

Title: DEVELOPMENT OF A PATIENT-CENTERED CONCEPTUAL MODEL DESCRIBING THE IMPACT OF LIVING WITH HEPATOCELLULAR CARCINOMA

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OBJECTIVES:

Patient reported outcomes (PROs) developed to measure health-related quality of life (HRQoL) in hepatocellular cancer (HCC) assess a range of disease-related concepts; however, it is unknown which of them is the most patient-centric. We aimed to develop a preliminary conceptual model to illustrate concepts describing the impact of living with HCC, via literature review, to ultimately guide the measurement and selection of PROs used in clinical trials.

METHODS:

A detailed and targeted literature search was conducted in EMBASE and PubMed MEDLINE® (between 2000-2019) to extract data from qualitative and quantitative research on HRQoL in HCC. Patient-centered concepts were identified from the literature and summarized into a data extraction results table. These results were used to inform the development of a preliminary conceptual model, structured according to the Wilson and Clearly (1995) framework.

RESULTS:

After removing duplicates, the search identified 335 records, of which abstracts were reviewed. From these, the 47 full-text articles on HCC and HRQoL were reviewed; 36 records (qualitative, n=3; quantitative, n=30; mixed, n=2 and a review paper, n=1) were deemed relevant and data were extracted from them. The resulting preliminary model consists of a primary factor level, symptoms and side effects, which includes physiological concepts. The second factor level is the impact of symptoms, which includes all concepts referring to functioning and overall quality of life. This factor has been further categorized according to seven sub-levels of impact: activities of daily living, physical function, interpersonal, emotional, social, work, and coping.

CONCLUSIONS:

This draft conceptual model provides a patient-centered perspective of living with HCC. Although this model should be ratified by in-depth face-to-face interviews, for now, the model offers a valuable tool

for evaluating the content validity of existing PROs and provides a guide for a patient-centered measurement strategy in HCC clinical research.