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Pathways Home: Comparing Voluntary IT and Non-IT Users Participating in a Mentored Self-Management Project

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Abstract

This research paper examines the challenges in the development and adoption of an electronic patient diary within the Pathways Home for Respiratory Illness Project. This project supported community-based patients suffering from chronic obstructive pulmonary disease (COPD) to achieve increased levels of self-management and self-efficacy using electronic-monitoring techniques and mentoring by community health nurses. Participants had the option of voluntarily adopting an electronic patient diary to support their self-monitoring, which provided patients, nurses and clinicians with access to symptom and psycho-social data. This aimed to improve the identification, comprehension and initiation of early action in relation to alterations in their conditions. The paper presents data on technology adoption, electronic diary usage and, self-reported data quality, as well as examining the impact of the technology on hospitalisations (frequency and duration). The participants who chose to use the online patient diary continued their involvement with the project for the entire trial period (85% vs 54% completion). Participants were more likely to maintain use of the online patient diary than the paper diary. Both the groups experienced a positive improvement in their self-efficacy to self-manage their condition scores. The data highlight the problems implicit in some of the assumptions underpinning existing information systems models, especially in evaluating impact and the end-points presumed to be relevant in systems development life cycles.

Keywords:

Chronic disease, Self-management, Information technology, Symptom monitoring, Self-efficacy, Technology adoption, Electronic diary.

Introduction

Chronic obstructive pulmonary disease (COPD) is the fifth leading cause of death worldwide [1] and is the third leading cause of 'burden of disease' in Australia [2] with sufferers experiencing multiple co-morbidities [3]. Individuals experience escalating psychosocial changes and functional problems as the disease progresses [4]. These include difficulties with home management, restrictions on recreational activities, loss of independence and feelings of social and emotional isolation [5]. Additionally, people with COPD often have poor quality of life [4,6,7] and low self-efficacy for managing life with COPD, including symptom management [8]. COPD is more prevalent among men in lower socio-economic groups. However, reflecting the increased popularity of smoking by women in the second half of the 20th century, the rates of COPD for women are rising. It is anticipated that over the next 20 years death rates from COPD in women will overtake those in men [9,10,11].

Evidence exists to indicate that the quality of life of people with COPD can be improved and that morbidity and mortality levels can be reduced through a range of interventions including patient education, pulmonary rehabilitation, self-management of exacerbations [10] and a patient-centred approach to care provision [12,13]. These integrated chronic disease management approaches are increasingly focusing on improving methods for engaging and supporting the direct involvement of patients in their own care.

The Pathways Home for Respiratory Illness project is a collaborative project involving researchers from the University of Tasmania's Schools of Medicine, Nursing and Midwifery, and Computing & Information Systems. This project aimed to assist patients with COPD to develop self-management skills, mediated through increased self-efficacy for patient-identified health behaviours (Note: reference to 'self-efficacy' should be taken to mean 'self-efficacy to undertake self-management'). Self-efficacy is a core construct identified in Social Cognitive Theory [14]. This project was also informed by the Transtheoretical Model of Change [15] through the awareness that individuals may vary over time in their motivation to enact behaviour change.

Bandura defines self-efficacy as: "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. Such beliefs produce these diverse effects through four major processes. They include cognitive, motivational, affective and selection processes” [16:*71*]. Thus, self-efficacy is the belief that one has the capabilities to undertake and complete a course of actions that are necessary to manage a given situation. Self-efficacy, is theorised to be an important predictor of whether one attempts the behaviour [17,18] and has been successfully tested within the domain of chronic disease self-management most notably by Lorig et al., [19] where positive improvements in health outcomes have been demonstrated through supporting self-efficacy.

Methods

Participants in the project were recruited while hospitalised with an acute exacerbation of COPD. They were then randomised into control or intervention groups according to the location of their residence with areas balanced for socio-economic and rurality factors. The quasi-randomisation was by domicile as community health nurses (CHN) performing mentoring were only located in certain areas. Participation was for a period of twelve months, with clinical and quality of life measures being recorded by a research nurse quarterly.

Upon discharge from hospital those participants allocated into the intervention group were linked with a CHN mentor who maintained regular telephone contact and monitored progress over a period of one year. Monitoring and responding to symptoms, a key self-management behaviour [20], occurred primarily via participants keeping a daily diary of their symptoms and any changes in them. The symptom monitoring diary was available to the participants in either paper or electronic format, with voluntary adoption of the electronic diary discussed with participants after an initial six weeks in the project. Participants were assisted with interpretation and understanding of changes in their symptoms by the CHN mentors. It was anticipated this would lead to more rapid and targeted changes in treatment. Mentoring was carried out primarily via the telephone, with electronic diary information made available to mentors via a secure internet site. The role of the mentor has been reported in a previous publication [21]. The inclusion criteria for participants were:

- Age over 45 years;
- Living in the catchment area –(Southern Tasmania);
- Diagnosis of COPD (based on COPDX Australia & New Zealand guidelines incl. use of spirometry [www.copdx.org.au];
- At least one exacerbation of COPD in the last 12 months;
- Passes a cognitive assessment with a mini-mental state examination score >21;
- Able to provide informed consent;
- Has telephone;
- No diagnosis of other active lung disease; and
- Not undergoing palliative care.

The project was approved by the Tasmania Health and Medical Human Research Ethics Committee (H8370).

During the initial stages of the project, information systems researchers utilised the project team’s knowledge of COPD to make preliminary technology design decisions. Following ethics approval, a detailed understanding of the potential range of technological experience and expertise of participants was acquired through direct interactions with them. As recruitment progressed it became evident that participants would not utilise the full range of technology options that had originally been considered. All participants with COPD stated at recruitment interviews that they did not use the telephone for banking or similar purposes and they disliked IVR (interactive voice response) systems. Short Message Service (SMS) was also considered but the majority of the COPD participants had limited experience with mobile phones and/or had impaired eyesight and/or dexterity. These factors led to the decision that the only monitoring options would be paper and web-based patient diaries.

It was also considered preferable that the introduction of any IT tool should be phased. Thus participants were commenced with paper-based monitoring systems and migrated to the IT system if and when voluntarily requested. Migration to the IT based diary was implemented by information systems researchers in the team and facilitated by the CHN mentors and other research team members. Each participant’s prior experience with computers was evaluated at an initial home visit by the IS team, when the online patient diary was demonstrated and their interest gauged. For each participant, training was provided in participant’s homes, commencing with a basic demonstration and explanation, followed by lessons in turning the computer on and off and progressing to using the mouse. Due to the disease process, associated co-morbidities, ageing and underlying educational levels, participant education issues can be pronounced in the COPD population [22]. This was a major challenge for many of the participants and they were encouraged to use the mouse to play electronic card games to improve their confidence and dexterity. All participants were followed up with a telephone call the day after the computer installation to see how they were progressing and to organise a follow-up visit. At the initial visit the home environment was also assessed and the most appropriate location for the computer was discussed with the participants. At the second visit the participants were then taught how to connect to the internet via the dial-up connection and introduced to the project website. Use of the online patient diary and the longitudinal feedback were also demonstrated. A full computer screen-by-screen user manual was provided for the participants to follow when undertaking diary entry. Desktop shortcuts were provided to simplify the processes for the participants. Activities were monitored online by the IS team and further training or support provided as required or requested by telephone or home visit.

Results

A total of 106 participants were enrolled in the project, 51 in the control and 55 in the intervention group. The two groups were well matched and there were no significant differences between groups for baseline demographics, with the exception of gender, there being a greater proportion of females in the intervention group (p=0.31 by Chi-squared test). There was a high attrition rate in both groups with only 68 participants completing the full 12 months, see Table 1.

Table 1- Control and Intervention Groups by Sex and Age

		Control Group			Intervention Group		
	Sex	**M**	**F**	**All**	**M**	**F**	**All**
Enrolment	**Number**	27	24	51	18	37	55
	Mean Age	71.1	68.0	69.7	70.2	64.6	66.5
Completion	**Number**	14	18	32	10	26	36
	Mean Age	70.6	67.2	68.8	71.6	64.3	66.6

In the intervention group, only 20 participants (36%) chose to use the online patient diary. A much larger proportion of those choosing to use online patient diary were female (80%), this was evident even though females predominated in this group. The mean age of those choosing to use the online patient diary in both the male and female groups was lower than those choosing not to use the online patient diary, see Table 2. In the IT Users group all those who did not complete the 12 months participation died prior to completion. In contrast only 27% of the Non-IT Users group died, the remaining (73%) withdrew prior to completion. Possible reasons for this difference are discussed below.

Table 2- IT Users and Non-IT Users by Sex and Age

		IT Users			Non-IT Users		
		M	**F**	**All**	**M**	**F**	**All**
Enrolment	**Number**	4	16	20	14	21	35
	Mean Age	67.8	59.9	61.5	70.9	68.4	68.8
Completion	**Number**	3	14	17	8	11	19
	Mean Age	65.7	61.1	60.2	66.3	66.7	68.0

The symptom monitoring diary was provided to all participants in the intervention group. The intention of the intervention was that the diary would be completed daily. The actual diary use was much lower than anticipated, with a total of 11,477 diary entries being received over the duration of the project from a possible 24,820 entries. As is evident from table 3 the diary usage was unpredictable. Although it is evident (Table 3) that the IT Users group displays a higher mean usage than the Non-IT Users group. Although these data are difficult to interpret due to the fact that people commenced the trial at different times over a two-year period and many of those who commenced did not complete their full twelve-month participation period. Further analysis may be conducted to calculate the number of days the diary was completed for those using paper or web-based entry and to express this as a proportion of the total number of days participants were active in the project. These will then be compared using Chi-squared.

Table 3- Total Symptom Monitoring Diary Usage

	Mean	Range	Total
IT Users	260.3	59-380	5,206
Non-IT Users	178.7	0-372	6,255

However, the differences between the groups becomes less marked when the analysis is limited to the diaries of those participants completing their 12 months participation (Table 4). The mean usage for the IT Users group equates to approximately 15 more entries than the Non-IT Users group.

Table 4- Completers Symptom Monitoring Diary Usage

	Mean	Range	Total
IT Users	285.2	83-380	4,849
Non-IT Users	269.9	49-372	5,128

A qualitative examination of the diary entries demonstrated little evidence of differences in the quality of entries between the IT and non-IT users. The hospital utilisation raw data reveals that the IT Users group had more admissions to hospital (Table 5). However, the average length of stay for the IT Users group was 1 day less than the Non-IT Users group.

Table 5- Hospital Utilisation Excluding Initial Admission

	Total days	Mean length of stay	Admission Number
IT Users	128.5	5.1	25
Non-IT Users	83.1	6.4	13
Total	211.6	5.8	38

Both groups demonstrated increase in mean mini-mental state examination over the period of the project. Essentially the mean MMSE scores were within the normal ranges: scores of 27 and above are considered normal; scores of between 23 and 26 indicate a borderline condition; and scores of 22 and below are abnormal. The minor increases in MMSE scores from enrolment to completion may be due to an initial adverse effect of the participants' exacerbation of their condition and subsequent hospitalization (Table 6). They may also reflect some variability within the measurements themselves.

Table 6- Mini-Mental State Examination Scores

	Enrolment			Completion		
Group	**Mean**	**SD**	**Range**	**Mean**	**SD**	**Range**
IT Users	27.2	1.7	23-29	28.4	1.7	25-30
Non-IT Users	27.1	2.5	22-30	28.0	1.7	24-30

The Stanford Self-efficacy for Managing Chronic Disease 6-Item (Stanford Self-efficacy) Scale is a validated measure of self-efficacy for self-management in people with chronic disease. As the Pathways Home for Respiratory Illness project was aimed at improving participants' self-efficacy for self-management this was a primary outcome measure. A calculated mean of the six items scored is the final Stanford self-efficacy score. Both groups demonstrated an increase in the mean and minimum Stanford self-efficacy scores (Table 7). However, the Non-IT Users group demonstrated a slightly greater increase than the IT Users group.

Table 7- Stanford Self-efficacy Scores

	Enrolment		Completion		Effect Size
Group	**Mean**	**SD**	**Mean**	**SD**	**Cohen's d**
IT Users	5.5	2.5	6.4	1.6	0.36
Non-IT Users	5.5	2.3	6.7	1.8	0.52

Discussion

This study has undertaken a preliminary comparison of the results from IT Users and Non-IT Users within the total intervention group of a clinical trial. The paper has considered outcomes that differentiate these two groups of users. These data will contribute to a forthcoming more comprehensive statistical analysis of the clinical trial and the quantitative impact of the online patient diary within the trial intervention. However, these preliminary results could be interpreted to provide evidence that the use of the online patient diary could be inhibiting the positive impacts of the intervention.

Previous studies, see for example [23] and [24], have indicated that computer use in the elderly is significantly influenced by gender. They found that males have greater computer knowledge, are more confident and less anxious about using computers than females. Interestingly this is not confirmed within this research data where females were much more likely to elect to use the online patient diary option.

In terms of demographic differences between the IT Users and Non-IT Users it appears that amongst the participants within the project the older age group, and particularly older males, were less likely to attempt to use the online patient diary. Those most likely to use the online patient diary are younger females. The participants who chose to use the online patient diary were more likely to continue their involvement with the project for the entire twelve-month period (85% vs 54% completion). All non-completions in this group were deceased. A similar number of Non-IT Users were deceased but 77.95% of those in the Non-IT Users group who failed to complete withdrew from the project. This suggests that participants engaging with the IT aspect of the project may have been more committed to the project although this requires further investigation. The data relating to the actual usage of the online patient diaries and the paper diaries does not provide a clear pattern of behaviour. Participants were more likely to continue to use the online patient diary than the paper diary. There was a marginally higher mean usage in the IT Users group than in the Non-IT Users group.

In relation to the development of self-efficacy to self-manage their condition using the Stanford self-efficacy scale both the groups experienced a positive improvement in their self-efficacy scores. However, the scores for the Non-IT Users demonstrate a greater improvement than the IT User. This appears to indicate that the use of the online patient diary impedes or limits the development of self-efficacy for self-management in people suffering from moderate to severe COPD. Alternatively it may indicate that those who were willing to take on change could adopt the online patient diary and develop self-efficacy but the degree of change was mediated by learning two tasks.

So what are the possible explanations for these findings? The most obvious is that the online patient diary and its use in some way interferes with the process of the mentored self-management. In terms of the Stanford self-efficacy scale the online patient diary appears to have weakened the positive effect of the intervention upon the development of participant's self-efficacy. This is possibly due to the additional learning burden of commencing to use the online patient diary. Alternatively, it is possible that the participants using the online patient diary have more regular interaction with their own symptoms, through the rapid online feedback; this may have raised their awareness of the limits of their self-management skills and as a result enabled them to reflect more critically on their self-efficacy than participants in the Non-IT Users group. In terms of acquiring skills that will assist in self-management behaviours during a life-time it can be argued that the online patient diary may have stimulated a more realistic assessment of participants' actual skills and knowledge.

Significantly, a qualitative analysis of a subgroup of the intervention cohort [25] has demonstrated that the introduction of the online patient diaries had a much broader influence upon the participants than was evident through the analysis above. These influences expanded to include the wider impact of the introduction of computers and the Internet into the participant's lives, the impact of changes in support networks from participation in the trial and the importance and impact of participation issues upon the participant's experiences of the trial [25].

Conclusion

Quality of life for those suffering from a chronic illness is "a product of complex interactions between subjective health, disability and the social environment in which the individual lives" (Anderson & Bury, 1988, p. 249). Thus, it is inadequate to attempt to understand the impact of any intervention in the lives of people with chronic illness solely in terms of generic instrument measurements.

For information system developers, this data highlights the need for more careful consideration of how the evaluation of impact in terms of adoption, usage and benefit is conducted. This paper also provokes the need for more complex analysis of the relationships that exist between clinical, social and technical measures of impact. For health informatics researchers there is also the challenge of the end-points presumed in the development of the technical systems produced to support patients to be able to self-manage – if self-efficacy is to truly be achieved then there is a need to be able to determine when the system is no longer necessary. Otherwise there is a danger of moving from medico-centrism to techno-centrism that artificially replaces one dependency for another amongst those we aim to support being able to self-manage.

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