# CLINICAL CARE AND TECHNOLOGY



# All together: Integrated care for youth with type 1 diabetes

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[Correction added on 28 August 2021, after first online publication: Peer review history statement has been added.]

#### Abstract

**Objective:** We describe the implementation and evaluation of an integrated, stepped care model aimed to identify and address the concerns of adolescents with type 1 diabetes (T1D) associated with diabetes-related quality of life (DRQoL), emotional wellbeing, and depression.

**Research Design and Methods:** The care model with 4 steps: (1) Systematic identification and discussion of concerns salient to adolescents; (2) Secondary screening for depressive symptoms when indicated; (3) Developing collaborative treatment plans with joint physical and mental health goals; and (4) Psychiatric assessment and embedded mental health treatment; was implemented into an ambulatory pediatric diabetes clinic and evaluated using quantitative and qualitative methods.

**Results:** There were 236 adolescents (aged 13–18 years) with T1D that were enrolled in the care model. On average adolescents identified three concerns associated with their DRQoL and 25% indicated low emotional well-being. Fifteen adolescents received a psychiatric assessment and embedded mental health treatment. Both adolescents and caregivers were appreciative of a broader, more holistic approach to their diabetes care and to the greater focus of the care model on adolescents, who were encouraged to self-direct the conversation. Parents also appreciated the extra level of support and the ability to receive mental health care for their adolescents from their own diabetes care team.

**Conclusion:** The initial findings from this project indicate the acceptability and, to limited extent, the feasibility of an integrated stepped care model embedded in an ambulatory pediatric diabetes clinic led by an interdisciplinary care team. The care model facilitated the identification and discussion of concerns salient to youth and provided a more holistic approach.

#### KEYWORDS

adolescents, integrated care, mental health, type 1 diabetes, youth

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# 1 | INTRODUCTION

Adolescents with type 1 diabetes (T1D) are challenged with balancing normal social, emotional, and biological changes<sup>1,2</sup> with the intense demands of chronic disease self-management.<sup>3,4</sup> Adolescents with T1D can experience decreased quality of life,<sup>5</sup> mental health concerns such as depression and anxiety,<sup>6-8</sup> and are at increased risk for the development of diabetes-related complications.<sup>9,10</sup> Therefore, clinical practice guidelines recommend regular assessment and screening for a wide variety of psychosocial issues (e.g., psychosocial well-being, family functioning, Diabetes-Related Quality of Life (DRQoL), and psychiatric disorders).<sup>11,12</sup> However, many pediatric diabetes clinics have not vet operationalized this recommendation<sup>13</sup> due in part to lack of evidence about best practices and care models to guide implementing such guidelines where it relates to what, where, when and how (e.g., measurement selection, screening frequency, who performs the screening, and how best to follow-up with appropriate care adjustments or referrals).<sup>14,15</sup>

While some diabetes clinics have started to implement routine psychosocial screening during regular visits,<sup>16-19</sup> there continues to be a need for evidence-based models to support the integration of mental health care into diabetes outpatient clinics.<sup>11,12,20</sup> Implementing routine psychosocial screening into existing or new care models requires practice change and can impact clinic and healthcare provider workloads and workflows.<sup>10,21</sup> Generally, when mental health problems are identified by diabetes clinicians, treatment is generally deferred to mental health specialists who often are not part of the diabetes inter-professional team and might not be aware of the nuances related to adolescent T1D experiences.<sup>15</sup> In our local setting, routine diabetes care visits for adolescents with T1D were primarily focused on physiological indicators of health, particularly glycemic control, and the risk of diabetes-related medical complications. Inquiries related to the adolescent's mental health and DRQoL were based on clinical judgment, rather than routine, intentional screening which raises the risk of failing to identify adolescents with psychosocial difficulties. Longitudinal studies have shown that routine monitoring and discussing health-related QoL improves adolescents' psychosocial health.22,23

To address our locally identified practice gap, improve our adherence to established diabetes care guidelines,<sup>11,12</sup> and address psychosocial concerns related to DRQoL, emotional well-being, and depressive symptoms, we implemented an integrated care pilot project in our clinic to identify and provide support for co-occurring mental health problems for adolescents with T1D. For our pilot integrated care project, we adapted principles of the Collaborative Care Model (CCM), which has emerged as a promising clinical model to facilitate the integration of mental health care with physical health care to simultaneously address co-occurring physical and mental health problems.<sup>24,25</sup> In this manuscript, we describe: (1) the implementation of a stepped, integrated care pilot project to systematically identify and address concerns related to DRQoL, emotional well-being, and depressive symptoms in adolescents with T1D, and (2) our initial findings from a formative evaluation of this pilot project using mixed quantitative and qualitative methods. Although this was a local study, our findings and conclusions are useful for researchers and clinicians to consider when integrating psychosocial care and developing embedded programs for adolescents with T1D and their families in clinical settings.

# **1.1** | Setting for integrated care pilot project for adolescents with T1D and their families

The pilot project was supported by the Medical Psychiatry Alliance (MPA), an alliance formed between three hospitals and a local university to improve the care of patients with co-occurring mental health and medical conditions. The project was launched at Trillium Health Partners (THP), a large community hospital in Mississauga; one of the most ethno-culturally and racially diverse cities in Canada where 50% of the residents are born outside of Canada.<sup>26</sup> The pediatric diabetes clinic is comprised of an inter-professional diabetes care team that includes pediatricians, pediatric endocrinologists, nurses, social workers, and dietitians. The clinic sees approximately 650 pediatric patients per year. Patients 13 to 17 years old with a diagnosis of T1D for at least 6-months attending their quarterly scheduled diabetes clinic visit were eligible for inclusion in this initiative. Prior to the implementation of the Care Model, the diabetes clinic did not systematically assess emotional well-being or DRQoL or screen for depressive symptoms. If low emotional well-being or depressive symptoms were identified during a clinical encounter, a referral was placed for a psychiatric assessment through the region mental health central intake. The waiting time for a psychiatric assessment, if indicated, within the system was 4-6 months.

# **1.2** | Integrated, stepped care model for adolescents with T1D and their families

A multi-disciplinary project team was formed that was comprised of clinicians representing primary care, pediatric endocrinology, psychiatry, and social work; administrative leads and researchers. This team in collaboration with the MPA research and clinical teams at THP had conducted extensive research and reviewed the best available evidence about clinical models of integrated medical and mental health care and recommended that the project be informed by the principles of the CCM.<sup>27</sup> The CCM is based on core principles including: (1) providing care that is patient-centered; (2) team-based; (3) population-based that is, targeting all patients; (4) evidence-based; and (5) measurementbased for example, systematic screening and monitoring with treatment to target.<sup>28</sup> This model has been effective in managing depression in youth in the primary care setting and in managing co-occurring depression and type 2 diabetes specifically in adult populations.<sup>29</sup> The integration of pediatric mental health care into primary care has shown promise in improving access to care, mental health outcomes and reduce stigma for youth struggling with mental health problems and physical disorders.<sup>30,31</sup> Further, we recommended that a stepped care

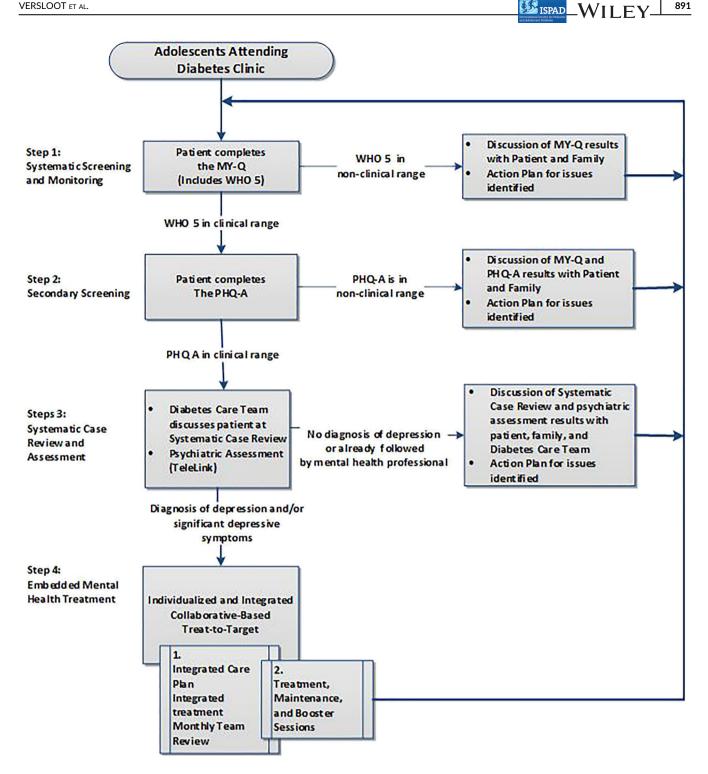


FIGURE 1 Flow diagram of the initial steps. Each step is a decision point based on a survey, systematic case review, or psychiatric assessment, where a patient either flows back to Step 1 or continues to the next step

approach was implemented, wherein the level of intensity of care was matched to the complexity of the issues raised.<sup>32,33</sup> The stepped integrated care model developed for this initiative (hereafter referred to as the Care Model) included four steps (see Figure 1). The Care Model was designed through ongoing working group meetings with clinicians and informed by engagement with clinicians, adolescents with T1D, and caregivers in a town hall meeting.

#### Screening instruments used in the 1.3 Care Model

The Mind Youth Questionnaire (MY-Q)<sup>19</sup> was selected to be used as the screening tool in Step 1. The MY-Q was chosen since it is specifically designed for adolescents with T1D and can be used to screen for challenges within different domains of DRQoL (social impact, parents, diabetes

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control perceptions, responsibility, worries, treatment satisfaction, body image, and eating behavior)<sup>19</sup> as well as to assess overall quality of life (QoL) and emotional well-being.<sup>34</sup> In addition, the MY-Q has an accompanying manual to guide a discussion of identified challenges between patients, families and the clinical team which supports the integration of mental health care into routine care delivery by the diabetes care team. The diabetes care team had indicated that they would like support with the integration of mental health care and the MY-Q manual and accompanied training for the diabetes care team provided this needed support.

The MY-Q has 36 questions, is self-administered, has established clinical cut-offs and has sound validity and reliability.<sup>19</sup> Each item is scored on a 5-point Likert-type scale. Responses at the negative end of the answer scale on an item indicate a concern. The World Health Organization Well-Being Index (WHO-5), embedded in the MY-Q, is a 5-item screening measure for emotional well-being that is also sensitive to identifying adolescents at risk for depression.<sup>34</sup> Based on the total score on the WHO-5, adolescents can be categorized as having low emotional well-being and at risk for depression (scores <13).<sup>34</sup> To screen whether adolescents are suffering from depression in Step 2, the Patient Health Questionnaire-Adapted version for Adolescents (PHQ-A) was used.<sup>35</sup> The PHQ-A is a self-reported questionnaire with nine questions used to screen for depression and is the adolescent version of the PHQ-9.<sup>36</sup> The PHQ-A has adequate validity and the raw total score can indicate severity of depressive symptoms and can be used to assess and monitor symptoms.<sup>35</sup>

## 1.4 | Iterative implementation of the Care Model

The clinical staff received virtual training from the developer of the MY-Q [MdW], on the use of the tool for screening and on the manual for guiding the subsequent clinical conversations between patients, families and the clinical team which supports the integration of mental health care by the diabetes care team in their routine care delivery. In addition, extra staffing was financed by the MPA for additional social work (0.5 FTE), physician (fixed yearly stipend as subject matter experts), and nursing (0.1 FTE) hours, and access to psychiatric services through the TeleLink Mental Health Program (presented in more detail in Step 3). A clinical clerical associate (0.1 FTE) was also hired to support the maintenance of a clinical tracking tool to collect data about adolescents engaged.

The iterative implementation of the different steps of the care model is described below including the adaptations that were made to improve the Care Model.

Step 1: Only adolescents with a diagnosis for more than 6-months were included to allow time to adjust after their diagnosis. Participating adolescents and their families who came to the clinic for regular followup visits were introduced to the Care Model and the adolescents were invited to complete the MY-Q at the time of check-in. The MY-Q was initially completed on paper, but due to negative impacts on clinic flow resulting from additional time requirements to review and summarize the responses, an electronic solution with automated scoring and report generation was implemented shortly after project the launch. With the electronic solution, patients completed the MY-Q within 10–15 min on a tablet device while waiting for their appointments. Upon completion, a summary report was generated that highlighted concerns according to the adolescent's experiences in the past 2 weeks. During the clinic appointment, the social worker or on occasion another member of the care team, and the adolescent reviewed and discussed all items of the MY-Q with emphasis on concerning responses and low emotional wellbeing scores. The consultation time scheduled for each adolescent with the social worker was about 10 min and mostly, this was ample time to discuss the results as guided by the MY-Q manual. The adolescent was asked at the start of the conversation if a family member could join the conversation and permission was almost always granted. Depending on the concerns, the physician, nurse, or dietitian could be asked to join the conversation as well. Together with the adolescent and family, a care plan was formulated based on identified challenges.

MY-Q completion was initially planned to occur at 6-month intervals; however, this schedule was adjusted to 9-month intervals to accommodate diabetes care provider feedback about staff workload and strain on clinic flow. In addition, the 9-month interval also allowed for data collection at different times in the year to account for seasonal changes that can impact an adolescent's experiences such as being on summer holidays or during school exam time.

Step 2: When the score on the WHO-5 component of the MY-Q was below the clinical cut-off (<13), the adolescent was asked to complete a secondary depression measure (PHQ-A).<sup>29</sup> Initially, a follow-up appointment on a different day was scheduled with the social worker for completion of the secondary depression measure; however, due to missed follow-up appointments, the process was adjusted and the secondary measure was completed in real-time after completion of the MY-Q. The questionnaires were mostly completed with the social worker before the adolescent was seen by other members of the care team. Some adolescents proceeded to secondary screening despite a normal WHO-5 score based on the clinical judgment of a member of the care team. This judgment was based on clinical concerns noted at prior visits or responses to MY-Q questions other than the WHO-5.

Step 3: Adolescents with a score indicative of moderate to severe risk for depression (>10 on the PHQ-A) were presented at the next systematic case review (SCR) meeting of the diabetes care team (standing meeting that took place every month) for which the consulting child psychiatrist would be invited to join through TeleLink Mental Health Program.<sup>37</sup> This program uses tele-video to provide virtual psychiatric consultations and the use of this program was funded by the MPA. Based on the discussion during the SCR, when indicated, an assessment by the psychiatrist was offered and scheduled with the adolescent and family through the same TeleLink program at a date convenient for all. In addition to the psychiatrist and the adolescent, the virtual consultation was usually attended by a family member (usually a parent) and a member of the diabetes care team (most often the social worker). The adolescent's primary care provider was also invited, but seldom able to attend due to scheduling challenges. At the end of the consultation, the psychiatrist provided verbal feedback and recommendations to the adolescent and family as well as a written report for the diabetes care team and primary care provider.

When suicidal ideation or behaviors were identified (i.e., a score of 1 or more on question nine of the PHQ-A), this information was shared with the team including the physician and the family. Based on a risk assessment, a safety plan was developed including providing crisis resources, and determining follow-up steps. If needed, the patient and family would be directed to the Emergency Department (ED) for an assessment with the Crisis Team and on-call psychiatrist. Fortunately, during this pilot no adolescent needed to be directed to the ED.

Step 4: For adolescents with clinical depression or any other significant mental health concern (as assessed by the psychiatrist), an evidence-informed behavioral health treatment was offered and delivered by the social worker from the diabetes care team. Treatment was based on principles of motivational interviewing (e.g., awareness building, problem-solving, goal setting)<sup>38</sup> and cognitive behavioral therapy (e.g., recognizing and tracking feelings, behavior, thoughts, and body sensations link) which have been shown to be effective in reducing depressive symptoms and increasing diabetes treatment adherence.<sup>39</sup> A collaborative treatment plan with integrated care goals targeting mental health and diabetes control was developed. To promote autonomy and empowerment, the adolescent was given a variety of treatment options and family involvement in the treatment was highly encouraged.<sup>40</sup> Despite these individualized options, it was still challenging to engage adolescents and promote regular attendance. Progress was monitored through regular SCRs, and psychiatric followup appointments were provided via TeleLink, when needed. Modes of contact included telephone or in-person at the clinic.

# **1.5** | Mixed quantitative and qualitative evaluation of the Care Model

# 1.5.1 | Evaluation design

This was a mixed quantitative and qualitative evaluation of a pilot implementation project to gain insights into the concerns reported by adolescents with T1D on the different screening instruments, the outcomes of screening at each step of the Care Model, and the experiences of adolescents and families who were engaged in these services. The project was approved by THP Research Ethics Board.

## 1.5.2 | Quantitative approach

Data from the MY-Q, PHQ-A, medical records (age, gender, date of diabetes diagnosis), hemoglobin A1c (HbA1C), and diabetes treatment method (insulin pump or injections) were collected for the initial 236 adolescents who participated in the Care Model between August 2016 and June 2019.

## 1.5.3 | Quantitative data analysis

Descriptive statistics were used to summarize demographic characteristics of the adolescent population as well as response profiles for the MY-Q and PHQ-A. Continuous measures are presented as means and standard deviations, while categorical measures are presented as counts and proportions. All analyses were conducted in R (version 3.6.3).<sup>41</sup>

### 1.5.4 | Qualitative methods and procedure

After obtaining approval from the local REB, qualitative data were collected between 2018 and 2019 through a series of focus groups and semi-structured interviews with adolescents and parent caregivers. An invitation to participate in either an interview or focus group was posted in the clinic and also included in a monthly newsletter distributed to clients and families. Inclusion criteria for the qualitative evaluation included a diagnosis of T1D, having participated in the Care Model for at least 3 months and being either an adolescent with T1D or family member caring for an adolescent with T1D. Eight telephone and three in-person interviews were completed that ranged in length from 30 to 60 min.

Our design included 4 focus group sessions (2 adult, 2 teen) as we felt that it would be valuable to explore patient and family perspectives on holistic diabetes care in an interactive, group format.<sup>42,43</sup> Focus groups allow health services researchers to learn about different and shared perspectives on a topic,<sup>44</sup> and are a recommended data collection forum for teen participants.<sup>45,46</sup> To encourage an open and comfortable discussion environment, separate focus group sessions for adolescents and caregivers were held on 2 weekday evenings for 2 h. Following a review of the informed consent and a discussion of focus group rules, we used semi-structured discussion guides tailored for adolescents and caregivers. Both the focus group and interview guides addressed the following topics: participant experiences with an integrated care approach to diabetes management; experiences with mental health screening tools and supports; and recommendations for future improvements for the design of diabetes management services for teens and families. The interview and focus group data were audio-recorded, professionally transcribed and subsequently entered into MAXQDA, a qualitative data management software program.

## 1.5.5 | Qualitative data analysis

Thematic analysis was used to identify themes within and across the data.<sup>47</sup> The research team [EM, JS, MM] read a purposive sample of transcripts independently to define codes and then met to discuss their independent analyses and develop a coding framework. Two research team members [JS, MM] used this coding framework to code the interview and focus group transcripts. Codes were subsequently combined into themes during a series of team meetings where the relationships between the themes were explored and summarized. The team maintained an audit trail of meetings, analytical questions that arose and decisions that were made to enhance transparency.<sup>48</sup>

# 2 | RESULTS

# 2.1 | Step 1: MY-Q completion, identified concerns, and emotional well-being

The characteristics of adolescents participating in the new care model are summarized in Table 1. Almost all adolescents who were asked to complete the MY-Q did so. Approximately 11 MY-Q's were completed per month (mean 10.9; SD = 6.7) with a range between 1–25. The average age of the adolescents was 14.9 years (SD = 1.4) with slightly more females participating in the Care Model (52.1%). On

TABLE 1	Characteristics of adolescents at first		
screening (N $=$ 236)			

Characteristics	N (%)	Mean (SD)
Age		14.9 (1.4)
13-14	103 (43.6)	
15-16	95 (40.3)	
17	38 (16.1)	
Gender		
Male	113 (47.9)	
Female	123 (52.1)	
Diabetes duration in years		6.39 (4.0)
Treatment method		
Daily injections	115 (48.7)	
Insulin pump	121 (51.3)	
HbA1c		
<7.5%	61 (26.3)	
7.5-9.0%	112 (48.3)	
>9.0%	59 (25.4)	
Missing values	4	

average, adolescents had been living with T1D for 6.3 years (SD = 4.0). Almost half of the adolescents used multiple daily insulin injections to manage their diabetes and 26% had HbA1c values at or within target according to the Diabetes Canada Guidelines<sup>49</sup> (<7.5% or < 58.5 mmol/mol). The results of the MY-Q revealed that on average, adolescents rated their overall QoL at 7.69 (SD = 1.61) out of 10 (0 being the worst possible life for adolescent and 10 being the best possible life for adolescents). The majority of adolescents (61%) indicated at least three concerns on the MY-Q across all DRQoL domains. Treatment satisfaction was rated very positively with the vast majority (94.5%) of the adolescents reporting being satisfied with their diabetes care team and 85% being happy with their diabetes management plan.

Among the screened adolescents, 27% (n = 64) had a score indicative of low emotional well-being (WHO-5 score < 13) and moved to Step 2. The number of concerns indicated on the MY-Q of these adolescents was significantly higher than adolescents who scored in the nonclinical range for emotional well-being (median = 8; IQR = 4-12 vs. median = 2; IQR = 1-4, p-value <0.0001). Table 2 presents the top five concerns for adolescents with and without low emotional well-being scores. Three concerns were the same for both groups: (1) feeling that their parents worried too much about their diabetes (62.5% and 38.6% among adolescents scoring in the clinical and nonclinical range, respectively); (2) not being able to count on teacher(s)/ coworkers to help with their diabetes (48.4% and 18.1% respectively); and (3) trying to control their weight/shape in different ways (40.6% and 32.2% respectively).

# 2.2 | Steps 2–4: Screening for depression, systematic care review, and psychiatric assessment

Half of the adolescents with low emotional well-being scores completed the PHQ-A depression screening tool (n = 32). The most

TABLE 2 The top five flagged questions for adolescents with and without low emotional well-being scores

Question	Top 5 issues	Low emotional well-being (n = 64) N (%)	Top 5 issues	Normal emotional well-being (n = 171) N (%)
How often do you feel that your parentsworry too much about your diabetes	1	40 (62.5%)	1	66 (38.6%)
How often do you argue with your parents about remembering to check your blood sugars/giving injections	2	31 (48.4%)		31 (18.1%)
I can count on my teacher(s)/coworkers to help me	3	30 (46.9%)	5	32 (18.7%)
How often do you feelyou have too much responsibility for your diabetes care	4	27 (42.2%)		25 (14.6%)
I have been trying to control my weight/shape in different ways	5	27 (42.2%)	2	55 (32.2%)
How often do you feel that your parentsact like diabetes is their disease, not yours		26 (40.6%)	3	41 (24%)
It is hard for me to pay attention in class/at work		19 (29.7%)	4	36 (21.1%)

common reason that adolescents with low WHO-5 scores did not fill out a PHQ-A was that the discussion with the social worker indicated that the low emotional well-being was not the result of an underlying mental health problem (e.g., being in the midst of exams, experience of a recent loss, having a cold or other minor illness). An additional four adolescents were asked to complete the PHQ-A by the clinician in the absence of a low emotional well-being score based on clinical judgment or observations. Of these 36 adolescents 25% (n = 9) had minimal to no symptoms of depression, 33.3% (n = 12) had mild symptoms, 19.4% (n = 7) had moderate, and 22.2% (n = 8) had severe symptoms of depression. Some adolescents (15%) had a positive score for suicidal ideation and received immediate (within the same clinic visit) assessment by the social worker using the safety protocol in place. The 15 adolescents with moderate to severe symptoms received a psychiatric assessment and were offered evidence-based treatment in the clinic. In addition to depressive symptoms, adolescents were also determined to be experiencing symptoms of anxiety and challenges with adjustment and relationships.

The median time from MY-Q completion to psychiatric assessment was 60 days (IQR = 35-90). Common reasons for delay included cancelations and no shows, and the need to make repeated attempts to obtain the required consent from adolescents and their caregivers in order for the psychiatric assessment to proceed.

# 2.3 | Teen and parent perceptions of the care model

In total, 12 adolescents and 12 parent caregivers attended a focus group meeting or participated in an in-person or telephone interview. The six female and six male adolescent participants ranged in age from 14 to 17 years, were enrolled in high school during the study period. Our parent participants included nine females and three males, all were working full-time and ranged in age from 30 to 59.

The feedback that we received about the new model of care during the qualitative evaluation was largely positive as both adolescent and caregiver participants were appreciative of a broader, more holistic approach to their diabetes management. More specifically, participants appreciated a diabetes management approach that included an opportunity to regularly check in around mental health concerns and discuss what was happening in adolescents' lives that might impact their T1D. Adolescents, in particular, observed that opening up about the impact of T1D on one's social and emotional life can be awkward. Participants shared that they sometimes did not want to answer "deep targeting questions" from a new mental health care expert; having a familiar diabetes care team member facilitating these conversations made it easier for young people. For many adolescents and their families, the clinic is an important resource and provides a sense of community as they get to know, trust and rely on staff. Addressing mental health and other life issues in a familiar clinical environment was a benefit adolescent reported associated with bringing a more integrated care approach to diabetes management. A participant shared her perspective on the benefits of engaging with a known and

trusted team of diabetes clinicians around mental health issues when discussing how T1D both influences and is impacted by her personal life:

I think it's good for everybody, like because the one thing I found is, there's more focus, instead of it being like, "Oh your blood sugar is a mess, like get on top of it!" Now there's more understanding as to why it might be a mess – like all the BS what's going on in my life. And then it kind of makes more sense, how you feel less like pressure and less bad about it. There's more understanding in that sense. (Teen FG1, P8).

Taking a more holistic approach to diabetes care could also contribute to increased self-esteem, feelings of empowerment in teens and positively alter the dynamics of clinical visits. The new model of care placed a greater focus on adolescents who were now encouraged to self-direct the conversation, lead discussions about their care, and also given the option of discussing diabetes care with or without their parents present. While most participants reported that they were comfortable including their parents in these discussions, adolescents appreciated being given a greater role and increased voice and choice during clinical encounters:

> I just like how they really let you get involved in your care. They talk more to you rather than your parents and they really encourage the person with the diabetes to like put in the effort rather than just the parents. They try to focus it more toward you rather than your parents. (Teen FG1, P6).

Although adolescents were very supportive of a holistic model of diabetes care, some participants cautioned against the risk of assuming that all mental health issues were a consequence of the disease. As a participant observed, it is important to not conflate T1D with all symptoms of depression and anxiety:

> I do find that other people are like, "Oh, well, this is just the diabetes." And I'm like, "No, there's so many other things that bother me." Just because I have this, does not mean that's the only reason I'm upset, you know what I mean? (Interview, P18).

Parents also appreciated the extra level of support the project provided, as many reported their concerns as adolescents learn to cope and more independently manage a chronic disease that impacts their whole lives. Some families reported seeking out external mental health counseling but had difficulty locating professionals who understand the mental health impact of T1D on adolescents. Being able to receive mental health care from their trusted team of diabetes clinic providers was a feature of the model that parents appreciated as it allowed adolescents to discuss challenges while avoiding perceived judgment and the need to retell their story. During an interview, a parent shared her understanding of how an 896 WILEY WILEY

integrated physical and mental health approach to T1D also helped normalize illness experiences for both youth and their families:

> The things that they talked about were actually pretty much the same conversations that she's been having with the other counseling people that she had seen. But being able to weave the diabetes into it and its impact here and there, it just seemed to make a - it just treated her as a whole person instead of pieces of her. (Interview, P17).

#### 3 DISCUSSION

The findings from our study demonstrate the acceptability of implementing an integrated, stepped care model into the routine care of adolescents with T1D within a multidisciplinary diabetes clinic. Nearly all adolescents were willing to participate in the new care model and all adolescents who completed the MY-Q participated in a discussion about the results with a member of the care team. However, our findings show limited feasibility. Due to negative impacts on clinic workflow and staff turnover, the clinic could only accommodate screening all adolescents every 12 months and not every 6-months or 9-months despite the augmented staff and funding.

Overall, the quantitative evaluation demonstrated that our sample of adolescents had similar characteristics in terms of gender, insulin pump use, and average A1c levels compared to US registries and European studies.<sup>50,51</sup> The subgroup of adolescents who had low WHO-5 scores, underwent secondary screening, and received a timely assessment by a child psychiatrist allowing access to follow-up care without the need for a referral to community mental health services. The timely assessments were facilitated by additional funding to support the TeleLink Mental health Program.

The qualitative evaluation showed that adolescent and parent participants found the integrated approach to physical and mental health to be valuable and beneficial. Introducing the MY-Q as both a measure of DRQoL and as a guide for how to discuss psychosocial health with adolescents, opened up dialoue on salient issues and allowed for a person-centered approach that broadened the care and steered the conversation to be more person-oriented and holistic. This holistic approach shifted the dynamic of the clinic visits, typically focused on biomedical assessments, by tending to the lived experience and emotional lives of the adolescents giving them space to openly discuss the impacts of T1D on their emotional well-being, their families, school, and social lives. Adolescents valued the time spent with clinicians without their parents and the opportunity to direct clinical discussions. The ability to independently discuss and bring up their own concerns with the diabetes care team is an important skill for adolescents to successfully navigate especially as they prepare for the transition into adult care where they will have to navigate the healthcare journey more independently.<sup>52,53</sup> Further, the stepped care approach provided targeted treatment to ensure the right intensity of care.<sup>20</sup>

The quantitative findings also showed that almost two thirds of the adolescents in our sample identified three or more concerns

related to a variety of domains such as worries, responsibilities, and family conflict, further illustrating the importance of a holistic approach. We found that adolescents with low emotional well-being indicated many of the same concerns compared to the adolescents without low emotional well-being. In both groups, about one third of adolescents indicated that they controlled their weight/shape in different ways. A positive answer to this question can be related to the presence of disordered eating symptoms or eating disorders which have been found to have a prevalence estimates of around 39% and 7% for adolescents with T1D respectively.<sup>54</sup> The discussion between the diabetes care team members and the adolescents who reported this concern often uncovered that the "different ways in which adolescents controlled their weight" were most often physical activity or limiting unhealthy foods rather by behaviors concerning for disordered eating Monitoring this question together with the dietician/ nutritionist of the diabetes care team is important.

Prior research has shown that adolescents who identify family conflict have poorer diabetes management and glycemic control.<sup>55-57</sup> Additionally, successful diabetes management requires shared responsibilities between parents and adolescents with T1D.58 which can be jeopardized when there is family conflict. Over the course of an adolescent's development into early adulthood, the responsibility for diabetes management shifts from being mostly with parents to being mostly with adolescents with parental monitoring and support.<sup>59</sup> This shift in responsibility during adolescence, can cause disruption in the parent-adolescent relationship resulting in increased conflict. Keeping parents involved in monitoring their adolescent's diabetes and teaching them to use a supportive communication style are key elements to restore or maintain the appropriate balance in parent-adolescent relationships, preventing family conflict and improving diabetes management.<sup>40</sup> The diabetes care team is in a unique position to model behavior to parents and adolescents that can help prevent conflict by using a care approach that emphasizes supportive communication strategies,<sup>60</sup> promotes engagement, and enhances a mutual understanding between the diabetes care provider, adolescent, and family.<sup>61</sup> Both adolescents and their parents might benefit from further education and targeted interventions (e.g., peer-led groups) to teach and support them in communication, conflict resolution and use of supportive language.<sup>62,63</sup> Ideally this would be done in combination with preparing adolescents for a successful transition to the adult health care system.

#### 3.1 Sustainability of the care model

The implementation of the Care Model was an iterative process and several learnings emerged. Having the adolescents complete the screening measures in the clinic expectedly impacted clinic flow. To reduce the impact on clinic flow in the future, an online platform could be sought where the adolescents fill out the screening measures ahead of the appointment. Due to the high volumes of patients seen in the clinic, nearly a year of data collection was required before all eligible adolescents had filled out the MY-Q questionnaire at least once.

Due to impacts on clinic workflow and clinician workloads, it was only possible to incorporate one MY-Q per year into patient visits and not more frequently as had been planned. Furthermore, funding from the pilot project supported additional administrative support and augmented work hours for the social worker, nurses, and physicians. To ensure the sustainability of the model, consideration should be given to ongoing training, clinic flow and workload management strategies, and mitigation plans for staff turnover. Sustainability would also require ongoing sponsorship from hospital leadership to ensure the availability of funds. An economic analysis might be helpful to gain insights into the direct and indirect costs of such a Care Model.

# 3.2 | Limitations

The conceptualization and implementation of the Care Model were not guided by a specific a priori theory of change model. The clinic did not collect socioeconomic (SES) or racial/ethnic data. Therefore, insights into the differential impacts of our outcomes across race and socioeconomic status are limited. As well, the sample size for the qualitative study did not support maximum variation sampling techniques. Additionally, this was a cross-sectional study and so the stability of mental health symptoms or the impact of the Care Model on biomedical and psychosocial outcomes over time could not be observed.

# 3.3 | Future research and interventions

Several other studies also show promising results for programs delivered within the diabetes clinic targeting behavioral, psychological and glycemic outcomes.<sup>12,18,22,64,65</sup> These programs can potentially be embedded into the stepped integrated approach presented here where interventions can be tailored to the identified concerns of adolescents. Quantitative and qualitative research designs could be strengthened in future evaluations of this model through stronger evaluation designs (e.g., randomized controlled trials) with longitudinal approaches and by including larger study populations supporting maximum variation sampling approaches. Further, since this was a pilot project, the application of more rigorous implementation and quality improvement methods including the collection of both outcome and balancing measures, could lead to improved understanding of how to further optimize clinical workflows, refine the Care Model to maximize impacts, ensure fidelity to Care Model, and for considering opportunities for scale and spread. Furthermore, additional guidance is needed on the optimal cadence of DRQoL assessment and monitoring diagnosis. In addition to screening adolescents in the clinic, it may be beneficial to screen and provide support to parents of these adolescents as a future initiative. Lastly, from a preventive lens, future studies examining systematic screening and monitoring of diabetesrelated QoL to identify concerns at an earlier stage to prevent the development or intensification of mental health problems may be warranted.

# 4 | CONCLUSIONS

These findings show the acceptability and to limited extend the feasibility of implementing an integrated, stepped care model into a pediatric diabetes clinic. The results demonstrate that this Care Model helps identify concerns that are salient to adolescents, identifies those adolescents that have mental health concerns, and enables the provision of timely, integrated care by a team familiar to the adolescent and family. In addition, the results support the appropriateness of a stepped care model that allows matching the intensity of care to the concerns raised by adolescents. Learnings from our experience can potentially be used to develop integrated stepped care models that are patient-centered, focused on team-based care, and provide early screening and access to mental health care for other adolescents with similar as well as other chronic diseases.

# ACKNOWLEDGMENTS

The authors acknowledge our original working group members: Rayzel Shulan, MD, Ph.D., David Daien, MD, Rose Geist, MD, Alison Freeland, MD. We would also like to acknowledge Monidipa Ravi, MD, our consulting psychiatrist at SickKids and Angelo Simone, MD, who was our subject matter expert on the project and the diabetes care team at Trillium Health Partners including Elaine Wilson and Leanne Montgomery. This work is supported by the Medical Psychiatry Alliance, a collaborative health partnership of the Centre for Addiction and Mental Health, The Hospital for Sick Children, Trillium Health Partners, and the University of Toronto, as well as the Ontario Ministry of Health and Long-Term Care and an anonymous donor.

# AUTHOR CONTRIBUTIONS

JV, EM, SP, IZ contributed to the conception of the current data analyses and idea for this manuscript; JV, IZ, EM, SP, AA drafted the manuscript; SCM, JM conducted the data analyses; JV, AA, EM, MM, JS, MDW, SP, IZ contributed to research execution along with acquisition and interpretation of data; DL, DS, SP, IZ contributed to the execution of the project and critically reviewed the manuscript; JV, AA, JM, JS, MM, SCM, DL, DS, MDW, EM, SP, IZ critically reviewed and gave final approval to publish; JV, AA, JM, JS, MM, SM, DL, DS, MDW, EM, SP, IZ critically reviewed the manuscript.

#### PEER REVIEW

The peer review history for this article is available at https://publons. com/publon/10.1111/pedi.13242.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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How to cite this article: Versloot J, Ali A, Minotti SC, et al. All together: Integrated care for youth with type 1 diabetes. *Pediatr Diabetes*. 2021;22(6):889-899. <u>https://doi.org/10.1111/pedi.13242</u>

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