

# Defining Transition Success for Young Adults with Inflammatory Bowel Disease According to Patients, Parents and Health Care Providers

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## Abstract

**Background:** The transition from pediatric to adult care is associated with changes centered around the patient taking responsibility for their health. As the incidence of childhood-onset inflammatory bowel disease (IBD) is increasing, it is important to address gaps in transition literature—specifically, the indicators signifying achievement of transition success. The study objective was to define transition success according to patients, parents, and health care providers involved in IBD transition.

**Methods:** This study used the method of qualitative description to conduct semi-structured interviews with patients, parents, and health care providers. During interviews, demographic information was collected, and interviews were recorded and transcribed. Data analysis was conducted independently of each group using latent content analysis. Participant recruitment continued until thematic saturation was reached within each group.

**Results:** Patients, parents, and health care providers all defined transition success with the theme of independence in one's care. The theme of disease management emerged within parent and provider groups, whereas the theme of relationship with/ trust in adult care team was common to patients and parents. Additional themes of care team management, general knowledge, care stability, and health outcomes emerged within specific groups.

**Conclusion:** This study demonstrated differences between how patients, parents, and health care providers view transition success. This finding reveals the value of using a multifaceted definition of transition success with input from all stakeholders. Further research should prioritize the identification of factors common to patients who do not reach transition success as defined by patients, their parents, and providers.

**Keywords:** *Continuity of care; Transition to adult care; Qualitative research*

## INTRODUCTION

Patients with inflammatory bowel disease (IBD) diagnosed in childhood or adolescence need to adjust to the changes of moving from pediatric to adult care. This period of gradual change of care from the pediatric system where the emphasis is on parental involvement to the adult system where patient independence is essential is known as transition of care (1,2). During transition, patients begin to take responsibility for their health rather than relying on parents or caregivers for disease management (3). Transition often overlaps with life events such as starting post-secondary schooling or employment, moving out or away from family, and financial independence (1,4). These additional stressors may diminish patients' ability to take responsibility for their own health by contributing to feelings of being overwhelmed.

IBD presents most commonly in the mid 20s and 30s (5); however, approximately 25% of patients are diagnosed in childhood (6–8). Furthermore, the incidence of childhood-onset IBD is increasing in western countries (5,9,10). When compared with those diagnosed as adults, patients diagnosed in childhood present more often with extensive disease and more frequently having perianal disease and/or upper gastrointestinal involvement (2,11). Additionally, these patients are more likely to be admitted to hospital and less adherent with clinic appointments (2,12). Due to the risks and complexity of a pediatric IBD diagnosis, a smooth, uninterrupted transition to adult care should be a priority.

Within the literature, the importance of transition readiness has been widely recognized (6,13), and although most studies have highlighted the specific skills needed to be successful, they tend to not specifically define a successful

transition (14–16). Because transition is a collaborative process involving the coordination of multiple stakeholders (17), a robust and comprehensive definition of success could be developed by engaging key stakeholders. We conducted this research based on the belief that establishing effective recommendations for defining transition success requires consulting patients, their parents, and health care providers.

## METHODS

### Study Design

This study used naturalistic inquiry to address the research question: “What is transition success according to patients, parents, and health care providers involved in IBD pediatric to adult care transition?” Naturalistic inquiry aims to study events in their natural state with no pre-selection or manipulation of variables (18,19). In theoretical alignment with this approach, qualitative description is considered the best method for this study (18). The goal of qualitative description is to stay close to the data by presenting facts in everyday language (18,20,21). This study was conducted by a student researcher (A.B.) as part of a graduate thesis.

### Study Population

This study recruited participants using purposive sampling from three different stakeholder groups—patients, parents, and health care providers (22). Participants were recruited from IBD clinics in Edmonton and Calgary, Alberta, Canada. Additional providers were recruited from British Columbia, Canada. Patients were identified through clinical records if they had transitioned to adult care from 2018 to 2020 and if they were diagnosed with IBD at least a year prior to transitioning. Patients were excluded if they had comorbidities unrelated to IBD. Parents of these patients were excluded if they had another child with a chronic disease other than IBD as it may be difficult to separate their experience with their other child. Providers included were pediatric and adult gastroenterologists or nurses with at least one year experience.

### Data Collection

Patients were approached in clinic by their gastroenterologist. Those who consented to being contacted were called by A.B. to further inform them about the study and answer any questions. Patients were informed that parents were also being recruited and if parents were interested, they should contact A.B. Providers with expertise in patients transitioning to adult care were recommended by the study’s authors. Providers were then contacted via email about study participation. All participants who expressed interest were emailed a recruitment letter, a study information sheet, and a consent form. After participants had time to read the material and ask any additional questions, a semi-structured interview was conducted either through Skype for Business, Google Meet or telephone, according to the preference of the participant. During the scheduled interview time, verbal consent was obtained and demographic information was collected. All interviews were conducted by A.B., tape-recorded and transcribed verbatim for data analysis using Microsoft Word 2010.

A separate interview guide was developed for each stakeholder group to achieve the aims: (a) to describe the stakeholders’ perspectives on what a successful transition looks like and (b) to describe stakeholders’ beliefs on how a successful

transition impacts long-term health outcomes and daily life. The interview guides are available in [Supplementary Material](#).

### Data Analysis

Data analysis was done concurrently with data collection using NVivo 1.2 (QSR International Pty Ltd., Melbourne, Australia) (23). This allowed for the identification of any areas that needed to be explored in subsequent interviews. Analysis of the transcribed interviews was done separately within each stakeholder group using latent content analysis, which is the process of identifying, coding, and categorizing patterns in the data (24,25). During the coding, A.B. highlighted sections of the transcribed interviews while making comments in the margins about what was salient in the data. When new codes emerged from subsequent interviews, all previously coded interviews were re-coded to reflect these new codes. Once no more codes seemed to emerge from the data, the researcher moved to grouping the codes into categories. After checking that the codes fit within categories with a critical friend (24), themes were formed to reflect how the categories related to one another. The role of a critical friend is to engage in ongoing discussions during analysis to ensure that conclusions come from interview data rather than the researcher’s assumptions. Additionally, all themes were then reviewed with AB’s supervisor—a gastroenterologist with direct experience caring for transitioning patients (K.K.)—to ensure conclusions were plausible. Recruitment was terminated within each group when thematic saturation was reached (26). Saturation is reached when there are no more themes emerging from the data (24,27). The identification of indicators that signify achievement of a successful transition was based on analysis of participants’ responses to questions about the key indicators they believe signify success, and/or the indicators that signify that their transition was successful.

### Establishing Trustworthiness

In qualitative research, the concept of rigor is suggested to be replaced with trustworthiness (28). Lincoln and Guba suggest four criteria for ensuring trustworthiness: credibility, transferability, dependability, and confirmability (28). Credibility was ensured through use of a critical friend (peer debriefing) and verifying/checking interpretations with participants throughout the interview. Transferability was addressed through providing a detailed description of the participants and setting of interviews. Dependability and confirmability were achieved through an audit trail where A.B. documented decisions, choices, and insights as it related to the study. Furthermore, this study was conducted by a graduate student (A.B.). A.B. practiced reflexivity throughout the study. As A.B. was in her mid 20s, time was spent reflecting on personal difficulties becoming an adult to ensure that any preconceived opinions did not influence the data. She also engaged in field notes after each interview to address any bias or opinions starting to form.

### Ethical Considerations

The study was approved by Research Ethics at all participating sites (University of Alberta: Pro00099184; University of Calgary: REB20-0979; University of British Columbia: H20-01722). Patients and parents were compensated with a \$15 electronic gift card as an appreciation for their contribution to the study.

## RESULTS

### Participant Demographics

Thematic saturation was achieved after 17 interviews in the patient group, 13 in parent group and 15 in the provider group. The median interview length for patient interviews was 29 min (IQR: 25–33); parent interviews was 35 min (IQR: 29–40); provider interviews was 30 min (IQR: 27–40). Demographics for each group are outlined in [Table 1](#).

### Transition Characterization

Patients and parents were asked if they would characterize their/their child's transition as successful or unsuccessful. Of the 17 patients interviewed, 16 indicated that they viewed their transition as successful. Ten parents thought that their child's transition was successful, whereas two thought it was unsuccessful, and one was undecided.

### Themes of Transition Success

Seven themes emerged from the interviews across the three groups: (a) independence in one's care, (b) disease management, (c) relationship with/ trust in adult care team, (d) care team management, (e) general knowledge, (f) care stability and (g) health outcomes. An additional theme of the impact of transition emerged within the interviews. Overlapping and themes exclusive to stakeholders are represented in a Venn diagram ([Figure 1](#)). Representative quotes from each theme have been outlined ([Table 2](#)).

#### *Independence in One's Care*

Independence in one's care was a theme that emerged across all groups as an indicator of successful transition. Seven parents, 12 patients, and 13 providers mentioned this theme. All groups mentioned the ability for patients to take responsibility and initiative for their care, including being able to self-advocate and ask questions. Additionally, patients making and attending appointments and having an awareness of what is happening in their care was deemed important. Nine of the providers interviewed emphasized the ability of patients to attend appointments on their own.

#### *Disease Management*

Eleven providers and seven parents described disease management as an indicator. This was characterized as patients adhering to prescribed medications and lab tests requested by providers, refilling prescriptions, and having the confidence to reach out when experiencing a disease flare up. Parents also highlighted the importance of being on medication that worked for the patient.

#### *Relationship With/Trust in Adult Care Team*

Twelve patients and nine parents described relationship with/ trust in the adult care team as an indicator. Patients reported feeling comfortable with their new care team, that they cared, took the time to get to know them, and was supportive of them as an indicator. Similarly, nine parents communicated that trusting and feeling comfortable with the new care team were indicators.

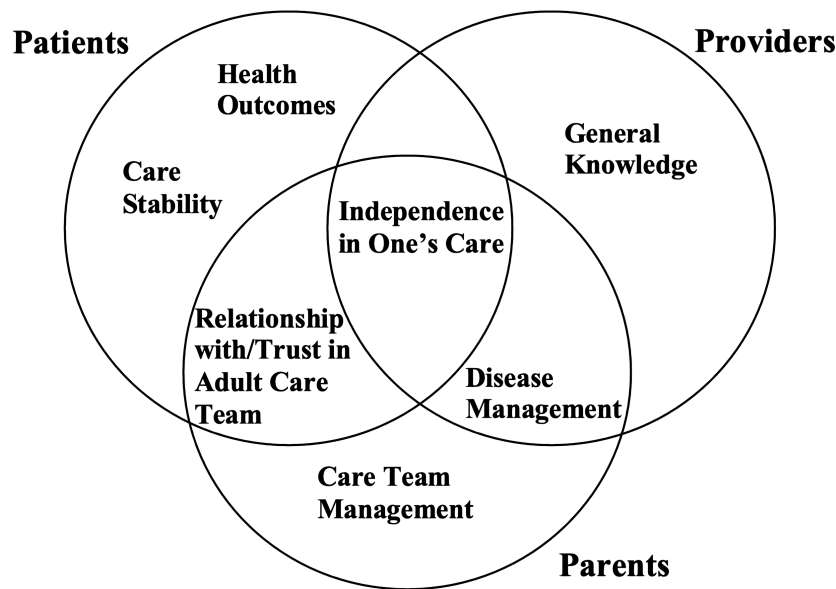
#### *Care Team Management*

Five parents mentioned how the adult care team managed their child's IBD as a determinant of transition success. Specifically, parents indicated that success required a care

**Table 1.** Demographics of patients, parents, and health care providers who participated in semi-structured interviews

| Demographics                     | Total N | n (%)     |
|----------------------------------|---------|-----------|
| Patients                         | 17      |           |
| Sex                              |         |           |
| Female                           |         | 10 (58.8) |
| Male                             |         | 7 (41.2)  |
| Diagnosis                        |         |           |
| Crohn's                          |         | 9 (52.9)  |
| Ulcerative colitis               |         | 8 (47.1)  |
| Age at diagnosis                 |         |           |
| 0–4                              |         | 0 (0)     |
| 5–9                              |         | 2 (11.8)  |
| 10–14                            |         | 5 (29.4)  |
| 15–17                            |         | 10 (58.8) |
| Location of clinic               |         |           |
| Edmonton                         |         | 8 (47.1)  |
| Calgary                          |         | 9 (52.9)  |
| Occupation                       |         |           |
| Post-secondary student           |         | 10 (58.8) |
| Continuing education student     |         | 2 (11.8)  |
| Full-time employment             |         | 5 (29.4)  |
| Parents                          | 13      |           |
| Relationship to Patient          |         |           |
| Mother                           |         | 13 (100)  |
| Father                           |         | 0 (0)     |
| Child Living Situation           |         |           |
| Lives with parent                |         | 5 (38.5)  |
| Does not live with parent        |         | 8 (61.5)  |
| Highest Education Level Attained |         |           |
| High school                      |         | 5 (38.5)  |
| Certificate                      |         | 2 (15.4)  |
| Diploma or undergraduate degree  |         | 5 (38.5)  |
| Master's degree                  |         | 1 (7.7)   |
| Providers                        | 15      |           |
| Sex                              |         |           |
| Female                           |         | 11 (73.3) |
| Male                             |         | 4 (26.7)  |
| Location                         |         |           |
| Calgary, Alberta                 |         | 5 (33.3)  |
| Edmonton, Alberta                |         | 6 (40.0)  |
| British Columbia                 |         | 4 (26.7)  |
| Job title                        |         |           |
| Adult gastroenterologist         |         | 5 (33.3)  |
| Pediatric gastroenterologist     |         | 2 (11.8)  |
| Adult IBD nurse                  |         | 6 (40.0)  |
| Pediatric IBD nurse              |         | 1 (6.7)   |
| Years of experience              |         |           |
| 0–5                              |         | 2 (13.3)  |
| 6–10                             |         | 6 (40.0)  |
| 11–15                            |         | 4 (26.7)  |
| 16–20                            |         | 1 (6.7)   |
| 21–25                            |         | 1 (6.7)   |
| 26–30                            |         | 1 (6.7)   |

IBD, Inflammatory bowel disease.



**Figure 1.** Venn diagram showing themes of transition success that emerged within each stakeholder group.

team that understood that their child was coming from a different care system and might need additional guidance and support. One parent described their child's adult care team as being flexible about the demands of attending post-secondary education. Additionally, parents thought attentiveness and regular follow-up from the team were important determinants of a successful transition.

### *General Knowledge*

Seven providers mentioned general knowledge was key. The patient having knowledge and an understanding of their current and past medication and disease history was mentioned by five providers.

### *Care Stability From Provider*

Seven patients highlighted having a doctor who is readily available and regularly checks in to provide consistent follow-up. Six patients further described a continuity of care in terms of no loss to follow-up from pediatric to adult care.

### *Health Outcomes*

Thirteen patients mentioned their health remaining stable as an indicator. Patients also mentioned that finding and adhering to the appropriate medication for controlling their disease were important. Two of these patients who were not in remission at time of transition said they were hoping to reach remission by the end of transition and that would indicate successful transition.

### *Impact of Transition*

Providers highlighted that achieving success in transition will serve as a foundation in the patient's care. They mentioned that patients will know who to reach out to when they encounter health problems, have more confidence, feel more supported in their care, and adhere to medications. Providers and patients said they believed that unsuccessful transition could impact a patient's mental health through increasing both general and social anxiety, and feelings of depression.

All groups said they believed that if transition is unsuccessful, a patient would likely experience health deterioration such as more frequent disease flare ups, abdominal pain, and disease progression with the eventual need of therapy escalation. All groups expressed the belief that health deterioration lowers the quality of life through more frequent feelings of tiredness, stress, and low energy levels. All groups indicated that such feelings would negatively impact patients' employment, schooling, and relationships. One patient speculated that if their transition had been unsuccessful, "I would probably be very much struggling in school. There is no way I would keep up with sports and I think that I would just sleep all day...". Another patient said "I think it would be difficult every day. When I have a flare, I don't have energy to do school, I don't feel comfortable leaving the house..." .

## **DISCUSSION**

This qualitative description study is the first to engage multiple stakeholders involved in IBD care using semi-structured interviews. We identified seven themes to define successful transition; some of which have been identified in other studies. Van den brink et al. conducted a three stage Delphi study with patients and providers to identify indicators of successful transition in IBD (29). Their study demonstrated a unified agreement on six items related to self-management skills and autonomy, and two items related to health-related quality of life and patient satisfaction about the transition process. Self-management skills and autonomy showed similarity to our theme of independence in one's care. In this Delphi study, patients and providers rated "independent attendance at outpatient clinic" low when compared with the other items. In our study, providers emphasized the ability of patients to attend appointments alone. This difference may reflect cultural differences as most participants for the Delphi study were recruited from Europe, whereas our study recruited participants from Western Canada.

Our provider interviews revealed themes of independence in one's care, disease management, and general knowledge,

**Table 2.** Representative quotes from each theme according to patients, parents, and health care providers

| Theme                                      | Group                 | Quotations   |
|--|-----------------------|--|
| Independence in One's Care                 | Patients              | <p>"It's nice having more responsibility with my appointments... when I get news and stuff, I get the phone calls and it's not to my mom anymore."</p> <p>"I would say definitely be more a part of your care, not saying that as a pediatric patient you can't but be really constant in your own care and ask as many questions as you need to, whether it is about the care you'll be getting or if you have concerns about your health and just ask questions and be part of your own care as much as possible."</p> <p>"Someone who is definitely more aware of their body and who is checking in with themselves, who can take that responsibility because you're not a kid anymore you can check in with yourself, being prepared, and comfortable doing that."</p> |
|  | Parents               | <p>"... the amount of administrative work on part of patient to manage setting up all appointments and making sure blood tests are done and making sure that all stool samples are done and sent in and correctly done."</p> <p>"I think it is booking their appointments, going to the doctors on their own - maybe procedures on their own."</p>   |
|  | Health Care Providers | <p>"Taking on that care versus having mom and dad tell them to do everything."</p> <p>"Patient is booking their own appointments, attending all those appointments and not missing them."</p> <p>"Advocate for themselves is also important and not relying on their parents to be their voice."</p>   |
| Disease Management                         | Parents               | <p>"That they will call and make an appointment when they are not feeling well."</p> <p>"She is finally on a medication that works."</p>   |
|  | Health Care Providers | <p>"They are taking their medications as they are prescribed, they know how to refill their medications and can keep track of that."</p> <p>"Basically, compliant with all the factors that they have to do with managing their disease - educated on it, being compliant with their infusions, labs and appointments and side effects, being aware of what triggers to look for, what side effects and when to call for help and therefore, avoiding flares, hospitalizations, and more recent flares"</p>  |
| Relationship with/Trust in Adult Care Team | Patients              | <p>"I can be open to talk and not be judged because I know that she knows it's tough going through transition from doctor to doctor and she wanted to make sure I felt comfortable."</p> <p>"I have found a doctor that doesn't have that judgement and understands that I'm younger and trying to deal with it all."</p> <p>"She asks not just how I'm doing with my disease but my personal life, so I thought that was very reassuring."</p> <p>"I just really wanted a doctor that I was close and comfortable with and someone who got to know me on a personal level."</p> <p>"The feeling of them taking the time to care. It's not just a job to them, they care for sure."</p>  |
| Care Stability                             | Parents               | <p>"We've found a doctor who we liked, who jived with us. We didn't ever once feel like we were out of place with that doctor ..."</p> <p>"Well, she has found a physician she is comfortable with. Flat out being the nurse that she speaks to and where she goes is exceptional and has taken her concerns seriously."</p> <p>"I would define it as gaining good rapport to all of the doctors."</p>   |
|  | Patients              | <p>"There being no drop off in your own health because of the change. I think that there should be same amount of contact with doctors."</p> <p>"The nurse checks up on me here and there and I haven't found that I have slipped through the cracks, which I heard can happen to kids."</p> <p>"Constant contact is still there and any issues I've had are addressed. I never felt like my health has gotten out of control because I didn't have access to anything."</p> <p>"They just never stopped being continuous with how I am feeling even if they don't see me for six months, they stay on top of that kind of stuff, which is great."</p>   |
| Health Outcomes                            | Patients              | <p>"I don't think my symptoms deteriorated in anyway..."</p> <p>"I never felt like my health has gotten out of control..."</p> <p>"I was hoping that I could be in remission and just get it all under control."</p>   |
| Care Team Management                       | Parents               | <p>"There was really not one blip in his care. Not one missed Remicade because no communication."</p> <p>"They made it easy - "oh he is going to school?" "Yup" "We can work this around his school schedule. We can work it around where he is living."</p>   |
| General Knowledge                          | Health Care Providers | <p>"What is their overall understanding of medications if they are on medications in terms of the overall safety and effectiveness of those medications."</p> <p>"He knew the importance of how these medications can maintain health and prevent any complications of his Crohn's disease and we had a very successful transition."</p> <p>"Having knowledge about what their disease is, and you know past medications and experiences that they've had related to disease and being able to talk openly about it."</p>  |

similar to other published studies in IBD and sickle cell disease (30,31). These studies revealed themes of health care utilization, health outcomes, quality of life, and a stable disease trajectory. The theme of healthcare utilization had similar components to our theme of independence in one's care and disease management because it incorporated the importance of the patient making and attending appointments, having recommended lab tests, and adhering to medications. Health outcomes were a theme that emerged with patients and was similarly characterized as health remaining stable throughout transition. Although the theme of quality of life did not emerge in our study as an indicator of success, it was highlighted as being influenced by successful transition.

Compared to a U.S. study that interviewed providers, patients and parents about transition success in type 1 diabetes, our results demonstrated some parallels with similar categories of appointment attendance and disease knowledge (32). Another theme that emerged, described as navigating a new health care system, was characterized in part by forming a relationship with the adult provider. Our analysis identified relationship and trust as a theme in and of itself; our participants may have more strongly emphasized its importance. The U.S. study identified additional themes: balancing care with other adult roles, such as socializing and schoolwork; and taking ownership for their disease. Several differences between the U.S. study of diabetic patients and our study of IBD patients should be highlighted. The age range of participants in the U.S. study was 18 to 25 years, in contrast to our study with 18 to 20 years. In the United States, pediatric patients can transition to adult care into their 20s, whereas in Canada, patients need to transition before their 18th birthday. As a result, patients from the U.S. study may be more mature and may have developed greater independence prior to transitioning. Additionally, the U.S. study combined interviews across stakeholder groups to determine when saturation was reached (themes potentially being driven by a dominant group), whereas we aimed to achieve saturation within each stakeholder group, potentially resulting in more consensus within each stakeholder group and more divergence across groups.

This research highlights the differences between how each stakeholder group characterizes successful transition. We believe that a key difference is the theme of relationship with/trust in the adult care team, which was common to patients and parents. When interviewed, many participants commented on the close relationship they had with their pediatric team and how they had hoped to develop a similar relationship with the adult team, which echoes the literature on transition in chronic diseases (33,34). Adult care providers who strive to offer successful transition experiences could prioritize getting to know their transitioning patients and striving to make them feel understood. Transitioning patients who feel that they have developed a secure relationship with their new team may reach out earlier when they have a concern related to their disease.

The finding that different themes emerged from the stakeholder groups suggest that only focusing on the opinions of one group could result in a failure to recognize themes important to other stakeholders. Although health outcomes were a theme that emerged within the patient stakeholder group, most providers cautioned against using this as a sole measure of transition success. Specifically, providers pointed out the natural fluctuations of disease activity (35) and how a patient

who has had a smooth transition may still experience a disease flare up. A comprehensive assessment of transition success, therefore, should use health outcomes in conjunction with the other themes of success, such as those identified in this study.

Selection bias is a potential limitation to this study. Individuals who viewed their transition as successful may have been more likely to agree to participate, whereas those who viewed their transition as unsuccessful may have declined to participate, perhaps wanting to avoid reflecting on this experience. All health care providers specialized in IBD and so these results may not reflect the opinions of general gastroenterologists. Further limitations include only mother's perspectives within the parent stakeholder group, and absence of information about ethnicity/race or socioeconomic status.

The strength of this manuscript is that it explores the various stakeholders' perspectives on indicators of successful transition. We recommend that future research focuses on measuring the identified indicators—potentially through administering a questionnaire with quantifiable scales or indices. This definition of transition success should be used both clinically to ensure patients have achieved success and in research to systematically evaluate transition interventions to allow for the development of an optimal transition program. Future research should also attempt to identify factors that impede transition success and hopefully provide the opportunity to meaningfully intervene to facilitate a successful transition.

## Supplementary Data

Supplementary data are available at *Journal of the Canadian Association of Gastroenterology* online.

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## Conflict of Interest

No conflict of interest to declare.

## Authors' Contributions

A.B.: study design, data collection, data analysis and writing of manuscript; N.H.: participant recruitment and revisions of manuscript; C.S.: participant recruitment and revisions of manuscript; K.G.: consultation on study design and revisions of manuscript; E.W.: co-supervisor of A.B., consultation on study design and revisions of manuscript; and K.K.: supervisor of A.B., consultation on study design, and data collection, and revisions of manuscript.

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