Patient Perspectives on Managing Type 1 Diabetes During High-Performance Exercise: What Resources Do They Want?

Stephanie Dizon,^{1,2} Janine Malcolm,^{1,2} Margo Rowan,³ and Erin J. Keely^{1,2}

ABSTRACT

Objective. Athletes with type 1 diabetes face unique challenges that make it difficult for health care providers to offer concise recommendations for diabetes management. Moreover, little is known about patient preferences for diabetes management during high-level and competitive exercise. We undertook a qualitative study to understand patient perspectives on managing type 1 diabetes during exercise.

Methods. A qualitative design using focus groups was selected. Samples of 5–10 participants per group were recruited to participate in one of three 1.5-hour sessions focusing on experiences in managing diabetes, supports, and desired resources. Sessions were audiotaped and transcribed verbatim. Data were analyzed iteratively among team members.

Results. The study included 21 participants (10 male and 11 female) with a mean age of 41 years. Most participants used trial and error to manage their blood glucose around exercise. Frequent monitoring of blood glucose was a common strategy and a challenge during exercise. Hypoglycemia after exercise and adrenaline-fueled hyperglycemia during exercise were the most prevalent concerns. Most participants relied on themselves, an endocrinologist, or the Internet for support but said they would prefer to rely more on peers with type 1 diabetes and mobile apps. Peer support or mentorship was strongly supported with recommendations for moving forward.

Conclusion. This study highlights the individualized nature of balancing glycemic control in athletes and athletes' heavy self-reliance to develop strategies. Expanding the availability of resources such as peer mentoring and mobile apps could potentially support athletes with type 1 diabetes.

thletes with type 1 diabetes comprise a unique group of individuals who risk becoming sidelined if they do not receive the support and guidance they need to remain active in their sport. Physical activity has many benefits for people with diabetes, including improved cardiovascular health, improved glycemic control, and decreased morbidity and mortality. However, some individuals may struggle with glycemic management during exercise (1). Athletes with type 1 diabetes have many challenges in striving to maintain optimal glucose levels in the face of unique experiences with regard to variable intensity of exercise, scheduling of activities, coaching and training support, blood glucose responses, and stress of competition (2). Without appropriate and individualized resources for managing diabetes during exercise, athletes with type 1 diabetes face the risk of disengaging from sport or physical activity (3). It is often challenging for health care providers to assess the needs of individual athletes and provide concise recommendations for diabetes management during exercise.

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Modification of the type, intensity, and timing of exercise; suitable medication adjustments; and appropriate food intake must all be considered for exercise (2-6). Although the literature provides general strategies for preventing hypoglycemia and hyperglycemia during exercise, the usefulness of these recommendations and of suggested resources for the challenges faced by high-level athletes with type 1 diabetes are unclear. A recent consensus statement by Riddell et al. (6) provides general considerations for people with type 1 diabetes but may not fully address the needs of athletes. Further to this, a descriptive study of adult endurance athletes with type 1 diabetes showed that 50% of respondents followed guidelines for exercise outlined by the American Diabetes Association (ADA) "most of the time" or "almost always," and 46% were not aware of ADA guidelines at all (7). Guidelines can serve as a starting point when initiating or changing exercise, but modifications may be needed to suit the requirements of individuals, and especially those who are exercising at a higher level.

Challenges in the athletic population include competition-associated rises in adrenaline causing hyperglycemia, as well as nutritional considerations and insulin requirements for maintaining euglycemia to maximize performance (4). A review by Horton and Subauste (8) provides general guidelines based on summarized review articles, literature on athletes with type 1 diabetes, and expert opinion on considerations for athletes with type 1 diabetes. They provide useful strategies but also recognize that athletes represent a unique population that requires a collaborative approach between patients and health care providers for glycemic management.

Although health care teams are an integral component for developing appropriate strategies for exercise, some may not have the knowledge or skills required for athletes. Although many athletes with type 1 diabetes learn how to manage their diabetes with exercise through trial and error (5,9), there is a gap in available resources for these patients. Furthermore, there is variable understanding of strategies, which highlights the need for diabetes self-management education in this population (7).

Little is known about patient preferences for diabetes management resources for high-level and competitive exercise, and there are no known qualitative studies that address barriers and strategies for exercise in an athletic type 1 diabetes population. Understanding the unique challenges of athletes with type 1 diabetes is important to both appreciate patients' experience and explore resources to support those who engage in sports. We therefore undertook a qualitative study to better understand the perceived challenges, strategies, and desired resources for management of high-level athletes with type 1 diabetes. Understanding the influences and resources that affect self-management for glycemic control during exercise and ascertaining what tools suit this population is the focus of this study.

Research Design and Methods

Design

A qualitative design using grounded theory was selected, using focus groups to allow participants to share experiences, build on each other's personal experiences, and comment on different perspectives among group members with regard to managing type 1 diabetes during sports or exercise. The study was approved by the Ottawa Hospital Research Ethics Board.

Participant Recruitment

Samples of 5–10 participants were recruited for each of three focus groups. Lists of potential participants were generated with assistance from endocrinologists and other health care workers at the Foustanellas Endocrine and Diabetes Centre (FEDC) at the Ottawa Hospital. Staff were asked to contact the lead principal investigator (S.D.) if they knew of patients who were ≥ 18 years of age, diagnosed with type 1 diabetes, English speaking, in touch with their current endocrinologist within the past year, and a current or previous athlete. An athlete was defined as an individual who engages in regular sporting activities or organized physical activity such as varsity, competitive, or professional athletes or individuals who engage in high-performance physical activity at least 3 days/week for a minimum of 6 hours/week. Participants were excluded if they had poor glycemic control with an A1C \geq 10%, were a beginner or recreational exerciser, or had a history of major mental illness.

Thirty-six participants were identified. Participants who agreed to be contacted were telephoned and asked whether they were interested in participating. Twenty-one people agreed to participate. Reasons for declining were conflicting schedules, having moved away from the Ottawa area, or not meeting the inclusion criteria. Individuals who chose not to participate were more likely to be younger and to have relocated from the Ottawa area. Those who agreed to participate were called or emailed shortly before the day of the focus group as a reminder.

Procedures

Three focus groups were held using standardized procedures (10). All focus groups were conducted in English at the FEDC between August and November 2016. At the beginning of each session, respondents completed a consent form and a short survey to identify their sports/physical activities, diabetes management, and demographic information.

Focus groups lasted ~1.5 hours and were led by two co-facilitators. One facilitator was a university-based doctoral-prepared researcher who was hired to conduct, analyze, and write a summary report on the findings (M.R.). The other facilitator was the principal investigator, who is a resident physician from the Division of Endocrinology and Metabolism at the Ottawa Hospital.

A moderator's guide was developed after an initial review of the literature on barriers to and strategies for managing type 1 diabetes during sports or exercise and a scan of existing resources or tools available. The co-facilitators used the guide to focus the discussion and provide consistency across groups. Main topics included 1) experiences in managing diabetes with sports or exercise, 2) resources to support diabetes management for physical activity, and 3) the development of a patient-focused tool for diabetes management during sports or exercise. The co-facilitators encouraged open discussion and probed deeper with general and direct requests from participants to further reflect on their experiences.

Participants in each group took part in a "dot exercise" whereby they were presented with two flipcharts and asked to indicate the resources that they most often relied on at the present time (flipchart one) and the resources they would prefer to rely on now or in the future (flipchart two). Each listed 11 resource options: apps, coach, diabetes nurse, dietitian, endocrinologist, family doctor, family member, friends/peers, Internet, trainer, and self. One by one, participants were asked to place five red dots beside the resources they most rely on and then five yellow dots for resources they would prefer to rely on. Participants were told that they could distribute the five dots among one or more resources, including placing more than one dot next to a single choice if they wished. Scores were summed, and the top two or three resources were discussed further by the group in addition to discrepancies between the resources they currently rely on and those they would prefer.

At the end of each focus group, the co-facilitators noted key emerging themes, convergent and divergent findings, and commonalities and differences among the groups. These notes were reviewed and incorporated into the draft coding framework, thus adding to its trustworthiness. In addition, they discussed whether certain areas should be addressed in pending focus groups. For example, "self" emerged as a key resource at the first focus group and was then added to the list of resource options for subsequent groups.

Data Analysis

All focus groups were audiotaped and transcribed verbatim. M.R. developed the initial coding framework based on the moderator's guide, a line-by-line reading of the first transcript, and constant comparison of statements among participants to identify a preliminary set of main themes that linked similar comments. In vivo codes were used as much as possible to label categories using the words or phrases of the participants. The term "in vivo codes" refers to chosen descriptors that are the words and phrases used by the actual participants themselves rather than ones created or paraphrased by the researchers (11).

M.R. and S.D. applied the draft framework to the second transcript to identify any new themes and to strengthen existing ones by providing "thicker" descriptions of groupings. "Thick descriptions" provide rich, detailed, and concrete descriptions of what participants are thinking so readers can better understand the findings. The draft coding framework was then shared with two other team members (J.M. and E.J.K.), who then independently applied it to separate portions of the third transcript. Written feedback and queries were directed to M.R., who made relevant changes to the framework.

By the third focus group, content saturation was considered reached on major themes, including strategies that worked well, challenges, and preferred resources to support diabetes management. Content saturation refers to the point at which no new themes are found (12). Data from the three focus groups were then entered into NVivo 11 software (QSR International Pty Ltd., Victoria, Australia) and organized/analyzed using the collaboratively developed coding framework. Coding summaries were generated and critically assessed by all team members to confirm the coded data and to identify relevant quotations. Discrepancies were resolved through consensus among the team. To enhance the trustworthiness of the data, disconfirming evidence was consciously searched for, and thick descriptions were provided of participants' thoughts and feelings via quotations and examples to authenticate main themes.

Results

Participant Characteristics

Table 1 summarizes the baseline characteristics of the 21 participants. The mean age was 41 years, mean duration of diabetes was 22 years, and average duration of physical activity was 10 hours/week. The majority managed their diabetes during exercise with an insulin pump (n = 12 [57%]). Participants in focus group 1 were notably younger and more active in sports than those in the other two focus groups.

Reasons for Exercise

Various reasons were expressed across all groups for why participants exercised. Several participants from each group viewed it as part of who they are, because they have always exercised. For example:

"I was a competitive swimmer. When I was diagnosed . . . one of the first questions is 'can I keep swimming?' . . . We called the pediatrician that night, and she said 'Sure, it's the best thing for you,' so that was great." (FG1)

Some participants indicated that they have occupations in the sports or health fields or have a love of sports. Several participants indicated that exercise helped to make specific improvements to their physical health in

| Group 1 (n = 10) Group 2 (n = 6) 30 48 31 4 (40) 4 (40) 4 (67) 1 (10) 1 (170 5 (50) 2 (33) 1 (10) 1 (170 5 (50) 2 (33) 1 (10) 1 (170 5 (50) 2 (33) 1 (10) 2 (33) 2 (20) 0 (0) 0 (0) 0 (0) 1 (10) 2 (33) 1 (10) 2 (33) 1 (10) 2 (33) 1 (10) 0 (0) 0 (0) 0 (0) 0 (0) 0 (0) 1 (11) 2 (33) Hockey/ringette (3) Hockey/ringette (2) Hockey/ringette (3) Hockey/ringette (2) 1 (11) 1 (11) 1 (11) 1 (11) 2 (20) 2 (33) 3 (30) 2 (33) 2 (20) 3 (50) 2 (20) 2 (33) 1 (11) 1 (17) 2 (20) 2 (33 | | | | Focus Group | |
|--|--|----------------------|---------------------|------------------------|------------------------|
| 30 48 30 48 4(40) 4(57) 4(67) 4(67) 1(10) 1(170 5(50) 2(33) 1(10) 2(33) 2(20) 0(0) 0(0) 0(0) 17.4 28.3 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Hockey/ringette (2) 17.4 28.3 17.4 28.3 18.4 28.3 19.4 28.3 19 | | Group 1 ($n = 10$) | 1 | Group 3 $(n = 5)$ | Total $(n = 21)$ |
| 30 48 1 (40) 4 (67) 1 (10) 1 (17) 5 (50) 2 (33) 1 (10) 2 (33) 2 (20) 0 (0) 0 (0) 0 (0) 0 (0) 0 (0) 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 17.4 28.3 11.10 0 (0) 11.10 0 (0) 11.10 0 (0) 11.10 1 (17) 11.11 1 (17) 11.11 1 (17) 11.11 1 (17) 11.11 1 (17) 11.11 1 (17) 11.11 1 (17) 11.11 1 (17) 11.11 1 (17) < | Background characteristics | | | | |
| $\begin{array}{c ccccccccccccccccccccccccccccccccccc$ | Mean age, years | 30 | 48 | 46 | 41 |
| 1 (10) 1 (170 5 (50) 2 (33) 5 (50) 2 (33) 1 (10) 2 (33) 2 (20) 0 (0) 0 (0) 0 (0) 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Hockey/ringette (3) Hockey/ringette (2) 1 (10) 0 (0) 1 (10) 0 (0) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 1 (17) 1 (17) 1 (17) 2 (20) 3 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (50) 2 (33 | Sex, female, n (%) | 4 (40) | 4 (67) | 3 (60) | 11 (52) |
| 1 (10) 1 (17) 1 (10) 5 (50) 2 (33) 1 (10) 2 (33) 2 (20) 0 (0) 0 (0) 0 (0) 0 (0) 0 (0) 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Hockey/ringette (3) Hockey/ringette (2) 1 (10) 0 (0) 1 (10) 0 (0) 2 (20) 3 (50) 3 (30) 2 (33) 1 (10) 0 (0) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 2 (33) 3 (50) 2 (33) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 2 (33) 5 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) | Highest level of education, n (%) | | | | |
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| 5 (50) 2 (33) 1 (10) 2 (33) 2 (20) 0 (0) 2 (20) 0 (0) 17.4 28.3 17.4 28.3 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) 1 (10) 0 (0) 1 (10) 0 (0) 1 (10) 0 (0) 1 (11) 0 (0) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 1 (17) 2 (20) 2 (33) 2 (20) 2 (33) 2 (20) 2 (33) 2 (20) 2 (33) 2 (20) 2 (33) 3 (30) 2 (33) 2 (33) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 2 (33) 2 (33) 3 (30) 2 (33) 2 (| Master's degree | 1 (10) | 1 (170 | 2 (40) | 4 (19) |
| 1 (10) 2 (33) 2 (20) 0 (0) 2 (20) 0 (0) 0 (0) 0 (0) 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Hockey/ringette (3) Hockey/ringette (2) 11 (10) 0 (0) 2 (20) 3 (50) 3 (30) 2 (33) 16.2 7.2 16.2 7.2 16.2 7.2 16.2 7.2 16.2 7.2 16.2 7.2 16.2 7.2 17.1 1 (17) 2 (20) 1 (17) 2 (20) 2 (33) 3 (50) 2 (33) 2 (20) 2 (33) 3 (50) 2 (60) 2 (50) 2 (33) 5 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) <td>Bachelor's degree</td> <td>5 (50)</td> <td>2 (33)</td> <td>2 (40)</td> <td>9 (43)</td> | Bachelor's degree | 5 (50) | 2 (33) | 2 (40) | 9 (43) |
| 2 (20) 0 (0) 0 (0) 0 (0) 17.4 28.3 17.4 28.3 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) 1 (10) 0 (0) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 1 (17) 2 (20) 1 (17) 2 (20) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 2 (33) 3 (30) 2 (33) 2 (33) 2 (33) 3 (30) 2 (33) 2 | College | 1 (10) | 2 (33) | 1 (20) | 4 (19) |
| 0 (0) 0 (0) 17.4 28.3 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Cycling (3) Hockey/ringette (2) 1 (10) 0 (0) 2 (33) Jue) 3 (30) 2 (33) Jue) 1 (17) 1 (17) Z (20) 1 (17) 1 (17) Z (20) 2 (20) 1 (17) Z (20) 2 (20) 2 (33) Z (20) 2 (33) 2 (| High school | 2 (20) | 0 (0) | 0 (0) | 2 (10) |
| 17.4 28.3 Running (6) Running (3) Cycling (3) Cycling (3) Jaue) 3 (30) 2 (33) Jaue) J (40) J (17) Cycling (3) J (17) J (17) Cycling (3) J (17) J (17) Cycling (3) J (17) J (17) Cycling (3) J (30) J (33) J (30) J (30) J (33) J (30) J (33) J (33) | Did not complete high school | 0 (0) | 0 (0) | 0 (0) | 0) 0 |
| Running (6) Running (3) Cycling (3) Cycling (3) Cycling (3) Hockey/ringette (2) Hockey/ringette (3) Hockey/ringette (2) 1 (10) 0 (0) 2 (20) 3 (50) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 3 (50) 2 (20) 1 (17) 3 (30) 2 (33) 3 (50) 2 (50) 2 (20) 1 (17) 3 (30) 2 (33) 3 (30) 2 (33) 5 (50) 4 (67) 3 (30) 2 (33) 3 (30) 2 (33) | Mean duration of type 1 diabetes, years | 17.4 | 28.3 | 19.8 | 21.8 |
| Running (6) Running (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Cycling (3) Hockey/ringette (3) Hockey/ringette (2) 1 (10) 0 (0) 2 (20) 3 (50) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 16.2 7.2 16.2 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 3 (30) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Sports/physical activities | | | | |
| Cycling (3) Cycling (3) Hockey/ringette (3) Hockey/ringette (2) 1 (10) 0 (0) 2 (20) 3 (50) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 2 (20) 1 (17) 3 (50) 2 (33) 3 (50) 2 (33) 3 (50) 2 (33) 3 (50) 2 (33) 3 (30) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Top sports or activities engaged in the most, <i>n</i> | Running (6) | Running (3) | Mixed martial arts (2) | Running (9) |
| Hockey/ringette (3) Hockey/ringette (2) 1 (10) 0 (0) 2 (20) 3 (50) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 2 (20) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) | | Cycling (3) | Cycling (3) | | Cycling (6) |
| 1 (10) 0 (0) 2 (20) 3 (50) 2 (20) 3 (50) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 3 (50) 3 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | | Hockey/ringette (3) | Hockey/ringette (2) | | Hockey/ringette (5) |
| 1 (10) 0 (0) 2 (20) 3 (50) 2 (21) 2 (33) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 3 (30) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | | | | | Mixed martial arts (2) |
| 2 (20) 3 (50) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 2 (20) 2 (50) 3 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Membership, n (%) | 1 (10) | 0 (0) | 0 (0) | 1 (5) |
| Jue) 3 (30) 2 (33) 4 (40) 1 (17) 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 2 (20) 1 (17) 3 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | School-based team (college or university) | 2 (20) | 3 (50) | 3 (50) | 8 (36) |
| 4 (40) 1 (17) 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 5 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Sports association (local, regional, or national league) | 3 (30) | 2 (33) | 2 (33) | 7 (32) |
| 16.2 7.2 16.2 7.2 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 5 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Other (e.g., professional athlete) Not applicable | 4 (40) | 1 (17) | 1 (17) | 6 (27) |
| 2 (20) 3 (50) 2 (20) 1 (17) 2 (20) 1 (17) 5 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Mean time per week in sports, hours | 16.2 | 7.2 | Ŷ | 9.8 |
| 2 (20) 3 (50) 2 (20) 1 (17) 5 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Use of coach or trainer, <i>n</i> (%) | | | | |
| 2 (20) 1 (17) 5 (50) 2 (33) 5 (50) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) 3 (30) 2 (33) | Coach | 2 (20) | 3 (50) | 4 (80) | 9 (43) |
| 5 (50) 2 (33) 5 (50) 4 (67) 3 (30) 2 (33) 3 (30) 2 (33) | Trainer | 2 (20) | 1 (17) | 0) 0 | 3 (14) |
| 5 (50) 2 (33) 5 (50) 4 (67) 3 (30) 2 (33) 3 (31) 2 (33) | Diabetes management | | | | |
| 5 (50) 2 (33) 5 (50) 4 (67) 3 (30) 2 (33) 3 (31) 2 (33) | Insulin management/monitoring for exercise, n (%) | | | | |
| 5 (50) 4 (67) 3 (30) 2 (33) 3 (30) 2 (33) | Multiple daily injections | 5 (50) | 2 (33) | 2 (40) | 9 (43) |
| 3 (30) 2 (33) 3 (30) 2 (33) | Insulin pump | 5 (50) | 4 (67) | 3 (60) | 12 (57) |
| 3 (30) 2 (33) | Continuous glucose monitoring use, n (%) | 3 (30) | 2 (33) | 2 (40) | 7 (33) |
| | Occurrence of severe hypoglycemia during exercise (requiring the help of another person, n [%]) | 3 (30) | 2 (33) | 2 (40) | 7 (33) |

relation to diabetes, and some found it improved their mental health. For example:

". . . I've found that exercise is . . . a very good way to control my diabetes, reduce my insulin, up my food intake, and I always found that . . . the effects last. . . ." (FG3)

"... If I don't exercise ... I'm a different guy. I get kind of miserable and depressed and nasty" (FG3)

Individuality of Athletes With Type 1 Diabetes

The unique and independent experiences of athletes with type 1 diabetes were revealed in a number of ways. Mentioned by the majority of respondents across groups was the application of trial and error to tailor what works to individual circumstances. For example:

"... with the endocrinologist ... you can go in and say, 'You know, I was thinking of trying this. What do you think?' Because you've already got a theory... [based on] experience" (FG2)

It was important that each individual be recognized as unique, and objections to a one-size-fits-all approach were mentioned by most respondents across groups. For example:

"... You might go to your coach and say, 'Hey, I'm diabetic,' and they've had a previous player who is, and they go, 'Oh yeah, I know what that means.' But it could mean something completely different to you" (FG1)

The majority of respondents across groups also noted the need to rely on and advocate for themselves. For example:

"Im there all the time. I'm the only one that can really deal with it, so I have to rely on me." (FG3) There was recognition by several respondents across all groups that athletes with type 1 diabetes were distinctive, somewhat "lonely" (FG2), and particularly unique from people with type 2 diabetes:

"... We're a rare breed.... Most people are type 2.... It's really uncommon to come across type 1.... So, when you finally meet a type 1, you get all excited" (FG3)

Finally, most respondents across groups highlighted their selfdetermination and bravery in not quitting or giving up exercise despite having type 1 diabetes:

"I always take it as an opportunity, as a challenge to figure out how I beat it." (FG3)

A few respondents associated this determination as a means toward being accepted as "normal":

"... Nobody has perfect control, nobody makes all the right decisions, and we all know better.... You know, it's our life first and then our diabetes second, and certainly it's not the other way around." (FG1)

Experiences in Managing Type 1 Diabetes With Sports and Exercise

Table 2 lists the most commonly reported strategies for and challenges of managing diabetes around sports or exercise. Overall, more strategies were mentioned than challenges, particularly those strategies used before and during exercise. Monitoring blood glucose was a common strategy but also a marked challenge during exercise. Hypoglycemia after exercise and adrenaline causing hyperglycemia during and immediately after exercise were the most prevalent concerns mentioned by several to most participants across all focus groups. General challenges across the exercise timeframe most frequently involved insulin management. Participants emphasized the uncertainty of experiencing

high or low blood glucose, and a few mentioned concerns with correcting and adjusting insulin (dose and type). All participants from one focus group mentioned that ketones were a significant challenge; however, ketones were not discussed at other groups.

Resources Used and Desired

Figure 1 presents the results from the "dot exercise" with mean scores across focus groups for current and preferred resources to support athletes in managing type 1 diabetes. The mean scores were calculated as the average scores (dots placed) across the three focus groups for each of the listed resources. Averages of each focus group were used because the unit of analysis was the individual focus group. Thus, we first demonstrated the results per group and then averaged the results of the three groups to determine the overall average number of dots per resource.

Two resources stood out as being more preferred than currently used. First, there was a desire for more apps that ideally allowed athletes to be "... impacted and inconvenienced as little as possible" (FG1), such as those that are simple and customizable; provide detailed analysis and reports; and integrate food, exercise, and other needs. Some participants mentioned apps that help with certain aspects of diabetes management, such as "My Fitness Pal" for tracking caloric intake and exercise and "GlucoseZone" to tailor exercise programs to food intake, glucose level, and heart rate, although there is not one app that takes into account all desired features. Second, respondents said they would prefer to turn more to friends/peers with diabetes for support and recognize a current gap:

"... There's not that many diabetics that play high-level sports, and it's kind of cool to see ... opening up that kind of a resource to ... chat with" (FG1)

In other words, because this is a limited subset of the diabetes population,

| TAE | TABLE 2. Most Commonly Reported Strategies for and Challenges of Managing Diabetes by Exercise Timeframe | es of Managing Diabetes by Exercise Timeframe |
|------------------------------------|---|---|
| Exercise | Themes and Selected Quotes | lected Quotes |
| Timeframe | Strategies | Challenges |
| Before exercise | Check or monitor blood glucose or adjust insulin: " Before going into a sport or activity, [I] see where I'm at." (FG3) Increase food intake or consume certain foods: " I have my stan- | • Fatigue: "[It] really depends [on] the fatigue I'm going into that activity with" (FG1) |
| | dard toast with peanut butter and banana" (FG2) Reduce or regulate basal rate: " | |
| During exercise | Remediate: " If I'm in the middle of a round, and I'm getting hammered [my coach] knows instantly [that I'm] low my glucose is in my bag I sort it out in between rounds." (FG1) | Adrenaline: " Especially in a tournament. That's when I really spike up and down because I have three games a day" (FG2) Intensity of exercise or sport: " At 16K. my body starts to stress. |
| | Adjust type or intensity of training or exercise: " What I found the most helpful is that I'll do my adrenaline heavy lifting first, and I'll correct that with my cardio, so my blood sugar will come back down" (FG1) | My blood sugars go way up The ketones start I get so dehydrated I have to go to the hospital" (FG2) Can't check or monitor during exercise: " With hockey, you don't really have the opportunity to Icheck your sugars]" (FG1) |
| | Check or monitor blood glucose: " My blood sugars actually start rising during the gamel get an alarm when we're play- ing, "Stop!" (FG3) | |
| After exercise | Correct or remediate: "[I] bolus heavily at dinner when I'm going to be up over the night in a resting state." (FG1) | Hypoglycemia: "I'm always afraid at night. I'd have a snack and maybe overdo it. Go a little bit high to sleep [because]you're always afraid of not waking up" (FG3) |
| General (before, during, and/or | • Check or monitor blood glucose: "I live my life check by check I have a glucose meter I'll check it 10 times a day All you | Insulin management: " A low and a high can feel the same" (FG1) |
| atter exercise) | נוטרו (דטר) השווש היו אי היו אי היו אי היו היו אי היו היו די היו היו היו היו היו היו היו היו היו הי | Food intake: " I struggle sometimes because I've had to stop do- ing marathons because I can't get enough food into me. I burn off my fuel too quickly" (FG2) |
| | thread here This is my sport. This is my lifestyle. This is how l'm going to react The key [is] having good control." (FG3) | Away from home: " When I was about 16, I was playing on the junior national team for softball, and I had a really bad experi- ence. We went to Mexico for a tournament, and I probably had a seizure just about every night from hypoglycemia because the diet was so different." (FG1) |
| | | |

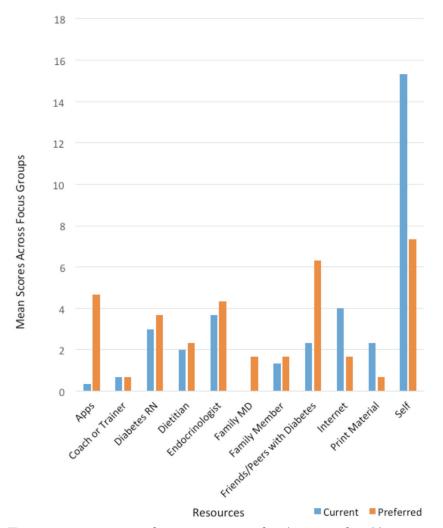


FIGURE 1. Mean scores for current versus preferred resources for athletes to manage type 1 diabetes.

there was a desire to have like-minded people to share experiences with.

There was little difference in current and preferred support from health care providers, with several positive comments made about care from a dietitian, diabetes nurse, and endocrinologist. Participants indicated that they currently relied mostly on their endocrinologist for support, some of whom stood out because of their experience:

"The ones that do get it are the ones that see the active diabetics, so they have more knowledge and experience." (FG2)

However, several participants had concerns that endocrinologists make wrong assumptions and do not take the whole person into account or specifically address their questions:

"... I had to change my endocrinologist ... [for] not getting the fine-tuned nature of my question... Don't tell me some ... large platitude that you tell people who don't care" (FG2)

Similarly, no difference was seen in current and preferred support from coaches or trainers. Several respondents across groups explained that they did not seek support from their coach or trainer because they were typically uninformed about diabetes:

"None of our coaches . . . know anything about it. Like, they're

learning from what I'm telling them "(FG3)

There was less preference for several resources. Although "self" was identified as the most popular resource ("I am my own app." [FG1]), participants viewed that as less desired. The Internet was currently used by some; however, it was less preferred, with a few participants indicating their hesitancy in using it:

"[The] Internet can be frustrating . . . if you're researching something and [can't] access the full scholarly article." (FG2)

Finally, print materials were less desired, although several participants across groups brought up the need for basic information when just diagnosed:

"... There's some basic stuff... that could be shared with people starting out or people who never were taught that at all." (FG3)

Medical Devices

Medical devices were raised as a separate type of resource for managing diabetes during sports or exercise.

Insulin Pumps

Several participants across groups had positive things to say about insulin pumps:

With the pumps . . . these days, . . . [you] can compensate for that snack now. . . . It's so . . . much more freedom." (FG3)

However, some problems were mentioned by several participants across groups, such as that the device was a nuisance to wear or that it did not stay attached. Furthermore, they needed to adapt their medical devices for better comfort or attachment during a sport or activity.

"So, when I train, I actually put my infusion set in my arm. I don't leave it in my stomach because I... use like a basketball shooting sleeve, and I double wrap it up top, and it

holds it. And then just a quick disconnect." (FG1)

A few participants had concerns that their sport was too rough to wear the pump, while others had ideas to better protect the pump during contact sports.

Continuous Glucose Monitoring Devices

Several participants liked how continuous glucose monitoring (CGM) provided more information during exercise:

"[With the CGM, you] see what your sugars are doing. And it's amazing. It's a real eye-opener. I print out a graph. I email it to . . . [my] nurse educator. . . . I wear my CGM for soccer, or I go for a run or something like that. You can see exactly every 2 minutes." (FG2)

Conversely, several others noted that they would prefer not to wear a device, a few revealing that they wanted to keep their diabetes secret to avoid being "labeled" (FG1). Some participants found CGM devices to be expensive or unreliable, and a few found that their CGM was inaccurate.

Peer Mentoring

Addressing the desire for more friends/peers support, participants across groups spent quite a bit of time discussing peer mentoring as a viable option to help high-performing athletes or exercisers better manage their type 1 diabetes. "Creating a space" (FG1) was seen as important for like-minded athletes with type 1 diabetes to come together and discuss their lived experience:

"Term mentorship . . . fits. . . . If you have people doing a particular sport who are diabetic, they can help in terms of just their experience. . . . You learn tricks . . . from them." (FG2)

Unlike advice from a health care provider, peer mentoring was viewed as more of a practical sounding board to relay personal stories about struggles and what works:

"... We just need a sounding board.... not necessarily someone telling us exactly what to do." (FG1)

Several participants across groups provided examples of peer mentoring groups for athletes with diabetes that they were involved in or aware of, such as: "Connected in Motion . . . a forum for type 1 diabetics who are athletes of all kinds" (FG3); an anonymous sign-up for those students in university with diabetes and looking for resources (FG1); and an "Animus pump . . . chat group" (FG2).

Logistics for organizing peer mentoring were discussed. Finding a mentor that they could trust to provide appropriate advice was a concern of several participants across groups. Ideal mentors were seen as those patients identified by endocrinologists who were interested in volunteering:

"... The doctors know their patients and could ask them, 'Are you interested in being a mentor?'" (FG3)

Patients or doctors with type 1 diabetes and good A1Cs were deemed suitable candidates by some participants. Developing mentor profiles and matching patients based on sport, knowledge, and experience were also mentioned by a few participants. It was recognized that finding suitable mentors may be a challenge when there is heterogeneity in the types of sports/activities, as well as individual preferences in who they could get along with. Three options arose for structuring the mentoring sessions: face-to-face group sessions with a professional to assist with the sessions, one-on-one sessions via email or phone such as a helpline, and leveraging social media or an app.

Discussion

This study highlighted the unique challenges of and strategies for optimizing glycemic control specific to athletes with type 1 diabetes and provides a basis for development of appropriate patient-centered resources. We found that athletes with type 1 diabetes had experiences that are unique to each individual. The participating athletes were independent, self-reliant, and willing to accept the uncertainty of experimentation when managing diabetes, and they demonstrated considerable resilience. When planning for exercise or sport, many draw on past experiences to develop strategies that work for them. Similar to others' findings, we found that individualized adjustments are necessary based on the various factors that influence glycemic control, especially until a predictable routine is established (4,13). Trial-and-error techniques were found to be a common strategy, as has been reported as an essential aspect to glycemic management in the athletic population (5,8), although our study population also expressed a strong desire to draw on other resources outside of "self."

A general story unfolded about the different strategies and resources used in exercise/sports at different trajectories based on lived experience. Novice exercisers may draw on readily available materials, established guidelines, or health care provider advice to adjust diet and insulin for exercise. As they progress or change exercise/ sports, modifications to glycemic management may be made more often on their personal experiences and various other resources they seek out. Although there are published articles, guidelines, and other reference materials for type 1 diabetes and physical activity (2,4,6,14), these may have limited utility with highperformance exercisers, who generally have a good understanding of required modifications for exercise. As they become experts in their sport, they may require further refinement, ideally supported by information from others with type 1 diabetes who play similar sports or have had similar

experiences based on their own trials and errors.

Although many participants in this study currently rely on themselves to adjust to challenges with exercise, there was a perceived need for other resources to build selfmanagement skills for glycemic control. In particular, our results emphasize the value of peer mentoring, specific members of the diabetes team (i.e., endocrinologists, diabetes nurse educators, and dietitians), medical devices (e.g., insulin pumps and CGM systems), and apps.

Peer mentoring was an area of expressed interest and was envisioned as having people who play similar sports compare their experiences and learn from each other. This type of knowledge-sharing has not been previously documented in the literature for adult athletes with type 1 diabetes. However, a study in adolescents and young adults with type 1 diabetes demonstrated that the majority would prefer mentoring to improve their glycemic control (15). To create a credible "mentor space," suitable oversight and screening would need to be provided.

Health care teams play a role in providing advice and support and as a means to check in to ensure that athletes are making sound decisions.

Apps were also viewed as a favorable resource that could be developed to integrate the different variables (i.e., type, intensity, and duration of exercise; food intake; and active insulin on board) that influence glycemic control during exercise. However, one must recognize that such a tool would be difficult to create to meet individual needs and personal preferences. Such a technological solution would be highly user dependent and may not appeal to all individuals.

Finally, many participants highlighted the importance of medical devices such as insulin pumps to allow for timely adjustment to insulin and CGM systems to closely monitor trends in glucose levels.

Taken together, there was a demonstrated interest in increasing

the availability of social/peer networks and the utility of resources (i.e., better apps and more knowledgeable health care professionals) to meet the needs of athletes with type 1 diabetes.

Limitations

The sampling approach used in this study is a possible limitation. The sample included current or previous adult athletes with type 1 diabetes in active or recent treatment at the FEDC. All participants were recruited from a single academic hospital institution, and findings may not be widely applicable. On average, participants had >20 years of living with this chronic disease. Consequently, the strategies identified by these groups may not necessarily appeal to those who have been recently diagnosed. Although only patients with an A1C <10% were included, we did not report on the adequacy of their glycemic control.

Further research could be directed at newly diagnosed athletes and those excluded from this study—namely, athletes with poor glycemic control with an A1C \geq 10% and beginner or recreational exercisers. Due to the individual nature of how athletes with type 1 diabetes cope, in-depth case studies would be useful to further explore this topic.

Conclusion

Athletes with type 1 diabetes are at risk of disengaging from exercise if the guidance and support they receive does not align with their unique needs to remain active in their sport. It is important that health care professionals understand the individual and unique nature of these patients' exercise experiences and support the need for individual experimentation to manage blood glucose. This study highlights that resources outside of themselves are desired by athletes with type 1 diabetes. Peer networks, medical devices, and apps that better support athletes with type 1 diabetes were seen as particularly desirable and should be advanced and researched.

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Duality of Interest

No potential conflicts of interest relevant to this article were reported.

Author Contributions

S.D. recruited participants, revised the focus group moderator guide, co-moderated the focus groups, reviewed transcripts and applied coding framework, and drafted the manuscript. J.M. reviewed the focus group moderator guide, reviewed transcripts, applied coding framework, and drafted the manuscript. M.R. constructed the focus group moderator guide, co-moderated the focus groups, analyzed the data, and drafted the manuscript. E.J.K. reviewed transcripts, applied the coding framework, and drafted the manuscript. All authors reviewed the coded sections for fittingness, contributed to the discussion, and reviewed/edited the manuscript. S.D. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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