Qualitative descriptive study – Protocol

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Title

Experiences of the use of an iPad application (ADOC-E) for shared decision making around goal setting in rehabilitation: a qualitative descriptive study

1. Background

Goal setting, defined as "the establishment or negotiation of rehabilitation goals"(Levack et al., 2012), is considered a key part of clinical rehabilitation (Levack et al., 2015). Goal setting within rehabilitation is a common practice ultimately geared toward helping patients make functional progress (Dicianno, Henderson, & Parmanto, 2017). Levack et al.'s (2015) systematic review defined rehabilitation goals as "a desired future state to be achieved by a person with a disability as a result of rehabilitation activities. Rehabilitation goals are actively selected, intentionally created, have purpose, and are shared (where possible) by the people participating in the activities and interventions designed to address the consequence of acquired disability" (p.8). The review also demonstrated that goal setting has face validity as a method to enhance communication and collaboration within rehabilitation teams and may result in improved patient-reported quality of life after rehabilitation.

Research from psychology suggests that the right kinds of goals can have a significant effect on human performance across a wide range of activities, where a goal is defined as an 'internal representations of desired states, where states are broadly construed as outcomes, events, or processes' (Austin & Vancouver, 1996, p. 338). For this reason, the act of sharing decisions between therapist and client is considered a fundamental part of the rehabilitation process. Several studies have shown that patient involvement in the complex activity of setting rehabilitation goals leads to measurable psychosocial and functional improvements (Dicianno et al., 2017; Lloyd, Roberts, & Freeman, 2014; Schoeb, Staffoni, Parry, & Pilnick, 2014; Tomori et al., 2012).
Shared decision-making has been advocated as a way to guide conversations between patients (and families) and the clinical team to improve the quality and person-centeredness of clinical decisions. The end result, or purpose, is to ensure that patients are well informed, meaningfully involved in the decision-making process, and receive tests and treatments that reflect their goals and concerns (Ekdahl, Hellstrom, Andersson, & Friedrichsen, 2012; Sepucha, Breslin, Graffeo, Carpenter, & Hess, 2016).

The use of technology and electronic tools (e.g. smartphone, apps and websites) has been suggested as a way to improve the engagement of users in meaningful goal-setting, and as a way to facilitate shared decision making between patients and health professionals (Dicianno et al., 2017; Parmanto et al., 2013; Rose, Rosewilliam, & Soundy, 2017).

The Aid for Decision-making in Occupation Choice (ADOC), created by Dr. Tomori et al. (Tomori et al., 2012) is an iPad application that helps patients express what they wants or needs to focus on in rehabilitation, and encourages them to participate in the goal setting process in rehabilitation.

ADOC involves the use of text and illustrations to enhance conversations around the possible goals of rehabilitation. Goal topics in ADOC are based on everyday activities and social roles, drawn from "activities and participation" domain of the International Classification of Human Functioning, Disability, and Health (ICF) (World Health Organization, 2001). By choosing illustrations, clients and therapists identify goals and the prioritization of occupations that influence choice of occupational therapy interventions. ADOC also includes tools to help prioritise goals, aids discussion of patient and therapist perspectives the goal of therapy. The app also provides a numeric measure of the client's satisfaction with the selected activities, which allows for re-evaluation and objective measure of the client's progress. This measure can be repeat at a later date to evaluate progress toward each goal from the patient's perspective.

The results of the goal setting and measurement can be printed out a document to be included in the patient's clinical notes. ADOC was initially developed for occupational therapy, but has wider application to goal setting for the interdisciplinary team.

ADOC has been tested extensively in clinical practice in Japan. Prior research on the Japanese version of ADOC has demonstrated that the app helps occupational therapists set person-centred goals in rehabilitation (Tomori et al., 2012), that patient satisfaction score derived from ADOC are valid and reliable (Tomori et al., 2013), and that people with Mini Mental State Exam score as low as 9 (indicative of moderate cognitive impairment) can use ADOC-E to communicate their preferences regarding meaningful areas of activity and occupation to their health professionals (Tomori et al., 2015).

A Level IV questionnaire design study was completed with 37 occupational therapy practitioners and 94 client participants aged 60 to 80 years in Japan. The study determined the effectiveness of ADOC app for client-centered goal setting. Both clients and occupational therapy practitioners perceived ADOC as a valuable shared decision-making tool for client goal setting. Mean measures for both the client participants and the occupational therapy practitioner participants were consistent in finding the ADOC app useful in the interview process to select occupations and leisure activities and to set client-centered goals for therapy (Tomori et al., 2012).

In 2015 an English version of ADOC, named ADOC-E was developed and tested with a Delphi-style survey involving 14 expert occupational therapists from four countries (New Zealand, Australia, UK and the USA) and 24 health service users from three disability and rehabilitation organisations in New Zealand. The results of the study show that the majority of the ADOC-E images can be identified correctly by rehabilitation or residential care service users as a fair representation of the concept they are intended to represent and so that they fit for purpose in terms of achieving the objectives of the ADOC-E application (Levack, Tomori, Takahashi, & Sherrington, 2018).

2. Research Questions

- How did health professionals and patience experience the use of ADOC-E app?
- What health professional like or do not like about ADOC-E?
- How health professional think the ADOC-E app can be incorporate into clinical practice?
- In which extent ADOC-E influence the share decision making for goal setting in clinical practice?
- Did ADOC-E change or effect patient's outcome?

3. Aim of the study

- To investigate preliminary experience of health professionals and patients regarding the use of ADOC-E to facilitate shared decision making around goal setting in rehabilitation.
- To develop an understanding of how ADOC-E-E can be usefully incorporated into clinical practice; what health professionals and patients like and do not like about the app; how ADOC-E-E aligns with other clinical processes and practices; how ADOC-E influences clinical decision-making in everyday rehabilitation setting; and what patient outcomes or process outcomes ADOC-E might most affect.

4. Study design

We will conduct a qualitative descriptive analysis consisting of semi-structured interviews with health professionals and patients from public and private rehabilitation services in the Wellington region, New Zealand.

The interviews will be conducted during the recruitment phase (only with therapists) and before discharge or within 4 weeks from using ADOC-E for first time (with therapists and patients).

5. Study activity

5.1 Participant recruitment:

We will recruit allied health professionals and patients from public and private rehabilitation services in the Wellington region (from the rehabilitation services at Hutt Valley District Health Board and ABI Rehabilitation in Porirua).

We will recruit 6 - 12 health professionals and provide them with an iPad, with the ADOC-E app already installed and with a short, in-person training in the use of the application ADOC-E. They will be asked to use ADOC-E with patients in their service as part of their usual goal setting process.

Therapists will not have any restrictions in the use of ADOC-E. They will be free to use it as many time as they deem necessary. Therapists will have to document the day they use ADOC-E, mention the initial of the patient's name and the duration of the intervention. Moreover, they will have to save the PDF that comes at the end of any ADOC-E session, in which all the data, the goals identified and the level of patient satisfaction are reported.

From those patients who have used the ADOC-E with their therapist, will be invited to participate in the study. The 6-12 patients recruited will be interviewed to explore their experiences and perceptions of the use of ADOC-E app for goal setting in rehabilitation.

To be included in the study, the health professionals must be qualified and registered allied health professionals (physiotherapists, occupational therapists, speech therapists or nurses), and undertake goal setting with patients in their rehabilitation service as part of their usual role. Participants will not be remunerated economically to participate to the study, however, the department will receive the free and latest version of the software ADOC-E for use on their own devices after the study.

Patients will be eligible to participate in the study if they are adults over 18 years of age, are current recipients of hospital or community based rehabilitation services, are able to have a basic conversation in English about their preferences with at least simple phrases and words and score a minimum of 3 on the Montreal Cognitive Assessment (MoCA) exam. The MoCA results within 3 has been shown to be equivalent of MMSE of 9 (Wong et al., 2018). Type of injury or illness and time since injury/illness onset are not reasons for exclusion from the study. All patients participating to the study will be rewarded with a 20$ voucher.

We will use purposeful sampling to aim to recruit health professional from different professional backgrounds, and with different durations of clinical experience. We will also purposefully sample patients in order to include people from a range of different age groups, both men and women, people from different ethnicities, and with different levels of cognitive ability based on the MoCA test. The health professionals will be welcome to use ADOC-E with any patient at their discretion. However, not all patients will be included in the study. The health professionals will also approach potential patient's participants for the study providing them with written information on the study and asking whether they might be interested in contributing information about their experiences. If they agree, our lead researcher will then meet with the participants to explain the study to them and to seek written informed consent.

5.2 Informed Consent

All participants must provide written Informed Consent form before contributing to any data collection. We will provide a "Participants information sheet" to all people, given them at least one day to consider the study and opportunities to ask questions in person before joining the study.
Participants will be free to withdraw from the study at any time for any reason without prejudice to future care, and with no obligation to give a reason for their withdrawal.

6. Data collection

All participants will be invited to participate in a face-to-face, semi-structured interview (see Appendix I). Two interviews will be conducted for each therapist and patient participating in the study, after they have signed the consent form.

The interviews with health professionals will take place in their working place during working hours. Each interview will last for approximately 30-60 minutes. Interviews will be performed between March and September 2020, with the first interview held when the therapist first starts using ADOC-E and with the second interview at approximately 2 months later.

The interviews with patients will take place in the hospital in an environment that is comfortable for patients and where they can feel at ease. Each interview will last for approximately 30-60 minutes, or more if the patient needs more time, including undertaking the interview in more than one sitting. Interviews will be performed between March and September 2020, with the first interview shortly after the patient has been involved in goal setting using ADOC-E (within a few days) and the second interview shortly before or after discharge from the rehabilitation service. For each patient we will also gather basic demographic information: age, gender, ethnicity, primary diagnosis and current residential status and MOCA scores.

Interviews will be recorded with a high-quality digital recorder and transcribed verbatim. Interviews will be confidential with pseudonyms used to identify each participant in the transcripts. Any typist who transcribes the interviews, but who is not otherwise involved in the study, will sign a confidentially agreement before starting this work.

7. Data Analysis:

We will use qualitative content analysis to explore the data from the interview transcripts. This entails a data reduction process by focusing on selected aspects of data that are relevant to our research question (Schreier, 2012, p. 7).

We will use NVivo, qualitative data analysis computer software, to help manage the interview data and data coding. As is consistent with qualitative thematic analysis methods, data coding will involve the constant comparative method to bring out the essence and meaning of the data that participants will provide (Lambert & Lambert, 2012). Each transcript will be read and re-read incorporating findings from additional interviews as the study progresses. Through coding we will outline the key themes from a large amount of data and we will organize the most important data to analyse and explore.

One researcher (CS) will undertake initial coding (open coding) on a line-by-line basis, with other reviewers on the team contributing independent (peer coding) of at least 30% of the transcripts in order to strengthen the credibility, trustworthiness, and richness of the analysis.

Participant's own words will be use "to guide the construction of codes and their definitions" (Hans, Gray, Gill, & Tiessen, 2018) and to reduce interpretation bias.

In subsequent analysis, we will explore the relationships between codes to identify overarching concepts. We will discuss and compare findings, along with reflections on the data collection, analysis, and study process, in regular team meetings.
The analysis of health professionals and patients data will be kept separate. We will analyse their involvements and understanding of the app (how they found the app; what was useful and not; what were the best features; did the app change their way of communicating meaningful goals). Toward the end of the analysis process, there will be some consideration of similarities and differences of statements rising from the interviews with health professionals from statements rising from the interviews with patients.

The presentation of data will involve a straight forward descriptive summary of the informational contents of the data that will be organize in a logical manner. Data presentation will be arranged with one of the following criteria: by time of occurrence; categories/subcategories; actual or reverse chronological order of events; most prevalent to least prevalent themes etc.
We will also provide a summary of the initial analysis to all study participants for comment.

8. Trustworthiness and quality of research

Methodological triangulation seems the most accurate choice to increase topic understating and, most of all, to achieve data validation in a qualitative descriptive analysis employed in social science research (Farmer, Robinson, Elliott, & Eyles, 2006). Investigator triangulation, which involves using several different investigators in the analysis process, will increase the validity and reliability of the findings of the research.

In this research project, data will be coded by more than one researcher in order to maximise richness and diversity in the analysis and to reduce the chances of data misrepresentation. Since the research has international co-researchers, we will meet by videoconference to involve our Japanese collaborators in these discussion.

Moreover, we will seek leadership from Māori health professionals to ensure that interpretation of data from any Maori participants is undertaken from within a Māori worldview.

9. Participant confidentiality

The study staff will ensure that the participants' anonymity is maintained. The participants will be identified only by a participant ID number on all trial documents and any electronic database. We will anonymise details in all interview transcripts, removing reference to names of people, place, and organisation that might identify individuals. All documents will be stored securely and only accessible by study staff and authorised personnel.

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