Telehealth as a tool for independent self-management by people living with long term conditions

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Abstract.

Telehealth is seen as a key component of 21st century healthcare, and studies have explored its cost effectiveness and impact on hospital admissions. Research has been carried out into how to best implement it, and the barriers to its adoption. The impact of telehealth on self management however has been a neglected area.

An evaluation of the implementation of a telehealth programme in one area in the South of England found that some patients were using the telehealth equipment provided to enhance their own self management abilities. Whilst the nurses managing the scheme felt that they had an education role they did not involve their patients in setting goals. The patients equally did not feel that were being educated by their nurses.

Patients were using the monitoring equipment independently of the nurses and the scheme to support their self management stategies. Therefore the concept of graduating from telehealth once good self management is established needs to be rethought. Patients in this study experienced less face to face contact with their nurse, but also reported that they were happy with the changes. This suggests that for some patients the contact with the nurse may well be able to be reduced or withdrawn however removing the monitoring equipment will remove the very tools essential to continued self-management.

Keywords.
Telehealth, self-management, participatory healthcare

Introduction

Self management for long term conditions is a central tenet of the health policy around the world, [1] [2] [3] [4]. In the UK telehealth is seen as one way of working towards this. Two of the aims of the English NHS (National Health Service) in introducing telehealth for patients living with long term conditions are to achieve ‘more effective self care’ and to ‘increase [patients’] confidence to manage their own health’.

How telehealth can contribute to self management has not however been a major research focus. Studies into telehealth have focused on cost effectiveness[5, 6]; effective working practices [7],[8]; barriers to adoption [9]; and reduction in hospital admissions [10] [11]. Where patients’ experiences were considered the focus was frequently on the perceived reassurance patients feel[12].

Where self management was explored it was frequently in terms of ‘adherence’[13], [14] or ‘compliance Schreir [15] Fewer studies gave prominence to patient partnerships, although patients prefer having ownership of their self management, and do not want a paternalistic approach[16].

This study

This study draws on an evaluation of a telehealth service for people with COPD implemented by the Dorset Clinical Commissioning Group in the south of England. Although evaluating the effectiveness of the service implementation some of the findings have wider implications. The service supplied patients with devices to monitor oxygen saturation, blood pressure, temperature and weight, all managed through an ipad style device that both presented questions about how they were feeling and sent their readings and replies to their nurse. The evaluation lasted 12 months, and included a questionnaire; telephone interviews with patients, and interviews with nurses.

Data Collection

The patient questionnaires were distributed via the telehealth system. Two questionnaires were used, one close to the patient starting on telehealth and the other after around 3 months to explore differences in attitudes initially and after experience of using the system. Although 299 telehealth pods were installed with users over the evaluation period only 118 had recorded consent to be contacted. 41% of these (no = 48) completed questionnaires.

Qualitative telephone interviews were held with a purposive sample of patients who had given prior consent to be contacted by the research team. 29 participants were interviewed in phase one. 24 follow up interviews were conducted. Reasons for not participating in the second interview were the patient died (n=3) admitted to hospital (n=1) declined a further interview (n=1). In both phases each interview took an average of 10 minutes (range 4-22 phase 1, and 4-24 phase 2). A semi structured approach was adopted, to ensure that common information was obtained from each participant, whilst also being responsive to each interviewee’s individual circumstances and experiences.

Due to the availability of staff one focus group of 4 nurses, and 6 telephone interviews were held. All the nurses had been trained in the use of the telehealth system and had at least one patient using the system.

There were limitations in the data collection. To maintain patient confidentiality the evaluation team received pseudo-anonymised information from the referral system. Only patients who had confirmed they were happy to be contacted by the evaluation team were able to be included either the questionnaires or the interviews. Initially patient information received frequently did not have this field completed, so these defaulted to non-consent. A further problem was encountered with the ability of the telehealth system to present questionnaires to users in the way the evaluation team would have preferred.

Results

The age of respondents ranged from 45 to 95, with both the mean and median being 71. 33% were female and 67% male. 54% had a primary diagnosis of COPD, 31% CHF and 13% both.

Questionnaire

The majority were satisfied with the way in which the telehealth system had been installed in their home reporting that the installation engineer had been polite, they had been given clear instructions on how to use the system. They found that monitoring their condition using the telehealth system was easy. The majority felt confident taking their measurements and viewing the results and they said they felt involved in their own health care decisions. 80% of respondents looked back over the history of their readings and the same proportion said that they felt telehealth made a difference to their lives with almost all respondents rating the telehealth system as liking or really liking it.

Interviews

The patient participants (identified by pseudonym) fell into two categories; those who felt supported and reassured by the knowledge that nurses were 'keeping an eye on them' and those who saw this an opportunity to better self manage their conditions.

People who valued the reassurance did not perceive the equipment as a barrier, *'Well they're keeping an eye on me y'know, I know somebody's watching all the time'* and Joan who described herself *'(I) talk to it and tell them how ill I am, how I'm feeling and everything and they get back to me'* [Bill]

Others, such as Doris, felt that having the equipment available enabled them to better self manage explaining *' I've been using it once a week, and transfer the details to [nurse] … but if I've felt unwell in the meantime then I've used it for my own sort of, to know what my sats are and how to deal with them, … and regulate the medication if I have to'.* John felt that his use of the system increased his confidence in managing his condition *'I like to know what's going on so the fact that I can look back at my readings and make comparisons is brilliant. And in a way that gives me confidence to move forward.'*

The nurse participants (identified by number) were generally unaware of how some patients were using the equipment to support their self-management.

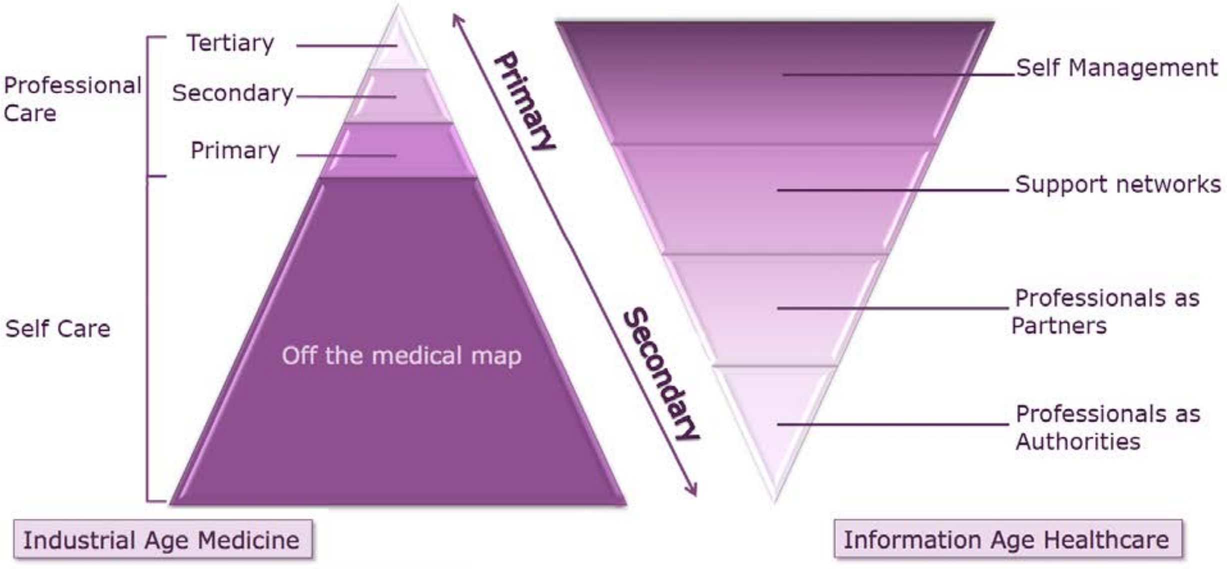
The protocol for starting patients on the telehealth system included setting goals. Nurses were expected to agree these goals with their patients. Patients however did not consider that they had been involved, Peter explained '*I just do the results and then I press send but that's all I was told to do'*, Comments from the nurses support this finding '*it's knowing your patient really 'cos it's the nurse that will normally set the parameters and then go through them with the patient'* [N2].

The potential for patient education was a missed opportunity. Peter discussed that he would like to understand more about the readings and what they meant. The nurses however felt that they were using telehealth for patient education, Sue explained *'I think generally if they're being monitored and you're doing visits anyway you do a lot of education with them'*

As with many telehealth programmes patients were expected to 'graduate' when they were effectively self managing. Graduation includes removing the equipment so that it can be used for a new patient. One nurse, talking about how long patients expected to stay on telehealth said' *I'll say to them this is our property in a nice sort of way and it could come out at any sort of time''* [N2].

Discussion

It is widely acknowledged that people who are effective self managers are active partners in their care, and share decision making with their care teams[17]. These patients expect to be seen and treated as an equal member of that care team[18]. This model of healthcare is also called participatory medicine, described some 20 years ago as the paradigm shift from industrial age medicine to information age healthcare by Doc Tom Ferguson [19] one of the pioneers of the participatory medicine movement.



Adapted from Ferguson, T. 1995. Consumer Health Informatics. Health Forum Journal. Jan/Feb pp28-33. http://www.doctom.com/slideshows/tf002/sld047.htm

Figure 1. Self Management in the Information Age
Adapted from Ferguson (2002)

This study however found that not all patients did feel supported in developing their self management strategies. Whilst most models of self management are healthcare professional lead, however a ‘self agency’ model, where patients placed importance on taking control of their condition, including deciding what information to share with their healthcare professionals is also proposed[20]. This was the approach adopted by some of the patients in this study, who used the telehealth equipment outside of the requirements of the telehealth programme, and made treatment decisions based on their readings.

Some of the nurses felt they had to retain ownership of the telehealth programme. Nurses have been found[21] to find working with self managing patients challenging. A study carried out with stroke therapists [22] found that their normal practice was to act as ‘benign dictators’ working in their patients best interests, but remaining in control. Moving to a model of patient led self management was supported in principle, but the therapists saw obstacles in achieving this change.

A qualitative study of nurses involved in delivering telehealth programmes in three areas of the UK [23] found that there were mixed views about its use. Nursing staff (community matrons and telehealth monitoring nurses) were concerned that it was an adjunct to their patient care, not a replacement. Nurses have also been found to be concerned about the impact of telehealth on traditional nursing roles[24]. The patients in this study did say that they experienced a change in the amount of face to face contact they had with their healthcare professionals, with it generally being substituted by telephone contact, however they were happy with the changes they encountered.

Conclusion

Although this evaluation found that patients were using the telehealth system to support their self management activities and felt more confident in their ability to self manage the process that supported this is not clear, nor is the role of the nurse in that process. Some patients are able to use the system to achieve this with minimal support, whilst others will need some assistance to learn how to use the monitoring equipment to best effect. Although both the policy and the stated aims of the nurses is to achieve effective self-management the paternalistic nature of some of the telehealth relationships is a barrier to moving this forward.

One significant implication of this evaluation is that patients are using the monitoring equipment independently of the healthcare professionals. Therefore the concept of graduating from telehealth once good self management is established needs to be rethought. Patients in this study experienced less face to face contact with their nurse, but also reported that they were happy with the changes. This suggests that for some patients the contact with the nurse may well be able to be reduced or withdrawn however removing the monitoring equipment will remove the very tools essential to continued self-management.

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