Building Healthy Babies: A Mixed-Methods Needs Assessment for a Pre-Conception Program in Ontario

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ABSTRACT

Objectives: The objective of this study was to gather Ontario clinicians' and public members' views on the design of a pre-conception patient education program.

Methods: In this mixed-methods study, online surveys comprised of rank order, multiple choice, and short answer questions were completed by clinicians and public members. Semi-structured focus groups consisting of 2–6 participants each were then held via videoconference. Demographic variables and survey responses were analyzed quantitatively using descriptive and summary statistics. Descriptive thematic qualitative analysis using the constant comparative method of grounded theory was completed on each transcript to generate themes.

Results: A total of 168 public members and 43 clinicians in Ontario completed surveys, while 11 clinicians and 11 public members participated in the focus groups. A pre-conception program in Ontario was felt to be important. An individual appointment with a primary care provider was the favoured program format per survey responses, whereas a virtual format with an interactive component was preferred among focus group participants. Important topics to include were pre-conception health (infertility, genetic screening, folic acid), prenatal and postpartum counselling (diet, activity, substance use, prenatal care, postpartum course), and medical optimization in pregnancy (high-risk medical conditions, medications, mental health). Both groups emphasized the need to consider accommodations for marginalized populations and various cultures and languages.

Conclusion: A standardized pre-conception patient education program is felt to be of high value by Ontario clinicians and public members. A pre-conception program may help improve obstetrical outcomes and decrease rates of major congenital anomalies in Ontario.

Keywords: obstetrics and gynecology; patient education; public health; pediatrics; qualitative; survey

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Disclosures: This study was funded by a Mount Sinai Hospital-University Health Network AMO Innovation Fund Grant (Grant Number: 410014879).

C. Jones is the program director for the GREI Fellowship at the University of Toronto. The fellowship fund, which supports academic endeavours, receives payments from EMD Serono Canada and Ferring Canada.

E. Cohen is a member of the Committee to Evaluate Drugs, which provides advice to Ontario's Ministry of Health on public drug policy.

Each author has indicated they meet the journal's requirements for authorship.

Received on December 11, 2023

Accepted on February 8, 2024

Available online February 23, 2024

RÉSUMÉ

Objectif : L'objectif de cette étude était de recueillir les points de vue des cliniciens et des membres du public de l'Ontario sur la création d'un programme préconceptionnel d'éducation des patientes.

Méthodes : Dans cette étude à méthodes mixtes, les cliniciens et les membres du public ont répondu à une enquête en ligne comprenant des questions à choix multiples, des questions à réponses courtes et des questions d'ordre de préférence. Des groupes de discussion semi-structurée composés de 2 à 6 participantes chacun ont ensuite été organisés et tenus par vidéoconférence. Les variables démographiques et les réponses à l'enquête ont été analysées quantitativement à l'aide de statistiques descriptives et sommaires. Une analyse descriptive thématique qualitative a été réalisée, par méthode comparative constante de la théorie ancrée, sur chaque transcription afin de générer des thèmes.

Résultats : Au total, 168 membres du public et 43 cliniciens de l'Ontario ont répondu à l'enquête; 11 cliniciens et 11 membres du public ont participé aux groupes de discussion. La mise en place d'un programme préconceptionnel en Ontario a été jugée importante. Un rendez-vous individuel avec un prestataire de première ligne était le format de programme préféré selon les réponses à l'enquête, tandis qu'un format virtuel avec une composante interactive était préféré dans les groupes de discussion. Les thèmes importants à inclure étaient la santé préconceptionnelle (infertilité, dépistage génétique, acide folique), les conseils prénataux et post-partum (alimentation, activité physique, consommation de substances psychoactives, soins prénataux, cours post-partum) et l'optimisation médicale pendant la grossesse (problèmes de santé à risque élevé, médicaments, santé mentale). Les deux groupes ont souligné la nécessité d'envisager des accommodements pour les populations marginalisées et les différentes cultures et langues.

Conclusion : Les cliniciens et les membres du public de l'Ontario estiment qu'un programme préconceptionnel normalisé d'éducation des patientes est d'une grande valeur. Un programme préconceptionnel pourrait contribuer à améliorer les résultats obstétricaux et à réduire le taux d'anomalies congénitales majeures en Ontario.

J Obstet Gynaecol Can 2024;46(6):102417

https://doi.org/10.1016/j.jogc.2024.102417

INTRODUCTION

Major congenital abnormalities (MCA) affect 3%–5% of Ontario newborns.[1,2] It is estimated that over 50% of these anomalies can be prevented through pre-conception counselling and education on modifiable risk factors that address medical, genetic, environmental, infectious, and lifestyle determinants of prenatal health. Preconception counselling well ahead of pregnancy can provide patients with opportunities to receive education on healthy behaviours, update their vaccinations, start folic acid supplementation, receive nutritional counselling and engage in substance use cessation if needed.[3] It can also be an opportunity for individuals living with chronic conditions to obtain guidance on the safety profile of their medications.[3,4] Increasingly available genetic screening panels, such as expanded carrier screening (ECS), can also allow prospective parents to screen for hundreds of inheritable genetic diseases simultaneously.[5] Given the significant impact of MCAs on patients, families, and healthcare resource utilization, it is important to increase awareness of preventive measures that can optimize the health of a pregnancy amongst those of reproductive age.

While many patients rely on primary care and obstetrical care providers to deliver pre-conception care, studies have demonstrated variability in how care is delivered between providers, ranging from opportunistic to routine, and uncertainty regarding which group of healthcare professionals is best placed to deliver this care.[6] A standardized public education program centred around the pre-conception period could address these inconsistencies and close this gap in patient care.

The objective of this study is to gather stakeholder opinions to inform the development of a pre-conception program in Ontario aimed at decreasing the incidence of pregnancy complications and MCA. Data was collected through an online survey and focus groups administered to clinicians and public members.

METHODS

Design and Participant Recruitment

This study was approved by the Research Ethics Board (REB) at Mount Sinai Hospital (REB 20-0150-E), Unity Health Toronto (REB 21-095C), and the Hospital for Sick Children (REB 1000076433).

Part 1: Survey

A novel survey was developed for the purposes of this study, given the absence of existing validated surveys that answered our specific research questions. Two versions of the survey were created for 1) clinicians and allied healthcare personnel with expertise related to pre-conception and antenatal care, and 2) members of the general public in Ontario (online Appendix 1 and 2). The survey was openly accessible online and advertised through social media, email lists, and posters in healthcare facilities. Completion of the survey was voluntary with informed consent provided. Surveys included a combination of rank order list questions and questions rating items on a Likert scale from 1 (most important) to 5/6 (least important). Descriptive analysis was used to summarize study participant characteristics. Survey response data was analyzed using summary statistics.

Part 2: Focus Groups

A convenience method of sampling was used to recruit public members from survey respondents. Purposive sampling was employed to recruit clinician focus group participants on the basis of their clinical area of expertise.

To be considered eligible, participants were required to be at least 18 years old and capable of communicating in English. All participants provided informed written consent to partake in the study.

Focus group meetings consisting of 2–6 participants each were held over videoconference lasting between 60–90 minutes. The discussion was directed by a female moderator (AL), who holds an MD and was a resident physician in Obstetrics & Gynaecology at the time of the study. Guidance on qualitative inquiry was provided by members of the research team (CJ, AS) with experience in qualitative methodology. A semi-structured interview guide with open-ended questions was developed by the research team and used during the discussions (online Appendix 3). Focus group meetings were audio recorded, transcribed verbatim, and anonymized. Meetings were not repeated. Field notes were not made after the interviews. Transcripts were not returned to the participants for comment.

Descriptive thematic analysis using the constant comparative method of grounded theory was performed on each transcript. Two independent investigators (AL, VMM) used inductive coding to identify important concepts in the text. VMM was a medical student with an MSc in epidemiology at the time of the study. Discrepancies among selected codes were discussed and resolved by a third investigator (CJ), who has an MD and experience in qualitative research. A coding tree was created with codes organized by category and clearly defined. Data collection concluded when data saturation was reached, which was defined as the point at which the ongoing analysis of new data no longer brings forward any new insights to modify the emerging theory.[7] Reflexive thematic analysis was then performed to evaluate the relationships between codes and generate a final set of themes.

RESULTS

Demographics

Between October 2021 and February 2022, 43 clinicians and 168 public members completed the survey. The majority of clinician respondents were family physicians (n = 17, 40%) and obstetrician-gynaecologists (n = 12, 28%). The majority worked in a city with an average population of over 100 000 people (n = 38, 88%). Among public members, the mean age of survey respondents was 35 years (range 22–49). The majority of participants completed post-secondary education, had an annual household income of $125,000 and over (n = 95, 57%), and lived in a city with a population of >100,000 people (n = 153, 92%). In total, 54% of respondents previously had a term live birth (n = 68) and 38% previously had a first trimester pregnancy loss (n = 49). Full demographic characteristics of this cohort are depicted in Figures S1 and S2 (online Appendix).

Eleven clinicians and 11 public members across Ontario participated in the focus groups. Participants included 2 general obstetrician-gynaecologists, 1 MFM specialist, 1 REI specialist, 3 family medicine obstetrics providers, 1 genetic counsellor, 1 nurse practitioner, 1 pediatrician, and 1 psychiatrist specializing in perinatal mental health.

Part 1: Survey

Pre-Conception Program Importance

Respondents were asked to rate the importance of a publicly available pre-conception program on a scale of 1 (most important) to 5 (least important). In the clinician survey, most respondents rated the importance of a public pre-conception program as 2 (n = 17, 40%), whereas the majority of public member survey respondents rated the importance of a pre-conception program as 1 (n = 90, 54%) (Table).

Pre-Conception Program Goals

Clinicians (n = 43) were asked to rank pregnancy outcome goals of a pre-conception program on a scale of 1 (most important) to 5 (least important) (Figure S3; online Appendix). The top-ranked goal was to decrease the rate of pregnancy complications (n = 18, 41%).

Pre-Conception Program Format

All respondents were asked to rank their top 5 choices for preferred program format out of 10 options. In both the clinician and public survey, the most frequently selected number one choice was an in-person individual appointment with a primary care provider (n = 13/44, 30% and n = 42/165, 26%, respectively) (Figure S4A, Figure S4B; online Appendix). Sub-group analyses showed no significant differences in opinion between respondents aged ≥35 versus those <35.

Pre-Conception Education Topics

All respondents were asked to rate the importance of multiple topics in a pre-conception program on a scale of 1 (most important) to 5 (least important). Among clinicians, the top-rated topics were folic acid (n = 32/44, 73%), recreational drug use (n = 31/44, 71%), tobacco smoking (n = 31/44, 71%), and pre-existing medical conditions (n = 28/44, 64%) (Figure 1A). Among public members, the most frequently top-rated topic was folic acid (n = 50/164, 31%), followed by

Table. Clinician (n = 43) and public respondent (n = 167) ranking of the perceived importance of a pre-conception patient education program

Rating	Number of clinician respondents (%)	Number of public respondents (%)
1	12 (28%)	90 (54%)
2	17 (40%)	18 (11%)
3	9 (21%)	13 (8%)
4	5 (12%)	17 (11%)
5	0 (0%)	29 (17%)

lifestyle measures (n = 26/164, 16%), mental health screening/treatment (n = 21/164, 13%) and pre-existing medical conditions (n = 18/164, 11%) (Figure 1B). Subgroup analyses showed no significant difference in the responses from those age ≥35 compared to those <35.

Pre-Conception Program Challenges

Clinicians were asked to rank their top 5 potential obstacles (1 = Most challenging, 5 = Least challenging) in the development of a pre-conception program. The top-ranked challenge was that patients could not participate if their pregnancy was unplanned (n = 16/44, 37%) (Figure S5; online Appendix).

Part 2: Qualitative Focus Groups

Reasons for the Need for a Pre-Conception Program

Reliable Patient Information Source. Both public members and clinicians felt that there is a current lack of reliable, evidence-based patient information about fertility and pregnancy. Public members often sought information from online sources with questionable validity or by word-of-mouth through friends and family. As one participant explained, “The Internet is like the Wild West and there’s so much, and it’s very overwhelming” (participant 12). Clinicians similarly emphasized the need for an evidence-based official source of patient information. One clinician expressed, “I would be much more satisfied with my practice if I felt like I had a very reliable resource to direct patients to” (participant 2).

Optimization of Patient Care. Clinicians identified different ways in which patient care could be optimized through a pre-conception program. One particular concern was that many patients are already beyond the first trimester, a critical period in fetal development, by the time they reach the care of their obstetrical provider. One explained, “I think, by the time I see the patients they’re already usually 12 weeks, and any kind of early optimization is... a bit late” (participant 2). Providers also noted a high degree of repetition during initial prenatal appointments due to common questions and similar education topics between patients. A standardized pre-conception program was also felt by clinicians to be a possible solution for a lack of standardization and consistency in the provision of pre-conception care.

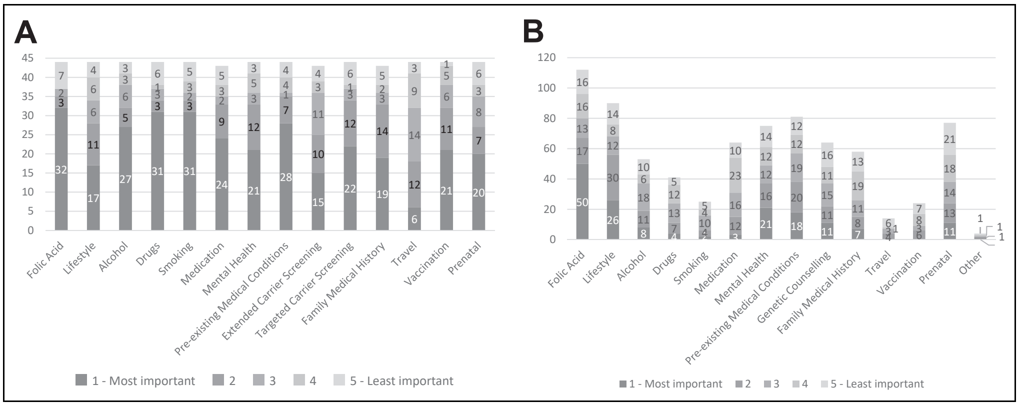
Topics to Include in a Pre-Conception Program

Fertility and Pre-Conception Investigations. Public participants strongly felt that a pre-conception program should contain information about fertility and conception, such as the menstrual cycle, methods of tracking ovulation, and fertility treatment options. One of the most significant recurring ideas was the importance of education on parental genetic screening. One clinician also felt that, for the purposes of decreasing rates of congenital anomalies in newborns, the most important thing to teach patients about was ECS. However, the cost restraints and low positive test rate of this were acknowledged.

Prenatal and Postpartum Course. Both groups felt that it would be important to include an overview of prenatal care and standard patient education topics. Examples given were diet (caffeine), activity, infectious teratogens, travel, substance use (tobacco, alcohol, illicit drugs), and social considerations (finances, healthy relationships, social supports). Suggested content for prenatal care included the frequency of prenatal visits, routine investigations, and screening options for fetal anomalies. Among public members, particular emphasis was placed on the first trimester as a time when they felt particularly vulnerable, especially in those who had previously experienced early pregnancy loss. One participant explained, “I found [that]... the first trimester was a place where there was very little... handholding, so you’re kind of on your own for the most of it” (participant 21). Both groups endorsed that information about pregnancy loss and related resources would be important to include in a pre-conception program. Postpartum information on newborn care and breastfeeding was also felt to be important to include.

Medical Optimization in Pregnancy. Participants believed that there should be information on how to optimize overall maternal health in pregnancy, such as folic acid and vaccination. Information tailored toward patients with

Figure 1. (A) Clinician survey results for topics to include in a pre-conception program. (B) Public survey results for topics to include in a pre-conception program.



pre-existing medical conditions, such as diabetes, and medication safety in pregnancy, was also highly valued. Several participants referenced the discontinued "Motherisk" drug safety program through The Hospital for Sick Children in Toronto, expressing a wish for a similar resource.

A dominant theme that emerged was the topic of perinatal mental health. Participants desired information about psychiatric optimization for those with previous diagnoses, risk factors for postpartum depression, and mental health resources for patients. Clinicians voiced concerns particularly around psychotropic medications and the potential for patients to discontinue them unnecessarily during pregnancy. One explained, "I have patients who discontinue their medications, and then have... a terrible... depressive episode and are scared to go back on it and the advice that they get is a little bit varied" (participant 1).

Pre-Conception Program Format

Virtual Mode of Delivery. Overwhelmingly, both groups felt that an online virtual format would be the best method to deliver a pre-conception program. Reasons cited for this were increased accessibility, efficiency, and user reach to more remote locations. Moreover, participants valued flexibility in an online program that could cater to different learning styles.

Interactive Component. Seven public participants reported a desire for an interactive component in a pre-conception program, with most expressing interest in a group format. Reasons cited for this were wanting a sense of community and a social support network. One described, "I think [a] group session is nice to kind of get other people's perspectives, and to normalize your feelings" (participant 17).

Accessibility Considerations. A particular area of concern was ensuring equitable access for marginalized communities, such as low socioeconomic and new immigrant populations. Participants stressed that efforts should be made to target advertising toward these groups. One explained, "I do think that . . . the marginalized population is crucial because others will know how to look for this information out there... [and] those who are more marginalized will not" (participant 6). Both groups also emphasized that a program should be available in multiple different languages and provided in a culturally sensitive manner.

DISCUSSION

This study demonstrates that both clinicians and public members believe that a pre-conception patient education program would be of value to the reproductive population of Ontario. Clinicians expressed that a pre-conception education program could serve to optimize health in pregnancy and reduce the risk of congenital anomalies and complications. Public members agreed that such a resource would be of significant benefit by providing a standardized patient resource with validated information. Topics to include fell under themes of fertility and pre-conception investigations, the prenatal and postpartum course, and medical optimization in pregnancy. The preferred program format varied with survey data favouring in-person appointments with a primary care provider, compared to focus groups which indicated preference for a virtual interactive setting. The main challenge of a pre-conception program is that people with unplanned pregnancies may not be able to participate.

While there are many available sources for prenatal and fertility information, there does not yet exist a standardized patient resource centred around pre-conception health that is widely accessible to the general public in Ontario. Multiple systematic reviews have evaluated the impact of pre-conception interventions implemented in other high-income countries such as the Netherlands, Australia, and the United States.[8-10] Although these countries differ from Canada in their mixed public and private healthcare systems, increases in patient knowledge and behaviour modification have been seen when programs involving both general and individualized pre-conception health education have been implemented.[8-10] These studies, however, are limited by insufficient data on direct pregnancy outcomes. Studies evaluating the implementation of similar prenatal education programs through public health units in Ontario have also shown promising results, with patients demonstrating significant increases in their mean knowledge scores and high satisfaction scores.[11] Given the inconsistencies in primary care access and emerging health issues among the reproductive population of Ontario, such as rising rates of cannabis use and obesity, a pre-conception program may serve to bridge critical gaps in health equity and access.[12-14]

While many of the pre-conception topics identified in our study fall within the scope of standard perinatal education, the concept of parental genetic screening was emphasized as an under-recognized topic with the potential to directly impact rates of MCAs. Although population-based genetic screening is available in Canada, ECS is associated with financial barriers, ethical implications, and differing levels of public awareness that may limit its usage. Uptake of ECS is higher in patients who received genetic counselling prior to pregnancy and in the early first trimester,[15] suggesting that there may be an opportunity to increase patient awareness of this option through pre-conception education.

CONCLUSION

A standardized pre-conception patient education program may help improve obstetrical outcomes and decrease rates of major congenital anomalies in Ontario. Topics related to conception, expectations during the perinatal course, and medical optimization prior to and during pregnancy were felt to be of the highest value to include. The findings from this cohort suggest that a virtual mode of delivery with an interactive group component may be most effective, with emphasis on optimizing access to marginalized patient populations.

SUPPLEMENTARY DATA

Supplementary data related to this article can be found at https://doi.org/10.1016/j.jogc.2024.102417.

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