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Attribute Development Using Continuous Stakeholder Engagement to Prioritize Treatment Decisions: A Framework for Patient-Centered Research

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ABSTRACT

Objectives: To develop a methodological approach for selecting, validating, and prioritizing attributes for health care decision making. **Methods:** Participants (n = 48) were recruited from community support groups if they had a child aged 26 years or younger diagnosed with a coexisting mental health condition and cognitive impairment. Six in-depth interviews eliciting care management experiences were transcribed and coded into themes following the principles of grounded theory and the constant comparative method. Six focus groups involving 42 participants assessed the relevance, priority, and meaning and inter-relationship among the themes. The positive predictive value and sensitivity assessed agreement on thematic meaning. A final list was selected from the top priorities with good agreement as candidate attributes. Attribute levels reflecting the range of experiences in care management decisions emerged from the verbatim passages within each coded theme. **Results:** Participants were the child's mother (73%), white (77%), married (69%), and on

average 48 years old. The children were on average 14 years old; 44% had an intellectual disability, 25% had autism, and more than half had anxiety or attention-deficit/hyperactivity disorder. All 14 attributes identified from the in-depth interviews were deemed relevant. The positive predictive value exceeded 90%, and the sensitivity ranged from 64% to 89%. The final set of attributes formed the framework for care management decisions consisting of six attributes (medication, behavior, services, social, treatment effects, and school) each with three levels. **Conclusions:** A systematic approach grounded in qualitative methods produced a framework of relevant, important, and actionable attributes representing competing alternatives in clinical decisions. **Keywords:** attribute development, health care decision making, qualitative methods, stated preferences.

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Introduction

Health care treatment decisions involve consideration of many competing alternatives and ultimately result in trade-offs among the different options available. Increasingly, discrete choice experiment (DCE) methods are being used to assess stated preferences and quantify trade-offs for health care treatment options across a wide range of medical conditions [1–4]. Typically, a DCE is embedded in a survey and is designed to elicit preferences for a hypothetical good or service depicted by a range of attributes, which could feasibly exist [4]. Because preference is a latent construct observed only through choices, random utility theory is the theoretical basis for DCE methods, such that individuals make choices that maximize their utility [4]. Choices reflect an observable component, which is a function

of the attributes, and a random component, which is a function of unobservable preference variation [4]. The random component is independently and identically distributed and can be estimated.

Identification of meaningful attributes that reflect real-world trade-offs is central to DCE designs [5]. Good practice guidelines emphasize the importance of attribute identification as an initial step in designing DCEs [6]. Because it is not possible to include every attribute deemed important, one must identify those attributes considered important to most individuals. Doing so avoids omitted variable bias [4], which renders data that are not interpretable because selections reflect inferences about omitted attributes. In addition, if an attribute closely resembles the underlying construct being measured, one attribute will dominate all others, and thus no information is gained about the other

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attributes [5]. The presence of a dominant attribute results in deterministic choices rather than stochastic choices, which violates the random utility theory assumption of nonzero probability for each choice [5]. Finally, the levels should be sufficiently different so that individuals do not ignore an attribute because each level appears to be the same [4].

Methods for identifying attributes include literature reviews, expert reviews, patient surveys, professional recommendations, or interviews and focus groups [7]. Despite support for qualitative research [8], there is a lack of adequate guidance on data collection and analysis to isolate key attributes [7]. Several investigators have conducted interviews and focus groups to identify a manageable number of attributes [9,10]. Studies, however, have not described in detail a systematic process for using qualitative data to identify attributes and levels that are most salient and important for health care treatment decisions.

The present study describes a qualitative approach for identifying, validating, and prioritizing attributes involved in health care management decisions. The target population is caregivers of a child with an intellectual disability and a coexisting mental health condition and who often requires services from the developmental disability system as well as the mental health system. These systems, however, are disconnected, and families must make trade-offs among care management alternatives that are available in one system or the other. By identifying attributes and levels, beyond solely the properties of a medical intervention, that represent real-world trade-offs and reflect variants in the delivery or availability of a service, the aim was to develop a DCE to assess caregivers' preferences for a care management plan for their child. A better understanding of the care management options, both type and mode of delivery, that are preferred can be used to enhance comparative effectiveness research. It is anticipated that the methodological approach outlined here can be tailored for other medical conditions and other populations.

Methods

According to recommended reporting standards [5], we provide the rationale for the qualitative methods, sampling frame, procedures, and data analysis.

Study Design and Rationale

The research design used qualitative methods iteratively using continuous patient engagement [11]. Grounded theory was the qualitative method selected because this generally is suitable when studying individuals' response to a particular experience [12,13]. In contrast, a phenomenological study investigates the meaning of an experience to an individual, and was not suitable for this study [13]. In grounded theory, textual data from the transcribed interviews are analyzed to generate categories, with the goal of identifying the dimensional properties of the category [13]. The categories can be viewed as attributes, and the dimensional properties can reflect attribute levels.

Academic researchers worked with coinvestigators who were stakeholder advisors who had raised a child with special health and mental health care needs. In this role, stakeholder advisors provided more than just an expert opinion; rather, they helped to conceptualize the research question, identify the target population, recruit participants, analyze the data, and prepare manuscripts. Stakeholder advisors were instrumental in identifying eligible participants with a wide range of experiences with health care decision making for their child with developmental and mental health conditions. The stakeholder advisors cofacilitated the focus group meetings, reviewed the transcripts from in-depth interviews and focus group discussions, and assisted with the

data analysis by verifying whether verbatim passages from the transcribed interviews had been coded accurately into categories that eventually would comprise the attributes. This input throughout the project ensured the interpretability and meaningfulness of the attributes related to health care decision making.

Study Population and Sample Recruitment

Eligible caregivers were identified through the stakeholder advisors, community outreach to organizations and support groups throughout Maryland, and our research partner PatientsLikeMe. The target population was caregivers of a child who was 1) 26 years old or younger at study recruitment; 2) had an intellectual, emotional, or social developmental disability; and 3) had a concomitant mental health condition. A flyer describing the study was distributed by e-mail or in person. Interested caregivers contacted the project coordinator (W.C. C.) who conducted a brief telephone screening through a questionnaire to confirm eligibility. In a face-to-face meeting with eligible participants, research staff reviewed the study purpose, the expectations for those who joined the study, and the alternatives if individuals no longer wanted to be in the study. Written consent was obtained from those willing to join the study. Participants were reimbursed with a \$50 gift card for completing the study. The study was reviewed and approved by the [blinded name] Institutional Review Board, University of Maryland.

Procedures for Qualitative Interviews and Focus Groups

Phase 1: In-depth interviews

Initially, in-depth one-on-one interviews were conducted to gather a rich description of care management experiences because individuals generally are more hesitant to share detailed personal experiences in focus groups. In a one-on-one setting, the interviewer is able to probe into the specific details of the circumstances associated with a health care decision and obtain rich descriptions of the process influencing an individual's health care decision.

Six individual in-depth interviews were completed in a private room at a clinic facility. Three research team members were trained by the principal investigator to conduct the in-depth interviews before going into the field. A semistructured field guide focused the discussion around topics related to individuals' experiences leading up to the diagnosis and over the course of care as well as care management decisions and the future outcomes they desired for their child. A rich description of the key informants' experiences from the time they first suspected a problem to their present situation was obtained from the one-to-one and half-hour interviews. All interviews were recorded, with permission, and transcribed verbatim.

Phase 2: Focus group interviews

Once the research team generated a list of attributes from the in-depth interviews, focus group participants completed brief activities to provide feedback to validate the attributes. Validation was achieved via triangulation of data from focus group activities, focus group discussions, and in-depth interview transcriptions. This ensured that attributes were relevant and important to a broader group of caregivers, and were not unique experiences of those who participated in the in-depth interviews. This also verified that investigators did not misinterpret or misrepresent attributes and ensured the tradability of attributes.

Five focus groups, conducted with 42 individuals who did not participate in the in-depth interviews, were held at a support group meeting facility and lasted for 2 hours. One group was conducted online through the PatientsLikeMe support network.

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