

Measuring the impact of Cancer on Quality of Life and Health using the Cancer Dependent Quality of Life Questionnaire (CancerDQoL) and Other Widely Used Patient-Reported Outcome Measures

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Conflict of Interest Declaration

Copyright in the CancerDQoL and sister -DQoL measures for other conditions is owned by Clare Bradley, who designed the original ADDQoL for diabetes and was closely involved with the design of all subsequent -DQoL measures.

The questionnaires are made available for others to use via her company, Health Psychology Research Ltd. ('HPR'), which was set up to license the questionnaires and manage their linguistic validation into other languages. License fees usually apply when the questionnaires are licensed by a commercial company though they are waived when the company sponsors linguistic validation work needed using the gold-standard procedures specified on the HPR website (www.healthpsychologyresearch.com). Royalties are paid to Clare Bradley when license fees are paid.

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The licensing process is important for protecting the integrity of the questionnaires and ensuring high quality linguistic validation procedures are used.



The other authors have no relevant financial or non-financial interests to disclose.

Importance of distinguishing quality of life from health status/functioning

- Monitoring and improving quality of life (QoL) is part of NHS England's 10-year plan for people living with and beyond cancer (NHS England, 2019)
- Generic and cancer-specific instruments, which focus primarily on health status/functioning, are often mislabeled as QoL or health-related QoL (Bradley, 2001; The Lancet)
- Mislabeling often leads to misinterpretation of research findings

The present study

- Aimed to illustrate the importance of distinguishing between health status/functioning and QoL in cancer by examining relationships between the new Cancer Dependent Quality of Life (CancerDQoL) and other PROMs
- Patients (n=159) with a range of cancers were recruited from Barts Health NHS Trust and Maggie's Centre at Barts
- PROMs completed included the CancerDQoL, EuroQoL 5 Dimensions Visual Analogue Scale (EQ-5D-VAS) and the European Organisation for Research and Treatment of Cancer-Quality of Life Questionnaire-Core 30 items (EORTC-QLQ-C30)

Examples of Generic & Cancer-specific PROMs

Generic: EQ-5D (https://euroqol.org)

• Instructions: "Under each heading, please tick the ONE box that best describes your health TODAY"

• **5 Dimensions:** Mobility, Self-care, Usual activities, Pain/discomfort, Anxiety/depression

" MOBILITY

I have no problems in walking about
I have slight problems in walking about
I have moderate problems in walking about
I have severe problems in walking about
I am unable to walk about"

• Visual analogue scale (VAS):

"We would like to know how good or bad your health Is TODAY

This scale is numbered from 0 to 100. 100 means the <u>best</u> health you can imagine. 0 means the <u>worst</u> health you can imagine

Please mark an X on the scale to indicate how your health is TODAY"

Cancer-specific: EORTC-QLQ-C30 (https://www.eortc.org)

- Instructions: "We are interested in some things about you and your health..."
- Items 1-7 physical capabilities: strenuous activities; taking a long walk; taking a short walk; need to stay in bed/chair; help with eating, dressing, washing, toilet; doing work/other activities; doing hobbies/leisure activities
- Items 8-25 symptoms 'in the past week': short of breath, pain, need to rest, trouble sleeping, weak, lacked appetite, nauseated, vomited, constipated, diarrhea, tired, pain interfered with activities, difficulty concentrating, tense, worry, irritable, depressed, difficulty remembering
- Items 26-28 physical condition or treatment interference on family life, social life and finances
- **Item 29**: "How would you rate your overall <u>health</u> during the past week?"
- **Item 30**: "How would you rate your overall <u>quality of life</u> during the past week?"

Example CancerDQoL item CancerDQoL: Impact of cancer on 23 life domains, impact weighted by importance for QoL and overall Without cancer, my feelings about the future (e.g. worries, hopes) would be: average weighted impact (AWI) score very much better much better a little better the same worse (b) My feelings about the future are: -5.00 very important important somewhat important not at all important 2 -4.00 10 11 12 13 14 15 17 16 -3.00 Impact 20 21 Weighted -2.00 impact 23 -1.00 0.00 Noix sition takes social liden dence about drink anily rehip neals popearance relationship neals procedured that having chiconfidence about close relationship neals referred that having self-confidence about the close relationship neals referred to the confidence of th Time taken

Spearman's *rho* co-efficient matrix for the CancerDQoL (AWI score, General QoL and Cancer-Dependent QoL overview items), health status (EQ-5D-VAS), and EORTC-QLQ-C30 (Summary score, Role and Physical functioning subscales)

	CancerDQoL AWI scores	CancerDQoL General QoL overview item	CancerDQoL Cancer- Dependent QoL overview item	EQ-5D-VAS (Health status)	EORTC-QLQ-C30 Summary score (combined Global Health and Global QoL)	EORTC-QLQ- C30 Role functioning
CancerDQoL General QoL overview item	.395					
CancerDQoL Cancer-Dependent QoL overview item	.698	.267				
EQ-5D-VAS (Health status)	.253	.527	.168			
EORTC-QLQ-C30 Summary score (combined Global Health and Global QoL)	.442	.708	.289	.673		
EORTC-QLQ-C30 Role functioning	.469	.604	.350	.619	.728	
EORTC-QLQ-C30 Physical functioning	.289	.562	.188	.647	.677	.756

All correlations shown were significant ($\geq P$ =.05) after Bonferroni-Holm correction for multiple comparisons

Conclusions

- CancerDQoL is the first individualised questionnaire measuring the impact of cancer and its treatment on QoL
- EORTC-QLQ-C30 and the EQ-5D focus predominantly on physical capabilities and symptoms
- CancerDQoL takes a broader view by focusing on the domains of life which may be impacted by cancer and its treatment, and important for the person's QoL
- CancerDQoL is ready for use in assessing the impact of cancer treatments on QoL in clinical trials and in routine clinical practice

Visit <u>www.healthpsychologyresearch.com</u> for these slides and access to the CancerDQoL

