

Abstract

Two related conceptual frameworks have been developed to guide outcome measurement. The Framework for Outcome Measurement (FROM) captures the integration of key generic concepts central to recent international thinking in the area of health and disability. The second, Living with Aphasia: Framework for Outcome Measurement (A-FROM), focuses directly on communication and is intended to guide thinking about outcome measurement in aphasia. User-friendly and accessible schematics represent potential outcome domains and highlight the centrality of quality of life. The frameworks and methods of development will be discussed. Guidelines for potential applications will be presented with examples from two A-FROM derived tools.

Full Text

Noreau, Fougeryrollas and Vincent (2004) suggest that there is a marked disparity between clinically based measures of skills and performance and what is available for measuring outcome in the area of social participation and meaningful life involvement across rehabilitation disciplines. Aphasia is no exception with research indicating that there is little agreement in the field regarding outcome assessment (Simmons-Mackie, Threats & Kagan, 2005). Reasons may include the complexity of outcome measurement, our traditional practice trajectory or the lack of a common framework for assessment and intervention that includes outcomes of aphasia interventions related to real-life participation. To begin addressing these challenges, two related conceptual frameworks have been developed in schematic form: first, a user-friendly and accessible *Framework for Outcome Measurement (FROM)* that captures the integration of key generic concepts central to recent international thinking in the area of health and disability (e.g. World Health Organization's International Classification of Functioning, Disability and Health, ICF, WHO, 2001; disability specific models such as Noreau, Fougeryrollas, & Vincent, 2002); and second, a derivation with specific application to aphasia, *Living with Aphasia: Framework for Outcome Measurement (A-FROM)*. *A-FROM* is a conceptual framework intended to guide thinking about outcome measurement in aphasia. The FROM and A-FROM focus explicitly on "real life" outcomes. In addition, the concept of quality of life (QOL) is represented within the schematic as a dynamic interaction of relevant life domains. Unlike more comprehensive frameworks (e.g. ICF), A-FROM focuses specifically on aspects of life related to communication. By using a common framework such as A-FROM, research can target meaningful outcomes of a wide range of interventions and contribute to a more effective and efficient organization of data related to evidence-based practice.

Methods of Framework Development

Development of these frameworks drew from a comprehensive review of current literature, current frameworks and models of health and disability, our own experience and the experience of colleagues. Most importantly, work on both frameworks was grounded in the needs and opinions expressed by various stakeholder groups via a focus group methodology. Focus group participants consisted of people with aphasia, families, speech-language pathologists and related rehabilitation professionals. Focus group discussions were recorded and transcribed and main themes extracted from the transcriptions. As input was generated via focus groups, frameworks were designed and altered, and additional input was sought. Thus, the process of framework development was cyclical and participatory allowing for on-going input and revision. The resulting frameworks (FROM and A-FROM) provide a schematic

representation of domains of life that are relevant to living with a health condition (FROM) or, more specifically, aphasia (A-FROM).

Framework Applications

Currently, two applications of A-FROM are in development. Conceptual features of the tools and how they relate to A-FROM will be presented in order to demonstrate application of A-FROM values and concepts. (Psychometric properties of the tools will not be discussed as this research is in progress). One application has been designed specifically to capture real-life outcomes for individuals with aphasia following participation in a community-based program. This tool captures the perspectives of people with aphasia across the life domains of A-FROM. The second tool focuses on capturing systems outcomes - that is, assessment of specific environments relevant to individuals with aphasia. In a prior study of communicative accessibility of health care facilities (Kagan, et al. 2004), investigators discovered a need for a tool that captured changes at the “systems” level, such as improvements in signage or use of aphasia friendly materials and the impact of such changes on patients/clients. Examples from both assessments will be presented and guidelines for developing applications will be discussed.

Conclusion

Consumers, clinicians, policy makers and funding sources deserve a coherent body of evidence regarding outcomes of intervention. Presently the aphasia literature provides evidence of reduced impairment and increased functionality after aphasia therapy; however, there is less evidence regarding the effects of aphasia intervention in domains such as life participation, emotional well-being or environmental support. This presentation will describe two conceptual frameworks, the FROM and A-FROM, that have been designed to guide outcome assessment. These frameworks have the potential for organizing research and clinical assessment and insuring that meaningful, real life changes are represented. Although A-FROM is designed to organize outcome measurement in aphasia, with slight adaptations, it would be appropriate for outcomes associated with other communication disabilities (e.g. motor speech disorders). The generic version (FROM) is applicable to a range of health conditions or communication disabilities.

Both frameworks are compatible with the World Health Organization’s ICF. Since the ICF is a classification system meant to provide broad indications of function, it does not specifically recommend assessment protocols. Rather the WHO is seeking assessment protocols and frameworks that can successfully map onto the ICF. The A-FROM addresses this request by adopting conceptual underpinnings of the ICF and providing structure to aphasia assessment. Thus, applications of FROM or A-FROM can be designed to translate to ICF codes and scoring. This is potentially useful in the event that ICF codes and scores become mandated by funders or government. The frameworks offer the advantage of simplifying ICF while retaining outcome complexity. Both FROM and A-FROM incorporate the important concept of “quality of life” as an intersect among the various domains of life, thus enhancing comprehension of the relationship between domain specific results and QOL measures. Other frameworks (e.g. ICF) do not explicitly address the issue of quality of life. Finally, A-FROM can be used to guide the study of aphasia intervention. For example, it can provide a framework for questions regarding the impact of intervention in one sphere of the framework on other spheres.

This presentation will describe the frameworks, the rationale and methods of framework development and a range of potential applications. Suggestions for, and challenges in developing applications of A-FROM will be discussed.

References

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