86 (0.83) | | -3 | 0 | | | 1.91 (0.87) | | 0 | 3 | | 14 | |
| Leisure | 23 |  | -1.78 (1.00) | | -3 | 0 | | | 2.09 (0.60) | | 1 | 3 | | 12 | |
| Enjoyment of food & drink | 23 |  | -1.74 (1.18) | | -3 | 0 | | | 2.48 (0.59) | | 1 | 3 | | 3 | |
| Freedom to eat & drink | 23 |  | -1.74 (1.05) | | -3 | 0 | | | 1.65 (1.11) | | 0 | 3 | | 18 | |
| Physical appearance | 23 |  | -1.70 (1.11) | | -3 | 0 | | | 1.83 (1.03) | | 0 | 3 | | 17 | |
| Motivation | 23 |  | -1.65 (1.27) | | -3 | 0 | | | 2.35 (0.71) | | 1 | 3 | | 8 | |
| Finances | 23 |  | -1.57 (1.31) | | -3 | 1 | | | 2.35 (0.83) | | 0 | 3 | | 9 | |
| Work | 17 | 26.09 | -1.53 (1.23) | | -3 | 0 | | | 2.53 (0.80) | | 0 | 3 | | 11 | |
| Getting out and about | 23 |  | -1.52 (1.34) | | -3 | 0 | | | 2.13 (0.92) | | 0 | 3 | | 15 | |
| Family life / relatives | 23 |  | -1.43 (1.16) | | -3 | 0 | | | 2.78 (0.52) | | 1 | 3 | | 7 | |
| Friendships /  social life | 23 |  | -1.39 (1.08) | | -3 | 0 | | | 2.22 (0.74) | | 1 | 3 | | 19 | |
| Cognitive function | 23 |  | -1.39 (1.27) | | -3 | 0 | | | 2.70 (0.47) | | 2 | 3 | | 10 | |
| Need to conceal | 11 | 52.17 | -1.36 (1.21) | | -3 | 1 | | | 1.82 (0.87) | | 2 | 3 | | 21 | |
| Feelings about future | 23 |  | -1.35 (1.34) | | -3 | 0 | | | 2.22(1.70) | | 1 | 3 | | 13 | |
| Holidays | 23 | 0.00 | -1.26 (1.10) | | -3 | 0 | | | 1.74 (0.86) | | 0 | 3 | | 22 | |
| Close personal relationships | 21 | 8.70 | -1.24 (1.26) | | -3 | 0 | | | 2.81 (0.40) | | 2 | 3 | | 16 | |
| Weight | 15 | 39.13 | -1.20 (1.01) | | -3 | 0 | | | 1.87 (1.06) | | 0 | 3 | | 24 | |
| Self-confidence | 23 |  | -1.09 (1.24) | | -3 | 0 | | | 2.39 (0.94) | | 0 | 3 | | 20 | |
| Past medical / self care | 23 |  | -0.91 (1.24) | | -3 | 0 | | | 1.43 (1.08) | | 0 | 3 | | 25 | |
| Spiritual / religious aspects | 21 | 8.70 | -0.81 (1.17) | | -3 | 1 | | | 2.48 (0.75) | | 1 | 3 | | 23 | |
| Having children | 2 |  | 0.00 (0.00) | | 0 | 0 | | | 1.50 (2.12) | | 0 | 3 | | 26 | |

Abbreviations: SD, Standard deviation; WI, Weighted impact score

Table 2. Domains of the CancerDQoL in descending order of impact of cancer on QoL, showing mean impact ratings (standard deviation), mean importance ratings (standard deviation) and position of domains in order of weighted impact among sample of Zimbabwean cancer patients.

[INSERT FIGURE 1 HERE]

**Table 3.** Spearman’s rho correlation coefficients between impact and importance ratings for domain-specific items of the CancerDQoL.

|  |  |
| --- | --- |
| Domain | Correlation between impact and importance scores. |
| Health | **-0.500\*** |
| Sex life | -0.082 |
| Time taken to do things | -0.203 |
| Dependency | -0.122 |
| Physical ability | -0.328 |
| Fuss or worry | -0.034 |
| Leisure | -0.309 |
| Enjoyment of food & drink | **-0.609\*\*** |
| Freedom to eat & drink | **-0.464\*** |
| Physical appearance | -0.338 |
| Motivation | -0.207 |
| Finances | -0.146 |
| Work | 0.210 |
| Getting out and about | -0.279 |
| Family / relatives | -0.179 |
| Friends / social life | -0.140 |
| Cognitive function | -0.284 |
| Need to conceal | -0.275 |
| Worries about future | -0.388 |
| Holidays | -0.107 |
| Close personal relationship | 0.021 |
| Weight | 0.192 |
| Self-confidence | -0.316 |
| Past medical / self care | -0.325 |
| Spiritual / religious aspects | -0.248 |

*Note. \*\** Correlation issignificant at the 0.01 level (2- tailed) \*Correlation is significant at the 0.05 level (2-tailed). The correlation scores for the domain ‘Having children’ were excluded due to this item being not applicable to most participants.