

LIVING WITH HIP OSTEOARTHRITIS AND WAITING FOR SURGERY IN A BRAZILIAN PUBLIC HEALTH CONTEXT: A PATIENTS' PERSPECTIVE

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Abstract

This paper reports a qualitative study developed by a multidisciplinary team to collect patients' experiences of living with Hip Osteoarthritis – a prevalent, chronic, painful and limiting musculoskeletal disease – in a Brazilian public health context, where patients have to wait too long times for joint replacement surgery, the solution for the severe cases. This waiting patient commonly faces the progression of the disease and worsening symptoms in situations of helplessness and precariousness. With the goal to design new services or products addressed at this

community, Human-Centred Design approach was used. This first phase research involved semi-structured interviews followed by qualitative thematic analysis. As a result, three categories were created regarding pain, information, and expectations. Discussion relates findings with the trends about patient-centeredness, patient education materials, and shared decision-making, considering the challenge of engaging with underprivileged population.

Keywords: human centred design, hip osteoarthritis, Brazilian public health system

Introduction

Osteoarthritis (OA) of the hip is a chronic degenerative disease. In severe cases, hip OA is a painful condition that restricts mobility and interferes with quality of life. Palliative treatments can temporarily reduce pain and improve function, however, there is currently no cure. Joint replacement surgery – Total Hip Arthroplasty (THA) – is needed when the painful condition worsens (Hunter and Bierma-Zeinstra 2019).

OA affects 4% of the Brazilian population, about 8 million people, generating a huge socioeconomic burden. Brazil offers universal health care (SUS) to a population of 210 million. Due to the scarcity of financing, SUS has an enormous assistance gap in the performance of THAs in relation to the average of Europe and USA (Ferreira et al. 2018). That leads to a long waiting time for surgery, which makes people cope with pain, loss of function, anxiety, morbidity, and potentially worse results.

The complexity of the needs arising from comorbidities and socioeconomic aspects require individualized care, while also seeking to rationalize surgical and non-surgical treatment options. Prevention programs in primary and secondary care will be increasingly important to contain the burden of OA on the health system (Cross et al. 2014). Surgery should be reserved for those who do not respond adequately to less invasive methods (Hunter and Bierma-Zeinstra 2019). The Osteoarthritis Research Society recommend an exercise program combined with patient education (Bannuru et al. 2019), and there is evidence that the two combined practices may reduce or delay the need for THA surgery (Svege et al. 2015). Other studies highlight the importance of patient education, exercise program and self-care management, focus on prevention and shared decision making (Kolasinski et al. 2020).

The theme of this study points to challenges (ageing, active life); opportunities (health communication, prototyping, co-design,

evidence-based design, digital design); and emerging trends (self-management healthcare, person-centred healthcare, health promotion, preventive medicine) (Tseklevs and Cooper 2017).

The study was designed by a multidisciplinary research team from University of São Paulo and Faculty of Medical Sciences of Santa Casa de São Paulo, gathering expertise from Design, Public Health, Orthopaedics and Rehabilitation.

The Hip Surgery Clinic of the Orthopaedics Department of Santa Casa de São Paulo assists SUS patients. It has more than 500 patients waiting for THA surgery, usually for longer than 5 years. In general, these are elderly people, with low income and low education. Besides sporadic outpatient consultations, there are currently no structured non-surgical care protocols for this waiting patient, who faces the progression of the disease and worsening symptoms in situations of helplessness and precariousness.

In the Brazilian context, there has been a lack of qualitative studies on life of OA patients. This study aims to address that shortcoming by giving voice to patients' experiences. The knowledge produced during this phase will inform the development of new services or products co-designed with this audience.

This study is characterized as action research, in which empirical-based social research focuses on solving a problem, in which researchers and participants involved in the problem work cooperatively (Thiollent 2011) This action research uses a Human-Centred Design (HCD) approach (Norman 2013, Giacomini 2014) placing the needs, capacities, and behaviours of the individual as the central point of the design action. HCD seeks to ensure that the solutions correspond to the identified demands, that the products created are understandable, usable and that they promote positive and pleasant experiences (Norman 2013).

Methods

Initially, exploratory bibliographic research was carried out in databases (Google Scholar; PubMed) on hip osteoarthritis, its pathophysiology and epidemiology, symptoms, care protocols, patient education, pain management, etc. Clinical data was collected at the Hip Surgery Outpatient Clinic of Santa Casa de São Paulo Hospital through consultation in electronic health records. Kellgren and Lawrence system for classification of osteoarthritis was used to identify the severity of hip OA based on patients' radiographic exams.

Patients with hip OA were recruited by convenience on their consultation date, while also considering attaining some variation in age, gender, and disease stage. The interview script was formulated as a conversation guide, adapted from literature (Brembo et al. 2016; Nyvang, Hedström, and Gleissman 2016). During immersion in the clinic, observation and semi-structured interviews were conducted with patients and family members in a private room. The interviews were recorded and transcribed followed by thematic analysis (Patton 2002).

Results

Nine patients were interviewed. Both genders were represented (4 females and 5 males), mean age 60 years (range 36-78). The majority had severe OA according to radiographic exams. Mean time with hip-pain was 4,4 years (range 1-10). Mean time waiting for surgery was 1,3 years (range 2 months to 3 years). Five patients attended physical sessions at some point. None of them has been doing physical exercises, neither seeking more information about Hip OA outside the hospital. Most believe that THA surgery is the only solution to their problem and wish to be operated.

From content analysis, three underlying categories were created regarding pain, information and expectations. Quotes from the interviews illustrate the findings.

Pain and functional limitation

The description of how pain feels and restricts life activities is poignant, specially by those participants with severe pain and functional limitation.

'My life lost its meaning; I can do nothing by myself. I can't walk, I can't shower alone, put on clothes.'

'My life has changed 100% physically, because it is a physical pain I have 24 hours a day ... it affects your sleep, affects your diet, you get stressed by anything, because it doesn't leave your head [...] it doesn't leave your body! [...] Since I had this limitation, I have practically no social life [...] because I know what my limitation will cause if I go to the cinema I will not be able to sit in a cinema chair. If I can sit, when I get up, I cannot step on the floor ... My leg already failed, I fell at work, I fell in the middle of the street, because suddenly my leg fails, as if I did not have a leg [...]

I avoid going places because I know I won't be able to, it will hurt to take the bus, to get into a car, to sit in a chair, so I avoid it [...].'

'We even loose the will to live. I cannot walk, I walk 10 meters and I must stop because the pain is unbearable. It's like burning like fire, like someone's hammering.'

The loss of autonomy and self confidence in walking was evident. Although many are already retired, they said they would still like to be working.

Information: understanding the disease and treatments

Findings indicate participants' understanding of the disease pathophysiology, often answered dubiously:

'I understand that the disease is due to weak bones.'

'The liquid dried up, the bones started to scrape together, and that was wearing away the bone, isn't it?'

'The femoral head cartilage wears out, and ends up rubbing bone with bone what comes to hurt.'

On the other hand, when asked if they look for more information on hip OA outside the hospital (on websites, social networks), many stated that they already know enough since they are the ones experiencing it. One participant reported not searching the web to avoid being overwhelmed by too much information and fake news:

'[...] even though I have pain for 24 hours, I want to try not to be thinking about it all the time. Sometimes you research something that is a lie, it's fake news, so I prefer not to seek anything, any information because I think it will do me more harm than help me.'

The same participant reported resentment about the lack of information received by doctors regarding the progression of the disease:

'It's been about 4, 5 years I make consultations here. At the beginning it was a return every 1 year, but the problem was getting worse. Until then I had no physical limitations, it was just pain. No doctor ever came to me to say that the advanced state would be physical limitations [...].'

Although nearly half of participants attended physiotherapy sessions at some point, they reported no improvement. None of the participants was acquainted about the advantages of performing physical exercises. When asked about it, most were resistant to the mere idea of doing physical activity in this condition of pain. One participant said he wished to have been informed about physical exercises in time:

'if I had a person who knew about this disease and could guide me, before it

happened I would have done it. But I used to take medicine, then I was 2-3 days without pain, until it got to the point that I couldn't do anything else.'

Expectations: coping with the waiting-time for surgery

Surgery is seen as the only solution to their problem. Some seem desperate to operate. Almost all were optimistic about surgery outcomes and stated great confidence in the hospital quality standard. Two reported being afraid of the procedure and recovery. A general feeling of being deceived about when the surgery will take place was noticed. Two participants mentioned being worried or even hopeless about the long waiting time.

Discussion and conclusion

This paper reports a qualitative study aiming to comprehend problems and needs of hip OA patients waiting for surgery in a Brazilian Public Health system. Regarding pain, information and expectations, most of the patients had moderate to severe pain for more than 2 years, lack of understanding of the disease and its evolution, most of them do not seek information about the disease and most of them had high expectations on surgery.

Qualitative studies on OA patients have reported on a care pathway model for the hip journey (Brembo et al. 2016) and on how OA affects the whole body and self, resulting in a feeling of loss as patients are forced to change the way they lived their lives (Nyvang, Hedström, and Gleissman 2016).

Giacomin describes HCD approach today as 'the use of techniques which communicate, interact, empathize and stimulate the people involved, obtaining an understanding of their needs, desires and experiences which often transcends that which the people themselves actually realized' (Giacomin 2014). HCD has been largely

applied to health, mostly for development of software applications, websites, and other technology platforms aiming to improvement of health and behaviour change that impacts on health (Bazzano et al. 2017).

By using HCD methods such as observation and semi-structured interviews in the hospital settings, researchers gathered vivid descriptions of how pain feels, and the myriad of functional limitations and emotional states of annoyance, stress, melancholy, resignation and hopelessness that were crucial to empathize with their situation.

Findings and literature converge on the need to better inform patients about the journey through the progression of Hip OA and its management in each stage. Results imply that engaging patients that may not desire to learn more is a challenge, another one is gaining their adherence to a structured education program. The trust patients show for doctors and the institutional reputation were identified as strengths for health communications strategies, which should be especially tailored to a low education population.

Indications to THA surgery could be clarified and discussed with patients in a shared decision-making process (Harwood, Butler, and Page 2016) so that patients became active partners on their healing process, while seeking to rationalize surgical burden on healthcare system. In Brazil, there is a chronic long-term waiting list for THA. From the patients' perspective, besides the risks of poorer outcomes of a delayed surgery, staying passively on a waiting list means having no influence on their future recovery. Empowering patients to self-efficacy while on the waiting list is especially important in this scenario.

Strengths of the study were field research on hospital settings; multidisciplinary team working in collaboration since the structuring of research project, during interviews with patients when

physiotherapy and design team acted together to better conduct conversations, and during discussions over clinical records in comparison to patients' testimonials. Despite the small number of participants interviewed, they provided aspects of their experiences that increment literature on this topic while also inform next phase of co-designing solutions (creation of personas and user journey maps). Qualitative methods alongside the participatory methodology of action research, with stakeholders involved in the process, aggregated new information to quantitative data typically gathered in health sciences.

Limitations of the study were small number of participants, all experiencing advanced stages of OA, some had difficulties answering the questions, lack of previous contact with participants may have inhibited some of the conversations.

HCD methods were chosen in this context for being innovation-oriented, agile, and cost effective. However, the urge to convert observations into prototypes can make HCD too agile and too narrowed by a few end-users' perspectives, thus may have a limited impact when scaled. Furthermore, improving the life of a waiting patient might be a fair and feasible purpose, but it fails to address the deeper systemic problems in the health sector that determine the waiting line itself.

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