Stakeholder engagement in diabetes self-management: patient preference for peer support and other insights

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Abstract

Background. Self-management support (SMS) for patients with diabetes can improve adherence to treatment, mitigate disease-related distress, and improve health outcomes. Translating this evidence into real-world practice is needed, as it is not clear which SMS models are acceptable to patients, and feasible and sustainable for primary care practices.

Objective. To use the Boot Camp Translation (BCT) method to engage patient, practice, community resource and research stakeholders in translation of evidence about SMS and diabetes distress into mutually acceptable care models and to inform patient-centred outcomes research (PCOR).

Participants. Twenty-seven diabetes care stakeholders, including patients and providers from a local network of federally qualified health centres participated.

Methods. Stakeholders met in-person and by conference call over the course of 8 months. Subject matter experts provided education on the diabetes SMS evidence. Facilitators engaged the group in discussions about barriers to self-management and opportunities for improving delivery of SMS.

Key Results. BCT participants identified lack of social support, personal resources, trust, knowledge and confidence as barriers to diabetes self-management. Intervention opportunities emphasized peer support, use of multidisciplinary care teams and centralized systems for sharing information about community and practice resources. BCT informed new services and a PCOR study proposal.

Conclusions. Patients and family engaged in diabetes care research value peer support, group visits, and multidisciplinary care teams as key features of SMS models. SMS should be tailored to an individual patient’s health literacy. BCT can be used to engage multiple stakeholders in translation of evidence into practice and to inform PCOR.

Key words: Community resources, diabetes, peer support, self-management support, stakeholder engagement.
Diabetes Association-recommended diet, engaging in regular physical activity and medication adherence. Diabetes self-management can be challenging, especially among low income populations (3). Barriers to self-management include lack of knowledge of self-care procedures, low self-efficacy, low perceived susceptibility to complications, mala- daptive coping mechanisms, depression, lack of social support and the patient-provider relationship (4). As a result, many patients experience diabetes distress—the sense of being overwhelmed by the emotional, regimen, health care and interpersonal burden of managing chronic disease (5). Diabetes distress contributes to poor diabetes control (6).

Self-management support (SMS) for patients with diabetes has been shown to be effective for improving health behaviours, reducing distress and lowering haemoglobin A1c (7,8). In SMS, care providers help patients set self-management goals, identify and access resources patients need to reach their goals, and arrange for follow-up to ensure needs are being met (9,10). SMS extends beyond traditional diabetes self-management education (DSME) (11). Primary care practices often lack the workforce and time for, and a culture that supports provision of, this effective but resource-intensive service (12). Translation of the evidence on SMS into effective interventions may significantly improve population health outcomes, but this has proven difficult to demonstrate in real-world practice (13).

A stakeholder engagement approach to evidence translation may help ensure these interventions are acceptable to patients and feasible and sustainable for real-world primary care practices (14). Boot Camp Translation (BCT) is a process by which community members (e.g., patients and health care providers) collaborate with academic researchers to translate evidence into messages or other interventions that are meaningful and engaging to those community members (15). It employs community-based participatory research (CBPR) principles and approaches and is a form of community engaged research that supports provision of, this effective but resource-intensive service (12). The purpose of this project was to use BCT to engage primary care practices, community resource representatives, patients with diabetes and their family members to translate evidence about diabetes distress and SMS into an intervention strategy that met multiple stakeholder needs. The focus was on informing interventions to address diabetes distress and assist with access to resources to achieve self-management goals. This paper describes the BCT process used, challenges encountered, the insights gained and outputs generated from these efforts.

Methods

Participants and recruitment

We first identified and recruited relevant stakeholder group representatives (18). Our goal was to include patients, health care providers and community organizations with a role in connecting patients with diabetes to community resources. Patients with diabetes, family members and care providers were from a local metropolitan area system of Federally Qualified Health Centers (FQHCs). Practice representatives were primary care clinicians, staff, diabetes educators and behavioural health specialists, already engaged through our practice-based research network (PBRN) activities. Practice representatives were given a profile of ideal patient characteristics and printed invitations to give to interested patients, whom they identified from their known patient panel. Resource representatives were from the state health department, a recreation centre, and a community health worker organization. A partnering non-profit public health and community engagement organization, well-connected in the local public health domain, identified and recruited the resource representatives.

Twenty-seven stakeholder representatives participated in BCT, including six clinical practice representatives (medical providers, diabetes educators, behavioural health providers and medical assistants), three community resource representatives, eight adult patients with diabetes (primarily Type II, some Type I) and three family members. Additional participants included two members of a partnering community engagement organization and five researchers with backgrounds in public health, community engagement, health behaviour change, health services research, diabetes SMS and health care informatics. All participants were paid for their time; patient participants received $100 each in grocery store gift cards.

Procedures

The BCT process involves facilitated discussions in extended in-person meetings (2–7 hours) and brief conference calls (30 minutes), led by a skilled facilitator and co-facilitator. The first meeting is an all-day ‘kick-off’, in which key goals are to: get to know each other, ensure all participants have an understanding of the evidence to be translated, gain an appreciation for all participants’ expertise and experiences, engage and brainstorm around what was shared and begin to focus on solutions. In subsequent discussions, the group narrows the focus and makes decisions, ultimately answering the questions posed.

To prepare, the research team studied the BCT Guidebook (19), participated in a 2-day BCT training and consulted with BCT experts. The research team and several practice representatives met to decide on the focal topic, schedule and coordinate space for the kick-off, identify and invite participants (patients, practice and resource representatives), facilitators and expert presenter(s) (all members of the research team) and prepare and distribute participant and facilitator agendas. The kick-off agenda included an overview of the BCT process, an expert presentation on diabetes SMS and diabetes distress, and the value of community resources, and a two-part rapid fire brainstorming session on messages to patients about ways to address distress and assist patients with access to resources. Following this initial kick-off, the group held a series of brief conference calls and additional shorter (2–3 hour) in-person meetings to elicit further input on how to enhance SMS for diabetes care and connect patients to needed resources, and make decisions about how to move forward with the ideas generated by the group. In between meetings, participants reviewed and gave input on meeting summaries via individual phone calls and emails, and informed next steps, such as by completing electronic polls on preferred approaches to care delivery. These ‘off-line’ communications were especially important for more introverted participants or those who were unable to attend a given event. Agenda topics for the BCT events are shown in Table 1.

Data sources

Data for this paper primarily come from detailed notes from BCT meetings and conference calls (research team notes, facilitator and group sticky note comments and flip chart notes). Additional data sources include one-on-one conversations and e-mails with BCT participants, meeting notes and records, and in-depth interviews with the three community resource representatives regarding their experience with BCT, conducted by a community engagement expert consultant.

Synthesis

The research team used a process standard to the BCT method for processing the notes following each BCT event. After each event, one person (typically the project manager) prepared raw meeting
notes combining all data sources from the event. Raw notes were prepared as objectively as possible, documenting actual quotes and tracking the discussion as it occurred. The raw notes were passed around the research team in serial, with each team member adding details from their notes and recollection. The research team then met as a whole to discuss and identify major themes and assess whether the group reached a decision around the event’s focal topic. While no formal qualitative analysis was done, the research team relied upon their considerable experience in qualitative research and thematic analysis. A summary document was produced, describing the meeting objective, any expert presentations made, key points from the discussion, the major themes and next steps. This document was distributed to the full BCT group for feedback and revision. Results are a compilation of themes from across BCT events.

**Results**

**Insights on diabetes distress**

Patients resonated with the concept of diabetes distress, and thought SMS services should help them recognize distress and understand its effects on diabetes control, quality of life and relationships with friends and family. SMS should help patients get support from the health care system and family and friends, who do not always understand the severity of or the struggle to manage diabetes. To reduce distress related to the health care navigation burden, patients noted that it was important to learn to self-advocate, acquiring the skills and confidence to ask questions of the health care team. Patients appreciated the team approach to care and believed it can be appropriate to delegate certain services to other care team members. However, the doctor should introduce other care team members and take responsibility for following up with patients, as the patient has a trusting relationship with the doctor first.

Patients reported feeling especially overwhelmed with information upon initial diagnosis of diabetes. This made it difficult to absorb the information and apply it to their lives. That is, patients struggled with ‘health literacy’, defined as ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions’ (20), an important factor in diabetes care (21). Thus, our BCT suggested that SMS needs to be tailored to health literacy by considering patient acceptance of their diagnosis and readiness for change, and by providing the right information for the right patient at the right time.

**Insights on connection to resources**

Access to resources was limited by logistical barriers—cost, location, transportation and childcare—and lack of knowledge, social support, confidence and trust. Patients noted that resources close to or within the clinic were easiest to access, as they knew they could get there (e.g. well-known bus routes). Lack of awareness of available resources, including contact information and any eligibility criteria, was a common theme for both patients and practice representatives. The engaged patients and family members were themselves a valuable source of information about community and practice resources. Patients shared with each other information about the practices’ own diabetes education classes, the Silver Sneakers® program, a local supplier of diabetes-friendly shoes, and websites, newsletters and cookbooks with diabetes-appropriate recipes.

**Desired self-management support care model elements**

Table 2 summarizes desired SMS care model elements and examples of how patients would like to see those elements in practice. Proposed solutions for linking patients to resources include individualized care plans that associate resources with individual patient goals, resource bulletin boards or directories (paper or electronic), holding coffee hours or potlucks, involving the family, patient navigators, a buddy system, visits with an entire health care team, improving environmental supports and maintaining a culture of open communication. Resources should help with acceptance of one’s diagnosis, diet and exercise, dealing with crisis and building self-management knowledge and skills. A resource directory listing or flyer on a bulletin board should include a name and contact information for a key person at the resource, eligibility criteria, a brief description of services, any fees and an address, directions and map.

Peer support was another popular care model element. Guest speakers were invited to several BCT events to help the group learn about peer support models, such as patient navigation and peer specialist services. The resulting proposed SMS model included diabetes ‘veterans’ (i.e. peer mentors) who would co-lead group visits with diabetes care professionals as well as work one-on-one with patients in the community. Patients wanted the group visit curriculum to include physical activity, healthy eating, taking medication, acceptance and coping, and social support, but noted that each cohort of patients in a particular group should dictate which topics were most relevant to them. Notably, groups should be formed on the basis of similar needs and concerns, such as those with serious mental illness. Patients wanted a centralized point person to serve as a liaison between the clinic and community resources, such as a patient navigator. This person could help with coordinating monthly support groups or coffee hours with professional speakers.

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**Table 1. Venues, length and agenda topics for stakeholder engagement events**

<table>
<thead>
<tr>
<th>Event</th>
<th>Venue</th>
<th>Length</th>
<th>Agenda(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-person Kick-Off (April 2014)</td>
<td>University</td>
<td>6 hours</td>
<td>Expert presentation and brainstorming on diabetes, self-management support, distress, and resources</td>
</tr>
<tr>
<td>Conference calls (×4)</td>
<td>Telephone</td>
<td>30 minutes each</td>
<td>Types of resources for a directory</td>
</tr>
<tr>
<td>In-person meetings #1 (July 2014)</td>
<td>Community recreation center</td>
<td>2–2.5 hours each</td>
<td>Expert presentations on peer support and patient navigation models</td>
</tr>
<tr>
<td>#2 (October 2014)</td>
<td>Health center</td>
<td></td>
<td>Expert presentation from peer specialists</td>
</tr>
<tr>
<td>#3 (December 2014)</td>
<td>University</td>
<td></td>
<td>Celebration and transition</td>
</tr>
</tbody>
</table>
Table 2. Patient perspectives on diabetes care needs and desired care model elements

<table>
<thead>
<tr>
<th>Diabetes care needs</th>
<th>Care model elements</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address individual patient goals and concerns to 'meet people where they’re at'</td>
<td>Individually tailored care plans and educational content</td>
<td>Providing education, counselling and skills-building specific to a patient's domain of diabetes distress or self-management goals</td>
</tr>
<tr>
<td>Address mental illness and behavioural health needs, including social support</td>
<td>Inviting the full health care team</td>
<td>Visits with the entire health care team, including behavioural experts, nutritionists, clinical pharmacists and others</td>
</tr>
<tr>
<td>Engender trust and empower patients</td>
<td>A culture of open communication, trust and asking questions</td>
<td>Family education night at the clinic ‘Buddy system’ for patients—pair newly diagnosed patient with a ‘veteran’ diabetes patient</td>
</tr>
<tr>
<td>Connect patients to resources relevant to goals and concerns</td>
<td>Infrastructure to facilitate and coordinate access to community (external) and practice (internal) resources</td>
<td>Group visit curriculum includes content on asking questions Patients drive topics and desired ‘professionals’ for group visits</td>
</tr>
</tbody>
</table>

Boot camp translation outputs
The research team, the practice representatives and the community resource representatives developed, refined and implemented multiple new programs, services and tools based on BCT discussions.

Resource directory component of web-based self-management support tools
A resource directory was built into an existing web-based SMS tool called ‘Connection to Health’. Connection to Health helps engage patients in assessing SMS needs and priorities (e.g. health behaviour change, distress) and create action plans with self-management goals (22). As dictated by patients in BCT, the resources are filtered by goals and clinic location, and key details are automatically inserted in the printable action plan. This tool has been tested at the participating FQHC as part of their participation in a project jointly funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Bristol Myers Squibb Foundation’s (BMSF) ‘Together on Diabetes’ Initiative. As suggested by BCT participants, patient use of Connection to Health was guided by patient navigators, a new resource at the participating clinics, who were partially (total 0.50 FTE) and temporarily supported through the BMSF grant.

BCT also informed practice facilitation strategies for implementation of SMS and the Connection to Health tools in participating practices. It was sometimes difficult to pique the interest of practice staff who had not participated in BCT, so the facilitator infused messages that these practices’ own patients had shared during the BCT process. For instance, sharing information about patient preference for peer support in the context of group visits helped build practice enthusiasm around group visit opportunities—reflected in new and modified services at participating clinics.

New or modified services at participating clinics
In accordance with patient input, participating clinics adopted a variety of approaches to help connect patients to resources and provide individualized support in group and multidisciplinary care team formats. This included diabetes resource bulletin boards, a new pre-diabetes group visit model and an expanded offering of ‘diabetes clinics’. These diabetes clinics are individual 60-minute visits in which patients see a health educator, a medical provider and a behavioural health provider in succession in 20-minute increments.

Diabetes classes at a local recreation centre
The participating local recreation centre director created a new class at the recreation centre called ‘Fitness, Food and Type II Diabetes’. It was taught by a registered nurse who is a certified diabetes educator, and a nutritionist gave a cooking demonstration.

Shared medical appointments with multidisciplinary teams, peer support and patient-driven curriculum
A long-term collaborative relationship developed among the research team and a subset of BCT participants, including three patients and family members, who formed a small group to write a grant to study the SMS model endorsed by the full BCT group. The proposed SMS model is consistent with shared medical appointments (SMA; a form of group visit) characterized by multidisciplinary care teams, peer support, and topics selected by the patients, a model for which there is evidence of effectiveness (23). A 2014 meta-analysis showed diabetes SMAs lead to significantly greater improvements in HbA1c compared to usual care, although significant heterogeneity of treatment effects were found (24). SMAs can have a variety of different features, but it is not known which features are most effective. Identifying the alignment between this gap in evidence and stakeholder input positioned this group to apply for funding opportunities in which stakeholder engagement is a core feature, such as through the Patient Centered Outcomes Research Institute (PCORI) (25). Notably, BCT aligns well with the principles of engagement in the PCORI engagement rubric (26). Expert presentations and sharing of multi-stakeholder perspectives and experiences facilitate ‘co-learning’ and ‘reciprocal relationships’. Sharing the synthesis and encouraging the group to edit and redirect decisions as needed ensure ‘transparency’, ‘honesty’ and ‘trust’. Continuing to collaborate to plan, conduct and disseminate the study over the long term reflects the ‘partnerships’ that emerge from BCT.
Insights on the boot camp translation process

This large, diverse group preferred longer, less frequent in-person meetings rather than short, frequent conference calls. Maintaining group engagement took considerable off-line communication and trust building. The group often chose a different path than what the research team expected, and what seemed like detours to the research team often led to valuable insights. Flexible guidance from the research team—providing guard rails rather than train tracks—gave the group license to make the process their own without losing focus. BCT was a lengthy and time-intensive process and the end point was not always clear along the way. Not including subsequent grant writing, this process took ten months, with eight months of intensive stakeholder participation. However, this investment has paid off with continued collaboration after the end of BCT.

In this large, multi-stakeholder BCT, participant roles were not always clear—notably, among the community resource representatives. Based on findings from in-depth interviews, each was inspired to join the project to enhance outreach efforts to benefit the health of their communities. This goal was realized in some cases, but proved challenging. It may have been helpful to frame their role in BCT as providers of information as opposed to change agents, allowing them to share their experiences instead of using BCT to improve their own efforts.

Discussion

Engaging patients and family members with diabetes, health care providers, and resource representatives to develop strategies for implementing SMS proved to be successful. We employed a well-developed engagement method, BCT, with minor adaptations in a manner that sustained engagement over the course of the project and yielded valuable insights on how to improve the care for and lives of patients with diabetes. Most notably, sustained and patient driven ways to address information gaps along with peer support emerged as important needs and strategies. As in prior work, BCT is a useful approach to engaging patients and other stakeholders in the design of health care interventions (27). However, it is a lengthy process and researchers must cede some control over the outcome to participants. The larger the group, the more schedules to accommodate, such that larger groups can make the process longer, less nimble, and less likely to lead to complete consensus within the group. The multiple separate outputs emerging from this BCT reflect the different pathways taken to translating stakeholder input to a participant’s own sphere of influence. Researchers may provide context to the joint effort by selecting the evidence to be translated into practice and posing initial questions to the group, but must be willing to follow the stakeholders’ lead. In this project, the researchers’ initial vision of a system for primary care practices linking patients to community resources was modified substantially over the course of BCT, as it became clear this vision was not consistent with stakeholder perspectives. Without stakeholder engagement, we might have tried to institute a technology-based solution to tracking patient linkage to community resources. Additionally, the peer mentor and group visit concepts were outside the scope of existing grant funding, and participating practices lacked payment mechanisms for peer services and enhanced group visits with multidisciplinary care teams. Thus, not all BCT outcomes are immediately tangible or able to be implemented without additional funding, which we found inhibited the group’s momentum and enthusiasm. The uncertainty regarding outcomes and timelines should be communicated to participants at the outset.

A key insight from this work suggests a confluence of the evidence on implementation of diabetes SMS, and the evidence on diabetes peer support, patient navigation, and health literacy. The body of literature in favour of diabetes peer support continues to grow (28). Given that patients with diabetes (at least those willing to participate in activities such as BCT) appear to prefer assistance with self-management from those with similar lived experience, and the evidence showing that peers effectively demonstrate modelling of self-management behaviours (29), peer support should be considered a core element of the delivery of SMS. This may be especially important for patients with comorbid diabetes and mental illness (30).

Conclusions

Stakeholder engagement in research is central to PCOR, and BCT is an effective engagement approach. Multiple stakeholder types can be engaged simultaneously, thus aligning various perspectives that inform a variety of strategies for improving diabetes SMS. PCOR funders and researchers should bear in mind the extended planning period required for projects involving BCT. Furthermore, peer support should be routinely incorporated into diabetes SMS models, and health care policy and reimbursement mechanisms should accommodate peer-led services. SMS should be tailored to individual patients’ health literacy level.

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Declaration

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Ethical approval: the work reported here does not constitute human subjects research and thus no human subjects ethics review was required; however, stakeholder participants were advised that confidentiality should be maintained outside the group and that they could choose not to share their own personal information.

Conflict of interest: none.

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References

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