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Original Paper

Patient Perspectives on the Challenges and Responsibilities of Living With Chronic Inflammatory Diseases: Qualitative Study

Graham George Macdonald^{1,2}, BA, MA; Cheryl Koehn³; Gail Attara⁴; Allan Stordy⁵; Marilee Allerdings⁶; Jenny Leese^{1,2}, BA, MA; Linda C Li^{1,7}, PhD; Catherine L Backman^{1,8}, PhD

¹Arthritis Research Canada, Richmond, BC, Canada

²Rehabilitation Sciences Graduate Program, University of British Columbia, Vancouver, BC, Canada

³Arthritis Consumer Experts, Vancouver, BC, Canada

⁴Canadian Society of Intestinal Research, Vancouver, BC, Canada

⁵Canadian Skin Patient Alliance, Vancouver, BC, Canada

⁶Arthritis Patient Advisory Board, Arthritis Research Canada, Vancouver, BC, Canada

⁷Department of Physical Therapy, University of British Columbia, Vancouver, BC, Canada

⁸Department of Occupational Science and Occupational Therapy, University of British Columbia, Vancouver, BC, Canada

Corresponding Author:

Graham George Macdonald, BA, MA

Arthritis Research Canada

5591 No. 3 Road

Richmond, BC, V6X 2C7

Canada

Phone: 1 604 207 0400

Email: gmacdonald@arthritisresearch.ca

Abstract

Background: Collectively, chronic inflammatory diseases take a great toll on individuals and society in terms of participation restrictions, quality of life, and economic costs. Although prior qualitative studies have reported patients' experiences and challenges living with specific diseases, few have compared the consequences of disease management in daily life across different types of inflammatory diseases in studies led by patient partners.

Objective: The aim of this study was to identify the significant consequences of inflammatory arthritis, psoriasis, and inflammatory bowel diseases on daily life and explore commonalities across diseases.

Methods: A cross-sectional Web-based survey was designed by patient research partners and distributed by patient awareness organizations via their social media channels and by sharing a link in a newspaper story. One open-ended item asked about burdens and responsibilities experienced in daily life. Informed by narrative traditions in qualitative health research, we applied a thematic content analysis to participants' written accounts in response to this item. This is an example of a study conceived, conducted, and interpreted with patients as research partners.

Results: A total of 636 Canadians, with a median age band of 55-64 years, submitted surveys, and 80% of the respondents were women. Moreover, 540 participants provided written substantive responses to the open-ended item. Overall, 4 main narratives were generated: (1) daily life disrupted; (2) socioeconomic vulnerabilities; (3) stresses around visible, invisible, and hiding disabilities; and (4) actions aimed at staying positive. Ways in which participants experienced social stigma, pain and fatigue, balancing responsibilities, and worries about the future appeared throughout all 4 narratives.

Conclusions: People living with chronic inflammatory diseases affecting joints, skin, and the digestive tract report important gaps between health, social, and economic support systems that create barriers to finding the services they need to sustain their health. Regardless of diagnosis, they report similar experiences navigating the consequences of lifelong conditions, which have implications for policy makers. There is a need for outcome measures in research and service delivery to address patient priorities and for programs to fill gaps created by the artificial administrative separation of health services, social services, and income assistance.

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KEYWORDS

patient participation; chronic disease; arthritis; inflammation

Introduction

Background

Patient engagement in health research has been building over the last two decades, with examples of effective collaborations between patients and researchers being reported with increasing frequency. The benefits of patient engagement across the research process include identifying research questions of greater relevance to patients' concerns, improved participant enrollment and retention rates, and knowledge translation strategies that are more readily understood or adopted by community members [1]. Benefits to patients involved as investigators or research partners include a sense of empowerment, confidence, and contribution to the greater good that arises from meaningful engagement in the research process from inception to dissemination [2]. This paper describes findings from a project led by patient research partners. It describes the consequences of inflammatory arthritis, psoriasis, and inflammatory bowel diseases on daily life and explores commonalities across diseases.

In particular, this paper focuses on inflammatory types of arthritis (such as rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis), psoriasis, Crohn disease, and ulcerative colitis. All of these are systemic, autoimmune conditions [3-5]. Their clinical presentation ranges from mild to severe, and they are characterized as episodic, meaning people live with the uncertainty of exacerbations and remissions either from the natural course of the disease or its medical management [3-5]. People who have 1 disease, for example, psoriasis, are at higher risk of concurrently having one of the other diseases, for example, arthritis or Crohn disease [4]. Studies on the impact of living with these inflammatory conditions show disruption to normal daily activities [6-10], reduced productivity [9-11], and high personal costs because of the loss of ability to work and medical and other costs associated with health maintenance, which threaten financial security [6,11].

Among women with early rheumatoid arthritis, McDonald et al found that the uncertainty of having an episodic illness with fluctuating symptoms was particularly problematic as women experienced good days (able to engage in typical routines and daily activities), bad days (experiencing limitations in typical routines and daily activities), and worse days (often halting usual activities because of pain, fatigue, or recovering from symptom flares) [12]. Adapting to activity disruption threatened self-identity and sense of self [13]. Similar experiences have been reported by adults living with established inflammatory bowel disease [14,15] and psoriasis [13,16,17]. For example, among men and women with inflammatory bowel disease, unpredictable symptoms restricted social activities, employment, travel, and shopping, presenting enormous challenges to leading a normal life or maintaining the appearance of normality to others [14]. A survey of Canadians with Crohn disease or ulcerative colitis reported participation restrictions in leisure activities and interpersonal relationships to be the most

frequently reported consequences of the disease, at 64% and 52%, respectively [6].

Objectives

Given the frequency of activity disruptions reported in these (and other) qualitative studies, which by nature focus on relatively small numbers of participants, we recognized an opportunity to draw connections across disease groups with a larger number of participants. Such studies are valuable to patients because they corroborate their experiences; show they are not alone; and provide strategies for living well, interacting with health professionals, and advocating for resources. They are valuable to professionals for enhanced understanding of the impact of living with different diseases, placing patient experiences in context, and ultimately help improve patient-provider communication for more compassionate care [18]. By inviting a large number of people to respond to an open-ended question typical of qualitative research, this study potentially verifies and extends the transferability of findings from small studies. The study examines similarities and differences across respondents with a wide range of inflammatory diseases. Its specific purpose is to describe the consequences of inflammatory arthritis, psoriasis, and inflammatory bowel diseases on daily life and explore commonalities across diseases.

Methods

Design

A cross-sectional descriptive design was used with a Web-based survey. This paper focuses on written text responses using qualitative content and narrative analysis. Ethical approval was obtained from the behavioral ethics review board of the researchers' university.

Study Context and Role of Patient Partners

It has been recommended that patient and public involvement in research be explicitly reported [19]. Each of the 4 patient research partners (CK, AS, GA, and MA) is affiliated with a national public awareness or charitable organization focused on education, information sharing, and encouraging research. Two are members of organizations focused on arthritis and joint diseases, 1 works with an organization for gastrointestinal and inflammatory bowel diseases, and 1 with an organization for psoriasis and inflammatory skin diseases. They volunteered as consumer and patient partners along with researchers to develop a grant application in response to a specific call for proposals to fund research teams with a focus on chronic inflammatory diseases. The bid was successful, creating PRECISION, a pan-Canadian team of over 30 researchers including patients working on a series of interconnected studies.

PRECISION is an acronym for PREventing Complications from Inflammatory Skin, joint, and bowel conditIONS, and the diseases under study are psoriasis, rheumatoid arthritis, lupus, ankylosing spondylitis, gout, Crohn disease, and ulcerative colitis. The team objectives include assessing the risk and burden

of complications and consequences of these diseases and testing novel health services aimed at preventing or mediating those complications, priorities identified through patient-researcher collaboration [20]. This context is important because this study is a direct consequence of the way patients chose to inform PRECISION's objectives.

The patient partners designed a survey to gather data to strengthen the patient perspective component of the grant application. When the volume and depth of data received was greater than anticipated, a systematic data analysis plan was developed in collaboration with 4 PRECISION researchers to give voice to the concerns raised by survey respondents. The role of the patient partners in this paper thus included survey design and implementation, participant recruitment, assistance throughout data analysis and interpretation, and review of manuscript drafts.

Participants

The patient partners, through the social media and e-newsletters of their 4 organizations, distributed the survey link to their subscribers nationwide. The patient partners also connected with a newspaper reporter who wrote a brief story that included the survey link in the print version of a metropolitan daily newspaper and the reporter's blog. There were no explicit inclusion criteria other than the survey notice that specifically invited people with inflammatory joint, skin, or bowel diseases to have a say in research and complete the survey anonymously. Consent was implied by submitting a completed survey. The survey was open for 3 weeks in the summer of 2013 and was hosted online on SurveyMonkey.

Survey Content

Patient research partners designed a Web-based survey to identify patient priorities for research to help justify the objectives of PRECISION. The patient research partners invited all team members to contribute items for inclusion in the survey and then vetted a large number of potential items to reduce the total number and ensure clarity of the retained items. In addition to basic demographic information (eg, diagnosis, sex, age group in 10-year age bands, and urban vs rural place of residence), the survey contained closed-response and open-ended items to gather patient perspectives on medication use, knowledge about potential disease complications, treatments and interventions, lifestyle habits (eg, physical activity), and experiences living with inflammatory diseases. The responses to closed-response items helped justify the grant application with respect to needs around specific diseases, complications, medications, and physical activity [21].

In this paper, we focus on text responses to the following open-ended question: *what are some of the burdens and responsibilities you face in managing or living well with your illness?* There was no word limit imposed on stories written in response to this item nor was it required that participants enter any text.

Data Analysis

Responses were downloaded verbatim into an Excel file for tabulation (keeping text responses linked to demographic

descriptors such as age and diagnosis) and analysis. The burdens and responsibility question generated numerous stories and commentary. Tallying was avoided because the spontaneous responses to the open-ended question meant that some respondents introduced new topics that, if tallied, would not represent the proportion of respondents who shared that view; counting was not found to yield specific or meaningful data [22]. Accordingly, we drew upon narrative traditions that allow personal accounts and experiences to conduct a thematic content analysis of these text responses [23,24]. We sought to understand *what* people experienced rather than *how* they described it, making thematic content analysis more appropriate than other forms of narrative models for this dataset [23]. Thematic content analysis is suitable to participatory types of research because it is generally understandable by all audiences, highlights similarities and differences within the dataset, and allows for socially relevant interpretations to inform policy development [25].

Trustworthiness depends in part on the description of the analytical process. We read and reread all responses to become familiar with the data and then identified common and repeated elements to broadly classify the issues and topics of concern to respondents. Our analysis began with open coding of the data in which we flagged phrases of interest from the responses. The initial codes were then clustered into categories based on recurring elements and common subjects. These categories were then analyzed for the character of the responses they contained and their narrative context. Categories were further clustered to derive tentative themes. Themes were then discussed and agreed upon by the team through discussion and review of written descriptions with supporting quotes. The final analysis was represented by 4 narrative themes.

Validating the Analysis

The preliminary content analysis was developed by 2 researchers (GGM and CLB) with qualitative research experience, who brought different lenses to the dataset (one is male, early career, and educated in the social sciences; the other is female, health professional, and senior researcher). The preliminary topics and supporting evidence (data extractions) were discussed by all coauthors at a team meeting, and draft categories were developed and circulated by email, and additional comments and interpretations were gathered through sequential iterations appraising data and interpretations. As the patient partners were representatives of organizations each dedicated to different disease groups, their feedback served as a form of member checking as to whether findings resonated with experiences and concerns of their respective groups.

The 4 patient partners and 4 researchers thus co-constructed narratives reflecting the common experiences within the dataset and agreed upon quotes to represent each narrative. Collectively, the 8 collaborators bring perspectives from men and women, young adult to late middle-aged, and health care, research, or lived experience across inflammatory skin, joint, and bowel diseases, experiences that contribute to the trustworthiness of interpretations. As a final step to enhance transparency and trustworthiness, the analytical process and findings were

reviewed with a peer experienced in qualitative methodology and health research.

Results

Demographics

We received 636 unique surveys. Respondents' age varied from 18-24 years to 85-94 years (median age band 55-64 years), and 80.0% (509/636) of the respondents were women, which reflects the higher prevalence of women affected by most of the diseases in this study. The majority, 71.1% (452/636), were from British Columbia (the location of the newspaper with the survey link), with additional respondents from all other Canadian provinces and 2 territories. Most (91%) lived in a city with at least one hospital. Moreover, 42.9% (273/636) reported multiple health conditions, often 2 of the 3 inflammatory disease categories part of PRECISION, for example, Crohn disease and arthritis. Consequently, the following proportions sum beyond 100%: 86.0% (547/636) reported inflammatory joint diseases, 25.9% (165/636) reported psoriasis, and 18.1% (115/636) reported inflammatory bowel diseases.

Of the 636 respondents, 540 (85.0%) responded to the burdens and responsibilities question. These varied in length from a single phrase (eg, "maintaining mobility and managing pain when I have flare-ups") to lengthy accounts of concerns for themselves and their families, descriptions of living with their disease or diseases in daily life, and efforts to take charge of their unique situation. Overall, responses outlined the ways in which the health care system and society in general are both helping and failing this population.

Overall, 4 key narratives were crafted to represent the substance of the large number of text entries: daily life disrupted; visible, invisible, and hidden disability; socioeconomic vulnerability; and staying positive. Verbatim data show considerable overlap among the themes; therefore, some quotes easily support more than 1 key narrative. Examples of social stigma, pain and fatigue, balancing work and family responsibilities, and worries about the future contributed to all 4 narratives. For example, *experiencing* symptoms such as pain and fatigue were precursor to the first 3 narratives related to disruptions in daily life, disability perceptions, and social vulnerabilities, and *coping* with symptoms was apparent in staying positive, the fourth narrative. Each narrative is described below; alphanumeric labels link to quotations in Tables 1-3. Each quote references the sex, age band, province or territory of residence (using postal abbreviation), and reported diagnosis.

Daily Life Disrupted

Respondents told stories characterized by disruptions to tasks, activities, and roles, ranging from inconveniences to major shifts in how they participated in life. The most frequently cited antecedent to disrupted activities was persistent and sometimes unrelenting pain and fatigue, reported by more than half of the sample. Managing symptoms necessitated setting priorities that tended to place obligatory work or household responsibilities ahead of equally important but more discretionary activities such as maintaining social connections or enjoyable leisure

activities (Table 1: A1 and A2). Although employment was often stated as high priority, many respondents struggled to sustain participation in work. Repeatedly, respondents outlined difficulties fulfilling the roles that others expected of them or shared serious concerns for the future if they were unable to continue work or take care of their own health (Table 1: A3 and A4).

Descriptions of disrupted daily routines and the need for planning ahead were more often reported by those with joint or bowel diseases than those with skin conditions. Disruption was a prominent narrative in social situations, and some found it very stigmatizing to "say no to social activities" and "curtail my hobbies and be vigilant of travel plans" to manage symptoms. Respondents experienced adversity in their social environments, feeling forced to adapt to circumstances and relationships that did not give credence to their illness experience (Table 1: A2). They reported concerns about being inadequate as friends, partners, or family members, and some expressed feeling inferior to their peers at work. Respondents with inflammatory bowel diseases reported constant stress over whether or not they will be able to access a bathroom facility at a moment's notice as curtailing social interaction (Table 1: B1 and B2).

Visible, Invisible, and Hiding Disability

Collectively, descriptions debated the extent to which these conditions are or are not visible, how that affects interpersonal relationships, and whether or not there is a need to consciously hide disability. A clear cluster of responses related to appearing sick versus well, of how "looking well does not always mean feeling well" and how this could be burdensome when trying to "give your family a break from your disease. Relationships take a beating." Visible disease characteristics such as psoriatic plaques affected relationships (Table 2: C1 and C2).

Although some respondents spoke about visible characteristics of their diseases, there were more descriptions of how invisible disability (appearing normal) led to individuals feeling marginalized (Table 2: D1) and wanting to explain, increase awareness, or find a way to foster understanding, assistance, or universal accessibility (Table 2: D2). Family, social, and employment relationships were reported to suffer because of a lack of empathy and understanding:

I guess the biggest casualty is that I never had the energy to create an active social life. A lot of people do not understand last minute cancellations for plans because all of a sudden you lack the energy to participate. [Female, BC, 55-64 years, psoriatic arthritis]

At times, respondents described feeling devalued by society as weak or dysfunctional and how those attitudes are held or contested by their spouses, friends, coworkers, or bosses (Table 2: D3 and D4). In contrast, other descriptions related to the desire or perceived need to hide the disease. Sometimes, this reflected wanting to participate in activities like anyone else, whereas other examples related to fears about being treated differently or losing opportunities or jobs (Table 2: E1 and E2).

Table 1. Daily life disrupted.

Subtheme	Quotes
Accommodating symptoms disrupts work	<p>A1: <i>The largest burden is the effect fatigue has on social and work life- I have had to adapt my sleep patterns so I can perform at work; in the end my social life suffers.</i> [Female; 25-34 years; SK^a; RA^b]</p> <p>A2: <i>The disease is sometimes invisible and people don't understand issues with fatigue or sudden onset of pain/flare. This has a profound impact in the work place and in personal relationships. I am often perceived as lazy when I can't get mobile in the morning (late for work) and tend to over-compensate by working late and taking on more than I can manage. This pattern will lead to a flare which continues in a downward cycle. I hesitate to ask for help because I don't look sick (don't use a walker or cane) and am often judged to be "weak." In one workplace, a supervisor told my coworkers not to coddle me and that I had a low pain threshold. My partner has a hard time understanding the fatigue part but is very sympathetic to painful flares.</i> [Female; 45-54 years; BC^c; psoriatic arthritis]</p> <p>A3: <i>I don't have the energy to do what I feel needs to be done, nor do I have the physical ability to do it. I want a pain free / tired free day. [I am] feeling inadequate in many aspects, losing my independence, always in pain, not being able to continue with my well-paying job.</i> [Female; 55-64 years; BC; RA and OA^d]</p> <p>A4: <i>Working full time and being a mom to 20 month old is very challenging, never mind finding time and energy to exercise, or even just be able to get enough rest.</i> [Female; 35-44 years; ON^e; RA]</p>
Disruptions specific to inflammatory bowel diseases	<p>B1: <i>The thing of most concern is that the only treatments mostly involving taking drugs with very significant and unpleasant (and dangerous) side effects. I know many with UC [ulcerative colitis] feel a bit like guinea pigs as we try to control our disease and be active and contributing members of society. Ulcerative colitis is very unpredictable. I have tried many "alternative" things, none of which have helped. I have experienced flares dozens of times and I have no idea why they happen when they do. The need for a washroom quickly is a huge burden. Also, public washrooms are neither private nor soundproof. It causes me emotional strain to wait in a stall until everyone has left, only to have someone else come in. It is embarrassing and very few people understand. I cannot always participate in activities with family and friends. I don't think they understand. I often feel they think I am making excuses (which I do sometimes to get around saying it is my colitis). I worry about the impact of my disease on my work. I worry very much that it will make my retirement less than what I dream of. I feel like a burden to my husband sometimes. I feel I complain too much although I try not to. I cannot talk to anyone about my actual symptoms as they are considered disgusting.</i> [Female; 55-64 years; BC; UC^f]</p> <p>B2: <i>Always looking to find a bathroom in case you need one, always having to explain to other people why you can't do or eat something, being disappointed in yourself because you can't do what everyone else is doing, disappointing your family (children) when you have to cancel plans at the last minute due to a flare up.</i> [Female; 65-74 years; BC; UC]</p>

^aSK: Saskatchewan.

^bRA: rheumatoid arthritis.

^cBC: British Columbia.

^dOA: osteoarthritis.

^eON: Ontario.

^fUC: ulcerative colitis.

Table 2. Visible, invisible, and hiding disability.

Subtheme	Quotes
Visible disability	<p>C1: <i>Red raised patches and skin flakes all over my body interferes with my interpersonal relations and social life.</i> [Male; 55-64 years; AB^a; psoriasis]</p> <p>C2: <i>Unsightliness of plaques. Annoyance as I have psoriasis. People's comments and the unpleasant look of it.</i> [Female; 45-54 years; BC^b; psoriasis, Sjogren syndrome]</p>
Invisible disability	<p>D1: <i>Having an invisible disease comes with a lot of judgmental bigots' attention. Having accidents because of denied use of washrooms, being overweight because of the side effects of the medications. The pain can be crippling. Imagine not having ANY control over when and where you need to go to the washroom...while your body is in pain.</i> [Female; 25-34 years; BC; Crohn, RA^c]</p> <p>D2: <i>[That] some people have a difficult time understanding or even believing I have to contend with illness can be trying. I was so surprised by what happened to me and by my diagnoses that I want to help others understand the complexities of rheumatic diseases.</i> [Female; 55-64 years; QC^d; AS^e, psoriasis, Crohn, Sjogren syndrome]</p> <p>D3: <i>Chronic pain and unpredictable flare-ups make it hard to manage life on a daily basis. I always have to carry painkillers with me. Often, I have trouble riding a bus or subway because I have limited mobility and joint strength. Navigating in public is hard when others do not seem to understand that someone who looks "normal" has trouble turning a doorknob, or holding a door open.</i> [Male; 55-64 years; BC; RA, psoriatic arthritis]</p> <p>D4: <i>Trying to manage a balance of work and family life while having chronic pain. Stress of not being able to support child if I have to take days off work. Being sick but not looking like a sick person is difficult as people don't understand.</i> [Female; 35-44 years; BC; lupus, Hashimoto disease]</p>
Hiding disability	<p>E1: <i>[It is a burden] making people aware of the disease without having a label put on you. Since my disease is not visible it is hard to hide pain.</i> [Female; 65-74 years; BC; AS]</p> <p>E2: <i>Being disciplined all the time. Not being a burden on my significant other and children. Hide the disease as much as possible from my employer.</i> [Male; 55-64 years; QC; AS, psoriasis]</p>

^aAB: Alberta.^bBC: British Columbia.^cRA: rheumatoid arthritis.^dQC: Quebec.^eAS: ankylosing spondylitis.

Socioeconomic Vulnerabilities

Respondents explained how they simply did not have the energy to concurrently maintain employment and family responsibilities and attend to their own health, which resulted in financial strain (Table 3: F1, F2, and G1). They spoke of “falling through the cracks” between health care and social systems because eligibility requirements for programs denied them access. They described experiences where the health system or government priorities and budget constraints shifted definitions of disability in ways that excluded them from accessing the pensions or resources they needed or relied upon in the past (Table 3: G2 and G3). Some respondents reported difficulty in being taken seriously by their doctors (Table 3: K1 and K3) and consequently suffered setbacks in their treatment and health or expended time and effort coordinating and seeking out proper

health care (Table 3: K2 and K4). For those living alone, their living arrangement was frequently cited as exacerbating the negative effects that their disease or diseases have on their quality of life (Table 3: F2 and K4).

Repeatedly, respondents explained how their disease makes them economically vulnerable because of employment insecurity or loss and the high cost of treatment and medication. It was difficult to buy items such as healthy food or services not funded by health plans to help them prevent complications (Table 3: H1, H2, and H3). The high cost of biologics as well as their unpredictable and potentially serious side effects or worries about long-term effectiveness were a burden common to many respondents regardless of diagnosis (Table 3: J1 and J2). The pressure and stress of dealing with health and social systems fostered a fear of the future and what it might hold (Table 3: J2).

Table 3. Socioeconomic vulnerabilities.

Subtheme	Quotes
Financial strain	<p>F1: <i>Full-time employment was not possible so there were financial concerns because I could only work part-time. Reduced finances because of part-time employment, coping with the physical challenges of household tasks like cleaning, shopping, cooking, having enough energy to socialize after doing essentials, not feeling like a burden to my family.</i> [Female; 55-64 years; BC^a; psoriasis, RA^b, OA^c]</p> <p>F2: <i>Chronic pain, immune symptoms, inflammation, quality of life. Financial burden of not working, being single and living alone in Vancouver. Having energy to eat well when I am flared up, and one of the biggest, is that patients really do need to be our own advocates in order to avoid falling through cracks in the system.</i> [Female; 35-44 years; BC; endometriosis, inflammatory bowel disease]</p>
Disability programs are inadequate and restrictive	<p>G1: <i>Having a chronic, painful illness at a younger age means trying to juggle the symptoms (including crippling fatigue) with children, spouse, home responsibilities, and work. Combined with a long commute, it's almost impossible for me to spend any time taking care of myself, like getting more sleep or exercise, or eating better. I want to get better, and I know I need to take better care of myself, but I can't figure out how to make it work. I don't think there are any programs or support (at least I've never heard of any) for young people managing these types of issues. Most programs are geared towards the elderly.</i> [Female; 35-44 years; BC; RA]</p> <p>G2: <i>Trying to manage working, running a house and exercising on limited energy. Helping my children deal with the unknown and day to day issues of a chronically ill mom and finally, disability programs do not deal well with chronically ill people able to work part time.</i> [Female; 45-54 years; AB^d; lupus, Sjogren, polymyositis]</p> <p>G3: <i>How to earn a living. No money means no options. If the government keeps rejecting disability claims because chronic arthritis is not disabled enough how does one make money? Cannot go to swimming pool or buy decent quality food to help fight inflammation, cycle becomes a revolving door.</i> [Male; 35-44 years; BC; AS^e]</p>
Added costs of maintaining health with a chronic disease	<p>H1: <i>[I feel the] financial burden of not having a lot of (realistic) job options - costs associated with disease management that have no coverage (i.e., are not prescription drugs), "high cost, high quality foods," alternative health care, gym/pool memberships, equipment, living with chronic pain -not sleeping- not easy in social situations, (bathroom availability, food/water sources available).</i> [Female; 45-54 years; BC; UC^f]</p> <p>H2: <i>The cost of helpful therapies e.g., massage, medications, etc. [I'm] now on a disability pension, the things that support my quality of life are difficult to get.</i> [Female; 55-64 years; BC; lupus]</p> <p>H3: <i>I cannot afford to eat a good diet, and pay for my medications, treatments, supplements, and pay my bills on what I get from disability and the small amount I am allowed to earn. I have to choose to eat well or take the medications, I can't afford both. Without both, I cannot manage my disease well.</i> [Female; 35-44 years; BC; lupus]</p>
The cost of biologics	<p>J1: <i>My biggest concern is that the [biologic] which currently controls my RA could someday become less effective or stop working altogether, and that no other treatment will be effective. My other concern is that perhaps despite the [biologic], I could still be slowly incurring joint damage leading someday to disability and deformity. The greatest burden is managing the high cost of biologics.</i> [Female; 55-64 years; ON^g; RA]</p> <p>J2: <i>I'm fearful of what my future holds in terms of health problems. In addition, because of the symptoms I am unable to work or obtain employment and this impacts me severely financially. The medications I am on are also costly and again cause financial burden.</i> [Female; 45-54 years; BC; lupus]</p>
Time and effort to manage own health care	<p>K1: <i>My biggest concerns are: 1) Doctors listen to what I am saying about my symptoms and not rely solely on test outcomes. 2) Take seriously my description of being in severe pain.</i> [Female; 55-64 years; MB^h; Crohn; OA]</p> <p>K2: <i>I have to be the captain (or co-captain) of my health care team. I have poor access to my medical records. There are a lot of out-of-pocket expenses. Important to be highly health literate, taking medications forever, social stigma, low level of socializing, hard to work full time, more disability in future.</i> [Female; 65-74 years; ON; RA, Sjogren]</p> <p>K3: <i>Although I appreciate my doctors, I often feel they do not appreciate me asking questions or taking part in my own care. I am very experienced with this disease. I find they push for invasive diagnostic procedures promising no pain, when in the end there is pain. I know they are trying to help but I think treating UC [ulcerative colitis] patients is not their favourite thing. I wish health professionals learned more about the day to day challenges of living with a disease such as colitis.</i> [Female; 55-64 years; BC; UC]</p> <p>K4: <i>Constant pain, not knowing when my hip will pop out of its socket, long term disability from work (12+ years ago) and dealing with CPP [pension plan] and long-term shortage of money due to being unable to work and do the activities I would like to do, poor balance and living alone in a small island place when my present doctor and specialists are in the greater Vancouver area. I am NOT allowed to have 2 G.P.s - so must keep the M.D. who has helped me with my condition(s) for the last 12+ years and take the ferry and bus to appointments in Victoria and Vancouver as Travel Assistance Plan forms can't be forwarded to me as the Medical Clinic on this island won't give me TAP forms and the G.P. and staff in New Westminster have no idea how to locate these forms - a nightmare!</i> [Female; 55-64 years; BC; arthritis]</p>

^aBC: British Columbia.^bRA: rheumatoid arthritis.

^cOA: osteoarthritis

^dAB: Alberta.

^eAS: ankylosing spondylitis.

^fUC: ulcerative colitis.

^gON: Ontario.

^hMB: Manitoba.

Staying Positive

Although the above 3 themes speak about undesirable consequences of inflammatory disease, there is a contrasting narrative arising from these written entries that tells a more positive story of resilience and adaptation. Examples of collaborative care, where health professionals and patients work together to ensure treatment both parties found appropriate, was 1 example. Some respondents shared strategies they found effective:

I have received strong encouragement from my nephrologist and my rheumatologists to exercise, and a wonderful, now-retired rheumatologist referred me to a physio. Physical activity has been absolutely critical to my well-being. I'm so grateful! [Female; age 45-54 years; BC; gout, lupus, Sjogren]

Another respondent described collaborative care:

My team of doctors listen to me, respect me and believe me. We work together to get me healthier. They are proactive in searching for answers and options. My acupuncturist and massage therapist have the same attitudes as the doctors. The very supportive environment this creates helps me stay focused on getting healthier; even when the pain is so bad I feel like I can't move, I know that it's my job to get out and walk and exercise. They're all doing what they can to help me and I, in turn, must do my part. Without their support, I'm sure there are many times I would have given up. [Female; 55-64 years; BC; psoriasis, rheumatoid arthritis]

Staying positive is presented as a serious but necessary challenge:

Pain management is my biggest burden. You must be constantly aware of your physical limitations and not make them your focus. Forcing yourself to stay active and positive despite how you feel. [Female; 55-64 years; QC; ankylosing spondylitis]

Keeping a positive attitude was cast by some participants as a struggle against fears and anxieties about the future. The following respondent shared reflections across several decades of living with inflammatory diseases, illustrating the episodic nature of both the disease and positive attitude:

Initially (in my 20s) with total body coverage of psoriasis, I was concerned I would never meet anyone that could tolerate how "ugly" I was (felt); then with onset of PsA [psoriatic arthritis] in my late 30's my main concern was keeping mobile and being able to care for our daughter. Now in my 70's after 10 years of clear skin and pain free joints due to the

effectiveness of the [medication] injections, I'm concerned the drug is losing its effectiveness and I will lose the wonderful "normal" life I have had – walking, cycling, dancing, sleeping, and pain free (almost) during the night. [Female, BC, 65-74 years, psoriatic arthritis, Sjogren]

Discussion

Principal Findings

Disruptions to daily life, systemic vulnerability, coping with (in)visible disability, and staying positive are interconnected aspects of living with chronic inflammatory diseases. Written passages from Canadians living with inflammatory joint, skin, or bowel diseases support 4 intertwined narratives, none of which exists in isolation, illustrating challenges encountered on a regular basis, regardless of diagnosis. The reasons for disruptions differed across diseases and individual experiences, but the overall consequences were quite similar. For example, the difficulty of maintaining steady employment and income threatens financial stability; consequently, one is less able to afford the goods and services that, alongside medical care, support a healthy lifestyle that makes the difference between inflammatory disease being a manageable condition rather than a miserable one. When daily life is disrupted, the relationships that hold peoples' lives together begin to unravel, whether it is a relationship with one's employer who sees inflammatory disease as a liability or one's coworkers, friends, or family who do not understand the burdens imposed by the disease. Many respondents stated a need to try to hide their disability, having encountered or anticipated a lack of understanding or compassion from those around them as essential to supporting a positive self-identity. Managing diseases, relationships, and life roles was a balancing act, consistent with prior smaller but more in-depth studies [12,14,15]. Thus, this survey of a large number of patients confirms the experiences described in prior research.

Some respondents regarded the responsibility to maintain a positive attitude while coping with chronic pain and disability as an ongoing mental and emotional challenge. However, this was not a universal experience because other respondents appeared to have mastered a positive perspective. They dismissed disease-related challenges as part of life and focused on things that mattered to them, such as enjoying with family and friends and enjoying activities, regardless of their health conditions. As the survey item used the phrase "burdens and responsibilities," it solicited responses regarding difficult experiences; however, the small number of respondents who spontaneously presented a positive narrative instead was nonetheless critical. What is unknown, given the limitations of a single, written submission from each participant, is the extent to which a positive perspective can be sustained by the

individual's resources such as access to health care, economic security, the presence of strong social networks, or responsibilities like caring for others—all of which contribute to health disparities. It is also possible that these descriptions of resilience, such as inflammatory diseases, are episodic or reflect a stage of adaptation to living with a long-term condition [26]. On the basis of the findings of this study, those with highly positive descriptions credited respectful, collaborative relationships with health care providers and understanding family, friends, and employers with supporting their outlook on life.

The findings suggest that many respondents' needs are not well served by a system that isolates each individual problem to the exclusion of seeing the bigger picture. This bolsters evidence for a biopsychosocial approach that integrates the social experiences of patients with the psychological and physical impacts of their disease or diseases. Finding solutions to the consequences of long-term illness requires a patient-led research agenda because as Rose argues, public and patient engagements are forms of civic participation and citizenship that work toward the democratization of science [27]. Patient engagement in research is an avenue for their concerns and priorities to be represented, and by extension, better addressed in health and social sectors. This confirmatory study with 540 participants shows that many health needs are unmet from the patient perspective, explained in part by lack of attention to social determinants of health. That patients seek symptom relief, strategies to support daily life, a functioning social safety net, and empathic social support and health services is not new, but the repetition across multiple patient experiences indicates these important and long-standing issues have yet to be resolved. This suggests one role for these findings is to inform system, policy, and service delivery change needed to resolve these issues.

Examples for engaging patients in research are widely available [28-30], and our experience had both strengths and room for improvement. Researchers are generally motivated to try public engagement because they feel it will increase the relevance of their findings, whereas patients may be motivated by the desire for more user-oriented services [28,18]. A moral rationale for patient-partnered research is that it honors and respects the patients' voice, supports participation, minimizes occupational disruption, and advances a role for patient organizations in public education of the need for societal supports, large and small [29]. Moving forward, a measure of patient engagement in research that can serve as a guide for assessing the quality and depth of patient engagement in a given project may be useful and lead to more user-oriented research [30-32].

Strengths and Limitations

The large sample in this study was a major strength as it ensured that all relevant topics to the study populations were uncovered. There are 2 key limitations. First, the survey was originally designed to inform research priorities and questions and not as an original research study; thus, items were neither standardized nor pilot tested. Second, the single open-ended question is a minimalist form of data elicitation, and although this paper presents a qualitative analysis, it was not a prospectively designed qualitative study. Although the opportunity to probe

further (as in other forms of qualitative inquiry) was not possible with this mode of collecting written narratives, we had narrative texts from over 500 Canadians. Typical qualitative research involves theoretically informed designs with in-depth descriptions from a small number of participants. What was lost in depth is counterbalanced by breadth, enhancing transferability to Canadians with similar diagnoses. We believe that this study is a valuable contribution to inflammatory disease research, despite the methodological limitations of qualitative analysis of open-ended survey questions. Through its rigorous self-awareness of the limitations of its data, relevance in identifying cross-cutting issues from other studies, and engagement with patient partners, this study meets the criteria set out by LaDonna et al that mark it as an exception to the general weakness of such methodological designs [33].

Prior studies of living with chronic inflammatory diseases have eloquently illustrated the burden and responsibility within a disease group such as arthritis, inflammatory bowel disease, or psoriasis [7,14,17]; our survey extends those findings across a large number of people and inflammatory diseases. The survey format allowed respondents anonymity and freedom to speak their thoughts, in contrast to the more personal interaction of a research interview. An advantage of this approach may be a lesser likelihood of social desirability—shaping responses, that is, that respondents tell the researcher what they believe the researcher wants or expects to hear. The limitation, however, of having to take responses at face value without more probing means that some clarity of meaning may be lost. As a survey administered “by patients for patients,” a platform was provided for critical input from respondents that may otherwise be elusive in more structured quantitative and qualitative studies alike.

Public engagement in research happens most often at the stage when researchers need patient input to help identify a relevant research question [34]. Although this was the case with our study, patient partners remained engaged throughout the research process, beyond the initial phase when it is advantageous to securing funding. We consider it a strength of this analysis that it was undertaken with respect to the values of patient and public engagement outlined by Gradinger et al, namely, a concern for the ethical, political, and normative values as well as for the process-based values such as respect, partnership, and equality [35]. When initiated, our survey was intended to demonstrate to the funding agency that patients were actively engaged in the proposal from inception. However, the insight gained from the survey not only helped develop a proposal to better understand the medical complications of inflammatory diseases but it also generated substantial data on the social and emotional consequences that are integrally tied to the provision of health care services and the patient-provider relationship.

Conclusions

Analysis of written responses to a survey created by patients for patients living with chronic inflammatory diseases shows many common experiences regardless of diagnosis, including disruptions to daily life and socioeconomic vulnerabilities that create and contribute to worries about the future. The issues raised by this paper concern the interrelatedness of health, social, and economic support systems and the gaps between them that

create barriers to finding and accessing the services people with inflammatory diseases need to maintain their health. However, respondents also describe examples of patient-provider partnerships and social systems that contribute to personal resilience and capacity to participate in life. This paper brings together the narratives of a large sample of patients to emphasize commonalities in the experiences of inflammatory disease

patients, who are often analyzed in the isolation of their specific diseases than as a broad category. It illustrates a meaningful collaboration between patients and researchers that suggests a patient-led research agenda in chronic inflammatory diseases would foreground the role of the social determinants of health in shaping disease outcomes. Such findings should inform policy and service delivery through system change.

Conflicts of Interest

None declared.

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Abbreviations

AB: Alberta

AS: ankylosing spondylitis

BC: British Columbia

MB: Manitoba

ON: Ontario

OA: osteoarthritis

PRECISION: PREventing Complications from Inflammatory Skin, joint, and bowel conditions

QC: Quebec

RA: rheumatoid arthritis

SK: Saskatchewan

UC: ulcerative colitis

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Original Paper

Involving Citizen-Patients in the Development of Telehealth Services: Qualitative Study of Experts' and Citizen-Patients' Perspectives

Hassane Alami^{1,2}, MSc, PhD; Marie-Pierre Gagnon^{1,2,3}, MSc, PhD; Jean-Paul Fortin^{1,4}, MD, MPH, MBA, FRCP

¹Institute of Health and Social Services in Primary Care, Research Center on Healthcare and Services in Primary Care, Laval University, Quebec, QC, Canada

²Research Center of Quebec City University Hospital Center, Hôpital St-François d'Assise, Quebec, QC, Canada

³Faculty of Nursing Science, Laval University, Quebec, QC, Canada

⁴Department of Social and Preventive Medicine, Faculty of Medicine, Laval University, Quebec, QC, Canada

Corresponding Author:

Hassane Alami, MSc, PhD

Institute of Health and Social Services in Primary Care

Research Center on Healthcare and Services in Primary Care

Laval University

Pavillon Landry-Poulin Entrée A-1-2, 3e étage

Bureau-A3410, 2525, chemin de la Canardière

Quebec, QC, G1J0A4

Canada

Phone: 1 418 821 4134

Email: hassane.alami.1@ulaval.ca

Abstract

Background: Decisions regarding telehealth services in Quebec (Canada) have been largely technocratic by nature for the last 15 years, and the involvement of citizen-patients in the development of telehealth services is virtually nonexistent. In view of the societal challenges that telehealth raises, citizen-patient involvement could ensure more balance between evidence from traditional research methodologies and technical experts and the needs and expectations of populations in decisions about telehealth services.

Objective: This study aimed to explore the perception of various stakeholders (decision makers, telehealth program and policy managers, clinicians, researchers, evaluators, and citizen-patients) regarding the involvement of citizen-patients in the development of telehealth services in Quebec. In particular, we explored its potential advantages, added value, obstacles, and challenges it raises for decision making.

Methods: We used a qualitative research approach based on semistructured individual interviews, with a total of 29 key actors. Respondents were identified by the contact network method. Interviews were recorded and transcribed verbatim. A pragmatic content thematic analysis was performed. To increase the capacity for interpretation and analysis, we were guided by the principle of data triangulation.

Results: Citizen-patient involvement in decision making is perceived more as a theoretical idea than as a practical reality in health care organizations or in the health system. There is very little connection between citizen involvement structures or patient and user groups and telehealth leaders. For the respondents, citizen-patient involvement in telehealth could increase the accountability and transparency of decision making and make it more pragmatic within an innovation-driven health system. This involvement could also make citizen-patients ambassadors and promoters of telehealth and improve the quality and organization of health services while ensuring they are more socially relevant. Challenges and constraints that were reported include the ambiguity of the *citizen-patient*, who should be involved and how, *claimant* citizen-patient, the risk of professionalization of citizen-patient involvement, and the gap between decision time versus time to involve the citizen-patient.

Conclusions: This study provides a basis for future research on the potential of involving citizen-patients in telehealth. There is a great need for research on the issue of citizen-patient involvement as an organizational innovation (in terms of decision-making model). Research on the organizational predisposition and preparation for such a change becomes central. More efforts to synthesize and translate knowledge on public participation in decision making in the health sector, particularly in the field of technology development, are needed.

KEYWORDS

patient participation; public participation; health services; telehealth; health technology assessment; decision making

Introduction

Background

Telehealth, defined as *health care and services, as well as social, preventive and curative services, delivered remotely by means of a telecommunication, including audiovisual exchanges for information, education and research, and treatment of clinical and administrative data purposes* [1], has become an inescapable part of health system reform strategies [2,3]. In recent years, many projects and programs have been initiated with the objective to develop new models of service delivery, capitalizing on the potential of telehealth to improve accessibility, quality, continuity, efficiency, and integration of health care and services, especially for populations with chronic diseases and those living in rural and remote areas [2,4-9].

To maintain its health system in a capacity to respond to population's needs, while addressing the problems of shortage or unequal geographical distribution of health professionals, the province of Quebec (Canada) considers telehealth as a major lever [10,11]. However, telehealth raises several challenges, including e-literacy, confidentiality and privacy, patient's data protection, and the medicalization of the living space, in addition to the symbolism that technology might endorse for some people or communities [12-15]. In the same vein, telehealth also raises issues related to digital democracy and the right of all citizens to equally benefit from advances made in digital health, which leads several authors to call for a better consideration of the perspectives of people and communities who are, or could be, affected by these issues [12,15-19]. To overcome such issues, at least in part, the idea of involving citizen-patients (the term refers to patients or their representatives, their family, as well as citizens, public, and communities who are actual or potential users of health services) in the decisions concerning the development of telehealth services has been proposed [19-23]. Moreover, this involvement should not only occur in the evaluation of telehealth as a *technical object* (eg, survey about technology acceptance and satisfaction), but in the prioritization, planning, and implementation of telehealth services.

Public Participation in the Health Sector and in Telehealth

Public participation is attracting increased interest from health sector decision makers [24,25]. It has come, in a way, to compensate for the limits of the historically dominant technical knowledge from expert systems by giving more voice to the various actors from different knowledge sources [25]. This context is accompanied by a movement of institutional relocation of collective action for more consideration of different perspectives and opinions, which could be described as *lay*.

Public participation in decision making is also a way of narrowing the gap between evidence from traditional research methodologies and the expectations, real needs, and subjectivities of populations [26,27]. Thus, public participation

could help to make informed decisions and reach a consensus (or at least a compromise), which would increase the legitimacy and scope of the policies and programs implemented [28].

In the field of eHealth, some studies report experiences of citizen-patients' involvement. In the United Kingdom, citizen juries contributed to explore the barriers and facilitators to the implementation of eHealth services [22]. This study showed that citizens expressed a desire to be included in the development of eHealth and that their suggestions were taken into account by decision makers. Moreover, in the United Kingdom, volunteer delegates were recruited to form a panel of citizens to discuss the issue of integrating eHealth into health care services [19]. This study showed that citizens have a good knowledge of issues related to the use of new technologies and thought that their involvement in the development of eHealth programs would be very illuminating. Another study in Denmark explored the potential to involve the public in telehealth implementation [29]. The authors conclude that the success of telehealth depends strongly on the inclusion of the public in the process of planning and development of services. In Australia, members of a community have been involved in the development of a telehealth planning framework based on needs assessment. According to the authors, if telehealth is not progressing enough and is struggling to integrate the routine of providing health care and services, it is notably because it does not sufficiently consider the needs, priorities, and expectations of the communities [23]. In fact, this perspective would provide an opportunity to reduce the tension between *universal and unbiased* assessment of the instrumental value of a technology and the values, judgments, and perceived needs of end users [30,31].

The relevance and necessity of considering the citizen-patient perspective in telehealth development have led us to question its feasibility in the context of Quebec. In this province, there is a will to involve citizens and patients in decisions that could affect their health, at least in the political discourse. In 2014, a report called *Clinical telehealth in Quebec: an ethical perspective* was produced to inform and sensitize decision makers, researchers, and the public on some ethical issues related to telehealth utilization [32]. This report emphasizes that telehealth should focus primarily on relevance and demand, not on the offer and technology development. Traditionally, decisions regarding telehealth in Quebec have been largely technocratic by nature, and the involvement of citizen-patients in the development of telehealth services is virtually nonexistent, except in some research projects. Therefore, many questions remain regarding the meaning, feasibility, and implementation of the citizen-patients' perspective in the development of telehealth services.

Objective of the Study

This study aimed to explore the perspectives of various stakeholders (decision makers, telehealth program and policy

managers, clinicians, researchers, evaluators, and citizen-patients) regarding citizen-patient involvement in the development of telehealth services in Quebec.

Our primary interest was to understand the meaning of citizen-patient involvement in telehealth decision making in terms of potential advantages, added value, obstacles, and challenges it raises for decision making. In this study, we used the term *involvement* generically without focusing on any particular form. This choice allowed us to explore the notion of involvement in general and what it meant to the stakeholders.

Methods

Data Collection

We used a qualitative research approach based on semistructured individual interviews with stakeholders involved in, or affected by, decisions related to the development of telehealth services in Quebec. The interview guide covered dimensions related to the perception, added value, relevance, as well as the challenges of citizen-patient involvement in telehealth (Textbox 1). Most questions were same for all participants, but some specific questions were asked according to the status of the respondent. HA did all the interviews (face-to-face or by phone) in French and in a place that respected participants' privacy. The interviews lasted between 45 and 120 min and were audio-recorded. None of the participants refused to be recorded. Participants received no financial compensation.

Potential respondents were identified by the contact network method [33]. For decision makers and managers, we contacted people through the network of our team that is active in the evaluation of telehealth programs and projects in Quebec. We contacted citizen-patients who had collaborated on some research projects in the past [33,34]. Internet searches were also conducted to identify other potential participants (*experts* and citizen-patients), particularly via government, organizational,

corporatist, or associative documents related to telehealth. This choice was justified by the need to have data and information from various sources to cover the perspectives of different stakeholders. In addition, during the interviews, some participants also referred us to other people.

Data Analysis

We performed a pragmatic content thematic analysis of the interview data [35-37]. Thematic analysis consists of identifying, classifying, and combining data to distinguish themes and to relate or integrate them with others [35-37]. The pragmatic dimension refers to the interpretative and emerging aspect of the data. Indeed, during the data analysis process, we used the comments of co-researchers or project-related people that could complement the analyses.

The interview transcripts were first read by HA who developed a preliminary coding tree. A research assistant independently coded 3 out of the 29 transcripts to propose, suggest, and add themes and delete or merge others if needed. This coding tree was then validated with the other researchers (MPG and JPF) to reach a consensus. To increase the capacity for interpretation and analysis, we were guided by the principle of data triangulation [38]. This was done at 2 levels: (1) methodological triangulation through the use of multiple data collection techniques (eg, semidirected interviews; informal discussions with researchers, policy makers, telehealth leaders, researchers, evaluators, and citizen-patients at conferences and symposia; or other events that occurred during the study) and (2) triangulation of data sources consisting of the search for information from various stakeholders [39,40]. The use of multiple techniques and data sources is recognized as being able to increase the credibility of the results [39,40].

We obtained ethical approval (number "2015-2016-18 MP") from the ethical committee of the Research Center on Healthcare and Services in Primary Care of Laval University (Quebec, Canada).

Textbox 1. Interview questions (translated from French).

Experts (eg, decision makers and managers, experts in telehealth and [or] in patient and public participation)

1. Could you give me your definition of telehealth?
2. Could you give me a portrait of telehealth in Quebec today?
3. According to you, how is telehealth developing in Quebec?
4. According to you, what are the reasons why existing telehealth projects are struggling to move beyond the phase of pilot project?
5. According to you, whose needs telehealth services are addressing? (Those expressed by professionals, organizations, or citizen-patients?)
6. According to you, what are the reasons why some citizen-patients express reluctance to be supported by telehealth?
7. Could you tell me about the way in which decisions are taken for the development of telehealth in Quebec (organizations, ministry)?
8. Did citizen-patients already express reluctance or comments about telehealth? If so, what suggestions or proposals did you make?
9. To your knowledge, are there already experiences of involvement of citizen-patients initiated by your organization on other topics (other than telehealth)?
10. How do you perceive the possibility to involve citizen-patients as leverage to better development of telehealth services?
11. How citizen-patients could contribute to the decision-making process to develop telehealth services?
12. How their proposals could be incorporated into the decision-making process?
13. What type of involvement would be more adapted to enable the development of services that are more focused on the needs and expectations of the population?
14. What kind of citizen-patient involvement would be more useful, depending on the level of involvement and its focus (strategic, operational, and clinical)?
15. According to you, how could this involvement be organized (should it be done within the existing decision-making structures, or should another one be created in parallel), why?
16. According to you, what are the advantages, benefits, constraints, and obstacles to citizen-patient involvement perceived by the decision-making authorities?

Citizen-patients

1. Could you give me your definition of telehealth?
2. According to you, how is telehealth developing in Quebec?
3. According to you, what are the reasons why existing telehealth projects are struggling to move beyond the phase of pilot project?
4. According to you, what are the reasons why some citizen-patients express reluctance to be supported by telehealth?
5. According to you, whose needs telehealth services are addressing? (Those expressed by professionals, organizations, or citizen-patients?)
6. Did you (or other citizen-patients) already express comments (enthusiasm or reluctance) about telehealth? If so, what suggestions or proposals did you make?
7. Were you already involved in the development of a telehealth services (or technological in general), or are you aware of citizen-patient engagement experiences in the development of technology projects (including telehealth)?
8. How do you perceive the possibility of involving citizen-patients as leverage for better telehealth development?
9. How citizen-patients could contribute in the decision-making process to develop telehealth services?
10. How could their proposals be integrated into the decision making?
11. What type of involvement would be more adapted to enable the development of services that are more focused on the needs and expectations of the population?
12. What kind of citizen-patient involvement would be more useful, depending on the level of involvement and its focus (strategic, operational, and clinical)?
13. According to you, how could this involvement be organized (should it be done within the existing decision-making structures, or should another one be created in parallel), why?
14. According to you, what are the advantages, benefits, constraints, and obstacles to citizen-patient involvement perceived by the decision-making authorities?

Results

Profile of Participants

A list of approximately 64 potential respondents was identified. In total, we were able to interview 29 people (Table 1).

The results are structured according to the following themes: (1) telehealth as technocratic or expert, (2) relevance and potential contributions of citizen-patient involvement in telehealth, and (3) challenges and constraints to involvement.

The codes used at the end of the quotes refer to the categories of respondents presented in Table 1. All interview quotes were translated from French to English.

Telehealth as a Technocratic or Expert Object

All stakeholders recognize that telehealth decision making is dominated by a top-down and technocratic perspective. Here, we can distinguish 2 levels: (1) the central level, emanating from the Ministry of Health or funding agencies that have a major role in the prioritization and choice of telehealth services and programs to implement and prioritize the use of telehealth in some specialties, levels, or locations rather than others, and (2) the local level, consisting of projects that are more often initiated by clinical, managerial, and technological champions in collaboration with researchers, usually funded through some research budgets, and offer telehealth services, often on an experimental basis and responding to the needs identified by those champions. At this level, there are some attempts to involve patients, mainly to evaluate the usability (eg, ergonomics) of the technological device downstream of its design and implementation, but less about how the service is delivered or organized (eg, relevance of the service):

Are people happy with technology?...Because people can love technology but not like how it is organized.
[M]

Here, respondents recognize that there is very little connection between citizen involvement structures or patient and user groups and telehealth leaders. Thus, the involvement of citizen-patients in the development of services remains very anecdotal or nonexistent.

Relevance and Potential Contributions of Citizen-Patient Involvement in Telehealth

Accountability and Transparency of Decision Making

The fact that decisions on public policy choices, including those regarding health services, need to be discussed, affordable, and understandable to the populations concerned has been reported regularly. Respondents believe that health care computerization policies involve issues that are important enough for individuals and communities to express themselves and be associated. As telehealth involves significant financial issues in terms of investments and expenditures for the health system, it is even more relevant to have a citizen-patient perspective that helps ensure accountability of decisions on such investments:

People will not all look for the Cadillac...There is also a question of simplicity and use. I think to put citizens, users around a table...It creates a minimum of obligation being to some extent transparent...than if it is only companies and healthcare providers who are together to choose the technology. [E]

Citizen-patients could also contribute to help to implement relevant services and to remedy the current situation where technologies are developing without a real overview and sometimes exponential costs:

When I look at the innovations in which we will invest a lot: both public funds and private funds for 7 years, 10 years of development, and then at the end of the race, have a technology that sometimes, doesn't always meet the needs, or doesn't meet the most pressing needs, and I think that perhaps if, early in the design of innovation, we had better examined both the needs of clinicians and populations? I think we would have avoided...useless expenses and useless turns. [E]

Pragmatic Decision Making and an Innovation-Driven Health System

Citizen-patient involvement was also seen as a means to influence and accelerate change and adoption of telehealth and integrating it into the health system. Here, reference is made to the repeated failures of telehealth and computerization projects in Quebec. According to some respondents, telehealth in Quebec today is associated with "it doesn't work." They estimate that leadership could come from the population, especially those living in rural and remote areas or living with chronic diseases. They can put pressure on organizations and decision makers and advocate telehealth as the center of priorities and strategic directions.

Tensions and conflicts between professional orders, unions, organizations, and the ministry regarding reserved acts, insurance, reimbursement, and remuneration issues accompany the use of telehealth. These challenges significantly contribute to the difficulties experienced by telehealth programs in Quebec today. This situation often leaves the right of access to services for the entire population as a *secondary objective*. Involving citizen-patients could help refocusing the debate on improving access, continuity, and quality of services for the population:

Well, but if the pressure comes from the population, in an environment where we say: "if we had such types of services in a region where there is a lot of diabetes, if we could treat like that, but we cannot because the union doesn't want, you know"...or the worker or manager says: "I cannot. My union doesn't want to," you know...Oh well listen, me, what I think, sincerely...as long as the patient will not stand up and say: "I am tired. I'm not waiting anymore. There are technological systems that make me no longer have to wait or travel"...There is no counterweight. There, I think we touch the system the most...We touch the crux of the problem. [C]

Table 1. Summary of interview participant's characteristics (n=29).

Type of participants (category of respondents)	Participants, n	Gender, n	
		Female	Male
Decision makers (D)	4	2	2
Managers, technicians, and clinicians-managers (M)	11	9	2
Citizen-patient representatives (C)	7	2	5
Experts in telehealth and/or in patient and public participation, ie, evaluation + research (E)	7	3	4
Total	29	16	13

Respondents recognized that the involvement of citizen-patients would not only increase the awareness of decision makers and health professionals of the potential of technology but also shed light on its importance in people's life. In addition, it would make decision making more pragmatic and rooted in the real needs and expectations and highlight the level of *acceptable risk* for individuals and communities. On this point, respondents believe that confidentiality and privacy requirements are rigidly addressed by the responsible authorities, which slows down the use of telehealth:

We, health system experts, have shown that we were unable to do it, and you know that it has been demonstrated, I think. And then, we even mentioned confidentiality reasons very, very often: "it is not safe; it's not confidential..." It's like if we didn't include in the discussion those who are the main concerned by technology; that is to say, the citizen-patients themselves, because there is, in all this adventure, a risk that is never zero, but which was acceptable considering the benefits of technology. And it seems to me that the acceptable risk arbitration can only be made by citizen-patients and not by the health system actors. It's a big mistake not to have associated them from the beginning so that these elements of acceptable risk can be addressed and discussed and decided by citizen forums...How far am I willing to take a risk that occasionally there is information that can circulate compared to the benefits it gives? Only the citizen or the patient can conclude on this acceptable risk. [D]

For example, current safety standards and regulations still greatly limit the use of Wi-Fi networks in health care organizations or prohibit that clinicians communicate with their patients via common chat technologies. Some respondents acknowledge that despite all these restrictions, there are clinicians using these "unsafe" technologies to communicate and monitor their patients while knowing that it is legally prohibited because they estimate that the benefits are greater than the risks for the patient. In such cases, citizen-patients should be given the opportunity to estimate the *risk-benefit* and decide whether or not they want to use these technologies to communicate with their providers because ultimately, the information and data belong to them:

Me, if we had a FaceTime service, because I like FaceTime. I like to see who I am talking to (...) It would be nice if it was more with a visual contact for

me and for many people (...) It improves the exchange, the exchange...I think, for a person who gets older, see the person you talk to [physician, nurse], if she has a smile, it's like an encouragement...It's reassuring, it's encouraging, and there are many people who live alone as they get older and have not prepared for their old age. You know, it's getting ready, loneliness. [C]

This argument was also supported by the fact that people have to travel great distances, sometimes several hundred kilometers for a simple routine consultation that can last 10 min:

So, we had clinicians and also clients who wanted to use Skype...There were obstacles. For the clinician, it was just more convenient to communicate like this with the client at home, but because we were not in the standards of confidentiality, Skype was banned from the clinical services, but clients, they agreed to use it...they are agreeing and consenting. They want! [M]

It was also reported that the rigidity of the health system and its difficulty in adapting to the trend of increasing use of digital technologies in people's life, in addition to its inability to capitalize on the potential of these technologies in the production and the provision health care and services, could lead people to search for health services through unconventional means and channels, including digital platforms that offer Web-based health services, with all the risks that this might present for them. Respondents recognized that the possibility to have access to services quickly and cheaply could be attractive to some people. However, in cases where people are victims of medical errors or receive harmful prescriptions via these platforms, the health system will have to assume their care, sometimes with serious complications that would result in significant costs to the public. In addition, it was also admitted that the ability of some people to have rapid access to health services goes against the idea of an equitable and universal health system:

As long as there was nothing else than that, it was fine, but someone comes to offer something else, you know. And that was the Internet and the optics companies in the USA that sold...It's the same as the taxi: "It doesn't make sense; it's illegal." Well that's what they say. Opticians still say it. OK? Well, people buy the glasses...Me, it's striking what happened with taxis. Everyone thought taxis were fine. Overnight, someone who took "Uber," he opens the door, the car is clean. Hey, that could be the taxi! [C]

In this vein, respondents believe that the citizen-patient perspective could help managers and decision makers to be more innovative. This will make them more aware of the new uses of digital technologies and see how they could capitalize on it to improve services. On this point, participants acknowledge that there is a significant gap between what health organizations and health system are able to offer in terms of technology-based services and how people use technology today. It is feared that such a gap will continue to widen, particularly in view of the bureaucratic heaviness of the system:

In general, patients are very, very open and even wish to use ICTs [information and communication technologies], and it's rather the health system that has reservations. When I look at how we can currently communicate with the health system, patients want to use e-mail, for example. While the system is very, very refractory; doctors are refractory; the Canadian Medical Protective Association warns doctors about this use. So, the obstacles are, in my opinion, much more at the level of the institution than at the level of the patients. It's very rare, patients...we see it with the Quebec Health Record...patients who have withdrawn their consent are extremely rare. [D]

The Citizen-Patient as an Ambassador and Promoter of Telehealth

Many citizen-patients are more and more informed about health and technology. They are in the capacity to propose alternatives or service improvements. Some of them even do information monitoring on the latest technologies for a given service. They can advocate for technology with organizations and decision makers, as well as the community:

Me, I have a Facebook that is read a lot, and from time to time, I post. Here's an application. People thank me "ah thank you, I'll try it." [C]

Respondents considered that the citizen-patient can become an ambassador and promoter of telehealth services to the population. On this last point, there is a great ignorance of telehealth and its potential within the population:

Well, the word itself, I never heard that word. Heh no, me "telehealth," I would have thought that it's medicine classes that are given at the university. Honestly, I have never heard. Yet, I read the press and I think I am a pretty informed woman, and still the two committees where I am, I have never heard...Are there many people who use that?...First, we should talk about it...It would be wonderful. [C]

In addition, another part of the population is still reluctant to use telehealth. There is also the idea that telehealth is associated with lower quality services or *poor medicine*, which pushes people to seek services in large urban centers. Respondents recognize that communication and pedagogy are necessary to explain and convince. They suggest that this could be done by people who had a positive experience with telehealth, sometimes better than professionals or experts. Thus, integrating citizen-patients in telehealth project teams would make them ambassadors to their families and communities. Respondents

acknowledge that the voice of users is more credible and listened to by others, with more weight than that of professionals and decision makers in some cases. Their opinion can thus influence other users, positively or negatively, because they speak the same language and share certain experiences:

There is nothing like a doctor to talk to another doctor, well, there is nothing like a patient to talk with another patient. [M]

On another level, some respondents reported that the citizen-patient could also be an ambassador of technology to health professionals, including doctors (advocacy). Examples have been reported of patients in rural areas asking their doctor to be consulted via telehealth while the latter was not using it:

This is an element that is very important and we, we live it and we have lived in some of our regions where the patient or the professionals tell the visiting doctor from the south: "can we do it by telehealth?" So, yes, there's a huge lack of information. The population must be more and more aware to ask the doctor: "Can I do it by telehealth?" There are cases where we cannot and cases where yes, we can and we avoid moving the patient. [M]

Relevant and Better Organized Services

Opinion, comments, and suggestions of citizen-patients have a significant weight with health organizations, clinical teams, and decision makers. Their feedback is in a way the *mirror* that reflects the relevance of the services offered to the population. For instance, in a telehomecare project, some patients have pointed out that they did not want to be "plugged in" the technology all day or on weekends; others asked that the service should be provided to them at particular times during the day, when the health professional could contact or consult them. These considerations lead to review and reshape the organizational model and adapt the service in the light of the reality of the patient.

Perceived Clinical Quality Versus Lived Quality

From a utilitarian perspective, some respondents also recognized that citizen-patient involvement in telehealth would reduce complaints received by professionals or organizations. This is a way to reduce the gap between the *perceived quality* by the health professional and the *lived quality* by the patient. Citizen-patients often lack the opportunity to express themselves. Involving them could be a means to gauge their satisfaction or dissatisfaction with services but also to make sure that technology does not create unrealistic expectations:

Because it's me who handles the complaints in the organization and sometimes, we don't understand between what the client wants and what we want for him. Sometimes, we want more for him or we want it differently. I think that if we had more client partners, we might better understand what they want and better adapt our services from the perspective of customer. [M]

Social Relevance of Technology

Respondents underscored the importance of considering the cultural particularities, subjectivities, and social contexts of individuals and communities:

Especially in an Indigenous communities where the mentality is not the same. You know, you have to talk about culture. Culture is not the same. So, if you want your project to work, you are better off to join the community with you, because you may be rejected.

[C]

Thus, citizen-patients can challenge the ethical and societal aspect of telehealth and raise awareness about the subjective and lived experience of people. So, it is central to develop services centered on individuals and communities and better take into account the diversity of backgrounds, paths of life, family, social, and cultural contexts. This would limit potential derivatives of the technology (*technological solutionism*), with a tendency to the standardization of services. Technology may not be for everyone (“you talk to a TV...it’s scary for some. [E]”), recognizing the need for a better understanding of the conditions in which telehealth is useful or not, and for what type of population:

In palliative care...the nature of the needs is different...the nature of the care and how to provide it also. Just to care for people who suffer from dementia, when we question the family caregivers...to ask them what is the thing that would make a difference in your life? Do you know what they tell us? Is it baths? Is it respite?...Our main need is that you recognize us as a human person. How are you going to solve that with technology? Once again, it is the capacity to recognize the caregiver not as an instrument at the service of the demented person, but a human being who has needs...The rigidity of our programs makes that we can’t meet the real needs. How, through technology, can we make this happen? It’s a challenge.

[D]

Some respondents considered involving citizen-patients as necessary as it is urgent to think of telehealth as a philosophy (*societal question*) that challenges the ways of producing and providing services for the population. Such a change requires clear and transparent communication with those concerned so that telehealth can allow providing services differently but not with less quality:

Telehealth should bring a new philosophy of care; not a logic of support at any cost. It must also be logical that telehealth is there to make sure that people are more autonomous at home. Unfortunately, it’s more complicated, because we’re, again, in this kind of obsession to offer the same types of services, regardless of the tool we use; the same levels (...) It’s not a question of offering less services; it is to offer the service differently with another way to do it....Telehealth is not just a tool...It grows a distant vision of the care; it grows a delegated vision of care...It affects the empowerment of people to take care of themselves.

[C]

Respondents also mentioned that telehealth should avoid increasing the digital divide (eg, literacy and e-literacy) at the population level and consider people and groups without sufficient education, knowledge, or means to use it. Thus, involving citizen-patients would make it possible to refocus the priorities, relevance, and needs in decisions surrounding the implementation of telehealth services, often reduced to questions of norms, standards, and administrative issues:

Yes, but here, telehealth, and if someone doesn’t have the Internet at home, what are you doing with that...

The rest of us, we have everything at hand; we will not ask the question. We say yes, it will work.

[M]

Challenges and Constraints to Involvement

Despite the added value and perceived usefulness as well as the opportunities inherent to citizen-patient involvement in the development of telehealth services, the observation is that there is a lack of practical and concrete experience reported in health organizations or at the health system level.

Ambiguity of the Citizen-Patient

From the point of view of decision making, citizen-patient involvement is seen as the introduction of an element of uncertainty. Decision-making processes still remain structured and codified environments that share common referents, a common language, and converging visions. The addition of citizen-patients, who have their own values, language, and expectations as stakeholders in the decision making, makes it possible to question existing equilibriums that make decision makers and managers fear the loss of control over the decision.

Some respondents also raised the issue of decision-making accountability: Who is responsible for a decision made with the citizen-patient? What is the degree of responsibility of the latter? Thus, several questions emerge about the place of the citizen-patient in this new decision-making configuration. In this vein, respondents recognized that decisions in telehealth services are largely formulated at the higher level (eg, ministry or administrators), which leaves little room for maneuver to integrate this new actor.

In addition, the idea was raised that the citizen-patient can become an element of *triangulation* in delicate decision-making situations, where their role could be perverted to put pressure on decision makers, managers or on clinical teams, especially when there is a divergence in visions. Another issue that was raised is that citizen-patients could become spokespersons of the industry or consumer advocacy associations, in other words, *lobbyists*:

Patients who have dissatisfaction, who have something to say, do they deal with him? Is it likely to bring us to triangulation rather than people talking directly to managers?...How does it fit? How are you going to live? What are the case trajectories and in which cases will they deal with situations? In connection with the complaints commissioner too. That’s what you know, you have the users’ committee, you have the complaints and quality commissioner,

and you have the patient...the person...I do not know how they can be called. [M]

In the same vein, there is a risk that citizen-patient involvement is *symbolic* or even perverted to legitimize certain decisions without the people having really contributed, but whose presence could be used as validating such a choice.

Some respondents were reluctant about the idea of citizen-patient involvement. For them, the *fashion* of citizen-patient involvement meant that, for some decision makers and professionals, the discourse has taken over the development of instruments to do so. It is recognized as a major and rapid change that destabilizes all levels of governance. There is a scope to learn because of the significant change it brings in the work of decision makers and managers. Here, some respondents referred to incidents where information leaked during sensitive decision-making processes (eg, closing a rural emergency service) and where it took a lot of energy and time to calm down media, reassure municipalities, and communities. Such experiences made some decision makers very dubious:

How can we explain to a rural community that the retiring physician will not be replaced, and that the service will now be provided via telehealth from experts based in Quebec City or in Montreal? [D]

A Complainant or Claimant Citizen-Patient

For some respondents, the involvement of citizen-patients in decisions was seen as confrontation. They considered them as mere claimants or complainants and not true partners or collaborators. Citizen-patient involvement is also perceived as slowing down the decision-making process:

To open the discussions to the citizens, to the patients? It's not natural. Managers and decision-makers must be convinced that patients bring added value, and I'm not sure, at present, in Quebec in any case, that the majority of managers are convinced of this and, on the contrary, I think that they see the patient as a drag, an obstacle...in any case, something that slows down the process much more than a decision aid. [D]

Some respondents also believed that the ambient discourse may fall into the caricature stating that citizen-patients are a virtuous source of good ideas at any times, hence the challenge of articulating the mechanisms to be able to produce the ideas, confront them, discuss, and question them publicly.

We must also be careful to not fall into excess and say that the citizens run the solution. That, I'm against...They can participate in the decision, but is not for them to make it. [C]

Professionalization of Citizen-Patient Involvement

With the new role that the citizen-patient can, or will, have in decision making, the issue of the professionalization of citizen-patient involvement emerged, even pushing some people to question whether citizen-patients will hold a *professional title*, be overseen by union conventions, and compete for budget within an organization:

A patient representative spoke to someone at the Ministry and said, "The patient's voice needs to be taken into account. We have to be involved in the decision" and the guy from the Ministry said "Are we going to put you in the Union?"...Me, I have already been told by a famous researcher that if we integrate patients into research projects, they will hijack research...The big question was what budget item are we going to put this in? [C]

Decision Time Versus Time to Involve the Citizen-Patient

Decision makers work within a decision-making frame, often subjected to time and calendar constraints. Involving the citizen-patient would result in slow decision-making process, as it involves consultations and exchanges with an actor who does not necessarily have knowledge of the functioning of the health system. In fact, according to the respondents, from the moment the citizen-patient is involved, the process must be transparent and not only be stingy with information but also be concerned to transmit the right information in a suitable language, free of jargon and technical acronyms. In addition, the question of when and how would citizen-patient involvement be useful and necessary emerged:

I think it's not a habit, first. Then, well, there may be an unwillingness to do so, because it makes the process heavier. Because we were looking for Mr. Everyone who may not understand the language, for whom we have to take time to explain. Maybe we have a vision of the result and we...to share with the client, it will be a too long process...Because it will delay time of implantation and things like that. [M]

Which Citizen-Patient Should Be Involved?

The question of the *right* citizen-patient to involve was often mentioned and respondents pointed out the diversity of profiles, knowledge, opinions, and experiences of individuals and communities:

Then, you see, the citizen, in relation to technology, it takes citizens who are awfully informed to be able to understand. So if we think about citizen participation in developing, better documenting needs, acceptable levels of risk, it must be citizens who have been informed, to whom we are able to explain the issues and who are able to give us a point of view on it. [D]

The Question of How

Many respondents rose the question on how to make the most benefits from citizen-patient involvement. Their main fear was that with increasing calls to involve them, it becomes more a tokenistic participation, so that decision makers and managers can say that they have associated the citizen-patient in their approach:

I tell you that with the patient partner, yes, it's a beautiful concept, but how does it translate into real life, the recipe did not come with it...It's fine in terms of diagnosis, but no one offered me instruments. [M]

Discussion

Principal Findings

To the best of our knowledge, this study is the first to address the issue of citizen-patient involvement in decisions related to the development of telehealth services in the Quebec health system. It is also one of the few studies that explore this potential from stakeholders' cross-perspective (decision makers, telehealth program and policy managers, clinicians, researchers, evaluators, and citizen-patients).

In this study, there is general agreement between the opinions expressed by *experts* and citizen-patients that telehealth decision making should further integrate the citizen-patient perspective. First, because such an approach, from a utilitarian and pragmatic perspective, would accelerate the adoption and diffusion of digital technologies in the provision of health care and services. In other words, involving citizen-patients would *push* organizations and the health system to be more innovative. This perspective, however, remains subject to criticism by the fact that citizen-patient involvement is reduced to a simple instrument that justifies the implementation of certain technologies that can have a harmful impact on the population (eg, with services of lesser quality for some individuals or communities). Second, citizen-patient involvement can constitute a major lever to build a health system able to offer services adapted to the needs, subjectivities, constraints, and real expectations of individuals and communities. This involvement could ensure that all citizens benefit from the potential of digital technologies in improving, maintaining, or restoring their health and well-being; limit the risk of possible drifts of technological progress; and force more accountability and transparency in decision making (eg, better organization of services, better quality of services, social relevance, and ethical issues).

However, some divergences were found in the discourse of *experts* and citizen-patients. Decision makers and managers have emphasized the operational aspect of this involvement. In this respect, they have raised several questions, among others: the profile of citizen-patients to be involved; the picture of a claimant, complainant, or lobbyist citizen-patient; decision time versus time to involve the citizen-patient; how and when to involve them in the decision making process; and their weight and responsibilities in the decision. Citizen-patients, for their part, have insisted more on the democratic aspect, which translates into the obligation for organizations and the health system to create a real space to better integrate their perspective into decision making, and that this involvement should go beyond the symbolic dimension. In addition, some citizen-patients, echoed by certain decision makers and managers, insisted that their involvement should not be intended to replace the work of decision makers and managers because the latter remain the ultimate people responsible for the decision.

Otherwise, our findings highlight the significant gap between the relevance and theoretical added value of citizen-patient involvement and decision making regarding the development of telehealth services in Quebec. Indeed, there is still an ambiguous perception and a certain caution toward the

involvement of citizen-patients in decision making. As reported in this study, there are still many issues to be clarified, particularly regarding the taxonomy of involvement and the development and availability of concrete instruments and mechanisms to operationalize it. This observation leads us to consider that citizen-patient involvement in the development of telehealth services is still at the stage of *innovation* in decision making, both for conventional decision makers and for citizen-patients. Indeed, it is introduced into the actual decision model, mainly technocratic, where policy makers, managers, and (sometimes) clinicians are the only ones at the table. Thus, as an innovation, citizen-patient involvement should provide evidence of its relevance and added value for these actors.

Here, innovation means a set of new routines and working methods that aim to improve the results, efficiency, profitability, relevance, or experience of the actors [41]. It is also a set of practices, ideas, or objectives that are considered new by an individual, a group, or within an organization [42]. In telehealth, decision making takes place in a context of uncertainty, where several alternatives are possible, as solid evidence of efficiency, effectiveness, quality, security, and social relevance is still fragmented, incomplete, and sometimes contradictory or inconsistent [43,44]. In this context, taking into account the different available options and resources as well as the values, expectations, and needs of individuals, communities, and society as a whole, could lead to an *optimal* decision that is expected to increase the benefits while mitigating the risks to the population [45]. That being said, conflicts remain ubiquitous in any decision-making situation, especially when there is no single choice that is best for all stakeholders [46,47].

As an innovation, citizen-patient involvement in telehealth may be in competition with other existing practices, balances, dynamics, cultures (organizational and professional), and powers (or hierarchies), which could lead to a confrontation between different visions or conception of reality. Indeed, user acceptance also depends on their perception of how the innovation will affect them in their practice and the interactions that exist between the actors in the specific context [41,42,48]. Analyzing our findings through the lenses of the diffusion of innovations theory [41,42], we inferred that, first, different stakeholders were able to identify benefits and advantages of citizen-patient involvement in telehealth decisions (*relative advantage*). For them, this perspective could be relevant to the work to be done and improve relevance of decision (*tasks and activities*). Thus, several respondents who had experience with participation or had experiences as health service users saw the benefits. For others, the benefits are to be demonstrated, which is necessary to convince them (*observability*). Second, a major issue is the operationalization of citizen-patient involvement: how can it be adapted to find solutions that meet the needs and values of the actors involved, given the differences in current working methods and standards? (*compatibility*). In addition, a majority of respondents have never tested or experienced citizen-patient involvement before in decision making in their organizations (*trialability*). Third, citizen-patient involvement is still perceived by key stakeholders as complex to use and to implement (*complexity*). In fact, it is expected to have a high degree of uncertainty (*risks*), which would make it difficult to

adopt and operationalize. In addition, for some respondents, there is a need of knowledge and instruments to properly involve the citizen-patient in decision making (*knowledge*).

On this last point, this study also showed that there is a problem of knowledge transfer and sharing of research results on citizen-patient involvement in the decision making. Some stakeholders still hold mixed or negative opinions about this involvement, such as power issues, management of complaints and claims, risks of blocking or complicating the decision-making processes (time and means required), and possibility of lobbying. However, the international literature reports a wide range of experiences and initiatives, involving both patients and the public, that can help inform decision making and make it more relevant: health care prioritization and health policy analysis [49,50], resource allocation and redistribution [51,52], services governance [53,54], and health technology assessment [55]. On this point, our findings support, to some extent, those of Chalmers et al that addressed the question of the actual use of research results in decision making [56]. In our situation, either this research is not really relevant to decision makers—which is not theoretically the case here—or there is a missing link between this and the decision makers concerned, which seems to be the case in our work. Therefore, it is important to focus on the issue of synthesizing, sharing, and transferring existing knowledge in terms of contribution and value added of citizen-patient involvement in decision making.

In addition, the issue of change management should be better addressed. Indeed, we noted that the resistance and reluctance of some decision makers and managers are more because of the ambiguity associated with citizen-patient involvement as well as the nature and importance of the changes, in particular of cultures and models, that it brings to decision-making processes. For example, respondents reported that their training does not cover this aspect and that they are not prepared for decision making with the public. Thus, the involvement of the citizen-patient as a new decision maker requires codifying and marking the process, better defining the concepts, and developing a clear taxonomy as well as ensuring the availability of necessary instruments (eg, implication strategy, training, toolboxes, and evaluation tools) to operationalize and integrate it into the decision-making routine. Future studies in Quebec, or in other similar jurisdictions, should establish a clear taxonomy of involvement to allow differentiation between the nature of the mandates, the levels (strategic, tactical, or operational), and the nature of involvement (eg, information and partnership) [57]. It is a fundamental step to better use the existing modalities of involvement and to adapt or develop others if necessary. Indeed, according to the literature, the relevance (even necessity), nature, level, and degree of participation depend on contexts, issues, projects, and interventions [31,58].

Moreover, there is also a need to clarify what voice to consider: citizen-patient or consumer [59]. Indeed, it is important to consider the emerging debate on the duality between *consumerist* (eg, consumer's rights associations and consumer lobbying) and *democratic* discourses regarding the relationship of citizens and populations with public services, which has a

strong impact on the nature of governance to be put in place [60].

Finally, in light of the challenges and questions raised by the omnipresence of digital technologies in the choices and priorities regarding the development and implementation of health services, the consideration of the citizen-patient perspective becomes unavoidable; this is regardless of how it takes shape. Indeed, digital health involves a number of societal choices and orientations that affect the values and the foundations of health systems: what role should digital technologies play in future directions? What are the inherent risks of using these technologies (equity, ethics, social relevance, and data governance)? Indeed, many challenges and questions related to the relation of individuals to technology are increasingly reported in the literature, such as quality of the services, clinical outcomes for patients, health and digital literacy, security and confidentiality issues, intrusion into the private life, medicalization of the living environment, depersonalization of the patient-clinician relationship, social and cultural relevance, and increase of inequalities on socioeconomic or geographic bases. In this respect, many questions are raised about the potential negative, intended or unintended, consequences of the use of information and communication technologies in health care (health-ICTs) on individuals and communities [12-15,32,61-66]. These questions can no longer be treated by experts within the health system in a way that is disconnected from the expectations and concerns of citizen-patients.

In this study, we have addressed the case of telehealth in the provision of care and services, but other issues that arise for countries, such as big data, social networks, robotics, artificial intelligence, nanotechnologies, personalized, and predictive medicine, would also require societal debates to find the best ways that these innovations can benefit the whole population, while keeping in mind issues of ethics, equity, and health democracy. Indeed, to improve the acceptability of the technology and its subsequent use, the expectations, concerns, and needs of the various stakeholders involved should be taken into account, making information available and transparent. On this point, it is recognized that one of the success factors of the implemented programs and policies would be a more active and explicit conception of expertise emanating from the experience of citizen-patients as well as their expectations [67]. However, it should be ensured that citizen-patient involvement is not only a simple pretext or medium that allows decision makers to justify their decision to implement technologies and services without any real consideration of the citizen-patients' perspectives.

Strengths and Limitations

This study explored stakeholders' perceptions of citizen-patient involvement in the development of telehealth services in Quebec. Our findings highlight a number of points that could guide future works on the contribution of citizen-patients in the development of digital health for the production and provision of care and services in a manner that respects ethics, social relevance, equity, justice, and the protection of citizens.

The diversity of study participants allowed considering a wide range of opinions and perspectives about opportunities as well

as challenges to be met before citizen-patients can be involved in telehealth decision-making process. In addition, the broad experience of the interviewees at all levels of decision making (policy, managerial, clinical, and technical) or as health system users increases the validity and reliability of our findings. Indeed, our sample made it possible to achieve saturation, diversification, redundancy, repetition, and stability of interpretations [37,68].

However, we recognize the limitations of the study. Given the exploratory nature of the study, we have selected *informed* individuals, including citizen-patients, who have a very good knowledge of the functioning of the health system and health-ICTs issues. This could have led to a convenience sample bias. Thus, our results do not necessarily represent the perspective of the whole population (eg, age, socioeconomic profile, and gender). In addition, the participation of only 7 citizen-patients, of whom only 2 were women, are also limitations of this study. Unfortunately, given the difficult context in which the recruitment took place, we recruited all citizen-patients who agreed to participate, regardless of their sociodemographic profile.

In addition, we also recognize that the timing of the study coincides with a major reform of the Quebec health system (the largest since 1971), which may have impacted the results. Indeed, many potential participants (managers and decision makers) could not be identified or joined because they changed positions or were unable to respond to our solicitation. Others had no visibility on the issue as they had just joined posts related to our research question. However, the particular context of the reform has been helpful in pointing out the gaps between the political discourse held in the reform, which calls for greater involvement of the public in decisions, and the reality of the

actors, in the health organizations in particular, who are required to translate these directives on the ground. That said, our results could have been different in a nonreform context. Although our study was conducted in a single jurisdiction, the findings could possibly apply to other health care systems that are facing the same challenges regarding the need for more citizen-patient involvement in decisions and the blooming of digital health.

Conclusions

In this study, we explored the perception of various stakeholders regarding the involvement of citizen-patients in the development of telehealth services in Quebec. Thus, the study provides a basis for future research on the potential of considering the citizen-patient perspective in planning and implementing telehealth services for a better alignment with the expectations, needs, subjectivities, and contexts of individuals and communities, while promoting a relevant and socially responsible integration of technological innovations into the health systems.

Our findings show that citizen-patient involvement in decision making is more perceived as a theoretical idea, carried as much by attractive idealistic and utilitarian discourses, than as a practical reality lived in organizations or in the health system. Here, there is a great need for research on the issue of citizen-patient involvement as an organizational and systemic innovation. The adoption of this new decision-making model with the citizen-patient would imply adaptations and adjustments by the various stakeholders concerned by telehealth, which is accompanied by changes and transformations in practices and cultures in organizations. Moreover, efforts to synthesize and translate knowledge on citizen-patient involvement in decision making in the health sector, particularly in the field of technology development, are needed.

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Authors' Contributions

HA, MPG, and JPF conceived and designed the study and were involved in data collection, analysis, and interpretation of results. HA produced the first draft of this manuscript and received input from MPG and JPF. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ICTs: information and communication technologies

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Original Paper

The Impact of Visualization Format and Navigational Options on Laypeople's Perception and Preference of Surgery Information Videos: Randomized Controlled Trial and Online Survey

Marie Eggeling¹, MSc; Martina Bientzle¹, Dr rer nat; Thomas Shiozawa², Dr med; Ulrike Cress^{1,3}, Dr rer soc; Joachim Kimmerle^{1,3}, Dr rer nat

¹Knowledge Construction Lab, Leibniz-Institut fuer Wissensmedien, Tuebingen, Germany

²Institute of Clinical Anatomy and Cell Analysis, Eberhard Karls University Tuebingen, Tuebingen, Germany

³Department of Psychology, Eberhard Karls University Tuebingen, Tuebingen, Germany

Corresponding Author:

Joachim Kimmerle, Dr rer nat

Knowledge Construction Lab

Leibniz-Institut fuer Wissensmedien

Schleichstr 6

Tuebingen, 72076

Germany

Phone: 49 7071979 ext 363

Fax: 49 7071 979100

Email: j.kimmerle@iwm-tuebingen.de

Abstract

Background: Patients need to be educated about possible treatment choices in order to make informed medical decisions. As most patients are medical laypeople, they find it difficult to understand complex medical information sufficiently to feel confident about a decision. Multimedia interventions such as videos are increasingly used to supplement personal consultations with medical professionals. Former research has shown that such interventions may have a positive effect on understanding, decision making, and emotional reactions. However, it is thus far unclear how different features of videos influence these outcomes.

Objective: We aimed to examine the impact of visualization formats and basic navigational options in medical information videos about cruciate ligament surgery on recipients' knowledge gain, emotions, attitude, and hypothetical decision-making ability.

Methods: In a between-group randomized experiment (Study 1), 151 participants watched 1 of 4 videos (schematic vs realistic visualization; available vs unavailable navigational options). In a separate online survey (Study 2), 110 participants indicated their preference for a video design. All participants were medical laypeople without personal experience with a cruciate ligament rupture and were presented with a fictional decision situation.

Results: In Study 1, participants who used navigational options (n=36) gained significantly more factual knowledge ($P=.005$) and procedural knowledge ($P<.001$) than participants who did not have or use navigational options (n=115). A realistic visualization induced more fear ($P=.001$) and disgust ($P<.001$) than a schematic video. Attitude toward the surgery ($P=.02$) and certainty regarding the decision for or against surgery ($P<.001$) were significantly more positive after watching the video than before watching the video. Participants who watched a schematic video rated the video significantly higher than that by participants who watched a realistic video ($P<.001$). There were no significant group differences with regard to hypothetical decision making and attitude toward the intervention. In addition, we did not identify any influence of the visualization format on knowledge acquisition. In Study 2, 58 of 110 participants (52.7%) indicated that they would prefer a schematic visualization, 26 (23.6%) preferred a realistic visualization, 17 (15.5%) wanted either visualization, and 9 (8.2%) did not want to watch a video at all. Of the participants who wanted to watch a video, 91 (90.1%) preferred to have navigational options, 3 (3.0%) preferred not to have navigational options, and 7 (6.9%) did not mind the options.

Conclusion: Our study indicates that the perception of medical information videos is influenced by their design. Schematic videos with navigational options are the most helpful among all videos to avoid negative emotions and support knowledge acquisition when informing patients about an intervention. The visualization format and navigational options are important features that should be considered when designing medical videos for patient education.

Trial Registration: Deutsches Register Klinischer Studien DRKS00016003; https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00016003 (Archived by WebCite at <http://www.webcitation.org/746ASSAhN>)

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KEYWORDS

attitude; decision aids; emotions; informed decision making; knowledge acquisition; medical decision making; surgery; video

Original Paper

Introduction

Background

In clinical practice, doctors and patients are sometimes faced with a situation that has no clearly optimal treatment. Nonetheless, they have to make a decision on the most-appropriate option. Such decisions are *preference sensitive*, because they should consider individual circumstances and preferences of the patient as well as scientific evidence. Most patients prefer making shared or autonomous medical decisions [1]. Although informed consent is required for any medical treatment and shared decision making has become more common in the last few decades, many patients find it difficult to participate in the decision-making process [2]. To make an informed decision, patients have to acquire knowledge about the process, risks, benefits, and alternatives. The decision-making process is also influenced by patients' attitudes, and patients should be able to make a choice that reflects their personal values and preferences [3]. Several studies have shown that shared decision making has a positive impact: Patients have more realistic expectations, feel more satisfied with the decision, and show more treatment cooperation [4]. In addition, they make more conservative treatment decisions: A previous review showed that the number of people undergoing major elective surgery decreased [5] as compared to usual care when the participants actively participated in shared decision making, and many patients chose a less invasive option [6] when they watched an educational video in addition to the standard encounter with a physician.

Implementing shared decision making is challenging. Many patients feel that they lack the knowledge to make an informed decision and therefore underestimate the importance of personal preferences and individual experiences [7,8]. Patients often remember little of the verbal information they received during a consultation, and doctors tend to overestimate patients' level of comprehension [9,10].

Decision-Support Tools

Decision-support tools are increasingly used to support patients who have to make a medical decision. They can be applied before, during, or after a clinical encounter; provide evidence-based information about options, risks, and benefits; and support the decision-making process by helping patients imagine the different options and clarify their personal values [11]. Decision-support tools are often computer based and include different media formats such as texts, pictures, and videos. They are not intended to substitute a personal consultation with an experienced doctor, but to prepare patients

for this consultation or allow them to learn more about the subject, revisit information, and visualize complex processes or structures [12,13].

Experimental studies that explicitly tested the use of decision aids during the informed-consent process found that the aids consistently had a positive impact on knowledge gain [13-18]. Only a few studies found a significantly higher satisfaction with the process [13,14,17], and usually, no difference in anxiety was observed [13,14,18,19]. However, these studies used different tools, ranging from complex multimedia interventions to short videos or pamphlets. In addition, they examined diverse medical fields with various kinds of decisions. Most importantly, only a few studies investigated the decision-making process, because the decision itself was often already made.

A review by Stacey and colleagues [5] showed that in 105 studies that compared decision aids with usual care, decision aids improved patients' knowledge about their options and reduced the decisional conflicts stemming from feeling uninformed and unclear about their personal values. Furthermore, decision aids stimulated people to take a more active role in decision making and increased the accuracy of their risk perceptions. In another review, Wilson and colleagues [20] compared multimedia and print health materials and found that the former were superior to print, but there were no significant differences in more than half of the outcome measures. Notably, the interventions and outcomes in these studies were diverse. Multimedia tools have the potential to support patient education and decision making better than a verbal consultation or print materials alone, but there is a need to investigate the circumstances under which they have a positive impact on knowledge and decision making.

Videos to Support Informed Decision Making

Videos are often included in many decision-support tools, usually as part of a more complex multimedia intervention. The use of videos as a source of medical information has increased in the past years [21] in a professional context as well as on platforms like YouTube [22], indicating that laypeople are interested in this format. Videos might help impart medical information to laypeople, because they can make complex anatomical information more vivid than text or pictures alone and provide patients a visual impression of a particular treatment. Additionally, patients can watch the videos more than once, and videos are a cost-effective way to communicate information [23]. Thus, videos may be a good resource for supporting informed decision making and appropriate for use in decision-support tools. Several studies have found that watching an informational video in addition to having access to classical information sources (consultation and information

brochure) had a positive effect on knowledge gain [17,24-27]. Regarding emotions, there have been different findings: Pager [25] found that patients who had watched a video explaining the expectations from cataract surgery expected the surgery to be riskier and more unpleasant, but felt less anxious during the surgery and were more satisfied after the surgery. A study with patients who underwent coronary artery bypass surgery showed that watching a video resulted in less fear and a stronger feeling of subjective well-being before the surgery and less depression after the surgery [28]. A few other studies showed a reduction of fear after watching a video [29-31], whereas others did not show such an effect [18,19]. Regarding decision making, Volandes and colleagues [32] found that watching a video had a positive impact on the ability to make a decision. In a study by Chiou and Chung [33], a video intervention reduced both uncertainty and decisional regret.

In summary, research suggests that videos can be useful in improving patient education, may regulate emotions, and have the potential to support decision making. However, the videos used in these studies were diverse, which may explain the difference in some aspects of previous findings. Thus far, there has been no research on the potential impact of different designs of video formats. In addition, only a few studies have specifically investigated the influence of different videos on decision making. For patient counseling, it is important to examine which features of educational videos may promote knowledge gain, evoke or avoid negative emotions, and support attitude formation in medical decision making.

Design of Medical Information Videos

The design of educational videos can differ in many ways. One possible variation for the *visualization format* is the use of schematic or realistic presentations. A schematic video consists of animated line drawings that present the most-relevant parts or components but omit negligible details. In contrast, a realistic video shows real representations and processes and depicts them in their actual complexity. In the case of a surgery video, a realistic film would show an actual surgery on a real body. Studies in nonmedical contexts have shown that schematic videos led to better learning outcomes [34,35] and were easier to understand than realistic videos, especially when people had little prior knowledge [36]. However, knowledge gain is not the only important outcome of educating patients. When designing a video to support informed, value-concordant decision-making, one needs to bear in mind that patients also need to form an attitude toward the intervention of their choice. As realistic videos are more vivid than schematic ones, they have the potential to generate more negative emotions, in particular, fear and disgust. However, a realistic depiction might make the actual procedure of an intervention easier to imagine, which could reassure patients of the realities of the potential surgery and support the formation of an attitude.

Another type of variation in educational videos is the amount of *user control*. The availability of basic navigational options to stop and skip forward or backward was found to facilitate the learning process in nonmedical domains [37-39]. To our knowledge, no studies have thus far investigated the effect of

such navigational options on emotions, attitudes, or decision making in the medical context.

Herein, we conducted two studies to compare differently designed videos in a randomized controlled experiment and to examine people's preferences for particular designs of medical information videos in an online survey.

Hypothesis and Research Questions

In our first study, we aimed to compare different visualization formats (schematic vs realistic visualization) and basic navigational options (available or unavailable) in medical information videos in terms of their impact on knowledge, emotions, and attitudes. In addition, we examined the influence of the two abovementioned factors on patients' decision to undergo one of two medical treatments. As a video topic, we chose *arthroscopic cruciate ligament surgery*, which is a common orthopedic surgical procedure and a frequently performed treatment after a cruciate ligament rupture [40,41]. Another frequently used, alternative treatment is intense physiotherapy. We decided on this topic because studies comparing the two methods are unclear about whether surgery or physiotherapy is the clearly superior treatment [42-44]. Therefore, each patient would have to make an individual decision about undergoing this surgery. In addition, a cruciate ligament rupture is a frequent sports accident and therefore easy to imagine for a sample of healthy participants.

As the influence of video design on attitude formation and decision making in a medical context has not been examined thus far, we investigated these influences in the form of explorative questions. Additionally, we asked participants for a general evaluation of the video.

Previous research has found that schematic videos made learning of complex topics easier as compared to realistic videos [34-36]. Accordingly, we expected higher levels of factual knowledge and procedural knowledge with a schematic video (H1). As the availability of basic navigational options had a positive impact on knowledge gain in other studies [37-39], we expected higher factual knowledge and procedural knowledge with the availability of basic navigational options (H2). Laypeople are not accustomed to watching a surgical procedure on a human; therefore, it might evoke negative emotions. Thus, we assumed that participants who watched a realistic operation would experience more fear and disgust than those who watched a schematic video (H3). Finally, we predicted a significant increase in certainty of the decision after watching the video, as the additional information should support the decision-making process (H4).

In our second study, we wanted to learn more about people's preferences for visualization formats and basic navigational options to complement the results of the first study. As in Study 1, we used the topic *arthroscopic cruciate ligament surgery*. In contrast to Study 1, which was conducted as a laboratory experiment, Study 2 was performed as an online survey.

Methods

Ethical Approval

This research was performed in accordance with the Declaration of Helsinki and received full approval by the ethics committee of the Leibniz-Institut fuer Wissensmedien (approval number: LEK 2017/041).

The trial was not preregistered as Study 1 was conducted before trial registration became standard policy at the Leibniz-Institut für Wissensmedien.

Study 1

Study Setting

We conducted a randomized controlled experiment in a laboratory setting. The participants were placed in a hypothetical situation where they would have to confront the possibility of surgery. They watched an educational video and responded to several questionnaires about their knowledge (factual and procedural knowledge), emotions (fear and disgust), and attitude toward the intervention as well as their decision and certainty of the decision.

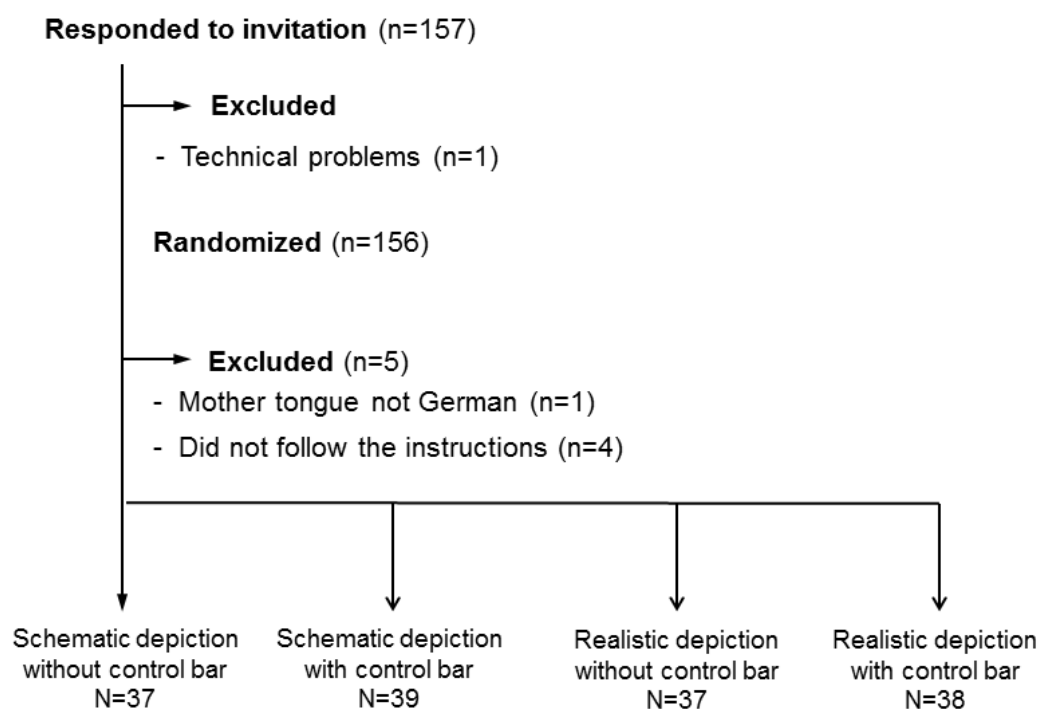
Participants

To be able to detect a medium effect size ($\rho=.30$, $\alpha=0.05$, $1-\beta=0.95$), a sample size of 40 per condition was required. The experiment was performed with 157 laypeople who were

randomly recruited from the participant database of the Leibniz-Institut fuer Wissensmedien and invited via email. Registration in this database was voluntary and open to everyone who was willing to participate in empirical studies. Medical or sports students and people working in a medical profession were not invited to participate, because we aimed to include participants who had no or little prior professional knowledge about the topic and wanted to determine how laypeople, in particular, reacted to the videos. In the invitation, potential participants were informed that during the experiment, they might watch a video demonstrating the surgery on a body donor. They were repeatedly informed that they could stop the video at any point without any negative consequences. Of the 157 participants who were initially recruited, 6 participants were excluded: 1 participant had technical problems, 1 had specified a mother tongue other than German, and 4 did not follow the instructions (ie, did not read the information sheet or consent to have their computer screen recorded while the video was running; see Procedure section). The remaining 151 participants (mean 25.90 years, age range 19-67 years, [Table 1](#)) were randomly assigned to the 4 experimental conditions. The sampling procedure is shown in [Figure 1](#). Across the 4 experimental conditions, the participants did not differ in age ($F(3,147)=1.62$; $P=.19$; $n=151$), distribution of gender ($\chi^2=7.44$; $P=.28$; $n=151$), occupation ($\chi^2=7.40$; $P=.83$; $n=151$), or education ($\chi^2=4.41$; $P=.62$; $n=151$). All participants provided written informed consent. The study lasted for approximately 45 minutes and was compensated with 6 Euros.

Table 1. Demographic characteristics of the participants in Study 1.

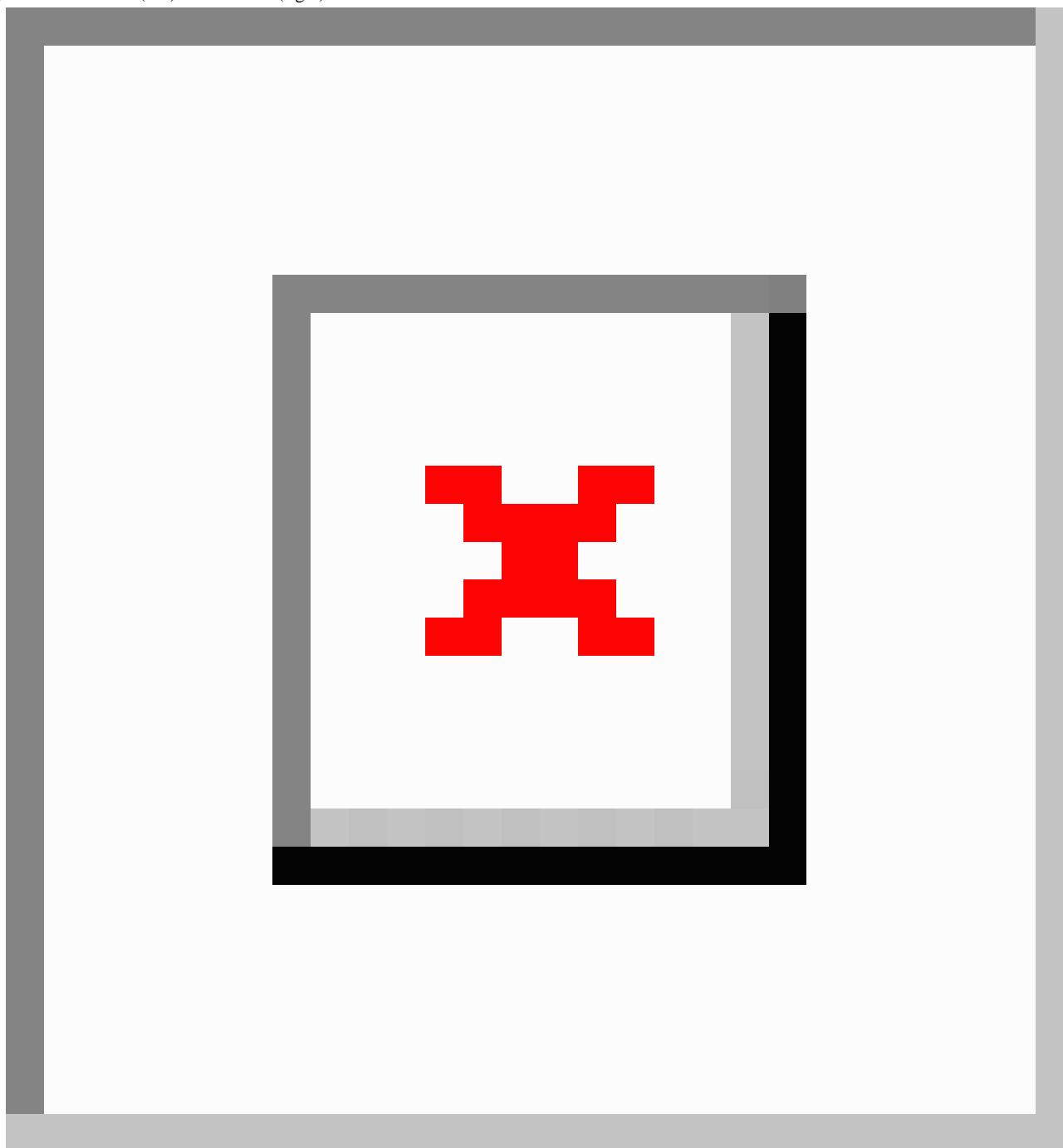
Characteristics	n (%)
Age (years)	
19-24	78 (51.7)
25-30	57 (37.7)
≥31	16 (10.6)
Gender	
Female	105 (69.5)
Male	45 (29.8)
Other	1 (0.7)
Occupation	
University student	132 (87.4)
Employee	10 (6.6)
Other	9 (6.0)
Education	
No graduation	1 (0.7)
School-leaving certificate	87 (57.6)
University degree	63 (41.7)

Figure 1. Sampling procedure of Study 1.

Procedure

All the instructions and questionnaires were presented on a computer screen. After reading the study description and signing the informed consent form, participants answered questions about their demographic data (age, gender, occupation, and education). Subsequently, they were asked to place themselves in a fictional situation where they had suffered a cruciate ligament rupture in a sports accident and were faced with a choice for or against surgery. They were asked about their decision (how likely they were to hypothetically undergo surgery), certainty of this decision, and attitude toward the potential surgery (premeasures). Thereafter, they were asked to imagine that before the next consultation, their doctor gave them an information brochure about their injury and recommended a video on the possible surgery. At this point, the same information sheet was handed out to every participant. It included general information on the location and function of the cruciate ligament and consequences of an injury and treatment options (surgery or intense physiotherapy). This information was provided in a neutral manner. Patients were also informed that in medical research, thus far, no treatment was found to be clearly better than the others and that each patient had to make an individual decision. This information sheet comprised 679 words. After they finished reading this sheet, the participants watched one of four different videos,

depending on their experimental condition. They were randomly assigned to the conditions by the survey program Qualtrics (Qualtrics LCC, Provo, Utah). The videos differed in their visualization format (realistic vs schematic depiction; [Figure 2](#)) and the availability of basic navigational options (with or without a control bar to stop and skip forward or backward). They were similar in terms of content (focusing on the surgical procedure). The realistic and schematic videos showed the same procedure in the form of a real operation on a human body involving real people or in the form of an animated line drawing. Both videos had identical spoken text and the same duration (approximately 3.5 minutes; [Multimedia Appendix 1](#)). The contents of the information sheet and the videos were reviewed by physicians and professional anatomy educators. All participants were allowed to take notes while watching the video. We recorded the computer screen while the video was playing in order to examine how participants used the navigational options. When the participants had finished watching the video, their notes and the information sheets were collected. Subsequently, they answered questions about their decision, certainty of the decision, and attitude toward the potential surgery (postmeasures) again. In addition, they answered questions about their emotions while watching the video and their general evaluation of the video. Finally, they received a knowledge test that consisted of questions about the information presented in the video.

Figure 2. Schematic (left) and realistic (right) video formats.

Measures

The knowledge test consisted of 6 items. Five items covered *factual knowledge* about the information provided in the video. The questions were either multiple choice or required the input of a single word or number. The mean score of these items was calculated, resulting in a maximum score of 1 point. *Procedural knowledge* was evaluated using a sorting task, where participants had to put 5 operation steps in the right order. One point was awarded to each correctly ordered step; this score was divided by 5, again resulting in a maximum score of 1 point.

To measure the participants' emotions while watching the video, we used the subscales *fear* and *disgust*, with 3 items each from the modified Differential Affect Scale [45]. On a 5-point Likert

scale, participants indicated how strongly they felt this emotion during the video presentation. The subscales showed good or excellent internal consistencies (Cronbach $\alpha_{\text{disgust}}=.95$, Cronbach $\alpha_{\text{fear}}=.82$). *Attitude* toward the intervention was measured using 4 bipolar items on a 7-point scale before and after watching the video [3]. Internal consistencies were acceptable or good (Cronbach $\alpha_{\text{att-pre}}=.70$, Cronbach $\alpha_{\text{att-post}}=.80$). The participants' hypothetical *decision* was noted before and after watching the video. On a 5-point scale, they indicated how likely they were to hypothetically undergo surgery in the situation they were given.

To measure *certainty* regarding the decision, participants were asked in 5 items how certain they felt about their decision for

or against the surgery. All responses were given on a 5-point scale, and the items showed acceptable internal consistencies (Cronbach $\alpha_{\text{cert-pre}}=.66$, Cronbach $\alpha_{\text{cert-post}}=.67$). General evaluation of the video was measured using 4 items. Internal consistency was acceptable (Cronbach $\alpha_{\text{sat}}=.66$). [Multimedia Appendix 2](#) provides an overview of all measures.

Analysis

Data analysis was performed using IBM SPSS 22 statistics for Windows (International Business Machines Corporation, Armonk, New York). To test for differences between the conditions, we performed analyses of variance, including repeated measure analysis for the pre-post comparisons. We report all data as means and standard deviations. The level of significance was set at $P<.05$. The partial eta-squared value was calculated as effect sizes of mean differences.

Study 2

Participants

The online survey was performed with 110 laypeople (mean 24.05 years, age range 18-72 years, [Table 2](#)) who were recruited from the same participant database as Study 1 and invited via email. Medical or sports students, people working in a medical profession, and persons who had already participated in Study 1 were not invited to participate in this study. Participants had

the option to participate in a raffle to win vouchers for an online shop. The survey lasted for approximately 5-10 minutes.

Procedure

The online survey could be completed on any electronic device. Participants read the study description, provided written informed consent, and answered questions regarding their demographic data. Subsequently, they were given the same situation as in Study 1 and answered 2 questions regarding the video they would choose to watch in this situation. To show the participants what the schematic and realistic videos would look like, they were presented with still images from the 2 videos ([Figure 2](#)).

Measures

In the first question, participants were asked if they would like to watch (a) a schematic video, (b) a realistic video, (c) any video without preference for the visualization format, or (d) no video at all. If they answered a, b, or c, they were asked if they would like to have basic navigational options (yes, no, I don't care). The survey only consisted of these basic questions and did not include any manipulation, since this study was intended to identify people's general preferences for medical videos.

Analysis

Chi-squared tests were used to test for differences in frequencies.

Table 2. Demographic characteristics of the participants in Study 2.

Characteristics	n (%)
Age (years)	
18-24	76 (69.1)
25-30	26 (23.6)
≥31	8 (7.3)
Gender	
Female	85 (77.3)
Male	24 (21.8)
Other	1 (0.9)
Occupation	
University student	98 (89.1)
Employee	10 (9.1)
Other	2 (1.8)
Education	
No graduation	4 (3.6)
School-leaving certificate	83 (75.5)
University degree	23 (20.9)

Results

Study 1

In contrast to Hypothesis 1, there were no significant group effects of the visualization format regarding *factual knowledge* (schematic: mean 0.62, SD 0.23; realistic: mean 0.60, SD 0.22;

$P=.32$) or *procedural knowledge* (schematic: mean 0.77, SD 0.26; realistic: mean 0.82, SD 0.29; $P=.57$).

As per Hypothesis 2, we expected participants who were given basic navigational options to gain more factual knowledge and procedural knowledge than participants without navigational options. However, we did not observe the expected group differences (factual knowledge: $P=.10$, procedural knowledge:

$P=.51$). There was a significant difference between the participants who had used the navigational options at least once ($n=36$) and those who had not used the options at all ($n=115$). Participants who used the options at least once performed significantly better in both *factual knowledge* (navigation used: mean 0.70, SD 0.22; navigation not used: mean 0.58, SD 0.22; $_{part.}\eta^2=.05$, $F(1,147)=8.18$, $P=.005$), and *procedural knowledge* (navigation used: mean 0.93, SD 0.17; navigation not used: mean 0.75, SD 0.31; $_{part.}\eta^2=.08$, $F(1,147)=11.94$, $P<.001$).

In support of Hypothesis 3, participants who had watched the realistic video experienced more *fear* (schematic: mean 1.49, SD 0.68; realistic: mean 1.96, SD 1.04; $_{part.}\eta^2=.07$, $F(1,147)=11.12$, $P=.001$) and *disgust* (schematic: mean 1.47, SD 0.79; realistic: mean 2.48, SD 1.28; $_{part.}\eta^2=.19$, $F(1,147)=34.14$, $P<.001$) than participants who had watched the schematic video.

In support of Hypothesis 4, certainty about the decision was significantly higher after the video presentation (mean 2.64, SD 0.68) than before the presentation (mean 2.22, SD 0.66) ($_{part.}\eta^2=.34$, $F(1,147)=75.71$, $P<.001$). In addition, we found no differences between the video types.

Regarding our explorative analysis, we found no significant group differences for attitude toward the intervention (all $P>.09$). However, there was a significant pre-post effect on attitude: Participants' attitude toward the intervention was more positive after watching the video (mean 4.31, SD 1.07) than before watching the video (mean 4.16, SD 0.91) ($_{part.}\eta^2=.35$, $F(1,147)=5.27$, $P=.02$).

There were no significant group effects on decision (all $P>.095$) or certainty about the decision (all $P>.54$). However, we found that participants who had watched a schematic video rated this video significantly higher (mean 4.36, SD 0.49) than that by participants who had watched a realistic video (mean 3.86, SD 0.86) ($_{part.}\eta^2=.12$, $F(1,147)=20.34$, $P<.001$).

Study 2

Of the 110 participants, 101 (91.8%) wanted to watch a video and 9 (8.2%) preferred not to watch any video ($\chi^2(1, 110)=76.95$, $P<.001$). Regarding the visualization format, 58 participants (52.7%) preferred to watch a schematic video, 26 (23.6%) opted for a realistic video, and 17 (15.5%) did not favor any format ($\chi^2(3, 110)=50.36$, $P<.001$). Of those who wanted to watch a video, 91 participants (90.1%) preferred to have basic navigational options, 3 (3.0%) preferred not to have navigational options, and 7 (6.9%) did not care ($\chi^2(2, 101)=146.69$, $P<.001$).

Discussion

Study 1

The results of this experiment showed that the use of navigational options supported the development of factual and procedural knowledge. Watching a schematic video led to fewer negative emotions, and the participants liked the schematic

video better than the realistic video format. However, the participants were randomly assigned to watch one visualization format and did not have the option to select their preferred format or watch no video at all. Therefore, it was important to address the extent to which people would be interested in watching an information video about surgery and the video design they would prefer. To this end, we conducted an online survey to expand on the findings of the experimental study.

Study 2

The results of the survey showed that most participants were generally interested in medical information videos, which is in line with former research [46]. Furthermore, schematic videos were preferred over realistic videos, and most participants indicated that they would like to have navigational options. These findings support the results of the experimental study, where a schematic visualization caused fewer negative emotions and was better than a realistic visualization and where the use of navigational options led to better recall of information covered in the video.

General Discussion

The research presented here aimed to investigate the potential of medical information videos for patient education and decision making. Such videos may be used in preparation for or follow-up of a medical consultation to support decision making. Former research has reported that such tools may support knowledge acquisition [5], but their benefit for decision making is unclear. Moreover, the results of their impact on emotions are varied. One problem was the diversity of videos used in previous studies, due to which it was difficult to identify the reasons for different findings. In our first study, we aimed to examine how visualization of differently designed information videos influenced learning, emotions, attitude, and decision making.

The laboratory experiment showed that watching a video about cruciate ligament surgery modified participants' attitude toward the intervention and increased their certainty about the hypothetical decision for or against surgery. These results are in line with those of other studies that reported positive effects of medical videos when informing viewers about an upcoming surgical procedure (eg, [15,47,48]). People require support to make informed decisions and reassurance to make individual choices for treatments that are consistent with their own personal values; our results suggest that videos may be a suitable medium to facilitate this process. The video format did not have a differential impact on the certainty of the decision, indicating that all videos were equally helpful in decision making.

The use of basic navigational options resulted in better performance on a knowledge test. In contrast to the findings of Hasler and colleagues [39], we found no benefit of the navigational options when they were made available but not used. Since participants who used the navigational options automatically spent more time with the video, their better performance in the knowledge test could have resulted from longer exposure to the content. This finding could also reflect differences in motivation among people who used or did not use the navigation tool. Nevertheless, this result is interesting, as it implies that watching a video only once may not be enough

and repetitions and pauses are beneficial to process the content. This finding is in agreement with that of Wilson and colleagues [20], who reported that participants who reviewed an information brochure at home performed better than participants who did not review the brochure at home. One advantage of multimedia tools as compared to personal consultation is that learning may be adjusted to the viewers' own speed and preferences, which is beneficial for learning.

In our experimental study, a schematic visualization was associated with fewer negative emotions and a more positive evaluation than a realistic visualization. This finding is particularly interesting, because recent technological developments have increasingly relied on schematic representations of surgical interventions (eg, [49]). In addition, the majority of participants in the additional online survey stated that they would prefer to watch a schematic video with navigational options, indicating that the design of medical information videos about surgical interventions can affect the participants' perception (eg, [50]) and might explain why studies have found different results for the impact of interventions on, for example, emotions.

The studies presented here have some limitations. First, the participants' decision-making process was hypothetical, as our participants were not patients. Although this approach allowed us to perform the study in a controlled experimental setting and choose a situation that might be relatively easy to imagine, the motivation of our participants to engage in the situation may be lower than that among patients, for whom the situation would be personal and relevant. Patients may place importance on other aspects and react differently to the videos; in addition, some of our participants may have faced difficulty in imagining their feelings and thoughts in the described situation. Second, a large number of our participants were university students and therefore relatively young and well educated. Consequently, one should exercise caution when generalizing these findings to an entire population. For example, younger people may be physically more active and may therefore be more likely to opt for surgery than older people, which is supported by the fact that the average attitude toward surgery was positive. Some previous studies found that patients with low educational levels benefited significantly more from multimedia interventions than patients with high educational levels [12,15,16]. As such, our videos may have been more useful for people with a low educational background. In addition, educational videos may need to be designed differently depending on the target audience. Third, our results only indicate that watching the videos supported participants' decision-making process, but did not explain the manner or reason for this finding. Future studies could resolve this limitation by asking participants to verbally explain their decision. Although we asked participants for prior experiences with the subject, we did not test their knowledge

prior to the intervention. However, as the participants were randomly assigned to the experimental groups, this omission may not be a problem. Nonetheless, inclusion of a pretest would allow evaluation of learning development and consideration of individual differences.

We informed participants that there were two possible treatment methods, but showed them a video that only addressed one method—surgery—because we wanted to focus on one intervention and clarify the reason for the possible effects observed. The disadvantage of this approach was that participants learned more about the surgery than about the alternative treatment, which likely influenced their attitude and decision-making process. Future studies with a larger sample size should create different videos about the different treatment options and compare their effects on the outcome variables. In addition, they should aim to transfer the research questions into more-realistic settings to determine if patients can benefit from such videos in the same way as the participants in our experiment did and show similar preferences regarding the video design.

Practice Implications

Medical educational videos are useful for providing knowledge to laypeople with little prior experience and support informed decision making. Our studies showed that the visualization format and user control options should be considered in the design of such videos. Our findings suggest that schematic videos with navigational options, along with encouragement to use them, may be most helpful in avoiding negative emotions and supporting knowledge acquisition.

Conclusions

Videos are a good medium for educating patients about medical topics and should be used as decision-support tools to make complex information more vivid and easier to understand for laypeople. Our studies show that the design of such videos can influence information processing. The schematic visualization caused fewer negative emotions, was liked better than the realistic visualization, and was preferred by more than half of the participants in our survey. In contrast, almost one-fourth of the participants showed interest in a realistic presentation format. To increase satisfaction and personal benefit, different types of visualizations should be offered and patients should be given the opportunity to decide individually which type they prefer. This approach would be easy to realize in decision-support tools. Since participants spent more time with the video and acquired more knowledge with the use of navigational options, navigational options should be made available to participants and participants should be encouraged to actively use them, for instance, to pause and repeat difficult or interesting parts of the video.

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Conflicts of Interest

None declared.

Editorial notice: This randomized study was only retrospectively registered because “Study 1 was conducted before trial registration became standard policy at the Leibniz-Institut für Wissensmedien.” The editor granted an exception from ICMJE rules mandating prospective registration of randomized trials, because the risk of bias appears low. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Multimedia Appendix 1

Script of the audio track in the realistic and schematic video formats.

[[PDF File \(Adobe PDF File\), 24KB - jopm_v10i4e12338_app1.pdf](#)]

Multimedia Appendix 2

Measures in Study 1.

[[PDF File \(Adobe PDF File\), 34KB - jopm_v10i4e12338_app2.pdf](#)]

Multimedia Appendix 3

CONSORT - EHEALTH checklist (V 1.6.1).

[[PDF File \(Adobe PDF File\), 175KB - jopm_v10i4e12338_app3.pdf](#)]

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Original Paper

Use of Video Consultations for Patients With Hematological Diseases From a Patient Perspective: Qualitative Study

Nina Primholdt Christensen^{1*}, RN, MSc; Dorthe Boe Danbjørg^{2*}, RN, MSc, PhD

¹Odense Patient Data Explorative Network, Hematological Research Unit, Odense University Hospital, Odense, Denmark

²Centre for Innovative Medical Technology, Department of Hematology, Odense University Hospital, University of Southern Denmark, Odense, Denmark

* all authors contributed equally

Corresponding Author:

Nina Primholdt Christensen, RN, MSc
Odense Patient Data Explorative Network
Hematological Research Unit
Odense University Hospital
Klørvænget 10, 12th Floor
Odense,
Denmark
Phone: 45 24643617
Email: nins49@hotmail.com

Abstract

Background: The need for the use of telemedicine is expected to increase in the coming years. There is, furthermore, a lack of evidence about the use of video consultations for hematological patients, and how the use of video consultations is experienced from the patients' perspective.

Objective: This study aimed to identify patients' experiences with the use of video consultations in place of face-to-face consultations, what it means to the patient to save the travel time, and how the roles between patients and health care professionals are experienced when using video consultation. This study concerns stable, not acutely ill, patients with hematological disease.

Methods: The study was designed as an exploratory and qualitative study. Data were collected through participant observations and semistructured interviews and analyzed in a postphenomenological framework.

Results: The data analysis revealed three categories: "Intimacy is not about physical presence," "Handling technology," and "Technology increases the freedom that the patients desire."

Conclusions: This study demonstrates what is important for patients with regards to telemedicine and how they felt about seeing health care professionals through a screen. It was found that intimacy can be mediated through a screen and physical presence is not as important to the patient as other things. The study further pointed out how patients valued being involved in the planning of their treatment. The patients also valued the freedom associated with telemedicine and actively took responsibility for their own course of treatment. Patients felt that video consultations allowed them to be free and active, despite their illness.

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KEYWORDS

consultations; telehealth; technology; patient; hematology

Introduction

Background

Hematological patients in Denmark may spend several hours traveling to the hospital as the treatment is centralized at a few university hospitals [1]. Therefore, the purpose of this study was to examine how hematological patients experience the use of telemedicine. Telemedicine is defined by the World Health

Organization as "the delivery of health-care services, where distance is a critical factor" [2]. Thus, the concept refers to a range of different services, for example, monitoring, treatment, and communication based on different telemedicine technologies. This project will focus on video consultations instead of or as a supplement to a physical consultation.

Several pilot projects covering telemedicine have been conducted in Denmark. These projects have shown that

telemedicine provides benefits in the shape of more self-supporting patients, economical benefits, and contiguous patient processes [3]. In a Danish study from 2016, telemedicine was investigated in patients with chronic obstructive pulmonary disease. It was found that teleconsultation was experienced as qualified and facilitated a close relation between the nurse and the patient. Furthermore, the patients became more active participants in their own treatment because they had to be more active in relation to the technical aspects and responsibility toward their own disease [4].

In general, it has been emphasized that telemedicine holds great potential for the delivery of health care services by enhancing access, quality, efficiency, and cost-effectiveness. It is predicted that telemedicine will continue in the relocation of health care delivery from the hospital or clinic into the home [5]. However, it is also emphasized that policy makers should be cautious about recommending increased use of, and investment in, unevaluated technologies [6]. Hailey et al [7] stated that research within telemedicine has been inadequate, and there is a need for investigations into the newer telemedicine solutions for well-defined patient groups.

Yet no projects involving patients with hematological diseases have been conducted in a Danish context, and a systematic database search shows very limited research on video consultations with patients with hematological diseases globally. The majority of the studies were derived from Australia and the United States, and only few European studies appeared in the search. In most of the studies found concerning telemedicine and hematology, telemedicine is used because of the long distances and to keep the specialized doctors available for patients despite the long distances. In a study from Kansas [8], the perceptions of telemedicine of 22 patients with hematological diseases were explored. In this study, the majority of patients expressed satisfaction with replacing the face-to-face contact with a video consultation, allowing them to consult a specialist. The study showed that the patient and the doctor have different roles according to and during the consultation but did not explore how this is evident. Another aspect is the audio-visual differences caused by the screen that make the consultation different from a face-to-face consultation. The study also indicated that some aspects of the communication were found to be inhibited because of the absence of personal contact and the insecurity about the technology. The study showed that further research is needed to explore how patients with hematological diseases experience their role during a video consultation and which communicational barriers they might experience.

Dinesen et al focus on the importance of defining which group of patients are suitable for using telemedicine and conclude that there is no *one-size-fits-all* approach when it comes to the use of telemedicine [9]. The diagnoses and patients differ, and there is a need for further investigation of the combination of technology and different patient groups. Kidholm et al [10] furthermore define that it is important to find the group of patients who can benefit from the use of telemedicine before the benefits show. They also define that telemedicine cannot stand alone without defined groups of patients [10].

In the future, the intention for the hospitals is to have fewer admitted patients and instead treat the patients in their own homes [11]. The need for use of telemedicine is expected to increase during the coming years, and therefore, it becomes important to gain knowledge about the use of video consultation for patients with hematological diseases as seen from the patients' perspective.

Aim

The overall aim was to explore how patients experience the use of video consultations. This will be uncovered through the following research questions:

- How do patients experience the use of video consultations in place of a face-to-face consultation?
- How do they experience the lack of physical contact?
- What does it mean to the patient to save the travel time?
- How are the roles between patients and health care professionals experienced when using video consultation?

Methods

Design

The study was designed as an exploratory and qualitative study.

The Intervention

This research project is part of a larger pilot study, where patients with hematological diseases from a small island to the south of Funen were given the opportunity to talk to a hematologist from the outpatient clinic in Odense through a video screen, while the patient is located at the local hospital on the island instead of a face-to-face consultation.

The intervention was initiated in cooperation between the municipality on the island, the Innovation Department at Odense University Hospital, and the Hematological Research Unit. In addition, 2 identical video screens were bought for use at the hospital on the island, and 1 screen was placed in the outpatient clinic in Odense.

The pilot study was initiated in April 2017 and continued until the end of December 2017. A total of 17 patients with different diagnoses have been included in the pilot study. The video consultations were used both for monitoring and treatment of the patients. Some patients got their blood pressure measured by the nurse at the local hospital. The doctor used the video consultation in combination with the blood results to determine whether the patients were suitable for next treatment or a new kind of treatment.

A research nurse from the Hematological Research Unit informed the patients about participation in the video consultations and initiated the video consultation with the hematology specialist. On the island, the patients were offered to have the nurse to participate, if the patient expressed a need for this. All patients were helped by a nurse to enter the room, and the nurse also provided assistance with the technology.

Sample

The study population is patients with hematological diseases living on the small island south of Funen (see Figure 1 for the selection process).

Inclusion Criteria

Inclusion criteria include patients with hematological diseases who can come to the hospital on the small island and who have participated in a video consultation in the pilot study, patients who can be assessed through video consultation, and patients who have been approved to participate in the video consultation. The approval was made by a hematology specialist who last saw the patient in the outpatient clinic. The hematology specialist selected patients who were in a period with stable disease and patients who did not receive intravenous treatment. Patients with all kinds of hematological diseases could be selected. After being evaluated for inclusion, the patient signed the informed consent form.

Exclusion Criteria

Exclusion criteria included patients who have not been approved by the hematology specialist to participate in a video consultation because of their specific diagnosis or general condition, for instance, if they were in an unstable period in their disease.

Data Collection

Participant Observation and Semistructured Interviews

Participant observations [12] of the patients during video consultations were conducted from November 2017 to December

2017. The first author made the observations. The observations were based on an observation guide that structured the focus as well as the field notes that were written during the observations. The observations provided an opportunity for open and informal follow-up interviews with patients regarding their immediate experiences with the video consultations. Furthermore, semistructured interviews with patients were conducted at the patients' homes on the small island.

A semistructured interview guide [13,14] was compiled focusing on the following themes: (1) technology issues; (2) how the consultation is experienced when it is technology mediated; (3) communication through a screen; (4) roles (health care professionals and patients and relatives [if applicable]);(5) everyday life and living with a hematological disease, and experiences of being ill; and (6) what impact does the long travel time to Odense have on the patient, and what difference the video consultation has made for the patient. The interviews lasted 30 to 50 min and were audio-recorded and transcribed verbatim. During the interviews, the patients were asked what their information technology (IT) skills were and if they used a computer, tablet, or mobile phone in their everyday lives.

Analysis

The collected data were analyzed in a postphenomenological framework with focus on technology-mediated perception, transformation, and constitution [15-18]. To organize the analysis process, we followed the steps from "systematic text condensation" [19-21]. The analysis was organized according to the steps taken in the analysis, as shown in Table 1.

Figure 1. The Consolidated Standards of Reporting Trials (CONSORT) diagram.

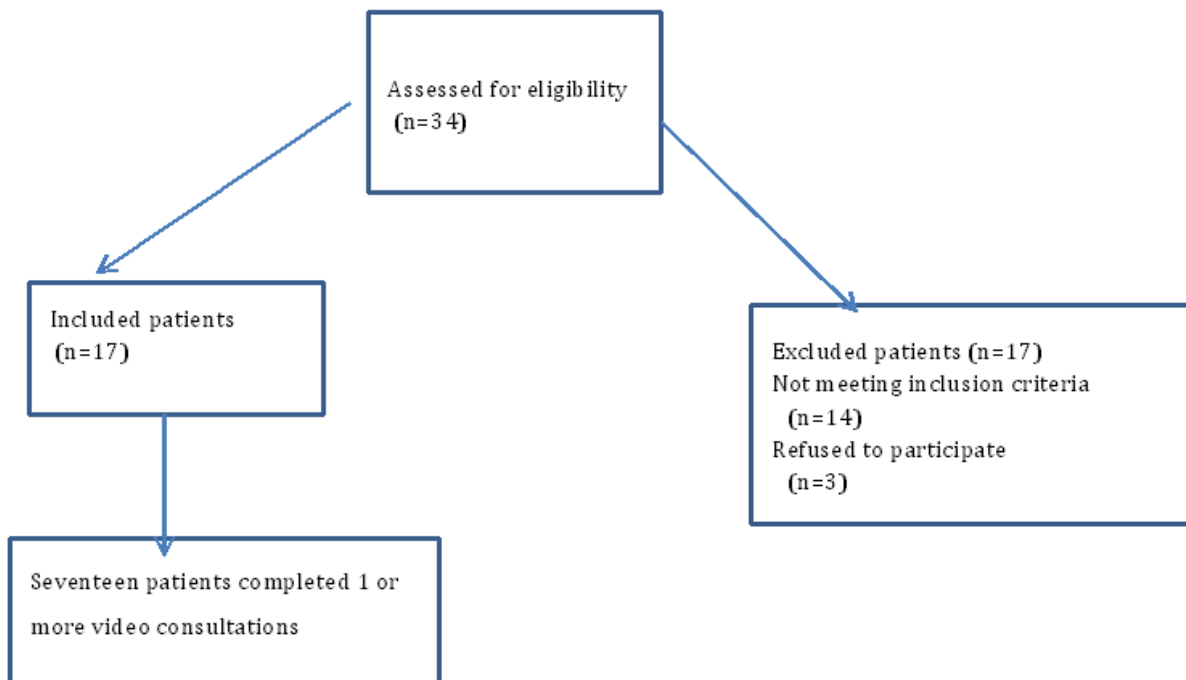


Table 1. The analysis process—examples from the analysis.

Themes ^a	Codes ^b		Meaning ^c
	Quotation	Code	
Demanding travel time	“It is such a hard trip. It takes all day—I’m picked up at appr. 6:45 or thereabouts, and I am back home at 4-4:30 pm and I also need to cook dinner and stuff like that. Yes, and then I fall asleep and sleep right through to the next day.”	Everyday life	Freedom
Eye contact	“Yes...yes, we did—really good contact. I looked at him, and he looked at me, and I actually rather liked that he was over there.” (laughs)	Intimacy	Intimacy

^aRefers to superior themes extracted after the first open reading (step 1).

^bRefers to transition from themes to codes and identifying meaningful units (step 2). The meaningful units are coded based on the superior themes.

^cRefers to transition from codes to meaning (step 3). The meaningful units are sorted into groups.

First, we captured an overall impression of the data, thereby obtaining a preliminary set of main themes. Second, the data were separated into meaningful topics relevant for the research question. Third, the meaningful topics were coded, and the topics were condensed. Finally, the findings were synthesized, involving a shift from condensation to descriptions and categories. The codes were developed based on the preliminary themes identified in the first step and the theoretical framework.

To enhance validation, the first and second authors worked on the analysis together. They discussed their overall impression of the data and then they highlighted the meaningful topics with a marker, and the codes were discussed between the 2 authors. The first author wrote down the analysis. The findings were then discussed in relation to relevant literature and a postphenomenological framework with focus on technology-mediated perception, transformation, and constitution.

Ethics

During data collection, the researchers were continuously reflective about the aim of the study and the methods applied [22]. Furthermore, the participants were informed thoroughly about the project, so they could make an informed choice on whether to enroll in the study or not. The patients were granted anonymity.

The study was registered with the Danish Data Protection Agency (2012-58-0018). The data are stored in a secure SharePoint site.

Results

Overview

The study included 12 participants aged 55 to 86 years with different hematological diagnoses. All participants were in a stable period in relation to their disease during the time when the video consultations took place (see [Multimedia Appendix 1](#) for details about age, gender, diagnosis, occupation, and educational level).

The majority of the interviews took place in the participants’ own homes—only 1 interview took place at a participant’s workplace. Moreover, 5 participants were observed during a video consultation at the local hospital. Results from the interviews and the participant observations revealed 3 categories reflecting the participants’ experiences with video consultations.

These categories are “Intimacy is not about physical presence,” “Handling technology,” and “Technology increases the freedom that the patients desire.” These themes will be described in more detail below.

Intimacy is not About Physical Presence

The analysis of the interviews revealed that participants found different things important in a consultation with the doctor. The participants found that they had a closer and more focused consultation with the doctor during the video consultation than during a consultation with physical presence. The reason was that the doctor was looking at and talking more directly to them—they felt intimacy and also a higher degree of eye contact, which was important to most of the participants:

No, I feel that we have eye contact (the dog barks). Even if it is through a screen, I feel that we have eye contact. [Male 4, 77 years]

A woman on the labor market stated the following, which accurately describes the intimacy and difference between a normal consultation and a video consultation:

Yes, there was only me and no noise, and he had to look at me and less at the computer (laughs), and we had a dialogue, and he couldn’t just walk away from the screen, could he (laughs), or anything else, and now there’s focus, and the contact was really good, so I would like to do it again. [Female 11, 60 years]

During the observations, it was noted that the participants used their body language a lot; they were looking directly at the screen and were very active with their body movements, yet at the same time they appeared relaxed. None of the observations showed that the participants were acting insecure or uncomfortable with sitting in front of the video screen. When the participants were asked if they missed the physical handshake, one of the participants expressed the following:

Interviewer: You were not unsure because you couldn’t give a physical handshake?

Woman: Not at all – no, I don’t think so. There are little words you can use instead, “hugs” and “hello,” and things like that. [Female 6, 55 years]

As the above quote indicates, the verbal and nonverbal communication changes when the consultation is conducted as a video consultation. It was also observed that the participants

often waved to the doctor when they said “hi” and “goodbye,” and they were laughing and smiling a lot.

The interviews and observations showed that the interior decoration of the rooms where the video consultation was performed did not play an important role in the participants’ experience of the video consultation:

Interviewer: It doesn’t sound like the room scared you off?

Male: No, no, not at all.

Interviewer: It is after all a rather special room – something like an operating room.

Male: No, that didn’t matter – I knew that I wasn’t going on the operating table and under the knife (Laughs). [Male 8, 70 years]

Most of the participants mentioned that the doctors examined them quite infrequently during a consultation with physical presence and that the content of the consultation mostly was a talk about the blood results and side effects—a talk that they experienced during this project could be replaced by a video consultation. The participants for this study were all stable in their disease. When they were asked whether they preferred to sit in front of the doctor physically or via a video screen if they were to receive bad news, most of the participants preferred to sit in front of the doctor physically. However, some participants preferred the opposite, as is reflected by what 1 male participant said:

Yes, and I would say that actually – theoretically that if I were to receive very serious news – if you think about that scenario – then I can see that you would react right off the bat and think that no, I’ll come over and hear it directly from you. But on the other hand, you could say that it would be less stressful just sitting by the video screen there and talk nice and quietly with the people in Odense who you would talk to anyway and then not have to go on a difficult journey afterwards and then be at home, but instead you can make it home in 5 minutes, and my wife could be involved in the consultation on the screen, if she wanted to – however, we haven’t tried that yet. But she would, of course, in a situation like that, sit and act the same as if it was in Odense, right. [Male 7, 69 years]

It was essential to most of the patients that they could talk to their usual doctor during the video consultations.

To have met the doctor in real life before having a virtual consultation means that it felt more natural to switch to nonphysical consultation because the contact was already established in the physical room. It was furthermore very important for some of the participants that their doctor showed their knowledge about their disease:

I feel safe that my doctor knows my disease and knows what is going to happen and if I am to come in. [Female 9, 78 years]

The results showed that intimacy in a consultation can manifest itself in many ways and that the verbal and nonverbal

communication—whether it is present in the virtual or physical consultation—are of great importance to the patients’ experience of intimacy.

Handling Technology

All participants express that both the sound and the image during video consultations have been of very good quality and that it is important for the overall experience of a video consultation. The fact that the participants have not encountered any technical issues was important for the overall experience and for the participants to feel safe:

Interviewer: And what about the quality of the picture and sound?

Male: It was outstanding – no problems at all. There really isn’t. [Male 4, 77 years]

One patient also experienced that it was possible for the doctor to *examine* him through the screen:

We talked really well, and I was actually impressed that she saw that I had kind of a red spot up here (points to his forehead) and I stuck my head really close to the screen, and I think she could zoom or something, but that’s amazing. Therefore the quality is really good – and I got some cream I could apply.

A majority of all participants have expressed that they were familiar with the use of IT, and most of them either had their own computer, tablet, or mobile phone available (see [Multimedia Appendix 1](#)). Despite this, the participants expressed confidence in the fact that the video consultation was taking place at the hospital, where the staff was responsible for handling the technology and could assist in case of technical problems. The fact that the staff took charge of the technical aspects of the video consultation meant that the participants could concentrate on the actual conversation with the doctor. During some of the video consultations, the staff was placed in the same room in case of questions and as security.

During the patient observations, it was clear that the nurses who handled the screens and informed the patients had an important role—the patients asked them questions and followed their instructions:

Female: Yes, I sad that it was OK that she stayed in the room with me.

Interviewer: Yes, maybe it was a comfort for you, in case something happened.

Female: Yes, with the screen or something. [Female 2, 82 years]

To the question of whether the patients were interested in the ability to speak with the doctor in their own home, the majority did not prefer this option. The reason was not a lack of IT skills but rather the feeling of too much responsibility. It was the fact of being responsible if the technology failed and therefore, also a risk of missing out on the time with the doctor:

In a way it is nice that the responsibility for the technology – someone over there has the responsibility for that – someone makes sure it works. [Male 7, 69 years]

Technology Increases the Freedom That the Patients Desire

The participants experienced that they saved themselves 6 to 8 hours of transportation with the ferry, car, or public transport and waiting time when they replaced the consultation in the outpatient clinic in Odense with the video consultation at the local hospital at the island. Saving traveling time had a great impact on all the participants' feeling of freedom. Some participants felt weak, and the long travel time meant that they had to sleep and recover 2 days after a visit in Odense—the travel time was demanding and draining for especially the elderly and physically weak participants:

And now I hope that this telefunction gets up and running so I can save the trip to Odense – it means so much – then I don't have to sleep 1-2 days after. [Female 6, 55 years]

In addition, the more fit participants experienced benefits from the less time spent on travelling—it gave them time to spend on their interests and also the feeling of self-determination. The participants got the opportunity to decide what suited them best in the actual situation they were in. The participants expressed in different ways that they were longing for the daily lives they had before they got sick and the opportunity to save a whole day of transportation:

It frees up some resources in a different way – I get a day where I can do some things. The entire day is not taken up by having to go to Odense. I sometimes have several things I have to do in a day. Today I can spend the time on several things and I wouldn't be able to do that if I was going to Odense. I am, among other things going out to play cards and I am having people over tonight – I wouldn't be able to do that if I was going to Odense. [Female 5, 72 years]

During the observations, the first author talked to a woman aged 72 years just before she was entering the video consultation. She looked a bit stressed and when the author asked for the reason, she said that she was so busy; because she found out that she has got extra time to spend as she did not have to travel to Odense, she had committed herself to baking pancakes for an old age home with 50 persons—she worked as a volunteer for 2 different organizations; these jobs meant a lot in terms of quality of life and made a daily life with relevant content for her.

One participant described how her everyday life was affected already the day before she was going to the outpatient day clinic:

Yes, the worst part is when we're off to Odense and I have to go there – and you know what – I can't hear anything. I saw the ear specialist the day before yesterday, and I have used a hearing aid for 16 years now. And when I have to get up in time in the morning, I can't hear the alarm clock, even if I've set 2, and I have bought a special alarm clock to be placed under my pillow, but I'm afraid it doesn't work. So when I'm going to Odense – and if I then wake up at 4 am, I am on pins and needles and get up and stay awake until 7am when I'm being picked

up – otherwise I'm afraid that I will go back to sleep...
[Female 2, 82 years]

A female participant also described how she often got infected with a virus after being on the ferry together with a lot of people. The fact that she can look forward to less transportation was of enormous importance to her. The amount of saved travel time has a measurable and positive impact on the participants' experience of freedom—especially when it is unclear to the patients why the doctors need to see them in person. On being asked when they found it necessary to travel to the hospital in Odense, an elderly woman aged 86 years and a woman on the labor market stated:

Only if I was to be examined and take my clothes off every time – but I'm not doing that at all – and then I can't see why I should go in there. [Female 1, 86 years]

But I have never heard that the doctor used that argument for me to come in, and I have never been examined when I've been in there. But it is a long time since I was in there as I always try to get out of having to go in and ask if they can't just call me. As I say to them I can measure my blood pressure, and I have blood samples done here, and what else is there...I damn well know where my blood pressure is at. But that is my situation, and I know that situations are individual. [Female 11, 60 years]

It was clear that the participants showed a great amount of responsibility in relation to their disease and that they were aware of what kind of information they needed. All of the participants knew their blood test results very well, and it was also the common talking point during the video consultations. Most of the participants showed that they were self-managing in the way they were dealing with their needs in relation to their disease, and it was shown across diagnoses, age, and sociodemographic background. One of the participants was still active on the labor market, and therefore the need for flexibility was high. She was also self-monitoring her blood pressure and paid close attention to her blood test results. However, she also emphasized that it was a mental strain being confronted with the memories from earlier admissions when she had to be at the hospital:

But when I'm kinda feeling good and everything is on track, I can't see any reason for going in, and I quickly feel made to feel sick when I go in and see people with all that stuff we had coming out of our bodies – can you imagine that? [Female 11, 60 years]

Throughout the analysis, it showed that all the participants had faith in the health system, the hospital, and the doctors they met during the treatment and control. The participants relied on the fact that they were treated and controlled correctly and also trusted that the doctors would contact them, if they needed to see them in exceptional situations:

But then I thought, oh, it's going to be a long journey and long day, but if that's the way she wants it that is what she is going to get. Of course she has to be allowed to say that I want to take a look at you. For she can see on our color and in our eyes if something

*is the matter with us and we can talk nice and quietly.
But I feel safe about it – I feel really safe about it.
And as I say – as long as nothing else is wrong with
me, then that's fine.* [Female 3, 72 years]

Most of the participants also lived near the local hospital and did not consider it difficult to go there. The desire to separate hospitals and homes was also one of the reasons why the participants expressed that they did not want to test video consultation from their own homes. Few of the participants stated that they would like to be placed in their own homes when talking to the doctor. They imagined that they would appreciate the flexibility with more time for their own interests. Participants with and without IT skills were interested in the possibility of video consultation from their own homes—so there was no relation between IT skills and the interest in trying the consultation in the participants' own homes.

One of the participants had a summerhouse in the north of Jutland, and when he found out that it was possible to have a video consultation from his summerhouse instead of driving back to the hospital in Odense, he became very satisfied with the flexibility it gave him and his wife:

Interviewer: Do you have a good internet connection at your summer house?

Male: Yes, we do.

Interviewer: Then that might be a possibility.

Male: Yes, and take your iPad with you and hook it up. No, we wouldn't go home for that... [Male 12, 74 years]

The participants' basic trust in the doctors had a great impact on the way the video consultation was used between the participants and doctors, and it also had an impact on their roles. During the observations, it was seen that the patients acted naturally and were asking the same number of questions—only the doctors were experiencing less distractions and according to the participants, the doctors seemed more focused in the communication.

Discussion

Principal Findings

The purpose of this study was to investigate how hematological patients experienced the use of video consultations in the outpatient clinic. Some of the main findings in this study were that the participants experienced a valuable feeling of freedom because they did not have to spend time traveling to see the doctor, and they could maintain their everyday lives. The participants valued that they were given the option not to go to the hospital in Odense, so they could spend time on what was important and not being reminded about the time they were admitted and sick. The study also showed that the participants experienced a higher level of intimacy and self-determination during the video consultation because it was experienced that the doctor was more focused during the consultation.

The Patient Role

The patients appreciated that they were able to feel normal and not feel like a patient when they were in a stable period. It gave

them a feeling of freedom. Studies from Australia and Denmark also showed that patients are very satisfied with the use of video consultation and that it brings out the patient to play a more active role in their own treatment and care [4,23].

The participants' everyday lives were affected by the fact that they had to travel for many hours to get to the consultation in Odense, and it gave them a feeling of decreased freedom. This is supported by a study concerning outpatient management of acute leukemia patients [24]. This study found that it was of great importance that the patients could maintain a normal everyday life together with their families and also be physically active. Most of the patients valued the feeling of being independent in the form of spending their time as they wanted. They did not feel they were able to do that when they were at the hospital because of waiting time for procedures and for the doctors to show up. A normal everyday life was of greatest importance [24].

The patients in the study can be viewed as self-managing as they all take an interest in their blood counts, and they often ran the consultations with questions. The study by Olesen points out that the patients are not automatically being empowered just because they are self-managing because the health professionals can be viewed as *their employer* who gives the patients tasks to solve in relation to their disease [25]. Olesen speaks about the patient as the *unpaid employee* [25]. However, the participants in this study expressed that they were empowered by the use of the video consultations because of the possibilities and the freedom the video consultations gave them. They felt that being able to participate in video consultations means that the disease does not have to control their lives, and thereby, they regained some control over their own lives. An Australian study also shows that involving patients as partners in the delivery of health care can make the development of new telehealth care solutions easier [26].

All patients with hematological diseases are asked to be aware of specific symptoms when being discharged from the hospital. Therefore, it was not new for the patients in this study to be aware of symptoms; however, they were given a more specific task as the doctor could not examine them, and one of the participants self-monitored her blood pressure. To be self-monitoring as a patient means that the patients can learn to understand themselves in a new way, which means that they can see themselves as responsible patients who react to their own symptoms and decide what kind of consultation they need at the time in question [27].

This was valued by the participants in our study as it was the possibility to decide for themselves. The participants could decide (if they lived up to the inclusion criteria) if they wanted a face-to-face consultation at the hospital or a video consultation. This is in line with the guidelines from the National Board of Health in Denmark [28]. The purpose of the guidelines is to support the health professionals to involve the patients in their own treatment and follow-up with the goal to increase patient satisfaction. They were showing signs of being active patients and expressed satisfaction about the option provided for an alternative way to complete a consultation. It became clear that the patients desired to feel free, that going to the hospital for

consultations and checkups was both time consuming and emotionally and physically draining, and they experienced that video consultations were less stressful as they were not confronted with the memories related to being at the hospital as a patient. Ihde in his study [18] explains that when technologies mediate between humans and structures, it also means that technologies play a role in how illness and patient are transformed. This indicates that technologies can transform how patients handle their illness, in our case that the technology can transform the patients to free and active patients as they can stay at home or at their local hospital for consultations. It gave the patients a sense of freedom to do what made sense for them.

Intimacy at a Distance

One of the most common fears of technology is that machines will replace human contact, making care *cold* by reducing it to mechanical interactions with machines [29]. However, the results of our study show that the patients experience intimacy at a distance, for instance, they state that the doctor was looking intensely at them and that they feel secure that the doctor can see them as the technology allows the doctor to see specific details such as skin changes. This was also found by Pols in a study, where the patients reported that the telecare system had the ability to bring people together and that it functioned as a new communication line to the users [29].

The common etiquette for social interaction such as a handshake is not possible when the consultation is long distance. However, it was not an issue for the patients as they, instead of shaking hands, would wave or use enhanced facial expressions. Having the contact mediated through a screen invited the participants to use other gestures. Ihde explains that technology is shaping our experiences of a situation, and using technology invites humans to act in certain ways [18]. In our study, the technology invited the participants to greet each other in a different way than when meeting face to face. This compensated for the physical contact. Sorknæs [30] also found this when investigating how patients with chronic obstructive lung disease experienced the use of video consultations with nurses.

Technology

The patients were happy that the health care professionals were in charge of the technology, as they expressed that it could have been a potential stress factor for them. However, as Ihde states [15], handling a new technology is a learning process. Handling a new technology is experienced as stressful until the user has learned how to use it, and the technology using Ihde's word is *embodied* —meaning that the technology is integrated as a useful tool for the user, for instance, like the remote control for most people.

Another thing to consider as to why the patients were hesitant to being responsible for the technology could have been the fact that it was an unfamiliar device and not a well-known consumer device. Most people use consumer devices in the form of tablets and mobile phones as part of our everyday lives. According to Statistics Denmark [31], the National Statistics Bureau, 4 out of 5 people aged 16 to 89 years used a mobile phone to access the internet in 2016 [32]. What we learned from our results was that the patients did not experience the technology as transparent

[18], which is why they were happy that someone else was in charge of the technology. On the other hand, they did not gain experience with handling the technology because the health care professional took responsibility. Therefore, it can be difficult to conclude whether the technology would have been easy to handle for the patients after a learning process.

The majority of the patients wanted to keep the hospital out of their homes, which is why they appreciated the possibility to go to the hospital for the video consultation. The integration process for the patients has different barriers as they experience the technology as a symbol of their illness and not just as a technology. Maybe if the video consultation were accessible on a consumer device, which the participants were used to handling in their everyday lives, it would have been different. However, other studies also point at the fact that patients may have mixed emotions about receiving treatment at home [33,34]. It can also be explained with Heidegger's explanation of the term "being at home." Being at home is almost sacred because this is where we experience that we belong [35]. However, some of the patients also stressed that it was a safe place to have conversations with the doctor because this was where they felt at home.

Strengths and Limitations

The limitation of our study is that it was a small-scale study; however, most qualitative studies are typically small scale. Therefore, despite the small sample size, the aim of this study, as other qualitative studies, was to provide in-depth exploration of the phenomenon under investigation. Therefore, the intention of this study was to understand and explain how patients with hematological diseases experience video consultations.

A selected group of patients who were in a stable period and therefore not representative of all patients with hematological diseases were included, which is why the results can be difficult to generalize to all patients with hematological diseases. Another limitation to the study is that all of the patients in this study had to invest significant time (6 to 8 hours) to attend a face-to-face consultation and that some of these results may not apply to patients with significantly less of a geographic barrier for face-to-face consultations.

However, we have provided rich descriptions of both the context of the study as well as the patients' experiences with teleconsultations. This lets the readers judge whether the work is possibly transferable to their own settings. The results cannot claim statistical generalizability, but analytical generalization, which emerges by means of the dialectic between theory and practice.

The 2 authors conducted the analysis together to increase the reliability. We presented the analysis process in a table to ensure transparency of the analysis. Quotations from the data were used to link to the participants' original statements to enhance validity.

Conclusions and Implications for Practice

There was a lack of evidence on how hematological patients experience video consultations. This new knowledge will benefit both patients and health care professionals in allowing the health

care system to provide a more tailored treatment and that will also mean improved flexibility for the patients.

We have gained knowledge of what is important for the patients in terms of seeing the health care professionals through a screen. We found that intimacy can be mediated through a screen, and things other than physical presence matter to the patients. Furthermore, this practice factored how important it is for the

patients to have a choice of their own—to be involved in the planning of their own course of treatment.

The patients valued the freedom, and they acted as active patients taking responsibility for their own course of treatment. They experienced that the technology gave them the possibility to feel free and active despite their illness.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Sociodemographic data.

[PDF File (Adobe PDF File), 76KB - [jopm_v10i4e11089_app1.pdf](#)]

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Abbreviations

IT: information technology

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Original Paper

Spanish-Speaking Hispanic Patients' Information-Sharing Preferences During Hospitalization: An Exploratory Pilot Study

Marge Benham-Hutchins^{1,2}, PhD, RN; Sharon A Brown¹, PhD, RN, FAAN; Erin E Donovan^{2,3}, PhD; Henry Guevara⁴, PhD, FNP; Alisha H Johnson¹, MSN, RN

¹School of Nursing, University of Texas at Austin, Austin, TX, United States

²Center for Health Communication, Moody College of Communication and Dell Medical School, University of Texas at Austin, Austin, TX, United States

³Department of Communication Studies, Moody College of Communication, University of Texas at Austin, Austin, TX, United States

⁴Dell Medical School, University of Texas at Austin, Austin, TX, United States

Corresponding Author:

Marge Benham-Hutchins, PhD, RN

School of Nursing

University of Texas at Austin

1710 Red River

D0100

Austin, TX, 78712

United States

Phone: 1 512 475 6351

Email: mbenhamhutchins@austin.utexas.edu

Abstract

Background: Self-management of chronic conditions, such as cancer or diabetes, requires the coordination of care across multiple care settings. Current patient-centered, hospital-based care initiatives, including bedside nursing handoff and multidisciplinary rounds, often focus on provider information exchange and roles but fall short of the goals of participatory medicine, which recognize the right of patients to partner in their own care and play an active role in self-management.

Objective: This study aimed to elicit Spanish-speaking Hispanic patients' perspectives on the exchange and sharing of information during hospitalization.

Methods: This exploratory pilot study incorporated a qualitative descriptive approach by using Spanish language focus groups, posthospitalization, to determine patient-identified information needs during hospitalization.

Results: Participants preferred paper-based Spanish language medical information. Doctors and nurses were key information providers and communicated with participants verbally, usually with the assistance of a translator. Participants expressed a desire to be informed about medication and treatments, including side effects and why there were changes in medication during hospitalization. In addition, they expressed interest in knowing about the progress of their condition and when they could expect to go home. Emotional readiness to receive information about their condition and prognosis was identified as an individual barrier to asking questions and seeking additional information about their condition(s).

Conclusions: Overall, participants shared positive experiences with providers during hospitalization and the usefulness of self-care instructions. Language was not recognized as a barrier by any of the participants. Nevertheless, future research on the influence of emotional readiness on the timing of medical information is needed.

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KEYWORDS

cancer; chronic disease; diabetes; Hispanic; self-management

Introduction

Current patient-centered, hospital-based care initiatives, including bedside nursing handoff and multidisciplinary rounds,

often focus on provider information exchange and roles but fall short of the goals of participatory medicine, which recognize the right of patients to partner in their own care and play an active role in self-management [1,2]. Research has shown that

patients who were more involved with their care had better health outcomes, fewer hospitalizations, and lower health care costs [3]. In the United States, the Patient-Centered Outcomes Research Initiative was established in 2010 to support the patient-centered care research component of the Patient Protection and Affordable Care Act [4], commonly referred to as Obamacare. The Patient-Centered Outcomes Research Initiative vision recognizes the importance of patients having “information they can use to make decisions that reflect their desired health outcomes” [5], but little is known about patient-identified information needs.

Self-management of chronic conditions, such as cancer or diabetes, requires coordination of care across multiple care settings. For example, in the outpatient environment, patients with cancer commonly participate in shared decision making, starting with treatment decisions when first diagnosed, monitoring laboratory results during chemotherapy and radiation treatments, and monitoring the efficacy of treatment and progression or remission of cancer through imaging studies [6]. Web-based ambulatory personal health record portals commonly include test results and visit summaries. Patients participating in the “Open Notes” project have real-time access to their ambulatory medical record, including clinician notes [7]. Participating patients have reported that this access helped them understand their medications and review and recall treatment decisions [7].

Hospitalization has been described as a disempowering experience [8] that can be particularly challenging for Spanish-speaking Hispanic patients as a result of cultural differences [9] and language barriers, which have been associated with patient safety risks [10,11] and misunderstandings that lead to adverse events during hospitalization and after discharge [12].

One way to support inpatient access to health information during hospitalization [13-15] is for health care providers to share medical information during interdisciplinary rounds and nursing shift change handoff at the bedside. Interdisciplinary rounds may include registered nurses, nurse practitioners, social workers, respiratory therapy, physical therapists, and multiple physicians (consultants, attending, and residents).

Sharing medical information with patients during these provider-focused events supports the exchange of health information such as treatment options, test results, care decisions, and discharge plans. Nonetheless, research has shown that patients may be reluctant to ask questions because of structural barriers, such as the way the care is delivered or organized, perceptions of paternalistic attitudes, and the power imbalance between patients and providers [16,17]. This pilot study aims to identify what health information Spanish-speaking Hispanic patients want and need during hospitalization and

explore participants’ views on inclusion in nursing shift change bedside handoff and interdisciplinary rounds held in their hospital room.

Methods

Study Design

This exploratory pilot study incorporated a qualitative descriptive approach. Spanish language focus groups, posthospitalization, were used to elicit patient-identified information needs during hospitalization and how hospitalization influences patient self-management of cancer across care transitions. Spanish language focus groups were selected because they have been shown to create a culturally supportive environment that encourages interaction between participants and facilitators [18].

Sample and Setting

Participants were eligible for inclusion if they were Hispanic; were Spanish-speaking; were aged ≥ 18 years; were living in the community; were diagnosed with cancer or another chronic disease; and have had inpatient hospitalization after their chronic disease diagnosis. Recruitment flyers with study information and research team contact information were distributed at a local cancer center, community clinics, and through the university Hispanic employee organization. In addition, Spanish-speaking team members were available through phone or at designated times at the cancer center to answer questions and sign up participants who met the inclusion criteria.

Study Procedures

First, the research team collaborated on the development of culturally appropriate focus group questions and probes. Next, a focus group interview guide was developed by the research team with input from 2 Spanish language focus group consultants and professional focus group moderators. The guide included an introduction that provided the purpose of the session, including the reason for the focus on Spanish-speaking Hispanic patients with chronic diseases, and introduction of the main study concepts. The interview and the demographic question questionnaire were translated into Spanish and reviewed by native Spanish speakers. The focus group facilitators used the research team-developed interview questions and guide. [Textbox 1](#) contains the English version of the moderator guide.

Focus group procedures followed established guidelines [18] and were facilitated by experienced Spanish language focus group moderators and Spanish-speaking research team members. In addition, Spanish-speaking members of the research team obtained informed consent and distributed the demographic survey. Furthermore, a research team member supervised the session recordings.

Textbox 1. Focus group moderator guide. Guide was translated into Spanish and focus groups were conducted in Spanish.

Introduction: Role of moderator; Independent moderator, not connected to research organization; general description of research; everyone can participate—no right or wrong answers; recording audio of session; anonymity

Introductory question: Tell us your first name, family life, and in which hospital did you most recently receive treatment?

Transition question 1: How do you keep track of your health information (mediations, appointments, treatments, etc) as you go from provider to provider and location to location?

- Probe: Personal health record, notebooks, electronic apps, calendars, other family member. What do you like about this method? Explain why some methods have not worked for you.

Transition question 2: What about when you are in the hospital during a hospital stay? How do you keep track of your health information (what the providers tell you about your medications, tests, and treatment plan) while you are in the hospital?

- Probe: In-patient portal (ask if they know what this is and explain what this is); white board in the room; personal tools—paper and pencil (eg, notebook; folders); electronic method, family member. What about this method works best for you? What does not work for you?

Key question 1: Tell me about the last time you were hospitalized. Who explained your self-management treatment to you? How did the conversation make you feel?

- Probe: Describe the conversation? Were you invited to participate in the discussion? Did they speak Spanish or did they have a translator? If you asked a question, did you feel that the personnel were responsive?

Key question 2: What kinds of medical information are you interested in knowing about or documenting when you are in the hospital? Explain why this information is important to you?

- Probe: Is there anything you would prefer not to know about when you are in the hospital? What information do you need while hospitalized to prepare you for managing your own care when you go home?

Key question 3: Could you tell me about a time when you got information in the hospital that really helped you with self-care after you went home?

- Probe: What about a time when things didn't go so well, what happened there and what do you think contributed to its failure? Do you think because you have trouble speaking English that you are treated differently (better or worse)?

Key question 4: When you first got home from the hospital, how confident were you that you knew what you would need to do to take care of your medical needs? Did you stop to think about whether you had all the information you thought you'd need? Did you know what to watch out for to recognize problems and what to do about it?

- Probe: What examples come to mind, good or bad? What barriers, if any, did you encounter? Did you feel you were given enough information to properly care for yourself?

Ending question: What factors do you think encourage patient participation in conversations about self-care? What factors do you think discourage patient participation in self-care?

- Probe: Does culture or language play a role? If so, in what way? What, if anything, should be done for those who are Spanish speakers? If you were in charge of the hospital and you were asked to redesign the self-care process to improve it, what would you do? (Probe: newer technology, better patient/doctor interactions) What would you do specifically to help Spanish speakers?

End Session

Measures

Demographic questions included participants' age, education, gender, ethnicity, primary chronic disease, secondary chronic diseases, hospitalization date, and length of stay. During the focus group, participants were also asked to recall hospital characteristics and information-sharing processes (eg, nursing handoff location and patient invitation to participate). Focus group questions included asking about patients' beliefs regarding existing self-management practices, the influence of hospitalization on self-management, patient information access during hospitalization, and information needed by patients to resume self-management after discharge.

Data Analysis

Descriptive statistics were used to analyze the demographic questions. Focus group sessions were conducted in Spanish,

audiotaped, transcribed, and translated into English by Spanish language focus group moderators. The research team members and focus group moderator were debriefed after each session. Analysis of the focus group transcripts followed the steps of conventional content analysis [19,20]. For this study, the focus group transcripts were translated from Spanish to English, and the analysis was completed on the English language versions.

Protection of Human Subjects

The University of Texas at Austin Institutional Review Board approval and cancer center permission were obtained before the study commenced. Spanish language informed consent was obtained per regulatory guidelines and institution institutional review board approvals. Participation was voluntary, and participant identification information was not collected during the focus groups. A US \$75 gift card was offered as an incentive for participants' time and transportation.

Results

Characteristics of the Focus Group Participants

The 2 focus groups, one with 6 and another with 2 participants, were conducted at the School of Nursing on the campus of the University of Texas at Austin. Focus group participants ($n=8$) were Hispanic women with an average age of 55 (range: 47-66) years. While primary chronic disease diagnoses included cancer and diabetes, secondary chronic diseases included hypertension, arthritis, idiopathic thrombocytopenia purpura, and heart or liver disease. Participants reported having been hospitalized within the last 2-8 months and were hospitalized for 2-14 days ($\mu=6$).

Qualitative Results

The English translation versions of the focus group transcripts were used for analysis. We identified 5 categories as follows: tracking health information; opportunities to participate in information exchange; information needs and desires; information shared by providers during hospitalization; and self-care and self-efficacy.

Tracking Health Information

Participants were asked about how they kept track of their health information (medications, appointments, treatments, etc) across multiple care settings and providers. Most participants did not have a specific method for keeping track, but some relied on "papers" handed to them by providers and on reminder calls initiated by the providers. Most did not have home computers or internet access but did have the ability to text using their mobile phones. When discharged from the hospital, participants reported receiving a folder or a bag with information about their condition and upcoming treatments. This information was commonly provided in both English and Spanish. When asked about reading the information, participants indicated a preference for Spanish language information, but 1 participant reported purposely not reading any of the information because she preferred not to know about her condition.

Next, participants were asked how they kept track of their health information while they were hospitalized. Results of tests, information on treatments, and medications were provided to patients, family members or relatives, almost exclusively in verbal format by nurses or other health care providers. Some participants reported receiving laboratory results and information about their treatment from their doctor in English, but always having a translator available either in-person or via telephone to assist. Furthermore, participants mentioned that they occasionally had a Spanish-speaking nurse or they relied on family members who spoke English to translate.

Participants reported that they did not actively keep track of test results, medications, or treatments in any written format or use any specific tracking system. Only 1 participant mentioned a family member taking notes. None of the participants reported having access to an inpatient portal during their hospitalization. Some participants mentioned a whiteboard in their room that provided the name of the doctor, nurse, nurse assistant, and medication administration times; others reported not having access to any of their health information while hospitalized.

Opportunities to Participate in Information Exchange

Of specific interest were opportunities for participants to obtain health information during nursing bedside shift change handoff and medical rounds in patients' room. During shift change handoff, most participants reported that both outgoing and incoming nurses were present in their room. Commonly, the nurse who was leaving introduced the new nurse and discussed the patient's treatment plan for the upcoming shift. Most participants reported they were able to participate in these conversations. In some instances, only an introduction of the new nurse took place without much treatment discussion and, at times, no introduction took place before a shift change. In contrast, participants reported that the doctor(s) visited them after surgery and during rounds when they would explain the treatments the patients were receiving. All doctors made a point to introduce themselves. Participants felt doctors were respectful and as patients, they were able to understand and ask questions through in-person translators or via telephone. Furthermore, doctors shared information with families if they were present.

Information Desires and Needs

Some participants in the focus group identified information that they would like to receive from practitioners including explanations regarding tests they are to undergo, test results, reasons for receiving certain medications or treatments, side effects of medications, and why there is a change in medications or the reason medications are not working. In addition, participants wanted to be informed about the progress of their condition and be informed regarding when they could expect to leave the hospital. Other participants wanted more information on the consequences of their condition (diabetes) when it was not controlled. Avoiding negative emotions and "sinking into depression after her cancer diagnosis" were concerns but the solutions varied. One patient indicated she wanted more information and another did not want to know more soon after the cancer diagnosis owing to feeling overwhelmed and depressed. Contact with social workers and counseling in Spanish were reported to have been helpful for some after leaving the hospital.

Information Shared by Providers During Hospitalization

When asked to recall the last time they were hospitalized and information they received about managing their medical conditions after they went home, participants reported receiving good information from a doctor or nurse and that there was always access to a translator in-person or by telephone. Participants shared that the information was well explained, they were able to ask questions through the translator, and they knew whom to call if they had further questions or concerns once they got home. On discharge, they were provided with paper-based information in English and Spanish to take home and refer to for their self-care and follow-up treatment.

Self-Care and Self-Efficacy

Most participants felt confident about their self-care at home once discharged from the hospital. They reported receiving the necessary information needed to take care of themselves after their discharge and what symptoms or signs to watch for to

identify problems. Specific information that helped them with self-management after going home included limiting activity and other instructions to reduce bleeding and infections, learning about diet to control their diabetes, learning how to use a pillow as a coughing aid after surgery to extract sputum, and learning about a new prescription and its side effects for a chronic condition.

None of the participants felt that they encountered problems due to not being able to speak English well nor did they feel they had been treated better or worse because of it. One participant with diabetes expressed being very hesitant and uncomfortable about having to inject herself at home, but a family member was able to help using information and video instructions provided by the hospital. Health care providers who were friendly, polite, and who made patients comfortable and at ease were identified as contributing to patients' willingness to ask and learn about self-management. Once at home, many participants noted that they received important self-management instructions (verbal and paper) from their pharmacists when picking up medications after treatments or hospitalization.

Discussion

Principal Findings

Participants did not hesitate to share their stories of diagnosis and treatment with the group and, in fact, seemed eager to share their experiences. For some of the participants, it was clearly the first time they had shared their story publicly. While the emotional consequences of undergoing diagnosis and hospitalization were not part of this study, the topic of depression came up in both focus groups. Participants shared their difficulties in coping emotionally with their medical condition. Research has shown that religious beliefs are an important coping mechanism for this population [21]. The focus group conversations were filled with religious references, such as "I prayed a lot" or "put it in God's hands," suggesting a strong faith belief among participants as a way of accepting or coping with their medical conditions.

Research has shown that psychosocial stress [22] and fear of cancer [23] and other chronic diseases, such as diabetes, impact readiness for learning and information-seeking behaviors. This study revealed that, for some participants, a major barrier to asking questions was their own reluctance to learn more about their condition, which some linked to their emotional response to dealing with their chronic disease.

Although language barriers have been associated with patient safety risks [14,15] and misunderstandings that lead to adverse events during hospitalization and after discharge [16], these Spanish-dominant patients did not believe that their inability to communicate in English acted as a barrier in understanding and implementing self-care because translators were always present or available either in-person or by phone. In the outpatient

environment, participants identified that pharmacists often provided self-management information, which is consistent with previous research findings [24].

These findings stand in sharp contrast to earlier work that revealed patient frustration with the lack of access to information [25,26], provider behaviors that inhibited patient participation in bedside handoff [26], and desire for electronic access to medical records. While differences in patient demographics between the studies may explain some of the differences, there is a possibility that our findings reveal that health care initiatives focused on being culturally inclusive [27] and breaking down language barriers by providing translators and translation services [28] are improving the health care experience of Spanish-speaking Hispanic patients.

Limitations

This study is one component of a larger program of research that focuses on patients' access to information during hospitalization and how access to information influences the self-management of chronic medical conditions. This preliminary study revealed foundational information, but it is important to acknowledge study limitations when interpreting the results. An important lesson learned during this study was how federal initiatives and resulting news stories may influence recruitment and participation in focus groups. Overall, 24 people were scheduled to participate in the focus groups, but many unexpectedly dropped out or did not show up on the day of the focus groups. Reminder phone calls revealed hesitancy to attend owing to a fear of government "representatives" and a perceived threat of deportation. Research is needed to learn more about the perceived threat of deportation influences participation in research studies and willingness to access health care services.

It is important to recognize that the final pilot study sample was smaller than planned and included only women. In addition, participants were recruited from a limited geographic area within the city of Austin. Future research will focus on increasing the number of participants and expanding the recruitment area. This will include holding focus groups at multiple locations, on different days, and increasing efforts to recruit men.

Conclusions

This study supports the need for research to elicit Spanish-speaking Hispanic patient perspectives on facilitators and barriers to obtaining the information they need during hospitalization and participation in traditional provider-focused, information-sharing activities such as handoffs and rounds. Overall, participants shared positive experiences with providers during hospitalization and the usefulness of Spanish language self-care instructions. Surprisingly, language was not recognized as a barrier by any of the participants. Future research on the influence of emotional readiness on the timing of medical information access and the pharmacists' role in patient self-management in the outpatient setting is needed.

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Conflicts of Interest

None declared.

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