An Evaluation of the Provision of Oncology Rehabilitation Services via Telemedicine Using a Participatory Design Approach

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Abstract

Background

The COVID-19 pandemic has fundamentally impacted the delivery of healthcare services globally. In line with UK government guidelines on social distancing, the use of telemedicine was implemented to facilitate the ongoing provision of cancer rehabilitation.

Purpose

We sought to evaluate and co-design telemedicine services to meet the complex needs of our patients and carers at a tertiary cancer centre.

Methods

Experience based co-design (EBCD) methodology was adapted to include virtual methods. Staff members (n = 12) and patients (n = 11) who had delivered or received or delivered therapies services at our UK cancer centre since March 2020 were recruited to take part in one-to-one virtual interviews. Patient interviews were video recorded, analysed and edited to a 30-minute summary video. Patient and staff virtual events were undertaken thereafter. A joint virtual patient and staff event occurred, where staff could see the video and with patients as partners, agree areas for change and develop groups for service co-design.

Results

Positive aspects regarding telemedicine provision were highlighted including reduced financial and time burden on patients, and increased flexibility for both staff and patients. The key concerns included digital exclusion, safety, communication and patient choice. Four co-design groups have been established to enact changes in these priority areas.

Conclusion

Using a participatory design approach, we have worked in partnership with patients and staff to ensure the safe, acceptable and effective delivery of rehabilitation services with integrated telemedicine.

Introduction

The majority of patients living with and beyond cancer will experience physical, cognitive and emotional impacts as a result of their cancer diagnosis and/or treatments received [1]. Functional impairments
during and following a cancer diagnosis and treatment can impact an individual’s social and vocational roles and can result in poorer survival outcomes [2]. Rehabilitation services provide vital interventions for people aiming to reduce the potential impact of cancer and cancer treatments on physical, social, emotional and cognitive functioning [2].

The COVID-19 pandemic has fundamentally impacted the delivery of cancer services globally and in response there was a rapid reorganisation of services to ensure that patients continued to receive essential care while minimizing exposure to the virus [3]. Cancer rehabilitation services at our centre also had to change quickly to comply with government guidelines on social distancing, to reduce footfall across our tertiary cancer referral centre and to help reduce potential transmission to our patients, many of whom were classified as ‘clinically extremely vulnerable’ patients [4]. Changes included the implementation of telemedicine services including video and telephone consultations, to ensure the ongoing provision of rehabilitation support and interventions.

‘Telemedicine’ and ‘telehealth’ are terms which are sometimes used interchangeably however there are two separate definitions in the literature. Telemedicine is described as the use of communication technology in healthcare in which the clinician and patient involved are at different locations during the consultation [5]. Telehealth involves the remote exchange of data between a patient and healthcare professionals as part of the patient’s diagnosis and healthcare management [6]. For the purposes of this paper, the term telemedicine is used to describe the use of telephone or video consultations for the provision of rehabilitation services to patients.

Telephone consultations have been used in primary care for over 100 years and the first documented use of video consultations occurred in 1964 in the oncology setting where patients accessed opinions on skin lesions from a melanoma consultant based at a different hospital [7]. With regards to oncology rehabilitation services, the use of telemedicine has long pre-dated this global pandemic, in particular for the ongoing care of head and neck cancer patients based in remote areas [8].

Acknowledging the balance of risk between missed care opportunities and transmission risks to both patients and health care providers during the pandemic, recommendations for practical approaches to managing patients with cancer during the pandemic were made [9]. Based on experience delivering cancer care during the SARS epidemic telemedicine was advocated as a possibility for delivering some aspects of outpatient supportive care, with evidence suggesting that it improves access to care and reduces healthcare costs [9]. The UK being less affected by the earlier SARS and MERS epidemics had evolved less widespread oncology telehealth services at the time of the COVID-19 pandemic.

Although the COVID-19 pandemic has caused huge human, financial and social costs to the UK and beyond, there have been some positives in particular the innovation and flexibility seen within the UK National Health Service and the short timescales where rapid change has occurred. Some changes in healthcare service provision may remain on a long-term basis including the more widespread use of telemedicine. On a local level, although the telemedicine delivery was acceptable and effective for some patients, digital exclusion remained a significant problem. Concern regarding the accessibility to such
services for all, and staff apprehension in delivering the majority of services in a non-face-to-face manner, necessitated the need to evaluate the rapid service development in the pandemic. However, service evaluation and quality improvement (QI) will likely be critical processes to facilitate the successful provision of new models of service delivery post-pandemic. QI and service evaluation can involve various methodologies to seek feedback that are then used to design or redesign services [10]. Previous quantitative studies have examined patient characteristics associated with choosing a telemedicine visit vs face-to-face consultation [11] and many studies have used survey/questionnaire design to assess patient and healthcare providers views on the use of telemedicine services [12][13]. However, such quantitative methods, may not capture the essence of patient and healthcare provider experience [14]. In recent years there has been an increased focus in the literature on moving towards co-design methods of service design [15]. Rather than using questionnaires to seek feedback on suggested changes in health care processes and services, co-design is a joint venture that involves service users and health care professionals working together as the co-designers of a service [16].

We sought to evaluate the provision of oncology rehabilitation services via telemedicine using experience based co-design methodology (EBCD) [17].

**Methodology**

EBCD is an approach that enables staff and patients to co-design services in partnership using six key stages (Fig. 1).

The project was approved by the hospital committee for clinical research (SE961) in July 2020. Patients and staff who met the eligibility criteria were invited to take part in in-depth semi structured interviews exploring their individual experiences of telemedicine rehabilitation services at the hospital since March 2020. Patients who were not comfortable in using/appearing in online meeting were also invited to contribute via written narrative. Staff and patient inclusion/exclusion criteria are summarised in Table 1.

Interviews were audio recorded (staff) and video recorded (patients) and were transcribed and main themes identified. Patient interviews were compiled into a 30-minute video to summarise the key themes from the patient interviews. Staff members were then invited to a staff group discussion to identify priorities for change in service provision whilst patients were invited to a patient group discussion where they could view the edited video. The video was used to stimulate a patient group discussion where key ‘emotional touch points’ (emotionally significant points) were identified and either positive or negatives feelings were assigned based on individual experience. The staff and patient participants then attended a joint event. The patient video was shown to both staff and patients, conveying to staff how patients experienced telemedicine services. Further group discussion was undertaken to identify joint staff and patient priority areas for change and smaller co-design groups were established to work on these areas.

**Results**
Eleven patients and 12 staff members were recruited to take part in the study. Zero patients were recruited to provide written narratives. Patient and staff criteria are summarised in table 2.

The key themes of the staff and patient interviews are summarised in table 3.

Patient and staff members identified four key co-design groups including:

1. **Inclusivity**: focusing on developing a telemedicine service which is accessible to all, limiting preventing any potential digital exclusion.
2. **Safety**: ensuring our interventions provided via telemedicine are safe
3. **Communication**: enhancing communication to patients regarding the range and choice of telemedicine and face-to-face appointments available and how patients may access these
4. **Peer-training**: the use of peer training to enhance patient access to telemedicine services

**Discussion**

We used experience based co-design to evaluate and start co-designing oncology rehabilitation services at a tertiary cancer centre. Staff and patient experience data was used to gain an in-depth understanding of the positive aspects of telemedicine and the areas for further development and refined design.

In line with previous research the positives of telemedicine were highlighted by both patients and staff members, [8][13] however, our patients and staff had a strong preference for a mix of both face-to-face and telemedicine to provide the highest quality standard of care. Both patients and professionals found telemedicine to be efficient as in previous studies [8][13] however, this was only the case when the technology performed as it should. Our study has highlighted that if there are IT issues, or indeed if the patient does not fully understand the instructions for joining a virtual consultation that this can reduce the efficiency of a clinic. This highlights the need to enhance patient communication/ training regarding access to telemedicine platforms. In contrary to recent research [13], both healthcare professionals and patients highlighted their concerns regarding the lack of physical examination and that in certain circumstances a direct physical examination would be required to provide safe and effective care. This would necessitate clear safety protocols to identify if and when a telemedicine consult would be appropriate and also clear methods of communication to the patient so that they can express their preference..

In line with previous research, we have found that successful telemedicine provision is more than just a question of technology. It requires fundamental changes in service design, with collaboration as a key determinant in successful implementation [18]. We sought to achieve this through collaboration and co-design with our patient partners and healthcare providers.

**Conclusion**
We have worked in partnership with patients and staff to ensure that we can deliver telemedicine rehabilitation services in a co-designed and co-produced format. Through the use of EBCD, rich insights have been gained into the barriers and facilitators to a positive and effective patient and staff experience of telemedicine in the context of oncology rehabilitation. This project will ensure our service is accessible and meets our patients’ individual and varied needs. This project is not without its limitations including a key area of concern that patients who were unable to or did not wish to access telemedicine services were not included in the project. As the project was undertaken during the pandemic, all interviews, group discussion and events took place virtually so there was a selection bias in terms of our sample. As we continue with this work, and with the easing of restrictions, we hope to involve more patients with the project including understanding why and how telemedicine was not accessible or acceptable to them during the pandemic. This will be a particular focus of the inclusivity group.

Declarations

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Ethics approval: The project was approved by the Royal Marsden NHS Foundation committee for clinical research (SE961) in July 2020

Consent to participate: written informed consent was obtained from participants

Consent for publication: written informed consent for publication of anonymised data was obtained
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Tables

Table 1. Inclusion/ exclusion criteria

| Inclusion criteria (patients): | Inclusion criteria (staff): |
|--------------------------------|-----------------------------|
| 1. 18 years of age or over    | 1. staff who have undertaken rehabilitative interventions using telemedicine services or supported others to deliver them during the COVID-19 pandemic |
| 2. adequate linguistic and cognitive function to participate in interviews and/or group discussions | |
| 3. have been offered and/or taken part in telemedicine rehabilitation services during the COVID-19 pandemic | |

| Exclusion criteria (patients): | Exclusion criteria (staff): |
|--------------------------------|-----------------------------|
| Does not meet all of the inclusion criteria | Does not meet all of the inclusion criteria |
# Table 3: Interview Themes

| Patients (n=11) | Staff (n=12) |
|----------------|--------------|
| **Male: 5 Female: 6** | **Male: 1 Female: 11** |
| **Mean age (range): 59 (37-77)** | **Professional role:** |
| **Tumour type:** | Divisional lead: 1 |
| Head & neck/ thyroid: 7 | Therapies lead: 1 |
| Gastrointestinal: 1 | Speech & language therapist: 2 |
| Breast: 2 | Physiotherapist: 1 |
| Haematology: 1 | Lymphoedema therapist: 2 |
| | Exercise specialist: 1 |
| | Dietitian: 2 |
| | Administrator: 2 |
| Themes                          | Staff                                                                 | Patients                                                                                           |
|--------------------------------|-----------------------------------------------------------------------|----------------------------------------------------------------------------------------------------|
| Cost effectiveness & efficiency| ‘Reduced hospital transport costs...no longer having to pay for hospital transport for our patients’ ‘reduced delays in clinic with patients arriving late due to transport issues’ | ‘No travel- ongoing care despite living many miles from hospital’ ‘Increased access to therapy support’ saves travel, money and less disruption when working’ |
| Flexibility                    | ‘More flexible with how we work, because of working from home I changed my hours. I condensed my four days in three and I am doing three long days’ | ‘much easier for the patient’ ‘questions answered from the comfort of home’ ‘one hour off work rather than a day/half a day’ |
| Importance of face-to-face     | ‘If you can’t do face to face, the next best thing is the video and then lastly telephone’. ‘I think having that [video], building up a rapport is so much easier than just on the phone. I found it very helpful when you are still getting to know patients in a little bit’ | ‘Face to face interactions are better if something has to be shown/seen’ ‘Videos not good for physical examination’ ‘Meeting old friends-virtual a bit more impersonal’ ‘Telephone not appropriate when more than one professional there’ ‘Phone calls are less intrusive than video consults. Coming to the hospital helps him prepare his mind for the consult/new’ |
| Patient centred                | ‘there are advantages to seeing them in their home environment, sometimes it is quite nice, because seeing them in a hospital you don’t really get a sense of what their set up at home is and their support’ ‘It is nice to see them in their home, where they are comfortable and family members can join’ | ‘much easier for patient to be at home’ ‘the answers to the questions, no travel required and no mask’ |
| Use of technology              | ‘clinicians didn’t have a dedicated space to contact patients’         | ‘able to initiate own access to appointment by email.’ |
‘a lot of our clinic rooms do not have IT access or telephone access. Also, our team sit in shared offices, which are not suitable to have consultations with patients’.

‘There are some general technical issues, like the signal is poor at home, the screen is freezing and not being able to hear me… It can be disruptive in an appointment and a bit frustrating… if they can’t hear what I am saying, or we are just freezing every few minutes… it just ends up taking quite a long time.’

‘I was OK but my mum wouldn’t be able to do it. It’s good for my generation’

‘Technology may cause others to panic’

| Change | ‘We went from a service with no telehealth to a service that was 100% telehealth’. | ‘before March 2020, nobody knew what zoom was’ |
|--------|--------------------------------|-----------------------------------------------|
|        | ‘The speed of the transition was very impressive for the NHS. I think one positive has been that now we can implement change much quicker than ever we would have considered’ | |

| Training | ‘needs to be training on how to deliver a video consultation, in terms of, when you are doing during the consultation, the posture, the language that you use, hand movements, how you talk, what information you share, where you sit, where is your camera, all of those things’ | ‘received appt via email with follow up text also containing tech support which was very helpful’ |
|----------|----------------------------------------------------------------------------------|--------------------------------------------------|
|          | ‘Patients also require training’ ‘Something to take them step by step though how to go onto [the call]. ‘Even if they [patients] have instructions, sometimes they struggle to follow that and I think that delays clinic.’ | ‘use video conferencing for work every day’ |
|          | ‘other patients who are older might feel panicked’ | |

| Safety | ‘We had to be a bit careful in terms of the safety aspects of doing these virtual sessions. Obviously, you are not there to catch someone if they fall and you cannot measure someone's heart rate.’ ‘You cannot really see how they are working… that is something which we have had to write into protocols’ | ‘element of guess work in absence of face to face, is professional getting the full story?’ |

| Inclusivity | ‘communication difficulties’ ‘language barriers can make telemedicine very difficult’ | ‘Older patients may struggle’ |

| Figures | |

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Figure 1

EBCD methodology (Point of Care Foundation, 2021)