EXPLORING A TELEREHABILITATION UNIFORM DATA SYSTEM

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INTRODUCTION

Concerns about access to healthcare have propelled much of the interest in clinical applications such as remote assessment [1] and intervention in medicine and rehabilitation [2-4]. The purpose of any medical care is to maintain or improve health, well-being, and access. The use of telerehabilitation (TR) applications (i.e. delivery of rehabilitation services at a distance) has increased all over the world as they differ not only in their services but also with respect to the outcomes being measured.

Demonstration and pilot projects have been valuable in confirming basic feasibility of TR but most have not been guided by a rigorous systematic research framework for evaluation. Such information is critical if policy-makers and decision-makers are to be convinced of the usefulness of continued investment in this technology, particularly given competition for scarce resources. Consistency and most important uniformity in outcome assessment allows comparability of results over time and among providers, thus increasing the likelihood for improving the processes of care and establishing cost-benefit guidelines [5], in addition to its efficacy and satisfaction. The development of evidence-based practice in rehabilitation is often hampered by small sample sizes and by the diversity of the sample population. The same problems of small sample size and lack of standardized interventions also limit the development of outcome measures in TR [6].

A Uniform Data System (UDS) is a minimum or limited set of variables identified as core data points, gathered across all practitioners/settings, which are managed in a central database. There have been specific UDS in certain disciplines that have guided the development of a TR UDS. The field of rehabilitation addressed this issue about 20 years ago with the creation of the Functional Independence Measure (FIM) [5] managed by the Uniform Data Set for Medical Rehabilitation and used across rehabilitation settings nationally. Additional examples of UDS include the Traumatic Brain Injury National Data and Statistical Center, the National Alzheimer's Coordinating Center Database, and the National Outcomes Measurement System for the American Speech-Language Hearing Association.

This paper presents a two phase TR review framework of activities that have occurred in the past year: 1) conducting a meta-analysis of TR outcomes; and 2) hosting an expert panel meeting of TR leaders from around the world to discuss the current status of TR outcomes.

METHODS

Meta-Analysis

Before conducting the meta-analysis, an internal group familiar with the TR literature met to discuss key outcome areas to assist with guiding the literature search. The three main variables agreed upon included; cost-effectiveness, efficacy, and satisfaction. These key areas were then expanded with sub-heading terms pertinent to the area of rehabilitation outcomes. The computer search, assisted by an expert librarian cognizant of complex database systems, assisted with the literature search. The following databases Medline, PubMed, EMBASE, for general medical issues, Cumulative Index to Nursing & Allied Health Literature (CINAHL) for nursing and

allied health issues, and Cochrane database for systematic reviews, PsychInfo, and Psychosocial were used based on resources within the University of Pittsburgh Library System. Studies published in peer-reviewed journals with a TR component were included with a specific set of inclusion/exclusion criteria. The articles were reviewed by the internal group along with a data extraction spreadsheet template with pre-defined variables such as types of participants, setting, outcomes being measured, and conclusions made. Studies were also then grouped within the three main focus areas (i.e. cost-effectiveness, efficacy, and satisfaction) to assist with dissemination of results for future use.

UDS-International Consensus Group (UDS-ICG)
An initial planning meeting for what is being called UDS-ICG was suggested by team members within the Rehabilitation Engineering Research Center on Telerehabilitation (RERC-TR) at the American Telemedicine Association's Annual Meeting in San Antonio, Texas back in May 2010. The UDS-ICG is made up of experts within the TR field assisting to systematically solicit, organize, and structure collective judgments and opinions on addressing a UDS for TR outcomes.
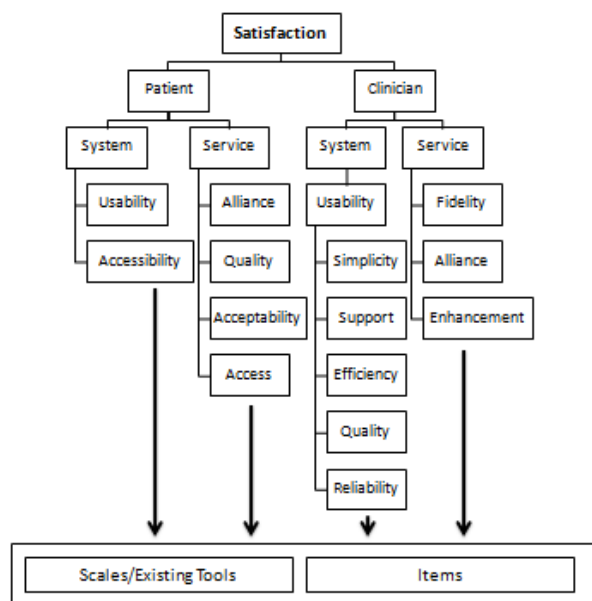
RESULTS

Meta-Analysis

Based on the initial computer search over 1700 articles were reviewed and 280 studies were retained after the initial screening of titles abstracts and full-text articles being retrieved. Each member of the internal group was an expert in one of the three variables while assisting in the other two as needed. Based on the literature search it was determined that there are no standardized outcome tools being used within to assess the overall quality of the assessment, including the cost-effectiveness, efficacy, and satisfaction. In addition, the quality of the methodology and or reporting of the studies were weak.

UDS-International Consensus Group (UDS-ICG)
Members of the RERC-TR internal group identified and enlisted 13 TR experts across
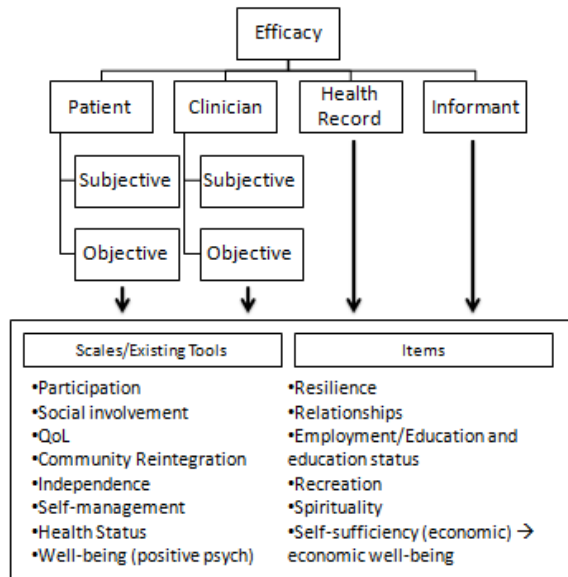
academia, public policy, and management roles based on their acknowledged expertise, publication, and programs within the TR discipline. The RERC-TR internal group forwarded a brief report with bulleted points from reported literature pertinent to the three main areas and questions to consider before attending a two day meeting in Pittsburgh, PA. Each one of the core areas was discussed at length as Figures 1-3 describe the services (i.e. patient and clinician) and what stakeholders (i.e. patients, clinicians, researchers, payors, and facility) should be looking for when developing a UDS for TR outcome tools.

Figure 1: Satisfaction Flow-Chart of Outcomes

Figure 2: Cost-Effectiveness Flow-Chart of Outcomes

Figure 3: Efficacy Flow-Chart of TR Outcomes

DISCUSSION

The UDS-ICG discussed the integration of TR outcomes within their respective organizations as three interesting themes emerged from the meeting: (1) the need for a TR UDS; (2) the need for aligning TR outcomes instead of creating independent measures within study designs; (3) the importance of disseminating these results to individuals who are currently implementing TR. Telerehabilitation is still in its infancy but undergoing rapid development. The main challenges acknowledged when creating a UDS for TR is the constantly changing of technology, lack of appropriate study designs, sustainability of applications, valuation of health outcomes, and implementation resistance.

CONCLUSION

The second phase of the meta-analysis is being conducted with the assistance of the UDS-ICG. An accepted, standardized set of definitions and outcome measures describing TR is critical for clinical decision making, optimal communication among caregivers, and research in different settings. Further investigation of a UDS consisting of the efficacy, cost-effectiveness, and satisfaction areas is being conducted.

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