Title: "It affects every aspect of your life": A qualitative study of the impact of delaying surgery during COVID-19

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Abstract (248/250 words)

<u>Background</u>: The COVID-19 pandemic has overwhelmed healthcare systems, leading many jurisdictions to reduce surgical services to create capacity (beds and staff) to care for the surge of patients with COVID-19. These decisions were made in haste, and little is known about the impact on patients whose surgery was delayed. This study explores the impact of delaying non-urgent surgeries on patients, from their perspective.

Methods: Using an interpretative description approach, we conducted interviews with adult patients and their caregivers who had their surgery delayed or cancelled during the COVID-19 pandemic in Alberta, Canada. Trained interviewers conducted semi-structured interviews.

Interviews were iteratively analyzed by two independent reviewers using an inductive approach to thematic content analysis to understand key elements of the patient experience.

Results: We conducted 16 interviews with participants ranging from 27 to 75 years of age with a variety of surgical procedures delayed. We identified four interconnected themes: individual-level impacts (physical health, mental health, family and friends, work, quality of life), system-level factors (healthcare resources, communication, perceived accountability/responsibility), unique issues related to COVID-19, and uncertainty.

Interpretation: The patient-reported impact of having a surgery delayed during the COVID-19 pandemic was diffuse and consequential. While the decision to delay non-urgent surgeries was made to manage the strain on healthcare systems, our study illustrates the consequences of these decisions. We advocate for the development and adoption of strategies to mitigate the burden of distress that waiting for surgery during and after COVID-19 has on patients and their family/caregivers.

Introduction

The novel SARS-CoV-2 virus (COVID-19) was declared a pandemic by the World Health Organization (WHO) in March 2020,⁽¹⁾ and healthcare systems across the globe braced for a potentially large influx of COVID-19 patients within hospitals. These situations played out in countries such as Italy, where healthcare systems quickly became overwhelmed.⁽²⁾ In light of the impact of the COVID-19 pandemic on healthcare systems globally, many Canadian provinces reallocated healthcare resources to care for COVID-19 patients by reducing surgical capacity. Consequently, a staggering number of non-urgent surgeries (surgeries not immediately threatening life or limb)⁽³⁾ were delayed. For example, early in the COVID-19 pandemic response, Ontario delayed 185,000 surgeries, while the number of delayed surgeries during the fourth wave in Alberta climbed to over 30,000 – a number that continues to increase at the time of writing.^(1, 4-6) The impact of delaying non-urgent surgeries in Canada has not been fully explored, but it is estimated that the backlog from just the first wave of COVID-19 in some provinces will take 84 weeks to clear.⁽⁶⁾

Pre-pandemic evidence suggests that excessive surgical wait times can lead to poor physical health, increased anxiety, decreased social interaction and ability to work and overall quality of life.^(7,8) Factors that mediate the impact of delays in access to surgical care include patient choice in the delay and communication from healthcare providers.^(7,8) It is unclear if these prepandemic factors are consistent with the effects of delaying surgery in the context of the COVID-19 pandemic because evidence of the impact of delayed surgeries during COVID-19 is still in its infancy.⁽⁹⁾ With the continued rise in delayed surgeries understanding the scope of the

personal impact on patients and their daily lives is of critical importance. To address this knowledge gap, the objective of this study is to understand the patient's perspective of having a surgery delayed during the COVID-19 pandemic response.

Methods

We adopted an interpretative descriptive approach as our methodological framework, which is aligned with the constructivist and naturalistic orientation of inquiry and aims to understand a phenomenon grounded in the data within a clinic context to apply the findings. (10-13)

<u>Participants</u>: We included patients and family/caregivers of patients in Alberta who had their surgery delayed due to the COVID-19 pandemic response. To date, the Province of Alberta has experienced four waves of COVID-19; the first wave (March 13, 2020 - early May 2020) resulted in a reported 30% decrease in surgical capacity, the second and third wave had no strategic decrease in surgical capacity, and the fourth wave (September 2021 to the time of writing in November 2021) resulted in all non-urgent surgeries being delayed (only emergent and urgent surgeries performed) with an estimated 60-70% decrease in surgical capacity.

Recruitment and sample selection: Recruitment posters were distributed through social media (Twitter, Facebook, Instagram) and local news outlets to allow us to reach patients across broad networks spanning the province of Alberta. Patients with delayed surgeries and their family/caregivers contacted the Principal Investigator (KMS) via email or phone.

Consistent with interpretative descriptive approach, we used a theoretical sampling strategy – we continued collecting data to achieve a purposive sample of anticipated variations in response based on age, gender, type of surgery and geographical location.⁽¹¹⁾

<u>Data collection</u>: Ten interviews were anticipated but we continued until we reached saturation (we no longer identify new themes or novel data) and recruited patients with varied ages, gender, type of surgery and geographical location.

Interviews were conducted by experienced facilitators (CS, JK, ES, NJ). The facilitators were female graduate students and a research associate with experience in qualitative methods, but not within the area of surgical care or COVID-19, who volunteered to conduct the interviews. Therefore, there were few assumptions or bias with regards to the results of the study. All facilitators had formal graduate training in qualitative methods or experiential training in interview facilitation. The Principal Investigator and facilitators did not have previous relationships with the participants or their healthcare providers.

The experienced facilitator used a semi-structured interview guide with prompts to elicit emergent ideas while maintaining focus on the topic (Appendix E – Interview Guide). The interview guide was pilot tested amongst the research team and feedback was solicited from the senior researcher (MEB) who is a surgeon and leader within the healthcare system.

Interviews were conducted virtually (using Zoom® or telephone) due to public health restrictions in Alberta during data collection, were audio recorded and transcribed. Field notes were included to clarify context, where appropriate.

<u>Data analysis</u>: Data were managed using NVivo 12.0⁽¹⁴⁾ and analyzed in keeping with our interpretive descriptive approach, by two independent reviewers using thematic content analysis to understand key elements of the patient experience.⁽¹¹⁻¹³⁾ An inductive approach was used so themes were drawn from the data rather than pre-existing sources. Data analysis was

iterative whereby the two reviewers coded transcripts, met to compare emerging themes to ensure rigour of the analytic process. Final themes were determined by consensus among reviewers. The results were reviewed by the interview facilitators and three participants to ensure trustworthiness of the findings.

This study was approved by the University of Calgary Conjoint Research Ethics Board (REB20-0753).

Results

We conducted 16 interviews between September 20, 2021 and October 8, 2021. The average length of the interviews was 22 minutes. Demographic characteristics of participants are described in Table 1. Briefly, the mean age of the participants was 47 years old, with the majority identifying as women. Most surgeries were scheduled in urban centres and the type of scheduled surgery varied considerably. Four participants had their surgery completed prior to the interview while nine did not.

Themes: There were four overarching themes that emerged from the data (Figure 1): 1] individual-level impacts (subthemes: physical health, mental health, family and friend impact, work impact, quality of life), 2] system-level factors (subthemes: communication, healthcare resources, perceived accountability/responsibility), 3] COVID-19-related impacts and 4] uncertainty. Table 2 describes each theme and provides example quotes.

1. Individual-level impacts

1. 1. Physical Health

Nearly all participants identified ongoing physical health issues related to their delayed surgery. Physical ailments ranged from mild ("The fibroids in my uterus were getting larger and causing me to become more uncomfortable") to pervasive and debilitating ("I have a very difficult time breathing, I have a very difficult time eating"). Several patients described ongoing physical pain and the effects on their daily lives; from modifications to exercise and activities of daily living, to inability to do one's job effectively or at all, and prolonged use of pain medication to manage the pain.

Issues around the impact of delayed surgeries on physical health consequently led to impacts on mental health, specifically around worry and anxiety. Uncertainty related to when the surgery would occur, and relief of physical health consequences was also expressed by many participants.

"So, this delay, basically I'm afraid I can have a heart attack or stroke, at any time. So, it's been very stressful on me and my wife as well."

1.2. Mental Health

All participants described an impact on their mental health and was the most discussed theme.

One participant described mental health impacts as their reason for participating in the study:

"I think the biggest reason why I wanted to participate is; just again, it's that emotional toll that it takes on people on a daily basis and I have to assume that the government thought about that, but perhaps they don't realize the actual toll that it takes on all of these other people's lives..."

The impacts on mental health ranged from disappointment to depression and anxiety. Participants expressed a feeling of depression with the delay of surgery and related to navigating the impacts of the delay. Feeling depressed ranged from passive comments of feeling low, (e.g., "Right now I'm a little depressed... but I keep telling myself let it go") to newly diagnosed depression. Many participants described anxiety and/or worry that was far reaching and extended beyond physical health (as described above) to concerns about their friends and family, their work and many aspects of their daily life. Many of these feelings of anxiety and/or worry were tied to a loss of control and uncertainty around the plans for their surgery, which are explored in theme four (uncertainty).

1.3. Family & Friends Impact

The impact of delaying surgery extended to family and friends in all cases. This was often related to requiring extra support with activities of daily living (e.g., housework or cooking) or emotional support due to physical and mental health challenges directly related to the delayed surgery. Another commonly described impact was related to social relationships where participants cancelled social plans and trips to visit family and friends out of fear of missing a surgery date. Some participants also expressed safety concerns around contracting COVID or other illness that would compound their existing health issues and prevent them from being able to have surgery.

Several participants also described strains in their relationships outlining that their partners were stressed and worried about the changes in their physical and mental health which in turn caused further stress for patients as they waited for surgery. Some participants also described

changes to their sexual relationship with their partners because of difficulty with intercourse because of their unresolved health issues.

1.4. Work Impact

Nearly all participants indicated that their delayed surgery directly impacted their professional life. While some described changes in their ability to work, others disclosed losing their employment; and for one participant this was described as a significant loss to their identity.

The theme of uncertainty re-emerged when discussing the impact on the participants' work life – participants felt that because of the uncertainty around surgical resumption they were unable to plan time off for surgery and this would have a downstream impact on work and colleagues.

Similarly, participants held-off taking vacation prior to surgery (prior to the cancellation), which in some cases led to burnout.

Other participants noted that they were unable to do their job normally or that they lost employment due to the physical or mental health impacts of waiting for surgery. This led to concerns about job security and many endorsed struggles with earning a stable income and financial stress.

"I haven't been able to work as well, which is another factor ... I'm going to lose business because of this."

Conversely, because of flexible, virtual work environments during COVID, some participants highlighted that this allowed them to be able to continue to work while managing their ongoing health issues.

1.5. Quality of Life

For many participants the culmination of impaired physical and/or mental health, strained social interactions, and employment challenges led to poorer quality of life. Interestingly, physical impairments were not always a driving factor; some participants commented that despite being able to physically function, their quality of life still declined. Many patients described their delayed surgery as having an overarching cloud over their lives.

"At home, I feel like I'm extremely distracted. I'm not present, because I'm constantly thinking about the surgery and the delay. At work, it's a lack of focus, it's a worry about how it's affecting my coworkers. And there's also the mental exhaustion of not being able to take time off at work because of it."

2. System-level factors

Participants described several system-level factors primarily revolving around access to and communication with the healthcare system, including their healthcare providers. Furthermore, several participants identified sources of accountability and responsibility for handling of COVID-19 including delayed surgeries and even provided suggestions for how to manage these delays in the future.

2.1. Healthcare resources

Several participants indicated that they required additional care or interacted with the healthcare system, beyond their baseline use, while they were waiting for surgery. This included more frequent visits with their primary care physician (including virtual care visits), consultation with psychologists, regular visits (every four weeks) to change a catheter, regular visits with a gastroenterologist for ileostomy including a day surgery and visits to the

emergency department. Some participants expressed less healthcare use due to concerns around contracting COVID-19 in physician offices or hospitals.

2.2. Communication

Discussion around communication focused primarily on communication with their healthcare providers, specifically how and by whom the delay was communicated. Participants' viewed communication as equally positive and negative overall. Negative comments were largely related to short notice of the delay and lack of information when communicating the delay. Participants who perceived communication to be negative expressed more anger and frustration. Conversely, many participants felt they were given sufficient notice about the delay and praised their healthcare providers for their communication. Participants who reported positive communication indicated that they received timely communication directly from their healthcare provider (surgeon or surgery clinic rather than the healthcare system) who demonstrated regret and concern for the patient.

There were also some concerns raised about communication by the government and media. Specifically, some participants raised concerns that the government and healthcare system communication categorized these surgeries as "elective"; voicing that although their condition may not be immediately life threatening, it was life-altering, and their surgery was far from "elective".

2.3. Perceived Accountability/Responsibility

When participants were asked what could have been done differently to minimize the impact of the COVID-19 response on surgery patients, discussion frequently deviated to anger and/or

frustration about the current situation; specifically, the high number of COVID-19 cases necessitating surge capacity in our hospitals and the resulting decision to delay surgeries.

One participant summarized the overall sentiment of most participants: "I understand it, but I don't like it". Anger and frustration with the current situation was frequently associated with uncertainty.

However, other sources of anger and/or frustration were related to responsibility for the COVID-19 situation in our province. Participants frequently cited the government's handling of the COVID-19 pandemic as the reason for having to delay surgeries. There were also strong feelings of divide towards people who have chosen not to get the vaccine.

"...surgeries have been delayed, cancer treatments have been delayed. All that with a vaccine on the table. Well, the last thing I checked there wasn't a vaccine for cancer, so why is someone missing a cancer treatment when the person with COVID who didn't get immunized."

Despite negative views about the current situation, including delaying surgeries, there were also sentiments of understanding, especially regarding the decision to delay surgeries during the first wave of COVID-19 when less was known about the trajectory of COVID-19 and when vaccines were not available.

3. COVID-19-related impacts

Participants highlighted unique factors related to COVID-19 that complicated their delayed surgery experience. Protecting and maintaining one's health and isolation were two common threads around COVID-19 impacts.

Participants expressed concern or challenges with accessing healthcare services due to COVID-19 but there were also some advantages to accessing care during COVID-19 with the advent of virtual care. Some participants indicated hesitation in accessing in-person healthcare for fear of acquiring COVID-19 in public places. Similarly, the fear of contracting COVID-19 or other illnesses in their vulnerable condition was a great concern. The fear was twofold; they were fearful of becoming severely ill but also fearful of further surgical delays if they were to become ill at a time when a surgery date became available. Their fear of becoming ill resulted in physical isolation and consequently psychological isolation for many participants. Moreover, their poor mental health also made socialization (virtual or in-person) more challenging.

4. Uncertainty

Uncertainty about health and surgery resumption had a large impact on participants. All participants found the uncertainty surrounding their surgery and physical health was pervasive and impacted many aspects of their life. Uncertainty was described as a loss of control and lack of information about surgery and underlying health. One participant described this loss of control as "being held hostage to what's happening in the hospital; like...total limbo".

In addition to feelings of uncertainty resulting from the perception of loss of control and being uninformed, uncertainty was also described as a reason for poor mental health. This association was rooted in feelings of anxiety and/or worry about the unknown consequences of delaying surgery on their physical health and uncertainty about the future.

Uncertainty resulted in poor mental health but also logistic challenges in several areas of life. For example, uncertainty impacted planning time off work for surgery and the subsequent recovery. As well, it impacted the participant's ability to commit to social activities, engage in family planning and pursue post-secondary education. Uncertainty frequently led to discussion about the impact of the delayed surgery on friends and family and their professional lives.

Interpretation

Our study found that the impact of delaying surgeries to manage the surge of COVID-19 patients was diffuse and consequential on the lives of patients. Four interconnected themes emerged: 1] individual-level impacts (subthemes: physical health, mental health, family and friend impact, work impact, quality of life), 2] system-level factors (subthemes: communication, healthcare resources, perceived accountability/responsibility), 3] COVID-19-related impacts and 4] uncertainty (Figure 2).

The physical effect of delaying surgery has been illustrated in the pre-pandemic setting. Exceeding optimal interval from diagnosis to surgery has been associated with poor outcomes in many diseases. (7, 8, 15-17) For example, delayed cancer surgery results in poor disease-free survival, (17-19) and patients with delayed cardiac surgery experience greater morbidity and mortality, longer hospitalizations, and are more likely to die post-operatively. (20, 21) Delaying surgeries considered less urgent, is associated with an increase cost to patients (e.g., increased pain, decreased quality of life) and the healthcare system. (22-26) Our study confirmed that perceived physical health was compromised due to the delays in surgery; however, the physical

impact was less prominent and perhaps the driver of more significant effects on participants' mental health and quality of life.

Distress among patients waiting for surgery has been previously described, however there is a need for additional research on the burden of delayed surgeries during COVID-19 given the unique and unprecedented nature of surgical delays during the pandemic. (27) A recent study of patients waiting for cancer surgery due to COVID-19 capacity limits reported similar findings to ours; participants had high levels of distress, stress, anxiety and depression. (9) The similarity between our findings and those of Forner et al., (9) despite few cancer surgery participants in our study suggests the experience of waiting for surgery during COVID-19 is similar across surgeries. We hypothesize the unifying characteristic among patients waiting for any type of surgery during COVID-19 is uncertainty; specifically, the unpredictability of the COVID-19 pandemic and response. Uncertainty was a prominent theme that arose in our study and many participants underlined the connection between the uncertainty and the distress and burden this placed on all aspects of their lives. Minimizing uncertainty is challenging in the context of COVID-19 because the pandemic has been, in and of itself, unpredictable. Our findings highlight that timely, personalized, pragmatic, and compassionate communication is needed and may minimize distress in patients waiting for surgery, even if certainty cannot be provided. (27-29) Moving forward. Managing surgical waitlists and transforming surgical care is important to mitigate the backlog of surgeries due to the response to COVID-19. Approaches to decrease wait time and increase efficiency of surgical care to create more capacity, and increase quality, have been proposed. (30-32) However, focus on improving the surgery waiting period could

minimize the impact of delaying surgery during and after the COVID-19 pandemic. The waiting period is fraught with consequences to patients' physical and mental health. (7) Based on our findings, interventions that support patient mental health are needed during surgery waiting periods. Studies suggest that strategies such as educating patients about the potential mental health consequences of waiting for surgery, regular communication with healthcare providers and mental health support (e.g., self-management approaches and peer-support) could improve the impact of surgical delays on patients' mental health. (27) Our findings support the need and potential utility of these strategies but future research needed to explore the critical components for successful strategies and their implementation.

Strengths and limitations. While this study has several strengths (data collection continued after we reached thematic saturation to ensure a broad perspective of a varied patient sample, we used iterative member checking, we captured patient perspectives from diverse backgrounds and clinical areas and our team engaged in peer debriefing during analysis) our findings should be interpreted with limitations in mind. Participants were limited to a single province, during the largest wave of the COVID-19 which may differ from the unique experience with COVID-19 of each province.

Conclusion. During the ongoing COVID-19 pandemic, healthcare systems have had to make difficult decisions with little evidence. While healthcare system decision-makers anticipated the impact of delaying surgeries on patients, they had little choice due to strained healthcare resources. Our findings illustrate the direct and substantial impact delaying surgery has on patients. The interplay between the themes identified in our study suggests it is important to consider all these factors when measuring and developing strategies to mitigate the impact of

delaying surgery. Investments in mental health, occupational and social supports with clear, personalized, and compassionate communication strategies during periods of delay could address all these factors and should be explored to improve surgical care during the ongoing COVID-19 pandemic and beyond.



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Table 1. Participant characteristics

Participant	Age	Gender	Residence (AHS Zone)	Surgery location	Type of surgery	Initial date	Surgery date	Notes
001	41	Woman	Calgary Zone	Calgary	Biopsy (suspected non- cancerous)	Mid- September 2021	NA	No new date
002	68	Man	Edmonton Zone	Edmonton	Prostate surgery (non-cancer)	Mid-April 2020	June 2020	Given sufficient notice
003	27	Non-binary	Calgary Zone	Calgary	Gender reallocation	Mid-May 2020	June 2020	Got in earlier due to a cancellation and day surgery
004	40	Woman	Edmonton Zone	Edmonton	Gynecologic	Decision to treat date: April 2020	September 2021	No date given after consult due to surgery delays
005	44	Woman	Calgary Zone	Community hospital	Gynecologic	October 2021	NA	No date or timeline – at least 6 weeks
006	65	Man	Calgary Zone	Calgary	Cardiac	September 2021	NA	
007A	48	Man	Calgary Zone	NA	Orthopedic	NA	NA	Son of patient (007B)
007B	75	Woman	Calgary Zone	NA	Orthopedic	NA	NA	Waiting for surgery

								consult for hip replacement but not date given
008	33	Woman	Edmonton Zone	Community hospital	Orthopedic	August 2020 – delayed until October 2021	NA	No new date for October cancellation.
009	31	Woman	Calgary Zone	Calgary	Gynecologic	September 2021	NA	No new date
010	49	Woman	Edmonton Zone	Edmonton	1) Endocrine2) Gynecologic	1) July 2021 delayed until September, 2021 2)September 2021	NA	Patient had done pre-op and was cancelled for an urgent case.
011	54	Woman	Edmonton Zone	Edmonton	Gastrointestinal	March 2020 Followed by subsequent surgery November 2020	July,2020 & March 2021	One day notice of cancellation for first surgery and hours notice for cancellation of second
012	47	Woman	Edmonton Zone	Edmonton	Gynecologic	September 2021	NA	

013	39	Man	Calgary Zone	Calgary	Neurosurgery	September 2021	NA	5 days notice of cancellation
014	40	Woman	Calgary Zone	Calgary	Gastrointestinal	September 2021	NA	2 days notice of cancellation
015	52	Man	South Zone	Calgary	Orthopedic	October 2021	NA	Anticipated date of November 2021

Abbreviations: AHS=Alberta Health Services; NA=Not Applicable





Table 2. Themes and quotes

Theme	Subtheme	Descriptive codes	Exemplar quote
		Pain Discomfort Quality of Life	"but you can see the pain on her face when she sits at the table, or whatever, and now she spends as much time lying in bed off her legs and her hip." [Participant 7A]
		Worry	"It seems like I'm gettingmy breath is getting shorter. I get tired quicker it seems." [Participant 6]
MPACTS	ţ		"This wasn't like you know, a health lifesaving surgery so it's been it was fine. Like my fibro [fibromyalgia] probably got worse because of stress." [Participant 3]
L-LEVEL I	Physical Health		"it's pretty hard for the ones that are waiting like myself included, it yeah kind of it would be nice to get done because everyday pain; I mean a lot of pain." [Participant 7B]
INDIVIDUAL-LEVEL IMPACTS	Phys		"I'm now on pain medication every day. Yep. At the moment, I don't do a whole lot because it hurts too much. [Participant 15]
<u>Z</u>			"I mean, the obvious [impact] is the continued pain. So, what I'm sort of dealing with on a sort of weekly basis is I'm not sure what causes it, but I'll get a sharp onset of pain in my abdomen just below my ribs So, it makes it hard and painful to inhale deeply. So, I find myself short of breath even in with simple tasks like climbing a flight of stairs." [Participant 14]

	Depression Anxiety	"It's been a challenge more from the mental health side of things." [Participant 1]
	Worry Frustration Anger Independence Isolation Uncertainty	"It's been a lot of mental strain, because I know the extra is going to be put on the people at work. And my limited activity at home and just the mental stress of having surgery, period. And then the ups and downs of watching the news to see how bad it's getting, and if it might get canceled. And then the relief of having a surgery date, and then the immediate crushing that it was canceled. So, it's been an extremely emotional toll on me." [Participant 9]
		"I mean just kind of like bummed me out. I've got body dysphoria; so having boobs was just lousy." [Participant 3]
		"In August I had a panic attackand talked to the doctor there and anyway, since that time I've been extremely; I have been quite calm OKAnd then they cancel my surgery so that stress level went up again." [Participant 6]
		"and again, like I know for me like it's not so much of an impact in a physical sense, so like in that case no. But, again, the emotional toll makes me sometimes not want to do anything." [Participant 9]
		"And we were able to stop and control the prolapse but every day waiting for that flap surgery, and every day waiting for the reversal. I held my breath that my intestine would not truly fall out of my body." [Participant 11]
		"So, there's kind of the stress over that, the stress over wondering if I do have to delay till April. Obviously, there's a risk that a gallstone can get stuck and cause a lot worse problems. So, there's that stress." [Participant 14]
INDI VID UAL	Mental Health	"So this delay basically I'm afraid I can have a heart attack or stroke, at any time. So, it's been very stressful on me and my wife as well." [Participant 6]

"I did contact my surgeon's office to find out how much notice I would get ahead of when the surgery was re-booked, because I have arthritis that's autoimmune. And so of course, when your stress levels go up, the arthritis tends to flare." [Participant 14]

"You worry all the time. You worry about what could happen, what might happen, why it isn't happening. So, there's a lot of depression and anxiety involved." [Participant 12]

"I'm going to be diagnosed with depression and I think it was ultimately a result of the delay because you're so excited you're counting down the days and then like I said just to be told a week before that after you've been waiting for so long that it's not happening, and you don't know when it's happening like that loss of control and all of those unknowns...Just like on a mental health toll it's impacted my day to day, and wanting to make plans." [Participant 10]

1967/19/

Isolation Independence Burden

"But it tells you, it shows you the stress. That my constant surgeries and the postponement because of Covid That my child could see how crucial this was. a teenager. *Interviewer: Yeah, it impacts the entire family*? Oh, to just an extreme." [Participant 11]

"So he [participant's father] ended up just like rejigging his schedule looks like he'll take a different day of work, whenever this actually happens. So, it was just like very stressful for a lot of people who had kind of like tried to reorganize their life around me." [Participant 3]

"At this point, my son, this is what I really want to stress, this wasn't just me. I have a 16 [year old son]. He's a competitive athlete ... and he made the choice to pull out of his training, even COVID-safe because at this point, we're two weeks before my surgery and if anyone's exposed to COVID I'm not going. So, my whole house shut down. We isolated and shut down completely. So, when you talk about socialization it wasn't just mine, I had a teenager and a home that it affected." [Participant 11]

"Socialization and relationships that didn't really... well... apart from in my marriage, I guess. I don't know if fibroids, if they were affecting my hormone levels. But I did decrease my libido so probably had an impact on my marriage as I was waiting. Not I don't know how you think it's not something you could quantify but that's just a sense that I got a change that I sensed in myself." [Participant 4]

"Like I'm fortunate, I have a really good husband at home, but I've definitely had to rely on him more like even some days it's hard to want to make dinner, for example, just because it's so emotionally tolling. So yeah he's definitely had to step up. and I've definitely relied on friends and family, a lot more, and just talking about everything and more detail, sometimes I feel like a broken record." [Participant 9]

Family & friend impact

NDIVIDUAL-LEVEL IMPACTS

Income Responsibility Identity Burden Insecurity

"I also have to worry about where I is my income coming in, I have to make sure that my mortgage is paid, my bills are paid and I can't be irresponsible because I don't want to suffer. I don't want to suffer due to the fact that COVID and the lack of surgeries and what's happening is going to affect me in the future, because it will." [Participant 10]

"I have to miss more work because I'm now going to massage therapy once a week and for deep tissue and then physiotherapy. I'm still on modified work duty for my last failed surgery of this. So that continues my work doesn't know exactly when I'm going to be gone now." [Participant 15]

"Yeah. I do find work challenging, especially with Zoom-type interaction. The project that I'm working on right now has expanded to a lot of new people across Canada. And so I have fairly frequent interactions with new people, and I get to see the shock on people's faces with how I come across. And that's definitely hard to see." [Participant 13]

"My job is quite physical, lifting relatively heavy things. So I've had to ask for others help with those types of tasks, which is another mental health thing because I don't like imposing on other people, and I don't like feeling incompetent." [Participant 14]

"For me, how it affected me was I couldn't go back to work. I was waiting like because of the surgeries I wasn't well enough. I was constantly waiting. Like for all care, even just support when you have a new appliance, COVID, it affects all of that. When you can't go into proper clinics, when you know there's just, it just affected every element. And at this point now, I find myself not employed, because at some point. Your employers have to move on." [Participant 11]

"Fortunately, I'm able to work from home most days and so when I'm not feeling well, I can kind of step away for my for my work and just kind of focus on me for a bit."

[Participant 9]

NDIVIDUAL-LEVEL IMPACTS

Work Impact

one successful successful completion to move to that next stage, to try and move you through Former through those yep through those periods, it affects your nutrition, it affects your sleep, it affects every aspect of your life." [Participant 11] "I think there's a line, of course, between life and death. And then there's a line between a quality of life, where a person is still affected daily. And I think that is just important as the life and death." [Participant 12]	INDIVIDUAL-LEVEL IMPACTS	Mental health Onality of Life	"I think there's a line, of course, between life and death. And then there's a line between a quality of life, where a person is still affected daily. And I think that is just a important as the life and death." [Participant 12] "But I did decrease my libido so probably had an impact on my marriage as I was waiting. Not I don't know how you think it's not something you could quantify but that just a sense that I got a change that I sensed in myself. So that was difficult." [Participant 4]
	INDIVID		I once was; I'm canceling on things constantly because either a) I've lost my voice, b) I
Tonce was, i'm canceling on things constantly because either a, i've lost my voice, b,			delayed surgery was supposed to fix] "But I work from home right now, and it's definitely difficult to interact with people on a professional level, with how I look. And
in so much pain I can't lift anything." [Participant 10] [referring to a deformity of their skull as a result of a previous cancer surgery that the delayed surgery was supposed to fix] "But I work from home right now, and it's definitely difficult to interact with people on a professional level, with how I look. And			

		Access Hesitancy	"Yeah, the only thing that I had to do, which was continuous since I had the catheter first put in, was going every four weeks and have it changed The only thing that changed on that, is that the health unit out here, instead of me going to them, they came to my home to change the catheter." [Participant 2]
SYSTEM-LEVEL FACTORS	ire Resources		"I had a conversation with my doctor, but she just did it over the phone, rather than making me go into the office. I just talked to her about that it is delayed, and you know that I would continue to take pain medication for it, but I have not had to visit any emergency room because of it." [Participant 8]
YSTEM-L	Healthcare		"I did have an incident where I shouldcould have gone in but I just decided not to. And yeah, just the waiting around in the emergencies just driving me crazy." [Participant 10]
S			"And once I was able to walk and talk, they wheeled me out into a hallway in the neuro ward. And I spent two weeks outside of a room, in a hallway at [hospital]. That was pretty uncomfortable. I've definitely seen what the effects of lack of bed availability looks like." [Participant 13]

Access Communication Responsibility	"I don't know about the avoiding delay, but I do definitely think it's a system and set a cutoff time. For example, if we are a-go as of 2:00 PM the day before surgery, we're not going to cancel it. In other words, not waiting until the last minute to cancel and have a cutoff time the day before. So at least that person isn't scared to go into the hospital the next morning and being afraid they're going to be kicked back out." [Participant 12]
	"They just said, "We'll just have to wait. We've got no idea what a realistic timeline is, and we'll keep you updated. So, I really have no expectations to hearing from them, until they know more. And I don't really have expectations of things getting better anytime soon." [Participant 13]
	"When the surgery was canceled, I didn't think to ask, but I also was not instructed what to do in terms of if I'm experiencing particular symptoms, whether that means I should go to the ER, that kind of thing. So, I've just been suffering through it on my own, I guess." [Participant 14]
	"Well, I did receive notification in a timely manner, so it didn't affect me in terms of any preparation, which, if they had done it on the spur of the moment, give me a day notice or something like that, it would've been different. I think I had at least a week's notice when they canceled my surgery." [Participant 2]
	Communication

SYSTEM-LEVEL FACTORS	Communication	Policy Government Healthcare provider Media	Interviewer: How do you think the people that were making the decisions could do a better job in the future? "I guess they could be more consistent like they come out and say one thing and then they come out and say another thing. You know." [Participant 6] "That just speaks to leadership, again, I think it just sent so many false messages so many confusing messages." [Participant 11] "And I probably shouldn't say that but he's a bit of a dick. So, the thyroid doctor he showed no mercy, he showed no kindness, he was just a jackass but his assistant was amazing." [Participant 10] "I definitely feel like giving more notice that a surgery's going to be canceled. Less than 24 hours' notice is just not enough time for a person. I think it's more emotionally devastating to be right on the cusp of finally dealing with the situation, and having it canceled. So, I think giving a more advanced notice of cancellations would've been better." [Participant 12] "I did connect with the oncology clinic and they've been super about it um, but I have
			nothing but praise for that clinic overall in terms of how they keep you informed and stuff like that so that's been good." [Participant 1]
			"I was impressed I got a phone call right like from the doctor, which it wasn't just a like a nurse or a clinic staff or someone like that. So, it was a personal phone call and she just apologized and said there was nothing she could do, and she would get back in touch with me when she could." [Participant 5]

SYSTEM-LEVEL FACTORS

	Understanding
	Frustration
	Anger
	Communication
	Vaccination
	Public policy
	Government
	Healthcare
	system
ity ity	
Accountability Responsibility	
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"Overall, this is a massive public policy failure." [Participant 3]

"Well, I mean, I understand that they had to maintain space in the health care system for COVID patients. And be able to create more ICU space, as is necessary, so I totally understand the rationale and thankfully I'm not speaking from the perspective of, say, a brain cancer patient where getting that surgery done now is so so important. I think my perspective would be different if that were the case, but my surgery was one that could afford to be delayed and I recognize the need for it to have been based on having to keep beds available for those covid patients." [Participant 4]

"I wish that things with regards to the pandemic had been handled much differently so that potentially patients and the hospital staff wouldn't have been put in this situation." [Participant 5]

"I'm disappointed, but also understanding. Like, I understand the reason needed for it, I understand why the hospitals are not doing surgeries right now. I don't hold ill will to the health care system." [Participant 8]

Interviewer: Did you think there was alternate options, maybe like something else, they could have done in your eyes. "I think more restrictions earlier on work definitely an alternative." [Participant 8]

"Our health care system is suffering, and I feel like the people that are making these decisions might be prioritizing social aspects before medical ones." [Participant 8]

"In my particular surgery, the chances of going to ICU after surgery were nil, very small. And so, I feel like my surgery could have been done, without adding to the ICU problem of being overcrowded. So, I think some of the surgeries that, in a limited quantity, should still have been done." [Participant 12]

COVID-RELATED IMPACTS		very reasonable. But then it's like cool I'm locked down for two weeks. Um and then it was like, a week out it got canceled. That was a week of locking down that was kind of wasted." [Participant 3] "Yeah, obviously with COVID I'm not really going out and socializing so that has been affected." [Participant 14] "Well, COVID in general has affected the ability to socialize. And the fact that if I'm going to be going into surgery, I can't take any chance of catching COVID, so socialization is nothing. It's not there, because you can't take that chance, because surgery might be around the corner. And you can't chance possibly being sick and it being canceled." [Participant 12] "There have been times that I've thought of about going in, even going into the doctor and stuff. And I've been hesitant about doing itBecause of going in, it feels like you're walking into a germ factory maybe, right now." [Participant 12]
MPACTS		was like, a week out it got canceled. That was a week of locking down that was kind of
	Isolation Uncertainty Healthcare access Vaccine	"Um, I think in terms of logistics it's just been a more of a preventative, just kind of keeping myself on the safe side at this point in terms of perhaps being a higher risk or maybe that are vaccine didn't quite give me enough of the boost that I needed or anything like that. But, you know better safe than sorry at this point." [Participant 1]

Worry Anxiety Quality of life Physical health Plan for future

"...anguish and uncertainty and whatever because of the lack of communication, no answers and no timeline well unfortunately it's well, you could die before you get your knee replacement right." [Participant 7A]

"Even the facts of like if I was going to go somewhere, right, I would love to make all these plans, but I can't because I don't know if I can speak and I don't know if I can; I don't know if I can make any kind of future plans, because I'm like oh, I have to wait for surgery." [Participant 10]

"It delays everything it puts absolutely everything on hold. I think when I mentioned a cumulative effect for me. Before the march 31, 2021 surgery which was the reversal. That had been postponed so, then I was postponed for November, scheduled for March 31. We are holding on by a thread in our home to see if I'm even going to get in. Or if things are going to be cancel because we watch the numbers; everyone's watching the numbers." [Participant 11]

"I'm at their mercy basically of when, when they'll get me back in. And just not really being given any sort of alternative option. I mean I don't know what that would look like, or what I even expect but yeah you just kind of feel very left in the dark."

[Participant 9]

"...loss of control and all of those unknowns it's just hard to comprehend, and I guess just yeah plan for your future because I have no idea. So even just like on a mental health toll it's ,it's impacted my day to day and wanting to make plans" [Participant 9]

"It would definitely be to just have that date in mind and just be able to mentally prepare for it. So, it was difficult to not have a date and to just be kind of in limbo and waiting and not knowing both personally and professionally how that was going to be affecting things in my life." [Participant 4]

UNCERTAINTY

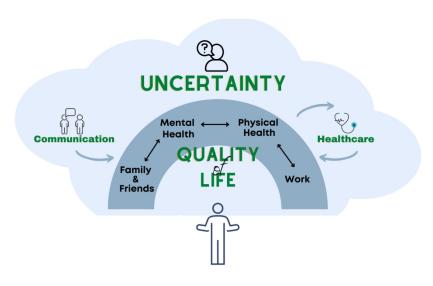


Figure 2. The identified themes are interconnected.

1540x1155mm (38 x 38 DPI)



Semi-Structured Interview Guide

Thank-you for taking the time to participate in this interview to help us understand the impact of delaying non-urgent surgeries on patients. My name is {insert name}, I am a {insert role}. The primary investigator is Dr. Khara Sauro.

You have been invited here today because we are interested in hearing your experience as a patient who had a planned surgery delayed during the COVID-19 pandemic response. We will ask for your experience and ask a few questions about the type of surgery you were planning to have, how that affected your health and everyday life.

Thank you again for your participation.

Before we begin, I would like to make sure that you know that there are no right or wrong answers in our discussion today; we are interested in all comments. We don't want to miss any of your comments and feedback, so we are taking detailed notes and audio recording our conversation.

Please be assured what is said and discussed today will be kept confidential and any information you provide will be kept in a password protected folder on a secure server, accessible only by members of the research team. As is noted in the informed consent, your participation is voluntary and you are free to decline participation at any point should you wish to do so for any reason. Please let me know if you have any questions.

Do you have any questions before we begin?

- 1. Please describe the surgery you were booked to have, as you understand it.
- 2. When were you scheduled to have your surgery and do you have a new date for your surgery?
- 3. Is this the first time your surgery is being re-scheduled?
- 4. Can you please tell us about how having your surgery delayed has affected your overall health? Prompts:
 - a. How has your healthy been since your surgery was delayed?
 - b. What about your mental health?
 - c. How have you interacted with your healthcare provider(s)? Is that different than before you were supposed to have surgery?
 - d. Have you had to visit the emergency room or hospital while you were waiting for your surgery? Can you tell me about that?
- 5. Can you please tell us about how having your surgery delayed has affected your everyday life, such as activities of daily living, work, income, socialization, family, relationships?

Ethics ID: REB20-0753

Study Title: Surgery during COVID-19: Impact to Rebuilding Capacity

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Version number/date: V1/May 21, 2020

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*Ask this only if they haven't touched on this question in their response to the previous question.

Prompts:

- a. Have you had to change many aspects of your daily living because your surgery was delayed? Can you tell me more about that?
- b. Have you had to ask for more help from family or a caregiver? Can you expand on that?
- c. Have you been able to do the things you normally would do?

What do you think about the decision to delay surgeries? Prompts:

- a. Was the right thing to do given the circumstances?
- b. What do you think the alternate options were?
- c. How could the people making the decisions do a better job in the future?
- d. What do you think was done really well?

I would just like to take a moment and summarize what we've talked about today. <Summarize key points>.

Do you have anything else to add that we may not have captured?

Thank you so much for speaking with me today and for providing your experiences.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Торіс	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team			
and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with			1
participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal	
the interviewer		goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	
		e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design	•		
Theoretical framework			
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.	
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,	
		content analysis	
Participant selection	•		
Sampling	10	How were participants selected? e.g. purposive, convenience,	
		consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,	
		email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-	15	Was anyone else present besides the participants and researchers?	
participants			
Description of sample	16	What are the important characteristics of the sample? e.g. demographic	
		data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot	
		tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or For Peer Review Only	

Topic	Item No.	Guide Questions/Description	Reported on
			Page No.
		correction?	
Domain 3: analysis and			
findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding	25	Did authors provide a description of the coding tree?	
tree			
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting	•		
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?	
		Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.