

to the patient. We therefore developed (i) a core outcome set (COS) for HD treatment, and (ii) a patient-reported outcome measure (PROM) evaluating symptoms and impact on daily life.

METHODS:

Literature review established outcomes most commonly used in studies evaluating HD treatment. A Delphi study with health professionals and patients was conducted to rank and discuss the outcomes in terms of importance and completeness, and reach consensus on a COS. In addition, individual patient interviews (n=15) were held to gain insight into patient experiences with HD and treatment. A panel of experts subsequently developed a PROM that focused on the core outcomes. Face and content validity were assessed (n=10) using a retrospective verbal probing technique.

RESULTS:

Recurrent symptoms, complications and treatment satisfaction were the primary focus for health professionals, while patients were more concerned with overall impact on daily life. Patients ranked blood loss, pain and itching as the most bothersome symptoms. A PROM was developed, consisting of seven items covering three domains: severity of symptoms, impact on daily life, and treatment satisfaction (if applicable). The questions and response options were clear to patients and content validity was good. The questionnaire took approximately three minutes to complete.

CONCLUSIONS:

We developed a COS and a PROM for HD treatment. The PROM can be used in clinical trials as the primary outcome measure evaluating treatment effectiveness from the patient’s perspective. It can also support shared decision-making regarding individual treatment pathways in clinical practice. A psychometric validation study is currently underway.

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OP143 Conceptualizing Patients’ Experience With Atrial Fibrillation

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INTRODUCTION:

Conceptual models (CMs) are useful tools for researchers and health technology assessment bodies to understand the interplay among environmental characteristics (e.g., health care system), patient characteristics, health behaviors, and patient outcomes. The objective of this pilot study was to elicit perspectives of patients with atrial fibrillation (AF) and health care providers (HCPs) to develop a patient-centered CM of the AF patient experience in a US-based sample.

METHODS:

We developed two preliminary versions of the Andersen model of healthcare utilization (standard and patient-friendly versions) based on the published literature and the help of a patient advisor. For example, instead of describing “predisposing characteristics,” the patient-friendly CM describes, “what is it about me, or other afib patients that could impact disease or outcomes;” “enabling resources” is swapped for “helpful resources,” and “perceived need” is changed to “what impacts whether I believe I need to be treated”. Five patients from an online patient community and 10 HCPs from the University of Maryland Medical System provided feedback on the preliminary models. Audio recordings of interviews were transcribed verbatim, analyzed, and findings incorporated into a revised CM.

RESULTS:

Interviewee additions under “what impacts whether I believe I need to be treated” included: absence of symptoms and fear of experiencing an AF episode; under “helpful resources” suggested additions include resources for navigating insurer formulary/benefits. Suggested additional outcomes of interest include anxiety, bruising, and shortness-of-breath. While patients found the patient-friendly version easy to understand, HCPs required explanation of standard-version headers, for example ‘predisposing characteristics’ and ‘enabling resources’, which had been adapted in the patient-friendly version.

CONCLUSIONS:

Soliciting input from stakeholders ensures CMs are pragmatic, reflect the real-world experiences of patients and HCPs, and incorporate variables or other considerations not currently described in published literature. Researchers can utilize CMs to aid in selection of variables for observational studies.

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