PATIENTS’ INVOLVEMENT IN THE EVALUATION OF PATIENT FACT SHEETS ON ORAL ANTICANCER DRUGS

INTRODUCTION

Oral chemotherapy prescription involves patient’s adhesion and home-based treatment management. Patients are looking for reliable and comprehensive information, in addition to verbal information provided by the healthcare team. Eleven French public structures develop patient information sheets on oral anticancer drugs, online-open access. The HAS "Haute Autorité de Santé" (French National Authority for Health) made recommendations regarding the conception of documents for patients. Do these existing fact sheets follow the HAS’s recommendations? Are they tailored to patient expectations, with clear and practical messages?

GOAL

The main objective of our work was to select among 280 existing patient information sheets on oral anticancer drugs (AKO), the information sheets to be preferentially offered to patients. Secondary objectives have then been identified: the latter are the availability of the selected tools to the hospitals and liberals professionals; the construction of a robust information sheet evaluation method in collaboration with patients...

RESULTS

Phase 1 is two independent evaluations by 2 healthcare professionals, approved by patients. It selects the 3 best information sheets per pharmaceuticals according to objective criteria of general presentation. At this point, 60% of information sheets are selected. Phase 2 is a triple independent evaluation of the 168 remaining information sheets by 198 patients with cancer. It evaluates the quality of the information sheet regarding patients’ need and expectations. A rigorous follow-up of patients' evaluations and feedback allowed us to obtain a response rate of 99.4% to all the questions and to collect 1169 patients’ comments. The remaining 114 information sheets undergo a final evaluation by a pharmacist/prescribing doctor duo (phase 3) in order to ensure that they contain the deemed necessary and sufficient information by the medical experts. The list of selected information sheets (1 to 2 fact sheets for 61 AKO) is on open-access online and is communicated to the health care team.

MATERIALS AND METHODS

A rigorous evaluation method with significant patients' involvement was built by a multidisciplinary professional working group representative of the patient care pathway. The evaluation was conducted in 3 complementary selection stages. It takes account of the HAS's recommendations. To conduct those three stages, three interview templates were created and tested with patients. The 280 existing information sheets, corresponding to 71 AKO marketed, are evaluated according to this methodology.

CONCLUSION

With 217 mobilized users, the originality of this work is the significant and permanent patients' involvement. The fact that the evaluation was done by the final recipients, made it possible to create the most adapted tools to their expectations. The perfect patient information sheet does not exist, we should use those chosen by patients.

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