

DESCRIBING SELF-CARE BEHAVIOURS IN CANCER PATIENTS TAKING ORAL ANTICANCER AGENTS

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Background: Oral anticancer agents (OAAs) are effective drugs that can be managed autonomously by patients at home with appropriate self-care behaviours. However, OAA-related behaviours have been poorly investigated. The aim of this study was to explore the self-care behaviours adopted by patients treated with OAAs.

Methods: We used a qualitative descriptive design, with semi-structured individual interviews in patients aged ≥ 70 years and on OAAs for at least 3 months. Interviews were recorded, transcribed verbatim and analysed using content analysis with a deductive and inductive approach. Two investigators independently performed a three-round coding of the text using NVIVO®. We followed the Middle Range Theory of Self-Care of Chronic Illnesses, including the dimensions of self-care maintenance (i.e. behaviours to maintain illness stability), self-care monitoring (i.e. monitoring symptoms and side effects) and self-care management (i.e. actions to respond to symptoms), as an organising framework for extracted codes and categories.

Results: Overall, 22 patients with cancer were interviewed (mean age: 76 [\pm 5]; male 59.1%; lower secondary school education: 36.36%; tumour site lung: 22.72%). The content analysis yielded 36 codes and 9 categories. Self-care maintenance behaviours included patient strategies for ensuring adherence to OAAs, dietary adaptations and physical activity. Concerning self-care monitoring, patients reported monitoring clinical signs and symptoms related to OAAs intake, monitoring their general health status and attending all follow-up visits as recommended. Self-care management behaviours included both pharmacological and non-pharmacological management of common OAA-related side effects and communicating to the oncology team about any emerging side effects (via phone or during follow-up visits).

Conclusions: This study gives insights into self-care behaviours adopted by patients at home while they are taking OAAs. Evaluating patient self-care behaviours is important for establishing specific interventions aimed at improving patient self-care and patient quality of life by promoting an appropriate and safe use of OAAs.

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AN EXPLORATORY QUALITATIVE STUDY TO DESCRIBE THE EXPERIENCE OF USING A QUESTION PROMPT LIST FOR PATIENTS IN EARLY PHASE CLINICAL TRIALS

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Background: The decision to participate in phase I cancer clinical trials can be complex. Prior studies have suggested that some patients on early phase trials may not fully appreciate the purpose, risks and low chance of benefit. Question Prompt Lists (QPL) have proven benefit in studies across different medical specialties in empowering the patient to participate in their consultation. Although there is literature assessing the value of QPLs in cancer clinical trials, it has not been explored specifically in the phase I setting. This single centre qualitative study has described the patient's experience of using a customised phase I QPL.

Methods: A phase I specific QPL was designed with patients using an experience based co-design process. Following this, 13 patients were given the QPL to use in their consent consultation. Semi structured interviews were conducted, recorded, transcribed verbatim and analyzed using Colaizzi's (1978) descriptive phenomenology. The questions explored the patients' experience during the consent consultation; how patients used the QPL, what value was placed on it and why it wasn't used.

Results: Between July-September 2020, 13 patients were interviewed; age range 38-73; 7 male, 6 female. Five themes emerged: 1. Emotions expressed 2. Benefits of the QPL 3. Questions asked 4. Barriers to using the QPL 5. Future recommendations Described emotions included; vulnerability, fear, desperation and hope of trial success. Patients felt the QPL improved their participation, reminded patients what questions they wanted to ask and triggered questions not previously thought of. Barriers to using the QPL included; time pressures, fear of being judged and avoidance of distressing conversations. All 13 patients recommended using a QPL.

Conclusions: A QPL is a simple tool that has the potential to improve the patient's ability to ask the questions that are important to them. Patients that used the QPL felt that their confidence was bolstered to articulate concerns. As early phase trials increase in complexity, better and earlier orientation to the QPL could address the described barriers of its use. Therefore a QPL has the potential to enhance the informed consent process for the patient.

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