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Telehealth as 'peace of mind'

Gale, Nicola; Sultan, Hamira

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Title

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

Author Names and Affiliations

Nicola Gale, MA, PhD[a] (Corresponding Author)
Hamira Sultan, MPH[b]

[a] School of Health and Population Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK.
Email: n.gale@bham.ac.uk
Telephone: +44(0)121 414 9089

[b] Sandwell Primary Care Trust, Kingston House, 438 High St, West Bromwich, B70 9LD, UK.

Abstract

Purpose: To develop a theoretical understanding of why some people with COPD experienced 'peace of mind' when a new telehealth service was introduced into a community respiratory service (CRS).
Results: 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.
Conclusions: The process by which technology can provide 'peace of mind' to patients with long term conditions should be taken into account when designing or commissioning a service.

Highlights

- For people with COPD, their homes become the primary health space as opposed to the clinic.
- They become physically and emotionally dependent on others and on medical technologies
- Situated interviews enable researchers to ask people to show and tell us their (health) spaces, including the effects of a new healthcare intervention.
- Telehealth does not cause extra disruption in the homes of people with COPD
- Telehealth brings peace of mind through legitimising their contact with healthcare professionals, and increasing their confidence in managing their condition.

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 the 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 health care services (Department of Health 2005, World Health Organisation 2002, Heller 2003, Heller 2003). Chronic Obstructive Pulmonary Disease (COPD) is a common LTC, affecting one person in seven in the UK (British Lung Foundation). It is a major cause of morbidity and mortality in the UK and worldwide (Lopez et al. 2006), costing the NHS in excess of £800m per year(Department of Health 2010, Department of Health 2010). Symptoms include long-term, chesty cough, wheeze, phlegm, breathlessness, anxiety and/ or depression(British Lung Foundation). 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 et al. 2003), loss of control (Simpson et al. 2009), anxiety and fear of breathlessness (Rozenbaum 2008). Research on the experience of people with COPD (pwCOPD) has identified the deployment of coping strategies such as acceptance (Pols et al. 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 health care professionals (HCPs) (Jarrold et al. 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 health care 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 et al. 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 et al. 2005, Horton 2008) as well as qualitative studies included as part of a small randomised controlled trials (Hibbert et al. 2004, Lyndon et al. 2010, Whitten et al. 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 et al. 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 et al. 2010, Whitten et al. 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 et al. 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 et al. 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 patients' experience and interaction with the technology, in order to understand *how* patients 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 health care 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 et al. 2011, Carpiano 2009, Jones et al. 2012, Jones et al. 2008, McDonald 2005, Trell et al. 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 hour, 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 (SP02), 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 et al. 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], and we continued the situated interviews until no new themes were emerging relating to our main emergent category (the explanation for 'peace of mind'), although we recognise that given the range of topics covered by the interview we cannot claim to have reached data saturation for all data categories that emerged during the analysis. In total seven patient interviews were needed (of 18 eligible patients, because 2 had died during the pilot).

2.4 Data Collection

The study was defined as service evaluation by the Birmingham and Black Country NHS Research Ethics Committee, therefore ethical approval was not required; however, we followed ethical practice standards by providing all participants with information sheets in advance and obtained written consent on arrival at the patients' homes. Both authors attended all interviews. NG was responsible for conducting the interview and HS for observational notetaking. Digital audio recordings were taken of the interactions. We developed a situated interview guide for the patients that provided a flexible framework for the data collection. The guide covered introductions (NG, HS, the patient and their carer, if present), their introduction to their home, their experience of COPD, their medical treatment and equipment including showing us where it was in their home, their daily lives (people and places), if and how things had changed since the introduction of the telehealth, and their personal evaluation of the telehealth technology. We also recorded observations of their home and the medical equipment, and about social isolation/connectedness. Before leaving, we checked that the participant was safe and had everything that they needed. Immediately after each interview we conducted a reflective debrief, taking notes.

2.5 Data Analysis

Digital audio recordings were transcribed *ad verbatim*, inserting appropriate descriptions of movement around the home where necessary and paired with the observational notes. All data were anonymised, and patients are from here on referred to as P1 to P7. Both researchers independently applied open codes to two of the transcripts/fieldnotes to identify any emerging themes that were of relevance to understanding the experience of users and the implementation of the service. We met to discuss codes, and developed a coding framework, which we applied to the rest of the data. We drew up a Framework Method (Ritchie et al. 1994) matrix to summarize and manage our data. We met regularly to discuss the analysis and focused on identifying commonality in the experiences of the participants and their environments, to move beyond a description of their experience to an understanding of *how* they incorporated telehealth into their daily life and space and *why* they valued it.

3. Findings

The traditional distinction between the 'home' and the 'clinic' in terms of their characteristics as 'health spaces', that constrain and enable certain types of health practices, is problematized in the context of people living with COPD. This is because pwCOPD often have severely restricted mobility and so spend a large proportion of their time at home, and they are subject to a complex regime of pharmaceuticals and other health technologies, which must be administered throughout the day. We argue that when the home is the primary health space, the introduction of a new technology does not have the disruptive effect that might be intuitively expected; indeed, the patients reported gaining 'peace of mind' as a result of the technology. In order to explain this finding, we, first, sketch a picture of the characteristics of our participants; second, we outline the characteristics of a home space that has been transformed into a highly technical health space, and assess the implications of the introduction of new telehealth technology for this space and for the relationship with the more traditional health services (nurses and general practitioners). We identified two components of peace of mind: *legitimizing contact with healthcare professionals* and *confidence to self-manage their condition*. We then go on to explore in more depth the implications of telehealth for the embodiment and emotions of people with COPD, to add further nuance to the theory about why they valued it.

3.1 Participants

All participants were from the Black Country, a deprived region of England (Communities and Local Government 2011), and were White British. Table 1 shows the characteristics of the participants in relation to our sampling criteria. [insert Table 2 near here]

The participants had a range of biographical experiences in relation to their COPD. Their medical history was the defining influence on whether COPD brought with it a profound sense of biographical disruption (Bury 1982), or whether, as Pinnock and colleagues have described it 'a way of life' (Pinnock et al. 2011). At one end of the spectrum, the COPD was just another stage in their illness history, not distinctive:

> *Well I've got a condition called Bronchiectasis which I've had a lifetime. I was eighteen months old when I had Whooping Cough and Bronchitis together so that left me with damaged lungs, so I've had, from eighteen months old, I've had varying degrees of being ill ... my quality of life has slowly got worse over the years but... it's been normal…it's been normal so I've just got on with it. (P1)*

But, contrary to Pinnock et al.'s findings, we did find evidence of cases where COPD was life changing and required a re-evaluation of identity, associated with serious emotional impact:

> *When you're used to being all over the place to sitting in at home more or less seven days a week, you know, it's a bit of a comedown … well it's a lot of a comedown, isn't it. (P2)*

> *We've worked all our lives, brought all the children up, worked part time and full time, and then all of a sudden, I've got this … And they said you have to change your lifestyle… from 100 mph like down to 10. (P3)*

Nevertheless, whether the onset of COPD was experienced as a sudden or incremental process, for all participants the progressive nature of COPD meant that over time their lives became gradually more restricted.

3.2 The home as the primary health space for people with COPD

For pwCOPD, as their condition worsens, their daily life occupies progressively less *space*. Restricted mobility, the risk of going outdoors in bad weather or catching chest infections from other people, and retirement from work mean that pwCOPD tend to spend more time in their own home:

> *(I) And so how often do you manage to get out the house, do you think, you said you liked getting out of the house?*
> *(P1) Well, I try at least once a week but –*
> *(Husband of P1) I don't think it's more than that, is it.*
> *(P1) If it's that, sometimes, I don't, especially if the weather's nasty, I'm better in the warm, I mean, while the really bad weather was -, our central heating was never off day and night, was it, for months and I just don't go out unless I've got an hospital appointment … I don't go out for weeks. (P1)*

> *I can't even get in the garden now. No, because it's sloped and I can get down a bit but when it comes to coming back, it's Everest, to be honest, it's terrible, like, you know, a slight slope it's absolutely terrible. (P4)*

Alongside this, the amount of medical intervention and care that they require intensifies:

> *I have my ventolin, the nebuliser, my other stuff but that's – I can show you my prescription if you want me to. I've got allsorts. I've got a chemist in there. I have to carry ventolin round with me, those inhalers, and I have tablets, I'm on aspirins, and aspirin a day – oh, you name it, I've got the lot.* (P6)

Home spaces must, therefore, be transformed into highly technical health spaces. This does not happen overnight, but is a gradual progression, punctuated by crises where relapses or acute illnesses, that often require hospitalization, produce dramatic changes in health. Our observations of the participants' homes showed that significant work was undertaken by pwCOPD and their carers to minimize the disruptive effect of the aesthetics and functionality of their homes (*qua* family space rather than health space); for instance, one participant (P4) had carefully pinned the tube for his oxygen along the skirting board up the stairs and over the door frame (like you might a telephone cable). Nevertheless, the technologies required

to manage their COPD remained highly visible. Adaptations to the home enabled people to perform daily tasks like washing themselves, dressing and climbing stairs safely. To get out of the house, being able to drive or having a partner or friends or relatives who lived nearby and could drive was a major advantage. Other adaptations were also required to get out of the home, such as walking frames and portable oxygen tanks.

As the home transformed into the primary health space, participants described their changing relationships with healthcare professionals. The CRS nurses became significantly more important to them than their GPs or hospital consultants, providing regular contact and monitoring of their care in their own homes:

> *I mean, as I say, the nurses do everything, what's needed to be done, you know, I mean, no need to see my GP really, I mean, when I had my flu jab, [the nurse] came here for it and done it.* (P2)

3.3 Introducing telehealth technology

In this context, the telehealth technology was only a very minor addition to the regime:

> *Once my carer's got me washed and dressed in the morning and I come downstairs, then I do my obs [telehealth readings], that's the first thing I do, then I have my breakfast then I carry on with the day* (P1).

However, its influence was not simply neutral; all the participants were extremely positive about the telehealth equipment: 'A boon! A god-send!' (P7); 'it's made the world of difference to me' (p5). All the participants expressed explicitly or implicitly that it brought them 'peace of mind':

> *It settles your mind more than anything ... peace of mind ... I've got to be honest with you on that. It does save me a lot of aggro* [colloquial: aggravation] *don't it? (P7)*

In the accounts, we identified two main components of peace of mind: legitimizing contact with health care professionals and increased confidence to self-manage their condition.

3.3.1 Legitimizing contact with healthcare professionals

The literature suggests that a potential benefit of telehealth systems is a reduction of demand on human resources (Lyndon et al. 2010). We did not get a clear message from our interviewees about whether patients felt that the telehealth resulted in more or less direct contact with their nurses in the CRS, but there was a resounding message that the contact they did have was more responsive and appropriate. The participants felt that the telehealth ensured that the nurses telephoned or made a visit when they were really needed.

> *Before ... I never knew whether I needed them, you know, and it was get up to A&E and admitted to hospital ... Well now I've got that [telehealth] I can get in touch with them [CRS] and they'll check the readings ... They will come out if you ask them to ... no problem ... If we had a blood test or things like that, had respiratory tests like, it could be up to 3 or 4 days, 5 days. Well you know yourself within those 3 or 4 days if [an exacerbation] catch[es] hold of you it does take a hell of a lot of moving ... but with that thing they're on the phone and they're within a couple of days you've got all your results. (P7)*

This arrangement was also more acceptable to the patients, who expressed strong values that were congruent with the principles of the National Health Service (NHS) in England – that high quality healthcare should be available based on need not ability to pay. They were well aware of the limited resources available within the NHS, and felt that even where they personally had less contact, this would release NHS capacity to deal with those that were more in need. These values also help explain why, for the participants, telehealth legitimates contact with healthcare professionals (cf. Pinnock et al, 2011). People with COPD have often had their condition for many years and so feel acutely that they are high users of the NHS and are loathe to bother health professionals (even in a service like the CRS where self-referral is embedded) fearing that they will waste their time:

> *And I'm not one for wasting people like that's time, because I saw that much of it in the ambulance service [which he used to work in] and I think to myself while I'm wasting their time, somebody who's worse than I am now, for want of a better phrase, could die because they're not there ... and that's the way I look at it. (P5)*

However, when the telehealth picked up a problem, they felt they were able to contact the CRS. Legitimizing contact was something that was particularly valued by the carers of the participants, who sometimes struggled to persuade their partners to contact HCPs even if their condition was worsening:

> *I think the problem is that somebody who's close to you, you know, I'll say 'I don't think your breathing's very good, I think you ought to ring the doctor or I'll ring the doctor', [she says] 'no, I'm alright', but if that [telehealth] tells us to ring, we'll ring. (Husband of P1)*

The participants' accounts hence provided support for the oft-cited argument that telehealth can reduce hospital admissions because they provide an explanation – through legitimizing contact.

> *I can see the early warning, I mean, I do think the last time I was hospitalised ... [I thought] I'll give it a couple of days and if I'm not any better I'll go and see the doctor and things like that. And, as I say, I got to the stage where I couldn't move ... and I suppose if I'd had the equipment then, I'd have picked it up. (P4)*

3.3.2 Confidence

As well as getting more appropriate support from health professionals, the participants reported feeling more confident about their ability to manage their condition:

> *'It's made me more confidence in myself because I now what's happening. Well, before I didn't, did I? ... If I didn't have that [telehealth], I wouldn't know how low I was, I'd just carry on with a normal day, wouldn't I? Now you've got that, it puts you aware of what's happening' (P6).*

> *'I seem to be eating a lot better ... I went to eight and a half stone from twelve, I'm back up to ten now ... I just didn't feel like eating ... it could be that I've got my confidence back ... I think it's more or less, give me, I don't know, more confidence, like, knowing how I was reacting ' (P2)*

These two components of peace of mind can be theorized by examining them through the lens of embodiment and emotions.

3.4 Embodiment

Different conditions and different health spaces produce different embodied experiences. People with COPD become more vulnerable and dependent on both medical technologies and other people. First, over time pwCOPD have significantly reduced mobility, which has implications for moving around and body care. In our observations, we could see the extent of this in their homes: everything was within easy reach of their favourite chair or the bed; they usually slept on the same floor as the main living space (or had a stair lift); the television was in the main room that they spent time in; their oxygen was next to their chair. All of the interviewees explained the various ways in which their body restricted them in their daily lives, and how in order to ensure their bodies could continue to function enough to live, they had to integrate medical technologies and occupational therapeutic strategies into their lives, such as walking frames. All patients had problems with mobility, with even simple activities being a challenge. One patient described going for a walk as 'playing musical chairs' (P1) because after having walked two or three yards, she would have to sit down. Another said:

> *If ever I move … I have to use my bottle [oxygen] and put that up to 3 litres to bring me back up to the least 90 mark [SP02 reading]… I move to go to the stair lift to go upstairs to the toilet and all that, but as for going out walking, no chance.* (P7)

These technologies came to be almost extensions of the pwCOPD's body in some cases (use of masks or intubation tubes for oxygen) and often attempts were made to disguise or minimize the aesthetic impact of them. In all cases, the technologies dissolved the boundaries between the body and its environment. The body was not only shaped by the content and structure of the home as primary health space, but quite literally was dependent on it for life.

One of our participants expressed evocatively the sense of restriction and invasion of medical technologies into their lives, by pointing to her oxygen tubes and saying that she felt like a 'dog on a lead' (P1). In this context, it is clear why the telehealth technology had minimal impact: all of the measurements could be done sitting down, apart from the weighing scales. The equipment was often placed in a convenient place and was not obtrusive, and certainly not in comparison to the oxygen tanks and other equipment they needed.

The participants were also heavily dependent on others; in an immediately physical sense, severe COPD meant that patients could not live without support – both formal and informal. For those participants with a living spouse, this responsibility largely fell to them, with some having other family around too,

> *He (husband) used to stand behind me so that, just in case as I was going up, because I'd got two handrails then and he used to follow me up, like, to make sure I was OK, well it was one step at a time to get up the stairs.* (P1)

> *They all drive if I need a car. His brother lives round the corner. They take me to the hospital or to the doctors.* (P3)

COPD resulted in a sense of embodied vulnerability (the emotional response to this is discussed in more depth below) yet, paradoxically, as noted above, often patients would

wait until things got really bad before contacting the health services. The reason why telehealth legitimized contact with health professions can be better understood through an embodied analytical lens. Patients were required to take their measurements and send them via the telehealth equipment to the CRS. This meant that they became confident over time with what numerical level was 'normal' or not and, hence, they came to understand and interpret their body through these numbers, and assigned priority to them over their own embodied sensations, or the concerns of their spouse.

> *So my oxygen levels today were 95, but they were 92 two days ago. 95 is really good, 92's good, 95 is like really good. So you think to yourself, 'I'm having a good day today'. That's what it does. Without this, I'm going to think, what's my oxygen levels today? Have they gone down or are they up? Do I need to call the nurse, do I need to see the GP? I'm not going to know without it. Because they've said to me, if your oxygen levels do drop 90 below, contact us ... You wouldn't know they'd dropped unless you take the readings (P3).*

In this way medical technologies and concepts were mediating the participants' embodied experience of their condition, building confidence and ensuring that they felt they were able to contact the CRS without wasting their time.

3.5 Emotions

In the participants' accounts there were two key emotional concerns: feeling panicky and feeling isolated. These link to the conditions of anxiety and depression, which are characteristic co-morbidities in COPD (Nicolson et al. 2003, Seamark et al. 2004). Panic attacks were common, largely due to breathlessness (a key symptom of COPD):

> *I have panic attacks because of the situation, really, it's quite easy to have a panic attack when you can't breathe, like, you know, when you have a panic attack you can't breathe even more, like, it can be a vicious circle. (P4)*

Telehealth was felt by the participants to be really important for managing this:

> *I haven't called them out so often since I've had the telehealth, because it's sort of, how can I put it, it's stopped me pressing the panic button so often, I mean, obviously, you know, it's the old saying, unless you've ever suffered from shortage of breath, you can't fully appreciate it. (P5)*

This patient went on to consider the consequences of the telehealth equipment being taken away:

> *If they take out tomorrow...and I go back to, have to rewire the panic button up again, you know, and that type of thing, am I going to be calling the girls [nurses] out more, am I going to be in hospital more, am I going to go back to square one just because of that equipment. (P5)*

While feelings of anxiety were readily shared with us, depression and suicidal feelings were generally more implicit in the accounts:

> *I mean I can sit here and cry at you. It's not like I'm even watching a sad film on the television. I took this one tablet on a Sunday morning and I sat here, tears coming*

down. He [husband] said what's the matter, and I said if I could tell you, I would! He says, 'that's through your illness' and there's a lot of depression. (P3)

Well to be quite honest I didn't want to be here. (P1)

Well sometimes I'm really out of breath and I've got no use of my body, and that's when you know you're low. Sometimes I don't want to get up. Sometimes I don't want to go anywhere and don't want to eat anything. I went off my food completely, just couldn't be bothered, and that's how you are. (P6)

Isolation was one of the major contributory factors to poor emotional wellbeing:

I mean, you know, it's the old syndrome, isn't it, you're on your own, I mean, the best thing that's happened to me is having them windows there, you can see what's going on outside. (P5)

This feeling of isolation meant that they particularly valued the 'connection' that the telehealth brought with the CRS nurses. It was seen as a benign form of surveillance:

I felt it was, I felt I was being monitored, I felt like a connection, to be honest, like you know, to the [CRS] team. (P4)

Related to this, it was felt to be important that at the other end of the line there was a real person:

Well, it's about confidence, isn't it? I know there's someone at the other end of that line that can help me, [when] my readings are cock-eyed. (P7)

It is important to note, however, that the increased (medicalised) knowledge and understanding of their condition was also a benefit, independent of the feeling of connection:

I'm quite chuffed with it, being able to understand what it's all about, you know, blood pressure, SBO2s, temperature and weight, I've been more relaxed, if you like, and content... I'd go so far as to say if I could afford it, I'd buy my own equipment, and this peace of mind syndrome, it relaxes you a lot (P5)

This is the only way we can keep a check on how he's doing as to whether he needs help or so we'll be sorry to see it go. (Wife of P7)

The telehealth enabled more proactive management of the condition by the pwCOPD and their carers, as well as providing a connection to their healthcare professionals that they felt comfortable with.

4. Discussion

In summary, we explore the experience of current users of the telehealth services (a group who had previously reported high satisfaction of the service) to understand why they valued it. Our main findings were that pwCOPD had transformed their personal living space into a highly technical health space in order to manage their condition and within this context the

new medical technology, telehealth, was absorbed relatively unproblematically. The acceptability of the telehealth was reinforced because it was congruent with their values; they felt that it redistributed NHS capacity to focus on the needs of those that were more severely in need. Indeed, the telehealth brought benefits to the pwCOPD by giving them peace of mind, which was underpinned by two processes: legitimizing contact with healthcare professionals and increasing confidence in the self-management of their condition.

We found that these findings could be explained more robustly by taking an analytic perspective that focused on embodiment and emotions. Despite severe bodily restriction and pain, the pwCOPD tended to wait until their condition had deteriorated seriously before seeking help. Even minor worsening of readings from the telehealth, which could indicate the risk of an exacerbation (and potential hospitalization), triggered a response from the CRS and the patients felt that this contact was legitimate. This contact also gave them a daily sense of connection with the CRS team, mitigating feelings of loneliness.

Taking the readings everyday on the telehealth equipment, although they were sent through to be assessed by the CRS, had the positive unintended consequence that it gave the pwCOPD and their carers increased (medical) understanding of how well their body was functioning on a day-by-day basis. In this way, they developed increased confidence in their own management of their condition, which also served to alleviate feelings of anxiety or panic.

Our study is in line with previous studies, that have considered different models of telehealth delivery for pwCOPD, that have found that patients consider telehealth to be a good way for them to receive care, that it 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 et al. 2010, Whitten et al. 2007). However, what our study adds is an integrated explanation of *why* the telehealth technology brought feelings of peace of mind. This finding is important to help inform what *type* of telehealth may have an impact on patients' experience of their condition. Several models of telehealth are now available, but our study suggests that to maximise patient benefit, it may not be enough to simply have a piece of technology to provide an interface between patients and health care professionals. The patient is likely to need some way of checking their own physical health to help them to decide whether they should access professional help. This has implications for how telehealth may be integrated into services, and wider policy implications in terms of identifying potential benefits to the health system.

There are some limitations to our study. Our findings need to be understood in the context of the specific model of delivery of telehealth, where it was triaged by staff from a community respiratory service, which retained all its previous services including self-referral. Patients who are part of different service structures may have different, including much less positive, experiences. In addition, benefits also need to be understood within the wider context of the high symptom burden and heavy care regimes of pwCOPD, and there may be careful judgements to be made for commissioners about the absolute benefits of introducing such technologies in relation to the costs in different contexts.

We recognise that other studies could develop competing theoretical explanations for patients' experiences of telehealth in COPD, because of our analytic focus on 'peace of mind'. However, we argue that there is a potential for analytic generalisation about how and why telehealth can have positive effects, i.e. peace of mind = legitimizing contact + increased confidence to self-manage. These concepts may also be transferable to different services for conditions that have some similar characteristics, i.e. severe long-term conditions, particularly those that result in restricted mobility. Indeed, for commissioners or service providers, understanding how and why patients benefitted from the service could help when re/designing telehealth services.

Other limitations of our study are that we were unable to triangulate the reported benefits of the service with objective measurements (e.g. GP consultations, CRS visits, hospital admissions) because the low numbers would not have produced robust conclusions; however, we refer to other literature (Polisena et al. 2010) for this information and see this study as complementary, offering theorization of the reasons for potential benefits, and supportive of calls for more research into the impact of telehealth on health and health service outcomes. In addition, our patients were all of White British ethnicity, which is not representative of the Sandwell population; however, our sampling for this study was limited by the population recruited to take part in the pilot. Through our interviews with staff, they did highlight one patient who had had a less positive experience with telehealth. We felt it important to get a perspective from a potentially deviant case, but despite three attempts to contact the patient, we were unable to arrange an interview. The major strength of this study is that we talked directly to patients, in depth, about their experience, rather than relying on healthcare professional reports about acceptability or simple questionnaires assessing satisfaction with the service.

5. Conclusions

Overall, our study found that positive experiences of telehealth can be explained because it helped pwCOPD to legitimise contact with their healthcare providers, and increased their confidence in being able to manage their condition, which resulted in greater peace of mind. The use of 'situated interviewing' enabled participant accounts to be collected in a way that was participant-led and sensitive to place, because people could show and tell us about their (health) spaces, and the effects of the new telehealth intervention. Although from a healthcare perspective, this particular model of telehealth delivery in Sandwell was not seen as viable within the existing resources of the community respiratory services, the detailed information we have gained in understanding why patients valued telehealth could be used to redesign existing services, or when putting together service specifications for the use of technology in managing long term conditions in the future. Furthermore, the study adds to the literature more widely by contributing further understanding of the growing role of information and communication technologies in health spaces. Although the home has always been an important place for the delivery of informal care and symptom management, the process of domestication of complex health technologies alongside their diffusion outside the walls of the clinic into informal health spaces is changing the health landscape, with more change inevitable in the future.

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