Telehealth as 'peace of mind': embodiment, emotions and the home as the primary health space for people with chronic obstructive pulmonary disorder

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ABSTRACT

A theoretical understanding of why some people with chronic obstructive pulmonary disorder (COPD) experienced 'peace of mind' when a new telehealth service was introduced into a community respiratory service (CRS) is presented in this article. This is based on analysis of in-depth, qualitative, situated interviews with COPD patients who were receiving the service. Telehealth brought peace of mind through two mechanisms: legitimising contact with health professionals and increased patient confidence in the management of their condition. When the home is the primary health space, the introduction of telehealth can modify emotional and bodily experiences to an extent that is significant for people with COPD. The process by which technology can provide 'peace of mind' to people with long term conditions should be taken into account when designing or commissioning a service.

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1. Introduction

This article explores the experience of people with Chronic Obstructive Pulmonary Disorder (pwCOPD) when a new 'telehealth' system was installed in their homes to monitor their health. This particular intervention can be seen as part of a wider trend to move medical technologies from the hospital (and other conventional health spaces) to home (NHS Choices, 2011), changing the meanings associated with and experience of both places. Overall, the intervention was enthusiastically received by the patients, who felt that it gave them 'peace of mind'. In this article, we unpick the reasons for this, by documenting and explaining how introducing a new medical technology into the home served to mitigate some of the key challenges of living with COPD.

Populations are ageing across the industrialized world. In the UK, life expectancy is now at 78 years for men, and 82 years for women (ONS, 2011). Long term conditions (LTCs) are more prevalent, and we must find more efficient ways to finance healthcare services (Department of Health, 2005; World Health Organisation, 2002; Heller, 2003). Chronic Obstructive Pulmonary Disease (COPD) is a common LTC, affecting one person in seven in the UK (British Lung Foundation, 2012). It is a major cause of morbidity and mortality in the UK and worldwide (Lopez et al.,

2006), costing the English National Health Service (NHS) an excess of £800 m per year (Department of Health, 2010). Symptoms include long-term, chesty cough, wheeze, phlegm, breathlessness, anxiety and/ or depression (British Lung Foundation, 2012). COPD is a life-limiting condition with severe physical effects and associated with psychological distress, feelings of loss, dependency on medication, disruption to social and family life, low self esteem (Nicolson and Anderson, 2003), loss of control (Simpson et al., 2009), anxiety and fear of breathlessness (Rozenbaum, 2008). Research on the experience of pwCOPD has identified the deployment of coping strategies such as acceptance (Pols and Willems, 2011), adaptation, and increased reliance on spiritual or religious resources to help manage their condition (Seamark et al., 2004). The experiences of exacerbations, which tend to require hospitalisation, are often distressing and patients have expressed the need for more support from healthcare professionals (HCPs) (Jarrold and Eiser, 2010; Polisena et al., 2010). On the basis of this evidence, there have been calls to improve self care amongst patients to reduce the occurrence of such exacerbations (Barlow et al., 2007; Connolly et al., 2006), such as through telehealth.

Telehealth allows healthcare professionals to monitor patients' health through the use of telecommunications. There have been many 'promises' made about the potential of telehealth technologies to improve the quality of care, reduce costs and solve workforce shortages, alongside warnings that telehealth devalues the interpersonal aspects of care (Pols and Willems, 2011).

A recent systematic review tentatively suggested that home telehealth could reduce the rate of hospitalisation for patients with COPD, but was limited by the quality of the studies included (Polisena et al., 2010). The European Commission Communication on Telemedicine has highlighted that although there is potential for telehealth to benefit in the management of COPD, further good quality research is needed (Mckinstry et al., 2009).

Small scale pilots (Holt, 2007; Mair et al., 2008; Waddington and Downs, 2005; Horton, 2008) as well as qualitative studies included as part of a small randomised controlled trials (Hibbert et al., 2004; Lyndon and Tyas, 2010; Whitten and Mickus, 2007) have been carried out throughout the UK examining the impact of telehealth in people with COPD, and those managing their care. The mode of telehealth has included video links and telephone monitoring, with either call centres or hospital nursing staff triaging the readings. These studies show a mixed result in terms of benefits to patients and staff. One study highlighted problems in actually recruiting COPD patients to take part on a trial of telecare, as patients were worried about losing face to face contact with clinical staff (Annandale and Lewis, 2011). In other studies, patients have reported generally positive outcomes: telehealth is a good way for them to receive care, gives them continuity of and rapid access to care, helps them have greater peace of mind, improves management of their condition and prevents them from having to go into hospital (Holt, 2007; Horton, 2008; Lyndon and Tyas, 2010; Whitten and Mickus, 2007). However, these studies have tended to remain descriptive, using simple questionnaire data, or relied on staff views of the patient experience to gain an insight into patient views. Research on staff views has shown mixed results: some found that telehealth undermined nurses' core values because it limited their face-to-face contact with patients (Hibbert et al., 2004), or found that staff lacked confidence in the safety of the equipment (Annandale and Lewis, 2011), while others found that the telehealth service helped HCPs to increase their capacity enabling them to focus on acutely ill patients, as well acting as a system to detect early signs of deterioration (Lyndon and Tyas, 2010).

In Sandwell, a deprived borough of the West Midlands, UK, a new telehealth intervention was introduced within a nurse-led community respiratory service (CRS). A brief survey conducted with the telehealth users had indicated high levels of satisfaction with the service (Lauder, 2011). The aim of this study was to document people with COPD's experience and interaction with the technology, in order to understand *how* they negotiated incorporating telehealth technologies into their everyday life and home space, and to understand *why* they valued it.

2. Methodology

2.1. Study design

The central purpose of telehealth is that interventions that have previously been conducted in hospital or other formal healthcare spaces are moved into the home. In medical sociology and geography there has been an explosion of interest in methods to elicit data (in the form of talk) from people in context, usually their neighbourhood contexts, though the use of 'walking' or 'go-along' interviews (Evans and Jones, 2011; Carpiano, 2009; Jones and Evans, 2012; Jones et al., 2008; Mcdonald, 2005; Trell and Van Hoven, 2010). These are a hybrid between interviewing and observational methods, focused on the former in terms of privileging people's own accounts of their own health, but recognising that engaging people in their daily environment, rather than taking them out of it (as often happens in the research interview) constructs data that is suitable 'to study people's

perceptions, processing and navigation of their environments' (Carpiano, 2009, 264). Homes have long been recognised as a potentially suitable place to conduct interviews, especially on health issues, because they 'separate' participants from the power and meanings of the clinic (Kelly, 2010). However, this separation is problematized when the home becomes filled with medical technology. Our purpose and intention was more precise—to ask people to show and tell us their (health) spaces, and particularly the effects of a new intervention (see below). We have used the term 'situated interviewing' to describe our approach.

2.2. Intervention

Sandwell Community Respiratory Service (CRS) offer a 12 h, seven days a week service which includes home visits, occupational therapy, oxygen assessment as well as pulmonary health. In addition, patients can self-refer at any time. A new telehealth service, as an additional arm to the service, was piloted, which sent patients' vital signs readings to the CRS team over a 9 month period. Patients were asked to record their oxygen saturation (SPO2), blood pressure, weight and temperature every weekday morning and readings were sent via a telephone line to the CRS team. A respiratory support worker within the CRS triaged the readings and any 'red' readings, indicating that patients' vital signs fell outside the normal range, were flagged for the attention of a nurse who took appropriate action. If readings were not received by a set time every day, respiratory support workers contacted the patient. Twenty patients with COPD were selected by the CRS team to take part in the pilot of the telehealth service. Patients were selected by the CRS if they were classed as 'frequent flyers' (three or more COPD related hospital admissions in a twelve month period) and were judged by the CRS nurses to be likely to be able to use the technology.

Previous interviews by the evaluation team with CRS staff members had shown that this model did not, in their opinion, restrict face-to-face contact with their patients (Sultan and Gale, 2011) because the service already had a self-referral mechanism, which the telehealth pilot did not change or replace. However, the team were not generally positive about the scheme; they felt it was a burden because it was offered as an extra service by the CRS team, without any extra resource (time or money) except the cost of the equipment. There was one exception, a member of staff who felt the telehealth did aid detection of early signs of deterioration. A quantitative impact evaluation was not carried out because of the low numbers. The aims of the pilot were limited to exploring the feasibility of introducing the service.

2.3. Recruitment and sampling

Participants were eligible to be recruited if they were participating in the telehealth pilot. Participants were sent a letter, and then telephoned to obtain verbal consent and arrange an interview. Written informed consent was obtained from all participating in the evaluation. Our initial sample aimed to capture some of the diversity of the population, according to age, gender, living alone or with family and the severity of COPD [see Table 1]. In our

Table 1
Comparison of characteristics of study sample with study population.

	Study sample	Population
Males, *n* (%)	5 (71%)	7 (39%)
Age (median, years)	69	67
Moderate COPD, *n* (%)	4 (57%)	5 (28%)
Living alone, *n* (%)	2 (29%)	7 (39%)