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Enhancing Self-Efficacy for Self-Management in People with Cystic Fibrosis

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Abstract: This paper reports on a research trial designed to evaluate the benefits of a health mentoring programme supported with a web and mobile phone based self-monitoring application for enhancing self-efficacy for self-management skills and quality of life for people with CF. This randomised, single-blind controlled trial evaluated two strategies designed to improve self-management behaviour and quality of life. Task-specific self-efficacy was fostered through mentorship and self-monitoring via a mobile phone application. Trial participants were randomised into one of three groups: Control, Mentor-only and Mentor plus mobile phone. Analysis and discussion focus on the experiences of participants through a methodology utilising descriptive statistics and semi-structured interviews. The results highlight the challenges of stimulating self-management behaviours particularly in adolescents and in the evaluation of the role of mobile applications in supporting them.

Keywords: chronic disease, self-management, information technology, m-health

1. Introduction

Managing and maintaining health care support for the chronically ill poses numerous challenges for conventional models of health care delivery [1]. These challenges are particularly evident where the chronically ill are primarily children or young adults, as in the case of cystic fibrosis (CF) [2]. In response, new models of care have emerged including some that aim to support more patient involvement through mentoring and self-management [3]. Some evidence suggests that these types of interventions can be as effective as the introduction of new medications [4], although it is acknowledged that there are limitations to the techniques that have so far been utilised to evaluate interventions of this type [5, 6]. At the same time, there has been an increasing diffusion of web based and mobile information and communication technologies (ICTs) to assist in improving care delivery [7]. These systems have strong potential for supporting home based medical care [8] and there are also a number of studies reporting positive outcomes achieved in patients with chronic illness through encouraging self–management supported by technology [9]. It is however, evident that these types of interventions are also highly complex and require sophistication in the approaches utilised to implement them [10] and to evaluate their impacts [11, 12].

This paper reports on a research trial designed to evaluate the benefits of a health mentoring programme supported with a web and mobile phone based self-monitoring application for enhancing self-efficacy for self-management skills and quality of life for people with CF. The paper focuses on the mobile phone application, its usage and participants' perception of its value in assisting them to self-manage.

2. Methods

This randomised, single-blind controlled trial evaluated two strategies designed to improve self-management behaviours and quality of life in adolescents and adults with CF. Task-specific self-efficacy was fostered through mentorship and self-monitoring via a mobile phone and web-based application. Participants were recruited from within the CF community across Tasmania. All potential participants received a letter outlining the study and requesting volunteers. Respondents willing to participate then attended their regular CF clinic to formally consent and to allow baseline measurements and randomisation to be conducted. A total of nineteen participants were recruited through the paediatric and adult CF clinics. The study was approved by the Tasmanian statewide ethics committee (H0008370) and all participants and their parents or guardians (if aged less than 18 years) provided written informed consent. Trial participation eligibility criteria were as follows:

Inclusion: formal diagnosis of Cystic Fibrosis (genotype or positive sweat test); able to provide informed consent; and landline telephone (to allow for mentoring).

Exclusion: diagnosis of other active lung disease; awaiting organ transplantation; or severe lung disease (FEV1 <35%).

Participants were randomised to one of three groups:

- **Intervention 1:** access to a self-efficacy program under guidance of a mentor.
- **Intervention 2:** access to the same self-efficacy program as intervention 1 plus the provision of a mobile phone and web-based application allowing participants to monitor their daily symptoms and quality of life.
- **Control:** participants in this arm received the normal level of CF care

Participants took part in the trial for a period of six months, with a further follow-up at a point six months post completion. Data collection involved both quantitative and qualitative assessments. With the primary quantitative outcomes measures collected at baseline, 3, 6, and 12 months being: SF36 version2 for subjective health status; Stanford Self-Efficacy for Managing Chronic Disease 6-Item Scale, CFQR (QoL); Respiratory function tests; forced expiratory volume in 1 second (FEV_1), and forced vital capacity (FVC). The data collected through these outcome measures were non-normally distributed and non-parametric statistics were used to analyse the data[1].

Primary qualitative data collected were: semi-structured interviews with all participants and mentors at completion of project. These interviews were audio recorded and aimed to explore the experiences of the participants.

Mentoring was conducted via telephone by trained health professionals and the ICT application facilitated electronic self-reporting of daily symptoms and access to feedback providing longitudinal views of self-reported data for comparison. The digital

[1] Quantitative data analysis subject of forthcoming paper.

symptom monitoring and feedback application posed a set of questions forming a daily symptom diary with an additional randomly generated question to improve data quality. On average it took a patient 1½ minutes to complete the diary. A data packet (via SMS) was sent to a messaging server and on to a database for consolidation and interpretation.

Participants were able to request and receive reports on their diary data via SMS. This supported viewing of a graphical representation of longitudinal electronic diary summary data blocked into periods of seven days. It was anticipated that by providing participants in Intervention 2 with this longitudinal data it would support them to reflect on changes in their condition and their development of self-management and self-efficacy skills. Mentors were able to login to the project website and review their mentee's diary entries and if necessary, they could make telephone contact with participants to discuss clinical status or revise action plans and goals.

The digital symptom monitoring and feedback diary application was designed to function at very low cost for the CF community thereby ensuring sustainability of the availability of the application beyond the lifetime of the trial. The application and technology platform consisted of development of three core components:

- A suitable mobile phone application that captured and rendered clinical and non-clinical information from patients.
- A mobile phone server application to capture and send clinical information to each patient involved in Intervention 2.
- A database with web interface to store all phone data, action plans and progress notes and provide graphical representation of longitudinal electronic diary data.

Critically, the approach underpinning the development, use and evaluation of this application acknowledged the clinical and information systems challenges faced in trying to understand the impact and outcome of this intervention on individual patients. While statistics on discrete variables highlight evidence of change at a cohort level they explain little about the 'lived experience' of the individual's self-perceived health status [13]. Similarly, from a technology perspective focusing on technological acceptance or usability often fails to reveal detail on the interplay of personal factors that make up an individual's technology experiences, attitudes and responses [14]. As a consequence a range of quantitative and qualitative data was collected and analysed.

3. Results

A total of 20 participants were enrolled in the trial. One participant, randomised to Intervention 2, withdrew and their data removed from the dataset. There was no significant difference in sex or age distribution between the groups (see Table 1).

Table 1. Participants by Sex and Age

Group	Male	Female	Median Age	Age Range
Control	3	4	19	17-47
Intervention 1	4	3	20	16-33
Intervention 2	3	2	20	14-45

Eighteen (95%) of the participants had mobile phones that they used frequently. 17 (89%) participants perceived themselves to be either expert or proficient users of mobile phones, with two identifying themselves as beginners. The most frequently

reported uses for mobile phones were SMS [N=14], phone calls [N=12] and camera [N=6]. While phone usage patterns are changing rapidly, these figures appear consistent with patterns of 'normal' teenage/young adult phone usage [15].

All participants in Intervention 2 used the symptom monitoring and feedback diary. Noticeably, one mobile phone user was particularly enthusiastic and completed over 100 diary entries. Table 2 shows the number of diary entries for each participant and their ages. Active participation was 6 months so maximum number of diaries was 183.

Table 2. Symptom Monitoring Diary Use by Age over the entire active study period

Id No	Total Diaries	First Quarter	Second Quarter	Age
8001	62	39	23	14
8002	26	22	4	17
8004	132	66	68	45
8005	47	22	25	21
8006	32	27	5	23
Total	301	176	125	

In relation to the Stanford Self-Efficacy for Managing Chronic Disease 6-Item scoring system, the control group experienced a decrease in median score over the 6 month trial period, but median score increased for this group at 12 months. In both Intervention 1 and Intervention 2 there was a significant increase in median self-efficacy score following active intervention, this was sustained at the 12 month point This is consistent with other research [12].

At the end of the 6 month active intervention period, from interviews it was clear that participants using the mobile application found it convenient and fitted their lifestyles. Several also felt the application assisted in thinking about their symptoms. There was a feeling that having a new mobile phone was 'kinda cool' and that it opened up potential social interactions with people beyond the trial. Across both intervention groups, participants expressed a strong sense that they had engaged in the trial to 'help the researchers' rather than to help themselves. This clearly highlights one challenge faced in engaging patients in self-management through clinical trials [16].

4. Discussion

This trial implemented and evaluated a mobile phone supported mentorship system for people with CF, aimed at aiding the enhancement of self-efficacy. Participants were experienced in ICT use and all participants in Intervention 2 used the device, although usage dropped off over time. The application was generally considered to be useful and allowed CF individuals to focus on changes in symptoms. Self-efficacy increased in subjects in both intervention groups, but it is unclear from the results if the application provided additional benefits beyond supporting the mentoring intervention.

This trial demonstrates that use of a mobile application is feasible with a geographically dispersed CF population and that most people with CF are confident with use of mobile platforms. Although self-efficacy improved in Intervention 2 it is unclear the extent of the role of the mobile application as similar improvements in self-efficacy were observed in Intervention 1. To answer these questions requires a larger study that is adequately powered to detect differences between treatment arms and to further delineate the contribution of the application to enhancing self-efficacy. To this end insights from this study have been incorporated into the design and implementation of a larger community-centric CF project in which health mentors in regional centres

are being trained and supported by web and mobile phone based applications that allow improved access to education for both healthcare workers and people with CF. The mobile and web applications have been refined to further support self-monitoring.

In summary, this paper examined participants in a RCT of a mentoring system plus or minus an ICT application to support the acquisition of self-efficacy skills in adolescents and adults with CF. The study confirms that people with CF are confident and prepared to use ICT devices for self-monitoring and appreciate the value of such an exercise. The results confirm the feasibility of interventions to improve self-efficacy, but the contribution of the ICT component remains to be determined in a larger study.

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