Reviewer’s report

Title: Integrating patient perspectives in medical decision-making: A qualitative interview study examining potentials within the rare disease information exchange process in practice

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Reviewer: Margaret Holmes-Rovner

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"Integrating patient perspectives in medical decision-making: A qualitative interview study examining the potential of shared decision-making in practice within the rare disease information exchange process" is an interview study of the patient and physician experience of clinical encounters. The purpose is to examine the implementation of the shared decision-making concept in the region of Lower Saxony in Germany. The authors further explored whether efficiency potentials exist for the health care system within the rare disease field. The authors suggest this advances the field of shared decision making, since rare diseases have not had much attention. Patient experience of clinical care and decision making may be different from other chronic diseases.

The design is conceptually appropriate. A strength is using the method of Mayring to do qualitative open-ended interviewing within theoretically established a priori categories. In this case, the choice of categories from Charles et al is helpful to addressing the major issues in the field, while still capturing the voices of the interviewees. An inductive-deductive approach was used using the predefined items. This approach, however, steers between over-defined categories and open-ended questioning. The categories taken from Charles et al are: 1. The "patient-physician relationship," 2. "Participation," 3. "Information exchange," and 4. "Decision-making." These provide a framework for the semi-structured interviews. Since the authors did not derive the categories from the interviews, as might be done in a "grounded" approach, it is important for readers to understand how the conversations were structured. This is not possible without examining the interview guide. The guide should be included as an appendix. The authors make the distinction between the semi-structured questions, and the analytic approach, saying that they, "evaluated the responses based on a qualitative content analysis in an inductive-deductive approach." This process is not fully described. The authors simply state that "all evolving topics in the evaluation process are assigned to the research items and the evolving subcategories". The results suggest they were successful in capturing patient/caregiver perspectives, as some categories specific to rare diseases are reported, such as travel to many specialists and the "psychosomatic corner" reflecting the often-encountered problem that providers may suggest patient symptoms are imagined rather than real.

The participant recruitment strategy is not well described. This is another problem of incomplete reporting of the strategy and the underlying patient population from which recruitment came. Patients and family members were recruited by the Freiburg Centre for Rare Diseases at the Department of Dermatology of the University Medical Centre. However, it is not clear if a systematic process was used, beyond the need to include a diversity of diseases. Was any kind of
balanced sampling done? The recruitment process is also not described. Was the contact by mail? Telephone? Was it in clinic visits? What was the response rate? If identified patients refused, what was the strategy to select the next person to contact? What kind of data set was used by the Freiburg group? Was it a research database? Was it a marketing data base? Etc. Had patients agreed in advance to participation in research? What kinds of bias might this introduce?

The comparisons among patients, providers and family members would be stronger if the physicians were those who saw these patients. It is understandable that recruitment might make this prohibitive, but it weakens the comparative nature of the analysis. The provider sample represents a diversity of types of physician practice and other providers. However, the level of experience with patients with rare diseases, and the proportion of patients with rare diseases seen by these providers is not described. Thus, it is difficult to know if these are representative of the types of providers patients might see across the spectrum of their search for care.

Results are robust and useful in expanding knowledge of shared decision making to those with rare diseases. The pattern of individual, informed decision-making by patients, followed by paternalistic approaches shows a level of frequent conflict between expert patients and physicians who worry that patients may not follow their recommendations. The dynamic that emerges is one that lacks candor, and that could potentially be well addressed by shared decision making. Adjudicating what counts as good evidence and viable options in this field is challenging. One minor problem in the organization of the manuscript is that new results appear in the limitations section. These data belong in results if they are to be reported, along with better description of the analytic approach. If these are ad hoc retrospective analyses rather than a priori planned ones, this should be stated. Otherwise, the authors should leave these data out if they do not contribute to understanding the sample.

Clearly, the dynamics of a long care-seeking process for patients drives much of their perspectives as reported in the study. The report is appropriately focused largely on patient perspectives. This is a major strength of the study. Perspectives of physicians and family members provide the clinical context and illuminate the constraints and possibilities for expanded shared decision making in this important field. The report is an important first step into further exploration of how information exchange could be improved to support better decision-making across multiple provider settings.

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

Unable to assess

Does the work include the necessary controls?
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No

Are the conclusions drawn adequately supported by the data shown?
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