

2024

Fertility Patient Experience Report



Background

This joint report by [Fertility Matters Canada](#) and [myStoria](#) is part of a collaborative initiative to explore fertility in Canada and the U.S. through a brief survey. The goal was twofold: to gain valuable insights into the current fertility landscape and to inform the development of their core offerings.

Fertility Matters Canada, Canada's fertility voice and a national registered charity, is dedicated to providing exceptional fertility support and education to the 1 in 6 Canadians needing access to fertility care. They actively engage in federal and provincial advocacy work to make fertility care more accessible, ensuring that those in need have the support and resources required on their fertility journeys.

myStoria, empowers individuals by putting them in control of their fertility journey. Through innovative tools, myStoria helps users advocate for themselves, connect with others who understand their struggles, and make their path to parenthood faster, more affordable, and less disruptive.

In the fertility space, the patient experience is often sidelined. This report seeks to shift that narrative by prioritizing the patient perspective, underscoring the urgent need for a more compassionate and informed approach to fertility care. It's time to recognize that the emotional and physical well-being of individuals navigating fertility should be at the forefront of discussions and decisions.

As part of their shared commitment to advancing fertility care, Fertility Matters Canada and myStoria have commissioned this report to highlight the major findings and support their work in advocating for a better patient experience.



Why This & Why Now

In July 2024, Fertility Matters Canada and myStoria jointly conducted a brief survey exploring experiences with fertility and fertility healthcare across Canada and the U.S. Our goal was a pulse check; we wanted to gain a broader understanding of what was going well, what was going wrong, and why.

We also wanted to gut-check our assumptions. As members of the fertility community, each with our own stories, perceptions, and challenges, we wanted to listen to experiences beyond ourselves and our immediate circle.

Fertility and reproductive healthcare are contentious topics. Reproductive bodies have become sites for social movements, political debates, and deep existential questioning. But beyond the discourse are the actual people who live and struggle with fertility, who want something that seemingly comes so easily to others, for whom reproductive health is not an abstract concept but a daily crisis.

Our goal in sharing this report is not to stoke any partisan fires. Rather, it is to bring the focus back to the human and the humane. For anyone who wants to engage reproductive health in whatever capacity, professional, regulatory, or otherwise, the stories that make up this community should be required reading.



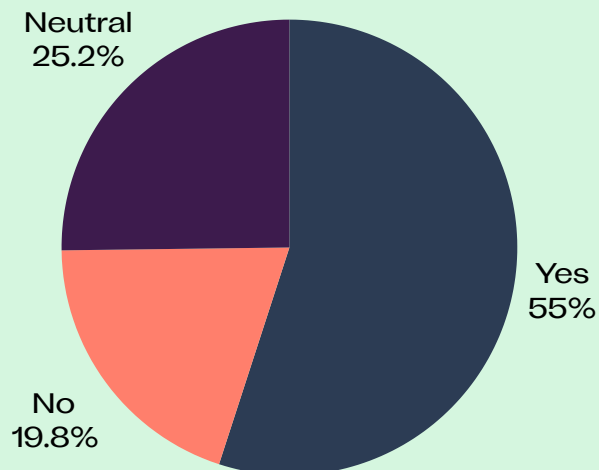
Data Insights

The following breaks down the key findings from our research, shedding light on the most important trends and patterns that emerged.

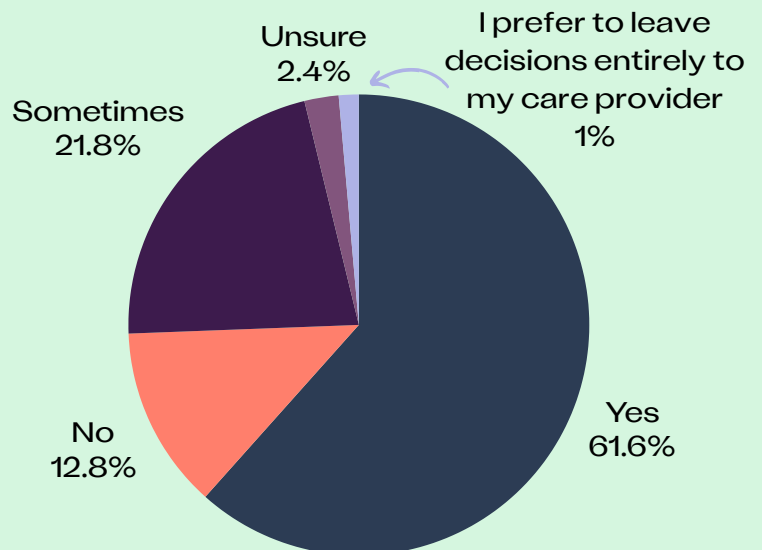
Initial results paint an optimistic picture

On the surface, fertility care may not seem to be in crisis. The survey results were initially encouraging: 55% of respondents felt they had all the information they needed to make informed decisions with their fertility care team, and 3 in 5 felt they had an equal say in their treatment decisions.

Do you feel you had all the information you needed to make an informed decision with your fertility care team?



When engaging with your fertility care team, do you feel you have an equal say in your treatment decisions?



While these are positive figures, they don't tell the whole story. Over a third of respondents did not share this experience. In fact, 13% felt pressured to follow whatever their care provider recommended without question, and 22% felt they had an equal say only sometimes, but not consistently. Even more concerning, 1 in 5 people surveyed (20%) said they did not have all the information they needed to make informed decisions about their fertility care.

Clearly, there's room for significant improvement. Perhaps the most important takeaway: only 1% of respondents preferred to leave decisions entirely in the hands of their care provider. The message is clear—people experiencing fertility struggles want to be active participants in their fertility journey, not passive bystanders.

You deserve better. Fertility care is missing the mark, and this report underscores the urgent need for change in how we approach fertility treatment and patient empowerment.

While most seek treatment, the majority are unsuccessful

The majority of respondents (95%) actively engaged in one or more treatment regimens. Only 5% of respondents had tried no treatments at the time of the survey.

Methods that did not involve medical assistance were the most common fertility treatment, followed closely by medication. More than a third of respondents had tried in vitro fertilization (IVF), and another 18% had tried intrauterine insemination (IUI).

Surrogacy was the least common treatment, with only 7% of respondents reporting.

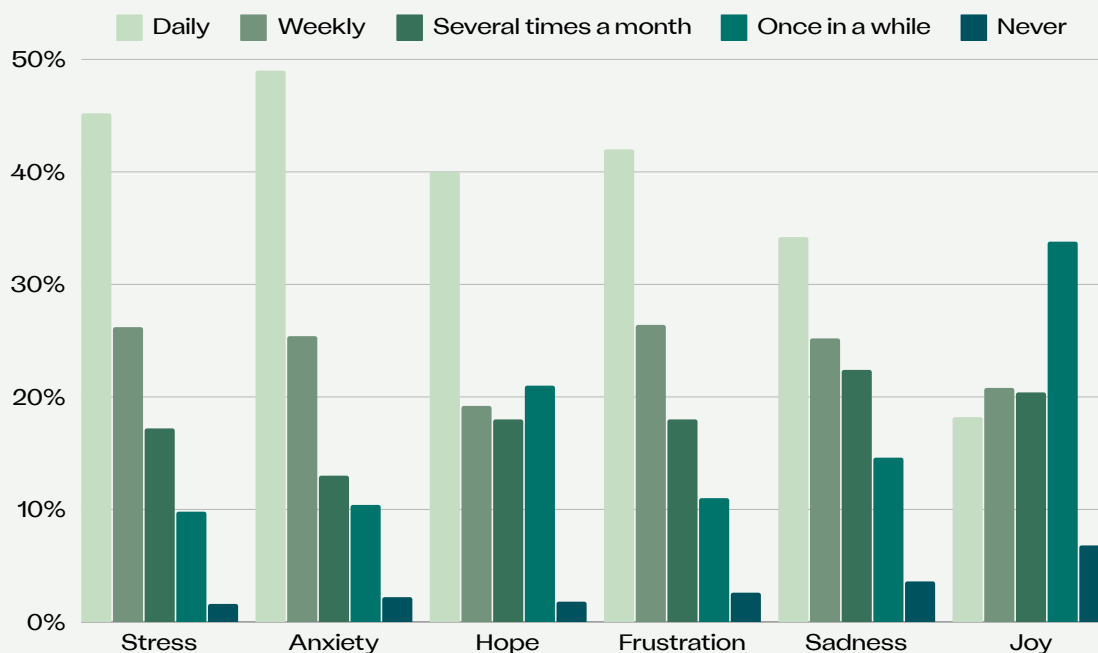
However, despite these efforts, over half of respondents did not have successful outcomes. 56% of respondents reported that their treatments were not effective in helping them conceive. Only 38% experienced success, while the remaining 6% abstained from answering.

These success rates speak to a staggering cost for those experiencing fertility struggles. This cost is not only financial, although the money needed for fertility treatment is a substantial strain to most and an outright blocker to many. (The Advanced Fertility Center of Chicago, for example, estimates the average cost of in vitro fertilization at \$11,000 to \$12,000.)

More profound is the emotional cost of seeking treatment. Indeed, handling emotional stress was the most common unexpected challenge respondents faced. 49% of respondents experienced anxiety on a daily basis. Likewise, 45% experienced stress, 42% were frustrated, and 34% were sad every day. While 40% of respondents experienced hope daily, only 18% felt joy.

When occurrences are extended to weekly and beyond, respondents paint an even more vivid picture of the emotional rollercoaster of fertility.

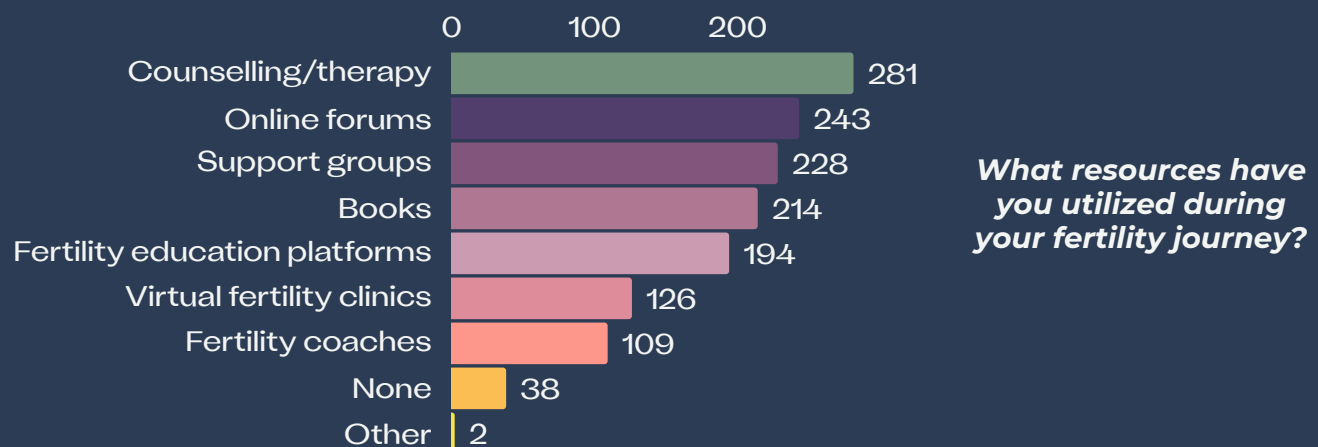
To what extent have you experienced these emotions during your fertility journey?



People struggling with fertility seek human connection

Most people (92%) are actively seeking resources to help them on their fertility journey. The most common resources were counseling and therapy (used by 56% of respondents), online forums (49%), support groups (46%), and books (43%).

A smaller number of respondents used fertility education platforms (39%), virtual fertility clinics (25%) and fertility coaches (22%). Only 8% of respondents claimed to use no resources at all.



We find it interesting that not only do the vast majority of respondents use resources to help navigate their fertility, but the most common resources share a common theme: human connection. Counseling and therapy, online forums, and support groups all involve reaching out to another person, professional or personal, in-person or online, to find advice, comfort, and understanding.

Research shows that individuals experiencing fertility struggles often face increased feelings of loneliness and isolation. Additionally, nearly 40% of women navigating a fertility journey have a psychiatric diagnosis, often anxiety or depression, as a result of the stress and strain on personal relationships. Furthermore, studies indicate that social support plays a crucial role in mental health, with a lack of connection correlating with poorer health outcomes, including increased stress levels and a greater risk of chronic health issues.

The research shows for itself: isolation can be tempting, but it's not a viable solution.

Human connection is proven to enhance resilience and overall health. Research demonstrates that individuals who engage in supportive relationships are better equipped to cope with stressors, leading to improved mental health and emotional recovery. Connection fosters a sense of belonging and validation, which can be especially vital during challenging times.

It's a deceptively simple truth: as much as fertility is a personal journey, it shouldn't be one you walk alone.

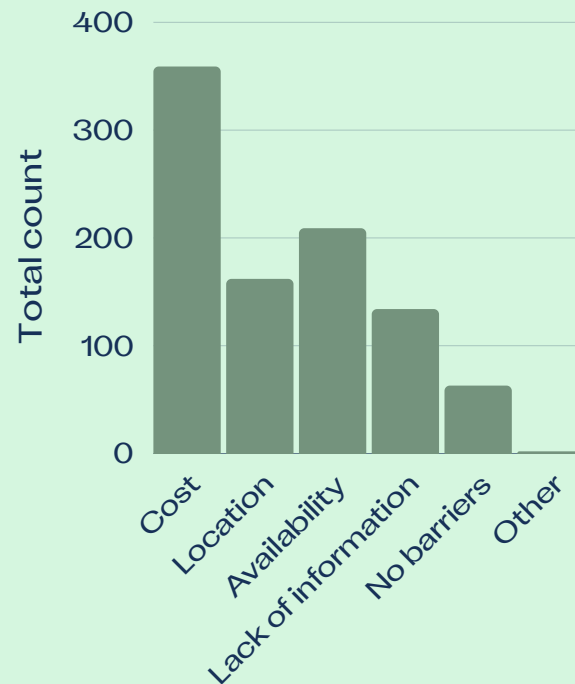
Education on fertility healthcare is incomplete

For most people, treating infertility is not a smooth process. The most common obstacle was unsurprising: cost. Nearly three fourths (72%) of respondents struggled with the financial dimensions of infertility. 42% experienced a lack of availability of treatments or resources in their area, while 32% struggled with their location.

In addition to navigating expected hurdles, encountering unexpected challenges is a nearly universal experience. Only one respondent in the entire study claimed to have not encountered any unexpected challenges. In other words, 99.8% of respondents faced the unexpected. The most common unexpected challenges did surprise us: handling the emotional stress (31%) and managing financial cost (30%).

Prior to this research, we hypothesized that topics like treatment regimens, treatment side effects, or navigating the healthcare system would have topped the list. That emotional stress and financial cost, the issues most commonly top of mind across conversation we've had with people experiencing infertility, were the most unexpected challenges, raises concern about the availability and quality of information readily available.

What barriers, if any, have you encountered in accessing fertility treatments or resources?



Indeed, more than 1 in 4 respondents (27%) reported a lack of information during their journey. This should be 0%. Furthermore, despite wide use of online forums (49%), support groups (46%), and books (43%), that nearly 100% of respondents experienced unexpected challenges strongly suggests a gap in the quality of data.

The mission is clear: the gaps in the availability and comprehensiveness of education around fertility healthcare must be addressed. And it is especially critical to make quality information easily available to individuals before undergoing infertility treatment. No one should have to learn the hard way.

Politics are influencing most to reevaluate their fertility treatment strategy

For nearly a third of respondents (32%), the current political climate around reproductive healthcare has not influenced their decisions regarding fertility treatments. However, the political climate has made nearly another third (31%) more cautious about their decisions. 1 in 5 respondents were motivated to seek treatments sooner, while 1 in 10 reconsidered their treatment options because of the political climate. For one respondent, the pressure was too much entirely, noting, “I am no longer trying. The future is too uncertain.”

Indeed, 60% of respondents reported feeling scared about the future of their fertility journeys due to political discourse on reproductive healthcare access.

Only 29% of respondents felt their government was well informed on the topic of fertility.

The political climate in the U.S. and Canada adds further complications to an already difficult fertility journey.



There is no one-size-fits-all narrative for infertility

15% of respondents “always” feel in control, while another 31% feel in control most of the time. Likewise, nearly two-thirds of respondents (62%) feel the sentiment ‘my body, my choice’ is a current reality. Only 13% somewhat disagreed with this statement, and 8% strongly disagreed.

As positive as these stats may seem, they are cold comfort to the 18% of respondents who rarely or never felt in control of their fertility journey. It also strikes us that for the 36% of respondents who said they feel in control of their fertility “sometimes.” It’s also important to note that if these respondents feel in control of their fertility “sometimes,” that also means they feel not in control of their fertility journey during the other times.

Interestingly, when asked whether they perceived a power imbalance in their doctor patient relationship, respondents were split down the middle. While 24% of respondents were neutral, 38% agreed that there was an imbalance, while another 38% denied an imbalance.

These results reflect both the complexity of experiences with fertility healthcare, and the polarizing nature of that care. As a deeply personal, yet also socially and politically charged experience, fertility, as with all aspects of reproductive health, defies the simple answer. One size does not fit all, and searching for such a narrative will ultimately do more harm than good.



Information, care, and empowerment do not guarantee a good experience

At the end of this survey, we asked respondents to describe their fertility journey in one word.

Despite encouraging trends in earlier questions, two thirds of respondents (68%) described their experience with their fertility journey as exclusively negative. In fact, the top five words used to describe respondent experiences were all negatively coded:

1. Stressful or stressed - 54 instances
2. Frustrating or frustrated - 53 instances
3. Overwhelming or overwhelmed - 30 instances
4. Long - 29 instances
5. Scary - 26 instances

Only 12% of responses were exclusively positive. Hope and hopefulness was overwhelmingly the most common theme across positive responses; many of these responses expounded beyond the one-word prompt to describe a journey that began with hardship but ultimately inspired hope. Another 11% of respondents offered multiple words that presented a mixed bag of positive and negative experiences. “An emotional rollercoaster” was a common idiom.

Even having all the right information, working with an empathetic medical care team, and feeling in control of your fertility journey does not necessarily translate into a positive experience. The reason for this is as simple as it is unsatisfying: fertility is not a positive experience.

For the vast majority of people who experience fertility struggles, it’s a bad deal. A friend once described fertility struggles as “the world’s worst club.” There is no amount of fancy tech or comforting mantras that will compensate for the frustration, anxiety, and, in far too many cases, lack of results that most people currently encounter.

Worst Club, Best People

The results of our first pulse survey were equal parts validating and distressing. On one hand, the experiences of our respondents echo our own struggles with the gaps in fertility care. Those experiences are exactly why Fertility Matters Canada and myStoria exist and what we have to offer. We've been there.

It is disheartening to see so many people still trying to navigate their fertility journey with the same frustrations, anxieties, and hopelessness that we encountered. When we conducted this study, we specifically targeted individuals with recent fertility care experiences. 2334 engaged in the study, and 500 qualified—that's 21%. Furthermore, we secured 500 responses in less than 24 hours.

But there's a couple of silver linings here. For one, if you're experiencing fertility struggles, you're not alone. Second, people are eager to talk about their experiences when given the chance. Fertility struggles may be the worst club, but it has the best people. And by sharing their experiences, these people not only let others know that they are not alone but also inspire the next generation of fertility care.

Our takeaways are these:

- Having all the information you need is one part of the equation. Everyone should have equal access to the best quality information so that 100% of people experiencing fertility struggles have all of the information and confidence they need to be an equal partner in their care.
- Having expert support is another part of the equation. No matter how much you study, you are still going to encounter the unexpected. No plan is perfect. And when that plan derails, everyone should have access to a team of expert care providers who can help get things back on track.
- Finally, a community is essential. We can't do this alone, and we shouldn't do it alone. Medical care needs to be supported with emotional care. Everyone should be empowered to connect with others who share their experiences, who understand the difficult decisions, and who understand it without having to have it explained.

That's where Fertility Matters Canada and myStoria come in. We are part of this community, built by us, for all of us. Our mission is to ensure that everyone facing fertility challenges has access to the information, expert support, and community they deserve.

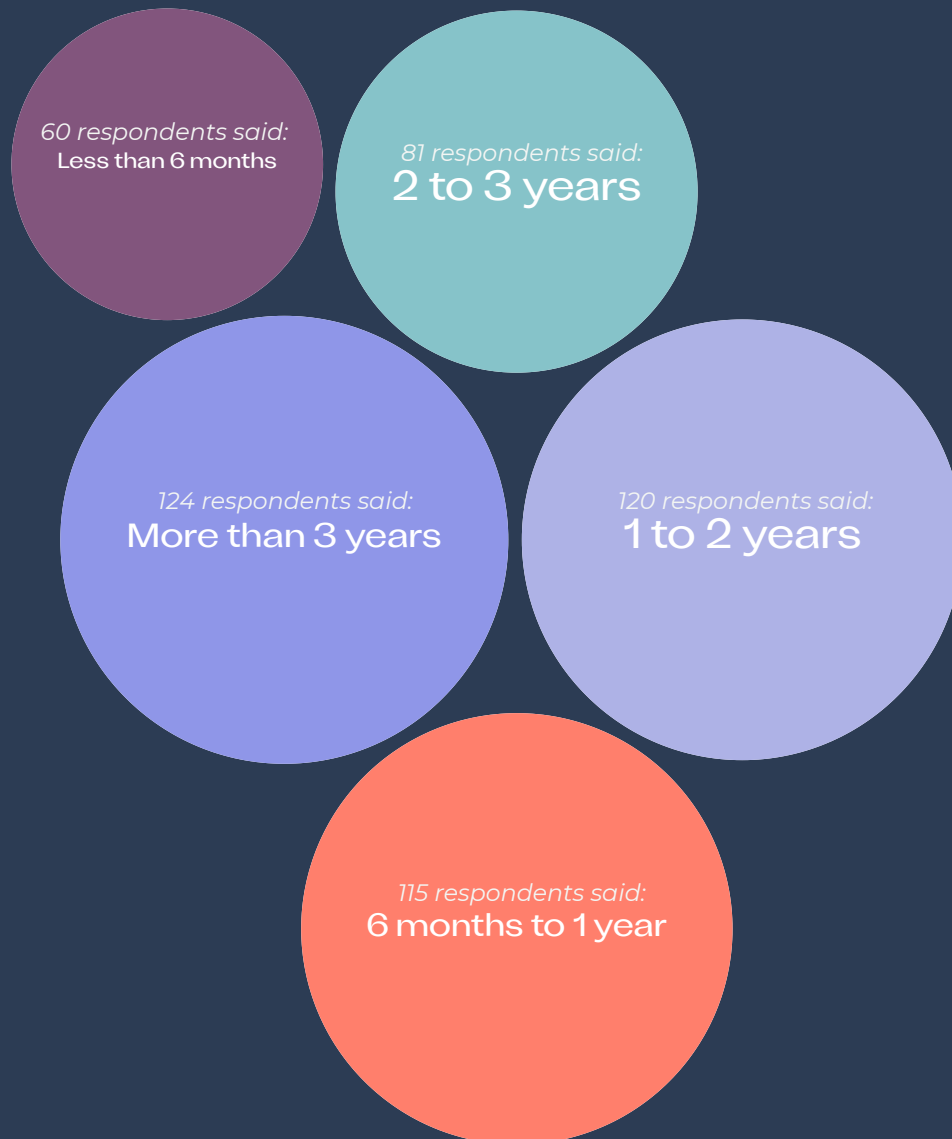


Methodology

We surveyed **500** respondents from Canada and the United States. All 500 respondents identified as female, and all had sought professional medical advice for fertility issues. While our sample included a diverse range of ages, the majority of respondents (74%) were 44 years old or younger.

All respondents were actively trying to conceive. 25% of respondents (n=124) reported trying for more than three years. 12% (n=60) had been trying for less than six months.

How long have you been trying to conceive?



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