

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Canadian Journal of Diabetes

journal homepage:
www.canadianjournalofdiabetes.com


Original Research

Storytelling to Support Disease Self-Management by Adults With Type 2 Diabetes



Enza Gucciardi MHSc, PhD^{a,*}; Anna Richardson MPH, RD^a; Stephanie Aresta MHSc, RD^a; Grace Karam MAN, RD, CDE^a; Souraya Sidani RN, PhD^b; Heather Beanlands RN, PhD^b; Sherry Espin RN, PhD^b

^a School of Nutrition, Ryerson University, Toronto, Ontario, Canada^b Daphne Cockwell School of Nursing, Ryerson University, Toronto, Ontario, Canada

Key Messages

- Group storytelling is starting to be used to support disease self-management, and it has been noted to be a suitable adjunct to traditional diabetes education.
- Patients are willing to self-direct and take ownership of the intervention; it can be used to self-identify management needs and share strategies to address them.
- Patient information exchanged during storytelling can also inform care providers' practices.
- Storytelling interventions can be delivered with high fidelity that is acceptable to patients and care providers.

ARTICLE INFO

Article history:

Received 14 February 2018

Accepted 5 June 2018

Keywords:

diabetes
group intervention narratives
self-management
story-based interventions
storytelling

Mots clés :

diabète
interventions narratives en groupe
prise en charge autonome
interventions fondées sur les récits
récit (nom) ou narrative (adjectif)

ABSTRACT

Objectives: This pilot project aimed to examine the acceptability and feasibility of a group storytelling intervention to support self-management among adults living with type 2 diabetes.

Methods: Two waves of a single-arm storytelling intervention, consisting of 8 sessions at a community health centre, were delivered to 8 adults with type 2 diabetes. Diabetes educators facilitated each session, in which patients shared stories about diabetes-self-management topics of their choice. Focus groups with both patients and facilitators explored the feasibility and acceptability of the sessions. External raters assessed the fidelity of the intervention's implementation.

Results: Overarching themes describe the acceptability and feasibility of the intervention: 1) the facilitation of patient self-direction, group cohesion, collective learning and support; 2) roles of facilitator educator, and peer learner; 3) the intervention's customization to patients' preferences. The sessions were delivered with high fidelity (averaging 84.4%).

Conclusions: Informal group storytelling enables patients to discuss, understand and give personal meaning to the information that was exchanged, and facilitates educators' better understanding of patients' concerns and gaps in knowledge and how-to strategies that can inform their practice. The group storytelling intervention is acceptable to patients and educators and can be delivered with high fidelity. Further research into effective patient recruitment methods and evaluation of the intervention's impact on diabetes self-management is required.

© 2019 The Authors. Published by Elsevier Inc. on behalf of Canadian Diabetes Association. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

R É S U M É

Objectifs : Le projet pilote visait à examiner l'acceptabilité et la faisabilité des interventions narratives en groupe pour favoriser la prise en charge autonome des adultes vivant avec le diabète de type 2.

Méthodes : Deux phases d'interventions narratives à bras unique qui consistaient en 8 séances dans un centre de santé communautaire ont été offertes à 8 adultes atteints du diabète de type 2. Des éducateurs en diabète animaient les séances au cours desquelles les patients partageaient leurs récits sur des thèmes de leur choix quant à la prise en charge autonome du diabète. Les groupes de discussion qui regroupaient

* Address for correspondence: Enza Gucciardi, MHSc, PhD, School of Nutrition, Ryerson University, 350 Victoria Street, Toronto, Ontario M5B 2K3, Canada.

E-mail address: egucciar@ryerson.ca

les patients et les animateurs exploraient la faisabilité et l'acceptabilité des séances. Les évaluateurs externes estimaient la fidélité de mise en œuvre des interventions.

Résultats : Les thèmes dominants portent sur l'acceptabilité et la faisabilité des interventions : 1) la facilitation de l'autonomie du patient, de la cohésion de groupe, de l'apprentissage collectif et du soutien; 2) les rôles d'éducateur, de pair et d'apprenant de l'animateur pour orienter la pratique; 3) la personnalisation des interventions selon les préférences des patients. La fidélité des séances s'est avérée élevée (84,4% en moyenne).

Conclusions : Le récit en groupe informel permet aux patients de discuter, de comprendre et d'interpréter de façon personnelle les informations qui étaient échangées et aide les éducateurs cliniques à mieux comprendre les préoccupations des patients et les lacunes dans les connaissances et les stratégies concrètes qui peuvent orienter leurs pratiques. Les interventions narratives en groupe sont acceptables pour les patients et les animateurs, puisque leur fidélité peut s'avérer élevée. D'autres recherches sur les méthodes de recrutement efficaces et l'évaluation des conséquences des interventions sur la prise en charge autonome du diabète sont nécessaires.

© 2019 The Authors. Published by Elsevier Inc. on behalf of Canadian Diabetes Association. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

Diabetes-self-management education (DSME) offers patients the knowledge and skills they need to manage their disease (1,2). However, disease-management programs have had minimal to moderate success in the short term (3–5). Many patients do not meet clinical targets for diabetes management, or they neglect aspects of self-management (6–9), which leads to health complications and adverse outcomes. Furthermore, DSME programs often have low uptake and high attrition rates (10,11).

Using a primarily biomedical model focused on meeting clinical targets, DSME tends less to diabetes' emotional and social aspects and may have limited capacity to motivate patients toward diabetes self-management behaviours, perhaps because the model does not integrate the meanings that patients ascribe to their disease (1,2). There is growing evidence that DSME's short-term benefits can be sustained by self-management supports (10,11). Such supports may include frequent follow up by health-care providers, peer support and linkages with community support groups. Evidence suggests that combining DSME with ongoing support can improve glycemic control, self-efficacy and self-care behaviours and can reduce diabetes distress and foot complications (10–12). Advocacy continues for a more holistic approach that integrates the ongoing needs of each patient while leveraging expertise from others with diabetes, family members, social-support networks and health professionals (13).

Storytelling is an approach that enables people with diseases such as diabetes to share their personal stories and experiences with professionals and other patients, helping them toward a better understanding of their disease and discovering self-management strategies (3). Storytelling can include learning about the disease, improving coping skills and developing motivation to change lifestyle (3). Shifting from the biomedical model to a strategy that incorporates patients' stories and experiences may empower patients to manage their illness in ways that fit their unique needs.

Few studies have evaluated the effects of group storytelling interventions on chronic-disease self-management (4). These evaluations had heterogeneous target populations, study designs, curricula and program implementations, limiting the evaluations' abilities to compare the interventions' efficacy (4). Furthermore, limited information is available about the feasibility and acceptability of storytelling among patients and care providers (3,5,6). Given the increasing prevalence of diabetes, along with rising per-patient treatment costs (7), storytelling may enhance patient competency and self-management motivation by valuing patients' stories, experiences and social interactions. Accordingly, we aimed to examine the acceptability and feasibility of storytelling for adults with type 2 diabetes.

Methods

Intervention

The storytelling intervention was delivered twice at a community health centre in Toronto, Ontario, between November 2013 and July 2014. The intervention was comprised of 8 group sessions over a 16-week period; each session lasted 1.5 h to 2 h. A nurse and/or dietitian, diabetes educator at the health centre facilitated each session after being trained. Facilitators were given a guidebook and appropriate resources for each session's topic. Following the intervention guide, facilitators were responsible for ensuring that sessions progressed, validating and correcting information, drawing out patients' stories and encouraging discussion of them, sharing personal stories when relevant, supporting group processes and encouraging the sharing of disease-management tips.

The intervention was patient directed; the group collectively decided on group norms (e.g. respecting the opinions and experiences of others without judgment, 1 person speaking at a time, participation by all group members). Patients brainstormed diabetes self-management topics and chose topics for each of the sessions. The first couple of sessions began with 15 min of social time and icebreaker activities to increase patients' comfort. Facilitators then introduced the session's topic and asked patients to tell stories they had prepared. Each patient was given an opportunity to talk and to respond to others' stories. Activities were integrated into the sessions, such as post-it activities to brainstorm thoughts and feelings associated with the session's topic. Educational resources and case scenarios were discussed in small groups to facilitate collaborative learning. Each session concluded with closing remarks by patients about what they had learned and reflections on needs for subsequent sessions. [Supplementary Table 1](#) lists the topics patients selected and discussed.

Facilitator training

Facilitators were trained in a half-day, in-person workshop and online reading materials with mandatory quizzes. The training materials and intervention guide were based on: 1) a literature review of group storytelling interventions related to chronic-disease self-management (4); 2) training manuals and information obtained from other researchers who have conducted storytelling interventions; and 3) team collaboration yielding expertise about diabetes, self-management education, behavioural change and intervention design.

Research design and data collection

A multimethod, single-group with repeated measures design was used to obtain data pertaining to the feasibility, acceptability

and outcomes of the storytelling intervention. Two focus groups (1 with patients and 1 with facilitators) explored experienced acceptability (concurrent and postintervention) (8). Acceptability “reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention” (8). The focus group discussions enabled immediate patient and facilitator feedback regarding the intervention; as a result, it could be immediately altered to meet patients’ needs. Each focus group session was audiorecorded and transcribed.

Feasibility was assessed by examining the logistics involved in intervention delivery, patient recruitment and retention rates and the intervention’s implementation fidelity. During sessions, facilitators also took field notes to capture implementation issues. Data were analyzed along with facilitators’ field notes, which added insight into facilitators’ experiences during the sessions and how they viewed the intervention’s acceptability and feasibility. All patients consented to participation and audiorecording of the sessions and focus groups. The study protocol was approved by the Research Ethics Board at Ryerson University.

Patients

Patients were recruited using posters and by diabetes educators at the centre. Eligible patients were at least 18 years of age, had type 2 diabetes and spoke English. In total, 8 patients were enrolled: 3 in the first wave and 5 in the second.

Qualitative data analysis

An inductive-descriptive approach guided the analysis (9,14,15). We used content analysis, the systematic classification of information into categories with similar meanings (15,16). We identified categories emerging from texts without being constricted by specific theories or conceptual models (17). Two members of the research team (SA and AR) coded the transcripts, and a third member (EG) independently reviewed the coding. A coding framework was developed and presented to the rest of the team for review after the coding; categories and emergent quotes that represented these categories were discussed, and consensus was obtained. Once the framework was finalized, SE, HB and SS reviewed and validated the overarching themes, subthemes and selected excerpts. NVivo (QRS Software, Garden Grove, California, United States) was used to manage the transcribed text and facilitate analysis. Preliminary analyses were shared with 1 of the facilitators to enhance the findings’ credibility. To ensure the analysis’ methodologic rigor and trustworthiness, the research team kept an audit trail and triangulated responses from the patient and facilitator focus groups.

Quantitative data analysis

Implementation fidelity is the extent to which the facilitators adhered to the intervention’s essential elements. We assessed agreement between planned activities and activities completed in each session. Checklists were developed listing all activities to be completed in each session, according to the intervention guide. An external reviewer assessed all session transcripts and confirmed that the activities to be carried out were completed. To minimize rater bias, a second external reviewer audited randomly selected session transcripts and verified the initial reviewer’s results (18). To help maximize consistency between reviewers, each was given the same rules for determining whether a task was complete or incomplete. Fidelity was expressed as the percentage of planned activities that were implemented.

Results

The patients had a mean age of 64 years (Table 1). Five were female, all were Caucasian, and most were married or divorced. The number of years since a diabetes diagnosis averaged 9 (range, 1 to 24), and 75% were receiving individual diabetes counselling from a doctor, nurse and/or dietitian educator during the intervention.

Qualitative results: intervention acceptability and feasibility

Three overarching themes were identified: patients’ self-direction, group cohesion, collective learning and peer support; striking a balance among the roles of facilitator, diabetes educator, and peer learner; and customizing the intervention delivery, structure and organization to patients.

Intervention facilitated patients’ self-direction, group cohesion, collective learning and support

Overall, both facilitators and patients characterized the storytelling sessions as being patient directed. In addition to selecting topics relevant to their own interests and concerns, facilitators observed patients’ voicing their learning needs, asking questions and debating various self-management viewpoints. Facilitators felt that this patient-driven approach may improve patients’ diabetes management (Table 2A).

Facilitators and patients noted that the intervention’s structure gave patients opportunities for collective learning: to evaluate what they know and do not know and to learn from each other by exchanging knowledge. Furthermore, facilitators observed patients taking active roles in learning by discussing their self-management techniques. Facilitators also commented that patients demonstrated how much they knew about diabetes management (Table 2B).

One facilitator remarked that sharing stories fostered patient discussions about their self-management experiences, strategies and resources and that stories provided teachable moments, regardless of literacy and education levels. Storytelling’s simplicity may eliminate barriers that might otherwise lead patients to feel excluded, embarrassed or nervous about participating in traditional workshops (Table 2C).

Patients viewed the group sessions as valuable additions to their individual medical and nutrition counselling because they shared their experiences in applying advice they had received. They also used the group to gather information and generate questions to discuss with their care providers and as supports to help them manage diabetes (Table 2D).

Table 1
Demographics of patients

Demographics	Patients, % (n)
Age, years	
50–59	25 (2)
60–69	37.5 (3)
≥70	37.5 (3)
Gender	
Female	62.5 (5)
Male	37.5 (3)
Marital status	
Married	37.5 (3)
Single	25 (2)
Divorced	37.5 (3)
Age at diagnosis, years	
<50	25 (2)
50–59	50 (4)
60–69	12.5 (1)
≥70	12.5 (1)
Receiving individual diabetes counselling during intervention	75 (6)

Table 2
Theme 1: Intervention was patient directed and facilitated group cohesion, collective learning and peer support; corresponding statements by study participants

A. Intervention was patient directed.
F2N: “I’m just observing they’re more self-directed, and you really see the adult principles of learning. It’s more pronounced in these sessions, where they’re really taking the initiative and effort to make that commitment, not just for us but really to make this experience more valuable and meaningful for them. And I think that’s what’s different and sets this apart from other programs.”
F2N: “I’m beginning to see more growth, with their learning experience, and how they really are taking on this whole journey, with real self-initiative—it’s almost like they’re really taking control over their chronic disease. As opposed to us having to do more of the directing.”
B. Collective and active learning by patients.
P1W1: “The education workshops gives you the information. These groups gives you the [information] if you have a question, sometimes you can bring up the question and then the professionals or the general [group] can give you input on, like, what’s going on.”
F1D: “In their regular conventional appointments, clients usually ask questions but don’t get the opportunity to show that they understand, or their level of understanding.... This is an amazing opportunity for them to not only say how they feel about managing their condition but also to show a lot of confidence. And comfort in dealing with their condition, which is an aspect that is completely missed in the conventional treatment.”
C. Intervention facilitated discussion and teachable moments, regardless of literacy and education level.
F1D: “I think this would be a great opportunity for people with different cognitive levels of understanding to participate because there are so many different people who can understand one topic from very different angles and trying to explain to one another.”
D. Storytelling is a valuable supplement to individual counselling sessions with health-care practitioners.
P2W1: “Another thing what this group does is, so we still meet with them individually for our own personal individual counselling, but these sessions bubble up the questions in my mind, what I need to ask. Without these sessions, I would have probably missed some of the questions if on my own, right? So I found that to be very good too, where I go, ‘Oh geez, that’s something that I need to talk to [care providers] about.’”
P3W1: “Yeah, because it’s psychological as well as the physical, [P2W1: Yeah, absolutely.] and I think it helped with the psychological side of it, learning to deal with the grips of it, that the educational workshops can’t give you that.”
E. Intervention atmosphere was friendly and welcoming, creating comfort for patients to engage and share their stories.
F1D: “All in all, patients seemed to feel much more connected with each other, conversations happened much easier among the more quiet ones.”
P1W1: “Here, I fit like a team. [At] the educational workshops I’m an individual sucking in information; here, I’m part of a team and it’s just so much better that way.”

Note: Code numbers were assigned to study participants, reflecting their category (patient or facilitator) and their unique number and wave; e.g. P1W2 stands for patient 1, wave 2; F1D stands for facilitator 1, dietitian; and F2N stands for facilitator 2, nurse.

Over time, facilitators described patients as becoming friendlier and more welcoming of each other. One said that the quieter patients felt more comfortable and confident in sharing their feelings and experiences with each passing week. All patients learned from and supported each other (Table 2E).

Facilitator role: striking a balance between facilitator, diabetes educator, and peer learner

Facilitators felt uncertain and nervous before starting the sessions. They wondered how patients would interact, how relationships would develop and what their roles as facilitators would entail compared to their diabetes-educator roles. This finding underscores the importance of facilitator training (Table 3A).

Diabetes educators were not accustomed to facilitating, and it took time for them to refrain from leading or teaching the group. They initially struggled with allowing patients to share their ideas

and experiences while keeping discussions within the specified topics and time frames. However, facilitators regularly addressed patients’ inquiries and validated their responses and concerns (Table 3B).

Responding to stories or questions, patients often advised other group members on the basis of their own experiences. Sometimes the advice was inaccurate (e.g. “You can have a potato once a year”), underscoring the need for clinician input. However, with time, facilitators observed a shift in their role to peer learners, which they found helped to build their professional capacities. They saw these sessions as “a learning experience.” Facilitators appreciated patients as experts in their own self-management (Table 3C).

Facilitators enjoyed their dynamic role, but at times, the shared personal information concerned them. When patients sometimes alluded to conversations during counselling with diabetes

Table 3
Theme 2: Facilitator role: Striking a balance between facilitator, educator and peer learner; corresponding statements by study participants

A. Facilitators were uncertain and nervous prior to the commencement of an intervention.
F1D: “I felt very nervous as this is a new group, and I am unsure of how the dynamics will play out, knowing there will be one quieter patient, one patient I’ve never met, one patient whose medical chart lists her to have early stages of memory loss.”
F1D: “I was anxious to find out how I will fit in now as facilitator only and no longer being a part of their diabetes team.”
B. Facilitators struggled with the role but later adjusted to listening rather than leading.
F2N: “I’m so used to being that health-care provider, directing the conversations despite giving the opportunity for the clients to talk—but sometimes I feel like I’m so limited in time I have to just get to the point, get to the conversation, get to the objective, but here I’m really forced to train myself to hold back, you know, because...they’ll answer their own question. And then I won’t have to address it. It’s just having that patience.”
F2N: “And um, whether it’s physically or verbally, and just really feeling that sense of whether I need to, you know, say something in that moment. Without taking away that natural flow. I think that’s my biggest struggle sometimes, should I say something now, or should I just wait a little?”
F1D: “I found a few spots I had to just answer clients’ inquiries, either by validating their right answers and elaborating or just telling them the right answer after they tried to solve their inquiry on their own.”
C. Facilitators struck a balance between facilitator and educator and found it enriching and valuable to their professional learning.
F2N: “If we need to interject, but so far it hasn’t quite happened, maybe there was that odd few moments where we had to maybe clarify something, but most times [it’s] the patients, and that’s the beauty of it, they really do, it’s like self-discovery. And also learning from other patients. So, it really takes away from, you know, the work that we have to do.”
F1D: “It’s such a great way for me to stop having to play the educator role but instead come as a peer in some sort of way, to guide conversations, and it’s great to see people cover things on their own and learn things. I see lightbulbs going off all the time, which is great....It really adds another layer to my professional practice as an educator. It enriches my other components of practice. Sort of having that experience that changes people.”
D. Patients responded positively to the educators’ facilitating role.
P2W1: “Both [facilitators] are not condescending, I mean they let us get out there and say what we need to say, and it’s great.”
P1W1: “They [facilitators] worked fine to control the sessions like most medical professionals would. They were more like they were part of the group, not controlling the group.”

Note: Code numbers were assigned to study participants, reflecting their category (patient or facilitator) and their unique number and wave; e.g. P1W2 stands for patient 1, wave 2; F1D stands for facilitator 1, dietitian; and F2N stands for facilitator 2, nurse.

Table 4

Theme 3: Customization of intervention to clientele: Delivery, structure and organization; corresponding statements by study participants

- A. A suggestion was made about how to improve the length and scheduling of sessions.
 P2W1: “So again, from my personal side, the only thing that I didn't like was that it can't be scheduled outside of working hours because it's difficult for me to take the time off work. So it would be great if it could be even a weekend thing or an afterhours kind of.”
 F1D: “...more participation [in] this wave takes more time for each person to tell [their] story? Feels unable to rush some activities as it felt important to allow more time and probing to explore the discussion at hand.”
- B. A suggestion was made regarding the composition and homogeneity of the group.
 P5W2: “I felt kind of alone being the person who'd had diabetes the longest and was able to share this, but um, I wish it'd been sort of, you know, at least one other person who'd been, who'd been diabetic as long as I, I have, so I can get the views of somebody my...well, you know, like the time...just in case I'm getting it all wrong in some way.”
- C. Anxiety was expressed as sessions drew to a close.
 F1D: “Patients appear sad this is the final session but glad they were a part of the program.”
 P3W1: “I would need a continuation of a group like this to feel secure in the future.”
- D. Storytelling format may not be suitable, or type of intervention may deter patients.
 P4W2: “I was actually afraid to come to the storytelling because I had no story to tell.”

Note: Code numbers were assigned to study participants, reflecting their category (patient or facilitator) and their unique number and wave; e.g. P1W2 stands for patient 1, wave 2; F1D stands for facilitator 1, dietitian; and F2N stands for facilitator 2, nurse.

educators, facilitators were unsure whether by engaging they might compromise privacy, even when patients led the conversations.

Patients also enjoyed the facilitators' unconventional role. Unlike their interactions with other health-care professionals, patients liked the way the facilitators allowed them to express their ideas through discussion, while also ensuring that sessions were kept on track without seeming to control them. Patients felt their experiences and opinions were valued and validated by facilitators and that facilitators communicated in nonpatronizing or nondetached ways. Overall, patients viewed the facilitators as trustworthy helpers with whom they could share their experiences (Table 3D).

Customizing delivery, structure and organization of the intervention to patients

Patients and facilitators suggested several ways of improving the intervention's design and implementation. Some noted that scheduling sessions during evenings would benefit working patients. Some suggested longer sessions because they tended to exceed allotted times, while others suggested shorter evening sessions (Table 4A).

Some patients suggested more homogeneous groups—women or men only, similar ages, similar cultural associations, newly diagnosed vs. experienced patients. They felt this could strengthen group cohesion, assuming similar patients might have similar experiences. In contrast, other patients suggested that groups be more diverse in diabetes experience; newly diagnosed patients value the insights and advice of patients diagnosed long before them (Table 4B).

Patients became anxious as the program neared its end. They felt uncertain about sustaining their self-management activities and expressed some dependence on the group to motivate self-management. They discussed continuing the sessions or adding a booster. Facilitators also noted patients' disappointment that the program was ending (Table 4C).

As much as facilitators emphasized inclusivity, they also felt it important to consider that storytelling may not be suitable or helpful for everyone, as the program relies largely on patients' willingness to share their stories. For instance, the intervention was

promoted using the term storytelling. Although this is a relatively novel format for chronic disease self-management, it resembles support groups. Lack of familiarity with storytelling created initial feelings of uncertainty and apprehension among patients before the intervention started. Some did not know what to expect or how to contribute, feeling they had no stories to share. One patient suggested naming the intervention something other than storytelling, using another term that more clearly represented the sessions' format (Table 4D).

The intervention's acceptability

For wave 1, 27 potential patients were approached; 9 indicated interest (33.3%) in the intervention, and 5 attended the first session. Only 3 (11.1%) attended all the sessions; the other 2 said they were no longer interested. For wave 2, 10 of 42 individuals who were approached indicated interest (23.8%), but only 5 (11.9%) attended and participated in all sessions. Reasons for not participating included busy work schedules or not enough time, recent health changes, feeling too reserved to be part of a group or having no interest in the intervention.

Fidelity

Fidelity percentages were obtained for all sessions in each wave (Supplementary Table 2). Overall, facilitators implemented the intervention as planned, as evidenced by a relatively high average fidelity of 83.3% for wave 1; 85.3% for wave 2; and 84.4% (range, 72.7% to 100%) for both waves. Inter-reviewer agreement attained 100% consensus.

Discussion

Patients praised the storytelling intervention as an adjunct to traditional DSME, referring to it as a welcome supplement to the individual counselling they received. Patients noted the value of combining both approaches to optimize knowledge acquisition and application. In contrast to the traditional diabetes-education model, in which patients typically have a passive role, during the storytelling intervention, patients took an active role in learning. Group storytelling encouraged engagement, gave patients opportunities to lead discussions, understand the information that was exchanged and derive personal meaning from the experience. These processes may enhance patients' empowerment and confidence in their abilities to contribute to the sessions (E. Gucciardi, E. Reynolds, G. Karam, S. Sidani, H. Beanlands. Unpublished data, 2017, “Story-based interventions: Functions by which storytelling can promote disease self-management among those living with diabetes.”).

Study patients suggested that the sessions informed and supported their self-management. This finding resembles other story-based interventions in which patients reported overall satisfaction. Study patients commented that the shared information and session activities enhanced previous knowledge about diabetes self-management. In Greenhalgh et al's (3) story-based intervention, lay facilitators described gains in patients' practical knowledge and skills as the greatest benefit. Their facilitators observed a transformation in some patients—increased motivation, confidence and hope for the future (13). At its core, storytelling is patient centred; it assumes that patients can best identify their self-management needs and barriers (3,19). Specifically, patients choose the topics that are relevant to them and direct the flow and pace of sessions, with some guidance from facilitators. Patients also create norms of conduct. This allows more flexible formats than the more rigid structures in information-based, biomedically guided self-management education (4).

Facilitators are the heart of story-based interventions—skillful guidance in a comfortable, supportive and confidential setting (6). The facilitators' role is to enable patients to analyze issues they themselves have raised (20). Facilitating diabetes support groups involves 4 strategies: 1) connecting, 2) exchanging information, 3) managing group dynamics and 4) promoting problem solving (20). In our intervention, the facilitators, reported early challenges in adapting to their role. They had to refrain from jumping in with advice and learn to leave the conversation open for patients to suggest their own solutions. At times, facilitators struggled to maintain the sessions' flow without interrupting patients' natural exploratory processes. Facilitators tried to ensure balance by asking patients whether they wanted to move on to the next activity or continue the current one. As sessions progressed, facilitators became more comfortable. Greenhalgh et al (3) reported similar findings; facilitators initially lacked confidence in their new role, tending to lecture, but this improved as they gained experience and were able to value patients' stories and use them to encourage reflection and discussion. Our facilitators were unsure how to react when patients disclosed information from private counselling. It might be helpful to ask intervention participants how they would like to handle private information discussed during prior counselling.

Study facilitators found their new role transformative. Storytelling interventions bring to light patients' experiential knowledge and self-management expertise. With time, our facilitators began to view themselves less as educators and more as peer learners, the sharing and learning were equally insightful for patients and facilitators. For instance, storytelling may reveal patients' concerns, gaps in knowledge and strategies. These can inform care providers' practice. Storytelling interventions allow patients to speak very openly and somewhat differently than they would in regular clinical settings (3). Our patients viewed educators as part of the group and were comfortable with their role. Facilitators also shared their own stories, inspiring trust (21). Together, our findings and previous research suggest that storytelling is acceptable for patients and for facilitators (3,4,6,22).

Patients' views differed about how patient characteristics might affect group dynamics. Some suggested that grouping people by gender, age or cultural association might foster even more connections, group cohesion and support. Kock and Kralick (23) also found that this approach may better facilitate expression of thoughts and feelings; their patients in a single-gendered intervention felt more comfortable discussing sexuality. It is not yet clear whether such findings would apply to patients with diabetes; this warrants further exploration. In contrast, other patients, particularly recently diagnosed patients, enjoyed their groups' diversity. They liked hearing from patients who had a long period of experience with diabetes and valued learning from a diverse group who had differing strategies and insights. One of the strongest assets of storytelling as a self-management strategy is its wide application. Storytelling is an important component of certain cultural traditions, but people of any age, gender, ethnicity or socioeconomic status can engage in it (24,25).

As found in previous research, planned activities were often incomplete in the time allotted for the sessions, suggesting that longer sessions may be needed (22). Length should be determined by patients' preferences and the setting's logistics, which may need to change based on clientele. As the storytelling sessions ended, some patients feared they would lose the motivation and confidence to self-manage; they wanted more ongoing support. Over the intervention's course, patients established close ties and gained support within the group. In another study, patients felt that the 5-session intervention had been too brief and that it should include more or longer sessions (22). Our intervention dosage (i.e. a total of 8 sessions) may not be enough to reach stable

achievement in self-management; some patients felt they needed to continue with the sessions to keep them on track with their management. This gives rise to the question of how long the intervention should be offered, which may very well be individualized and self-selective. However, peer support could be encouraged outside the intervention.

Study limitations

This pilot study's sample was small. Of those who refused to participate, some expressed concern about having no stories to contribute. Thus, the ambiguity of the intervention's name may have lowered our participation rate. Others who declined participation were not drawn to large-group meetings and may prefer private self-management support. Storytelling interventions could be called information-sharing sessions; many patients attend groups to meet others with diabetes and learn about treatment options and coping strategies (26). Logistical issues such as session timing may also have lowered recruitment and retention. Patients' attitudes toward intervention, appropriateness, suitability and convenience are known to affect recruitment (8).

Practice implications

Informal group storytelling can complement traditional DSME, by providing ongoing self-management support. Patients collectively select topics and direct the flow and pace of sessions with some guidance from facilitators. Storytelling targets patients' experiences, knowledge exchange and patients' self-management expertise, which appear to encourage patient engagement in active learning. Patients felt the sessions were informative and supported their self-management. With time, facilitators began to view themselves less as educators and more as facilitators and peer learners. The intervention allowed educators to better understand patients' concerns, gaps in knowledge and management strategies, which informed their practice.

Conclusions

Diabetes has received significant international attention, as have advances in its treatment and management, however, self-management outcomes are suboptimal. Focusing solely on DSME does not sustain improved outcomes, but participation in continued support-focused interventions such as storytelling can help patients maximize their self-management potential, particularly given the progressive nature of diabetes. In our study, patients and facilitators attributed much of the storytelling intervention's acceptability to it being patient driven. The intervention encouraged engagement and facilitated collaborative learning. Our findings suggest that group storytelling interventions can be delivered with high fidelity and, overall, are perceived by patients and facilitators as being positive and beneficial. Further research should identify how to better recruit patients and evaluate story-based interventions on self-management behaviours and outcomes.

Supplementary Material

To access the supplementary material accompanying this article, visit the online version of the *Canadian Journal of Diabetes* at www.canadianjournalofdiabetes.com.

Acknowledgments

The authors acknowledge the efforts of Sharon Koo in assisting in the logistics of starting and completing this project. Ryerson University Health Fund supported this project.

Author Disclosures

Conflicts of interest: none.

Author Contributions

EG, GK, SS and HB conceptualized the design and methodology of the work; EG, GK, AR, SA, SS, HB and SE were involved in the acquisition, analysis or interpretation of data for the work; EG, AR, SK, SS, GK, SE and HB drafted the work or revised it critically for important intellectual content; EG, AR, SK, SS, GK, SE and HB provided final approval of the version of the manuscript to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

References

1. Finucane ML, McMullen CK. Making diabetes self-management education culturally relevant for Filipino Americans in Hawaii. *Diabetes Educ* 2008;34:841–53.
2. Stuckey HL, Tisdell EJ. The role of creative expression in diabetes: An exploration into the meaning-making process. *Qual Health Res* 2010;20:42–56.
3. Greenhalgh T, Campbell-Richards D, Vijayaraghavan S, et al. New models of self-management education for minority ethnic groups: Pilot randomized trial of a story-sharing intervention. *J Health Serv Res Policy* 2011;16:28–36.
4. Gucciardi E, Jean-Pierre N, Karam G, Sidani S. Designing and delivering facilitated storytelling interventions for chronic disease self-management: A scoping review. *BMC Health Serv Res* 2016;16:249.
5. Goddu AP, Raffel KE, Peek ME. A story of change: The influence of narrative on African-Americans with diabetes. *Patient Educ Couns* 2015;98:1017–24.
6. Worswick J, Wayne SC, Bennett R, et al. Improving quality of care for persons with diabetes: An overview of systematic reviews: What does the evidence tell us? *Syst Rev* 2013;2:26.
7. Siminerio L, Ruppert KM, Gabbay RA. Who can provide diabetes self-management support in primary care? Findings from a randomized controlled trial. *Diabetes Educ* 2013;39:705–13.
8. Speri-Hillen J, Beaton S, Fernandes O, et al. Are benefits from diabetes self-management education sustained? *Am J Manag Care* 2013;19:104–12.
9. Sherifali D, Jones H, Mullan Y. Diabetes self-management: What are we really talking about? *Can J Diabetes* 2013;37:2–3.
10. Struthers R, Hodge FS, Geishirt-Cantrell B, De Cora L. Participant experiences of talking circles on type 2 diabetes in two Northern Plains American Indian Tribes. *Qual Health Res* 2003;13:1094–115.
11. Skovgaard R, Ploug U, Hunt B, Valentine W. Evaluating the cost of bringing people with type 2 diabetes mellitus to multiple targets of treatment in Canada. *Clin Ther* 2015;37:1677–88.
12. Sekhon M, Cartwright M, Francis JJ. Acceptability of healthcare intervention: An overview of reviews and development of a theoretical framework. *BMC Health Serv Res* 2017;17:88.
13. Gaglio B, Shoup JA, Glasgow RE. The RE-AIM framework: A systematic review of use over time. *Am J Public Health* 2013;103:e38–46.
14. Glasgow RE, McKay HG, Piette JD, Reynolds KD. The RE-AIM framework for evaluating interventions: What can it tell us about approaches to chronic illness management? *Patient Educ Couns* 2001;44:119–27.
15. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *Am J Eval* 2006;27:237–46.
16. Weber RP. Basic content analysis. 2nd edn. Thousand Oaks (CA): Sage Publications; 1990.
17. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
18. Griffin SF, Wilcox S, Ory MG, et al. Results from the active for life process evaluation: Programme delivery fidelity and adaptations. *Health Educ Res* 2009;25:325–42.
19. Donaldson L. Expert patients usher in a new era of opportunity for the NHS. *BMJ* 2003;326:1279–80.
20. Stringer ET. Action research: A handbook for practitioners. 1st edn. Thousand Oaks (CA): Sage Publications; 1996.
21. Evans BC, Crogan NL, Bendel R. Storytelling intervention for patients with cancer: Part 1: Development and implementation. *Oncol Nurs Forum* 2008;35:257–64.
22. Comellas M, Walker EA, Movsas S, Merkin S, Zonszein J, Strelnick H. Training community health promoters to implement diabetes self-management support programs for urban minority adults. *Diabetes Educ* 2010;36:141–51.
23. Koch T, Kralik D. Chronic illness: Reflections on a community-based action research programme. *J Adv Nurs* 2001;36:23–31.
24. Connelly FM, Clandinin DJ. Stories of experience and narrative inquiry. *Educ Res* 1990;19:2–14.
25. Greenhalgh T, Collard A, Begum N. Sharing stories: Complex intervention for diabetes education in minority ethnic groups who do not speak English. *BMJ* 2005;330:628.
26. Purk JK. Support groups: Why do people attend? *Rehabil Nurs* 2004;29:62–7.

Supplementary Table 1

Topics selected by patients in each intervention wave

Session number	Wave 1	Wave 2
1	Introductory session	Introductory session
2	Dietary guidelines and glycemic index	Food basics and carbohydrate counting
3	Foot care	Food basics, continued
4	Best information resources	Physical activity
5	Aging gracefully with diabetes	Diabetes risks and complications
6	Medications	Best information resources
7	Natural supplements and reading food labels	Aging and foot care
8	Talking to your health-care professionals and conclusion	Social supports and conclusion

Supplementary Table 2

Fidelity values of each session for waves 1 and 2

Session number	Total number of activities (session guide)	Total number of completed activities	Percentage of (session guide) activities completed
Wave 1 (average: 83.3%)			
1	18	14	77.8
2	29	27	93.1
3	30	28	93.3
4	23	21	91.3
5	31	24	77.4
6	26	21	80.8
7	20	15	75.0
8	18	14	77.7
Wave 2 (average: 85.4%)			
1	34	34	100
2	44	32	72.7
3	35	30	85.7
4	31	27	87.1
5	34	30	88.2
6	30	25	83.3
7	33	25	75.8
8	30	27	90.0