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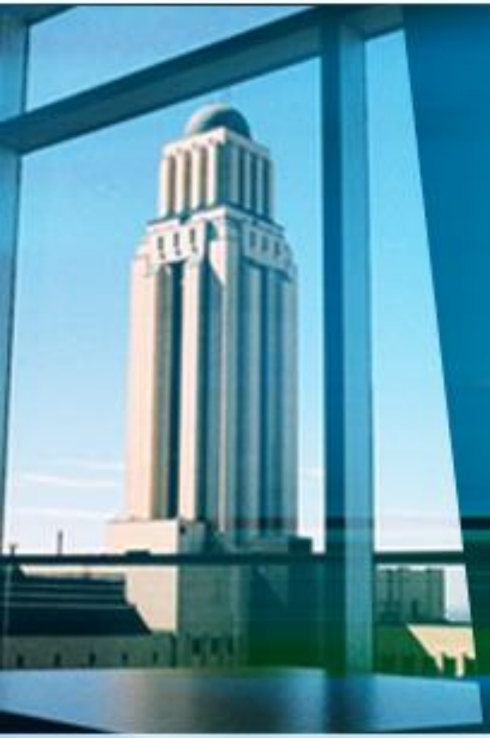

# Adolescents' perspective on the physical, social and psychological aspects of being on a waiting list for orthopaedic surgery

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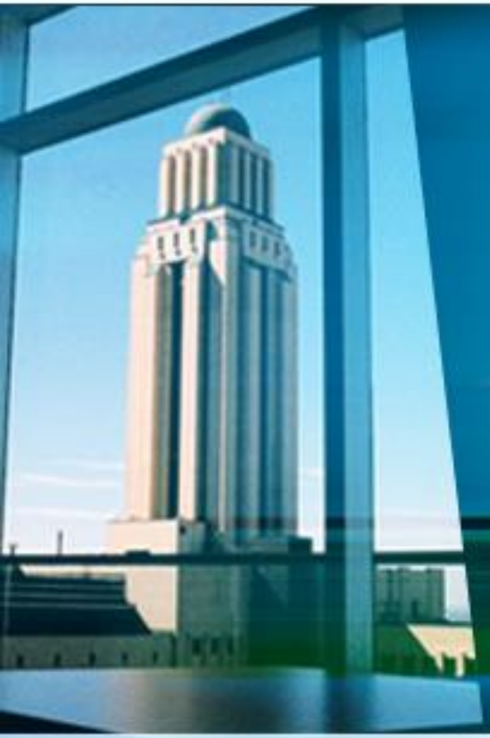
This project was born out of the concern of the surgical team at CHU Ste-Justine for the wellbeing of their patients with adolescent idiopathic scoliosis (AIS) or damage to the anterior crucial ligament (ACL) and waiting for surgical repair. It was made possible by a partnership with researchers from the department of psychology at Université de Montréal.



**Aim:** Describe the experience of teenagers waiting for orthopaedic surgery.

**Goal:** Inform the development of a tool box for them while waiting.

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# Background

Wait lists are an important reality in many health care systems, namely in Quebec.

Expectations related to health services in Quebec usually exceed what the system can offer. This condition is mainly the result of a shortages in nursing and medical resources *(Buerhaus et al., 2005; Gonzalez 2013).*

This leads to long waiting lists in multiple sectors of the health system.

Studies have documented the negative impacts of being on a waiting list in adults waiting for surgery or waiting to be assessed and treated by specialists *(Desmeules, Dionne, Belzile, Bourbonnais, & Frémont, 2009; Llewellyn-Thomas, Arschinoff, Williams et Naylor, 1998; Oudhoff, Timmermans, Knol, Bijnen, & Van der Wal, 2007; Peacock, 2005)*:

- Increased stress, pain, social withdrawal
- Deterioration of global functioning and QOL
- Increased risk of post operative complications
- Patient dissatisfaction with waiting and waiting times

# Background

Children and teenagers are likely to be affected. The literature to date has focused primarily on adults and on the clinical impacts of waiting *(Desmeules, Dionne, Belzile, Bourbonnais, & Frémont, 2012)*

Duration of the wait at our centre : over one to two years *(Drs Grimard and Parent, personal communication)*

Two studies on the impact of surgery (but not waiting time) in AIS *(D'Agata & Pérez-Testor, 2012; Rullander, Isberg, Karling, Jonsson & Lindh, 2013):*

- Post-op risk for depression and social withdrawal
- AIS and undergoing surgery are risk factors for identity and body image issues

Studies on ACL, mostly athletes, post op *(Arendt, Agel, & Dick, 1999)*

# Research questions and assumptions:

At this period in their life, activities with friends and social relationships play an important role in identity development. Being excluded from friends and activities because of physical handicap or reduced mobility may have a devastating impact on the adolescent’s life.

1. What are the physical, psychological and social impacts of waiting?
   - Signs of impaired mood, depression, anxiety
   - Impaired functioning and increased isolation due to physical limitations and impaired mood

2. What are patients’ perceptions about being on a wait list?
   - Negative (disturbance, worry, irritation, nervousness)

# Methods:

- Qualitative descriptive approach using individual interviews with open and semi-structured questions to document participants' narrated experience of being on a wait list.

- Convenience sample recruited by phone from the patient waitlists of a university affiliated paediatric hospital in a large urban area.

- Eligibility criteria:
  - Aged 12 to 19
  - Male or female
  - ACL or AIS waitlisted for surgery
  - French or English speaking

- Exclusion criteria:
  - Prior surgery or contraindication to surgery
  - Pervasive developmental disorder
  - Language barrier

# Methods:

- Participants : N=12 (76 calls)
    - Male = 2
    - AIS = 7
    - Aged 12 to 19 ($\bar{x}\approx 14,7\ \text{ans} \pm 2,7$)
    - Waitlisted 1 to 14 months at interview ($\bar{x}\approx 6,1\ \text{mois} \pm 4,3$)
    - Knew date of surgery = 2

- Individual interviews by the same interviewer (MG) lasted 45 to 60 minutes.

# **Interpretative Phenomenological Analysis** (IPA, *Smith et al., 2009*).

1. Read and re-read the first transcript several times to immerse oneself in the original data.

2. Initial noting, examine semantic content and language use by adding descriptive, linguistic and conceptual comments to the transcript.

(2 coders working separately: VL, ML).

3. Develop emergent themes.

4. Search for connections across emergent themes.

(2 coders and principal investigator: VL, ML, MA).

5. Moved to the next case and repeated the first four steps for the other eleven participants.

6. Looked for patterns across our 12 participants.

(VL, ML, MA)

# RESULTS

# RESULTS: Positive aspects

Patients' discourse suggests *tolerance*, *acceptance*, and *optimism*:

Patients perceive their life as virtually unchanged, particularly in terms of their interpersonal relations, day to day functioning, mood and activity level (other than physical activity).

They are optimistic about the outcome of the surgery and consider being on a waitlist as a nuisance that is temporary, « a necessary evil »

*«[...] it's gonna go better after than now.» (P5)*
*«[...] after it's going to be better, I know it.» (P7)*

About not knowing when the surgery will take place or the OR being reserved for others types of surgeries and more urgent cases:

*«[...] I am not in pain, I'm gonna let those who need it more than I do go ahead.» (P2)*

# RESULTS: Positive aspects

The waiting period is perceived as a time of *mental preparation* for the surgery, having to wait comes as *a relief*.

An *active search for information* is undertaken, which helps alleviate the initial apprehension about having to undergo surgery and reduce the stress of having to wait.

> *«[...] as I heard more about it and as I searched, I saw that more and more, scoliosis is being treated with surgery [...] and that they [the surgeons] know what they are doing. [...] You realise that a lot of other people have the same illness [...] and that there is less than 12% of patients for whom something happened and it was minor. So I'm not stressed.» (P4)*

Having to wait is perceived as a time for reflection and a time *to catch up with emotions* and accept what is happening.

> *«[...] 'waiting', told me: 'Ok, this cuts me some slack; I'm going to have time to get over my emotions'.» (P2)*

# RESULTS: Positive aspects

ACL patients use the time to *prepare physically* for the surgery by doing or continuing physiotherapy.

*«So I told myself: 'OK, it'll give me time to do more physio so I can gain more muscle'.» (P7)*

AIS patients are freed from their back brace; *intense relief* as wearing a back brace is experienced much more negatively than wearing a knee brace :

*«[...] you know since I took it off, I perceive myself as more free and beautiful than I ever have. » (P4)*

Patients plan their absence from school and how to access their schoolwork during the convalescence period.

# RESULTS: Resources

Patients’ discourse suggest they draw on *intrapersonal* (personal resilience, ability to adjust) and *interpersonal resources* (perceived support from parents, peers) to maintain their optimistic stance.

*«Really, it’s my best friend who helped me the most. And my parents, because, you know, they have faith in the doctors and my best friend, she has faith in me. So it’s like a mix of the two, it’s really going to help me, it helps me now.» (P2)*

# RESULTS: Negative aspects

The most common source of *negative affect* appears to be the significant *limitations to physical activity*, a phenomenon most present among ACL patients. They describe feelings of *sadness*, a sense of *injustice*, of *inferiority*.

Concerns regarding the surgery, in particular the *fear of being anesthetised* and the fear of *facing the unknown*, are expressed.

*«[...] the worst is that afterwards, I don't even know what to expect.» (P6)*

Concerns are also expressed regarding the *post operative phase*, especially with respect to *pain* and the *return to physical activity.*

*«[...] I hope I won't be in too much pain after.» (P9)*

These fears are described as *most present early on* during the waiting period and diminish considerably with the *search for information*.

*«Initially I feared the operation [...] but then I learned about the operation and I was less stressed because I know it's not that bad.» (P11)*

# RESULTS: Negative aspects

Patients' discourse suggested a certain *frustration, disbelief* and *lack of comprehension* regarding the slowness of the medical system in taking charge of them; more present among AIS patients.

*«I feel like I am being pushed back to the end of the line. I'm told that I am a priority, but I feel like NO, it's the contrary, I am not a priority. I'm being left out to dry.» (P4)*

*«Why does it take so long to get an appointment at Ste-Justine?» (P2)*

This attitude can lead to *non adherence* to medical recommendations as patients perceive the system as being inconsiderate.

*«So I find that waiting makes me feel like saying: 'well, it [my condition] can't be that bad; I'm gonna do it anyway!' . For me, that's what happened, the fact that I continued to push my body to the limit without realising that it's severe and that I can really make things worse. » (P7)*

# Discussion

Contrary to expected, waiting is not a unilaterally negative experience:

- time for mental and physical preparation;
- information seeking plays a key role;
- relief, optimism and faith in the process.

There are negative aspects, however, and it is of concern that frustration and feelings not being considered can lead to non adherence behaviour.

About their « everything's pretty normal » attitude:

- limits of the study (selection bias; interviews took place at the hospital)
- attempt to feel/appear normal *(Barrera et al., 2012; Lugasi et al., 2012; Malboeuf et al., 2015)*

# Discussion

Implication for future research:

Longitudinal prospective study involving the two populations to evaluate their mood and QOL over time through the waiting period, peri operatively, and post operatively. Data for a larger and more representative sample.

Clinical implication:

Propensity to by means of information seeking is not novel (Miller, 1987). Youth gather information from a variety of sources that include parents, medical professionals and the Internet (Gray et al., 2005). Studies show that youth appreciate that the Internet gives them access to information that goes beyond their own experience (Gray et al., 2005; Suzuki & Calzo, 2004).

They are cognisant of the importance of having access to reliable information and wary of the risk for "cyberchondria" (Anonymous, 2000). They need to be guided in their search for valid health information (Skopelja et al., 2008).

Develop an expert-validated website to their intention.

Thank you!

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