

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

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## Objectives

- Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer. Patients with HCC have been found to have poorer quality of life (QoL) than the general population.<sup>1</sup>
- Conceptual models can be a valuable way of clarifying the expected impacts of a disease on patient well-being. There is currently no conceptual model of QoL in patients with HCC.
- The objective of this work was therefore to develop a preliminary conceptual model of QoL in patients with HCC.
- This preliminary conceptual model was used to guide the selection of Clinical Outcome Assessment (COA) tools included in a Phase III clinical trial in HCC.

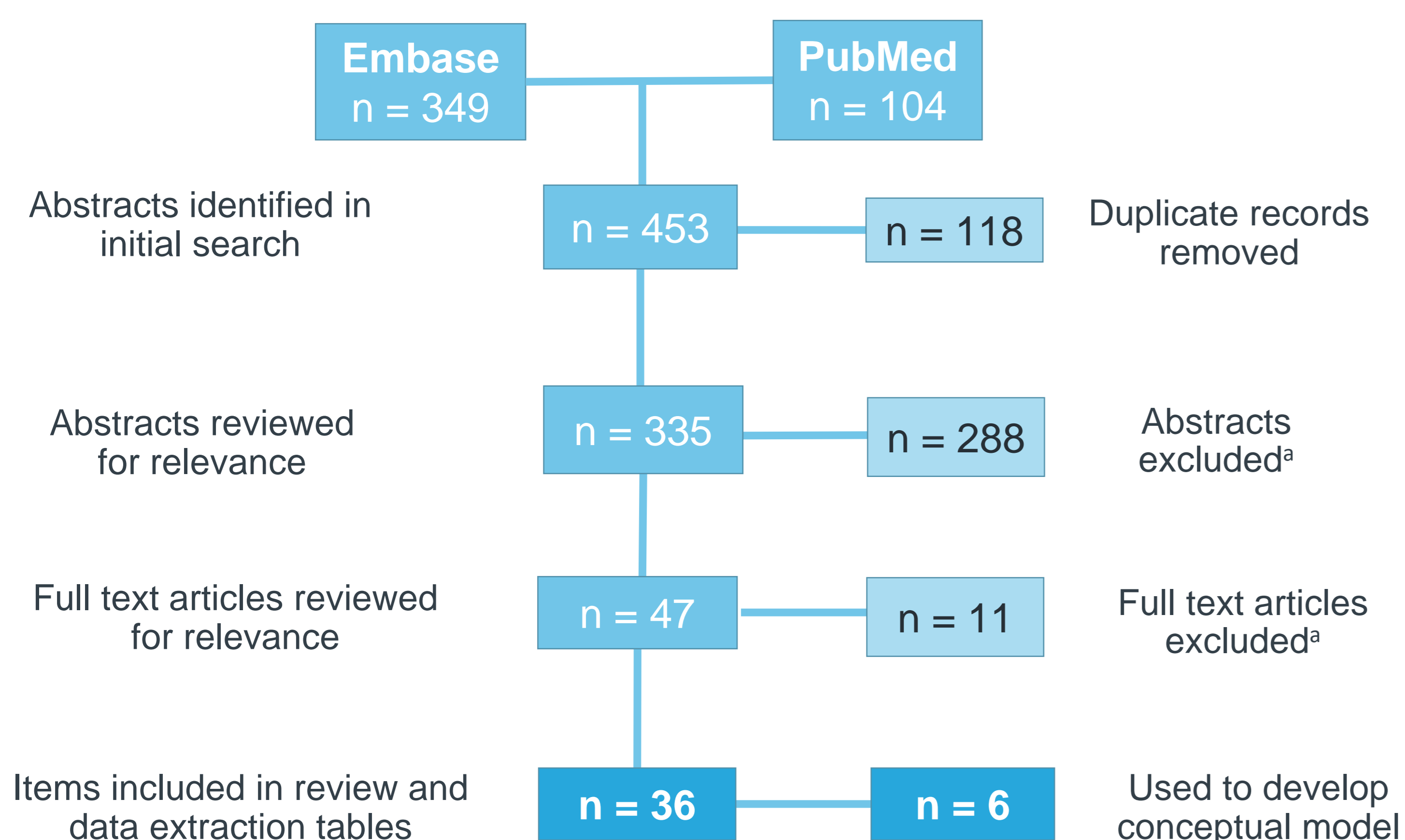
## Methods

- A targeted literature search was conducted in EMBASE and PubMed (2000-2019) to extract data from publications reporting qualitative and quantitative research on QoL in HCC.
- Concepts relating to the QoL or experience of living with HCC were identified from the literature and the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-HCC18<sup>2</sup> and summarized into a data extraction results table and grouped according to topical domains.
- These concepts were used for the development of a preliminary conceptual model, structured according to the Wilson and Cleary<sup>3</sup> framework.
- Each group of concepts was given a unique title to summarize its content; these were then arranged into factors (representing overarching themes) and sub-factors (representing more detailed themes within each factor).

## Results

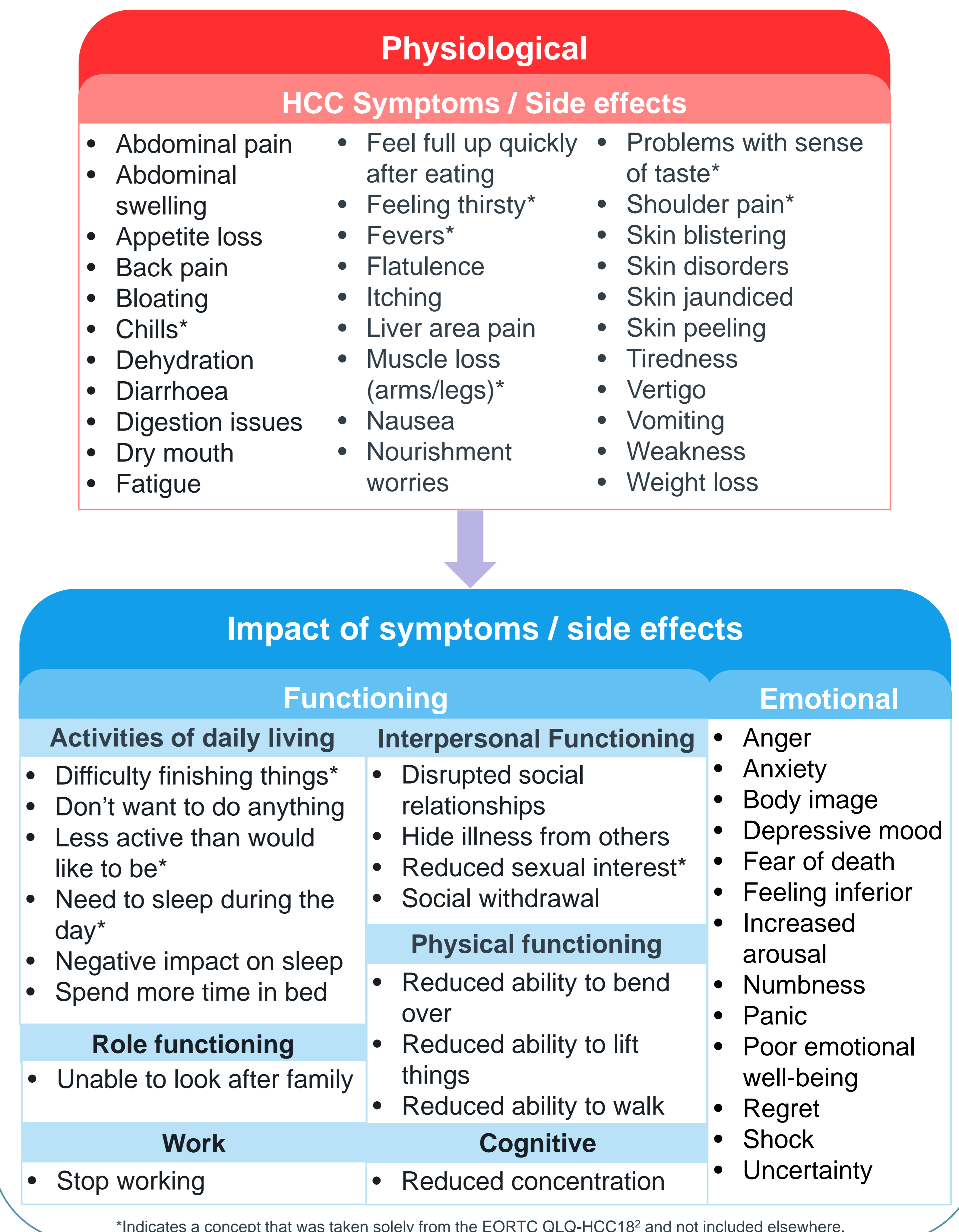
- 36 abstracts and full text articles were included in the literature review (**Figure 1**).
  - 30 abstracts and full text articles described quantitative research, 3 described qualitative research, 2 were mixed and 1 was a review paper.
  - Six of these full text articles<sup>3-8</sup> contained results (i.e. unique patient reported concepts relevant to QoL or patient experience could be identified) that were suitable for use in the development of the preliminary conceptual model.
- Two main factors were identified: **physiological** and **impact of symptoms/side effects**. Within the impact of symptoms/side effects factor, two sub-factors were identified: **functioning** and **emotional**.
  - The **functioning impact** sub-factor was grouped into the following: activities of daily living, interpersonal functioning, role functioning, work, cognitive and physical functioning.
- Two further factors were identified: **coping strategies** and **illness perceptions**. These were not included in the preliminary conceptual model as there is a lack of existing evidence to explain the relationship of these factors with the physiological factor and its impact. Furthermore, these are not symptoms, side effects or impacts, but are instead related descriptions of patient experience.

**Figure 1: Flow of abstracts and full text articles in literature review.**



<sup>a</sup>Items were excluded if: the population studied was not patients with HCC; they did not include information about the QoL/experience of patients with HCC; they were case reports, economic models, study protocols or studies with healthcare professionals (not patients).

**Figure 2: Preliminary conceptual model of QoL in patients with HCC.**



## Conclusions

- This preliminary conceptual model provides a patient-centered perspective of living with HCC.
- Six full text articles identified in the literature review<sup>2,4-8</sup> contained unique concepts relevant to QoL or patient experience, which were used in the development of the preliminary conceptual model.
- The preliminary conceptual model found that physiological side effects/symptoms of HCC impacted the following: activities of daily living, role, work, interpersonal, physical and cognitive functioning and the emotional well-being of patients.
- While further work is needed to ratify the preliminary conceptual model with patients, this model offers a valuable tool for evaluating the content validity of existing COAs and provides a guide for a patient-centered measurement strategy in HCC clinical research.
- Further qualitative research is needed to explore how illness perceptions and coping strategies may relate to or interact with the concepts within the existing model.

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