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A R T I C L E

Partners in Diabetes

Action research in a primary care setting

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ABSTRACT

Diabetes is a growing problem that threatens both individual health and health care systems throughout the industrialized world. This study analyzes the process and evolution of a collaborative project dealing with diabetes and employing action research methodology and the Citizen Health Care model. Partners in Diabetes (PID) was created through a democratic process among patients, families and providers in a primary care setting in the United States. Fourteen PID 'support partners' were nominated by their physicians to receive training and then reach out to other patients and families across a variety of contexts (e.g. home, clinic, telephone). We conducted qualitative analyses of detailed meeting process-notes spanning more than three years, and key-informant interviews with providers, patients and family members. We identified key developmental themes, including how providers and patients learned to overcome traditional hierarchy, how PID was designed and implemented, what challenges were encountered and what mistakes were made. Lessons for extending similar projects are highlighted.

KEY WORDS

- chronic illness
- Citizen Health Care
- community-based participatory research
- diabetes
- Partners in Diabetes

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Many observers believe that the United States health care system needs a funda-mental redesign if we are to have a healthier population and avoid exhausting our economic resources (Future of Family Medicine Project, 2004; Institute of Medicine, 2001). As efforts in medicine extend beyond visit-based services into the less familiar territory of preventive and patient-and-family oriented care, a call has emerged for increased partnerships between providers and patients (Chiu, in press; Hayes, 1996; Standridge, 2000). These partnerships stand in contrast to traditional hierarchal modes of medicine that position physicians and other providers as experts who deliver services to passive consumer patients. Involving patients and families through such partnerships facilitates the tapping of resources heretofore untapped, thereby overcoming conventional barriers of limited resources and time constraints that frequently impede new initiatives (Agency for Healthcare Research and Quality, 2004; Mendenhall & Doherty, in press; Minkler & Wallerstein, 2003).

Study rationale

Diabetes is one of the most widespread chronic diseases in the United States, with current estimates exceeding 18 million. More than 2000 new cases of the disease are diagnosed each day, and it represents the seventh most common pre-senting problem in family medicine (American Diabetes Association, 2005). Globally, an estimated 194 million people live with diabetes, and this is expected to rise to over 333 million by 2025 (International Diabetes Federation, 2005). Over six percent of the US population is directly affected, and racial/ethnic minorities are disproportionately affected (Centers for Disease Control and Prevention, 2000; National Institute of Diabetes and Digestive and Kidney Diseases, 2004).

A host of educational and psychosocial interventions for patients with diabetes have been employed, including programs oriented to the improvement of diabetes-related knowledge and problem-solving skills (e.g. Brandt & Magyary, 1993; Gilden, Hendryx, Casia & Singh, 1989; Lucey & Wing, 1985; Pichert, Smeltzer et al., 1994; Pichert, Snyder, Kinzer & Boswell, 1994), psychosocial stress and coping (Grey, Boland, Davidson & Tamborlane, 2000; Marrero et al., 1982; Smith, Schreiner, Brouhard & Travis, 1991; Smith, Schreiner, Jackson & Travis, 1993; Wing, Marcus, Epstein & Jawad, 1991), and behavior/self man-agement (Marrero et al., 1995). While the majority of interventions reported in the literature show modest improvements across a variety of outcomes, method-ological and systemic reviews maintain that these improvements are often not sustained over time (Brown, 1992; Delamater et al., 2001; Gage et al., 2004; Hampson et al., 2004). Researchers have highlighted the need for continuous support, thereby moving away from the idea that a single intervention in time (or

over a select period of time) is adequate. Diabetes is a disease that does not go away, and attention to effective disease management should similarly endure.

A significant problem with conventional interventions in the context of chronic conditions such as diabetes is that conventional interventions tend to be expert-driven and externally funded. As such they are not organizationally sustainable. Programs designed and maintained in such a manner are vulnerable when funding expires or when the principal (professional) leader of the initiative shifts his or her focus to another project, changes jobs, etc. (Mendenhall & Doherty, 2005, in press). These initiatives are not 'owned and operated' by the communities in which they are positioned; patients and their families do not possess a sense of ownership in these projects' design or implementation, and maintain little power or influence to uphold them when professional infrastructures fold.

As providers, clinical researchers, patients and families struggle with this issue, they must uncover new ways to design and implement programs that can be sustained within their communities. These programs must involve the active participation and co-ownership of professionals and lay persons alike, and should be supported by human and tangible resources that are not connected to a temporary external funding source that carries with it a priori conditions set forth by persons or agencies who are not, themselves, part of the work. Community-based participatory research represents a response to this challenge (Bradbury & Reason, 2003; Hambridge, 2000; Minkler & Wallerstein, 2003).

Community-based participatory research: Engaging patients and families in health care

Community-based participatory research (CBPR) is an action research approach that emphasizes close collaboration among researchers and community participants who are directly affected by an issue to generate knowledge and solve local problems. Hierarchical differences are flattened through this partnership and all participants work together to create knowledge and effect change (Agency for Healthcare Research and Quality, 2004; Lewin, 1946; Mendenhall & Doherty, 2005). Community-based participatory research has gained credibility in medicine, nursing, public health and behavioral health since the early 1990s because of its ability to inform understanding of patients' and community members' experiences, improve or generate services, facilitate community outreach and engagement, enhance education and augment cultural awareness (Chavez, Duran, Baker, Avila & Wallerstein, 2003; Chiu, 2003; Tobin, 2000; Ward & Trigler, 2001). Projects carried out through this method have effected improvements in health audits, dental and mouth-care practices, management of preoperative fasting, patient problem-solving skills, overall physical well-being, patient and practitioner satisfaction, patient and practitioner empowerment, patient–practitioner

communication and a number of other significant health care issues (Bruce & McKane, 2000; Hampshire, Blair, Crown, Avery & Williams, 1999; Lindsey & McGuinness, 1998; Meyer, 2000; Smith, Willms & Johnson, 1997).

Because community-based participatory research focuses on a problem within a specific site or community, the 'local' problem is addressed directly and in context (Caballero, 1999; Hambridge, 2000). Several key assumptions permeate these projects (Bradbury & Reason, 2003; Mendenhall & Doherty, 2005). Themes include: 1) a democratic partnership among key project members (e.g. clinical researchers, community participants) working as collaborators through every stage of knowledge- and intervention-development; 2) a deep investment in change that carries with it an element of challenging the status quo and improving the lives of members in a community or practice; 3) a cyclical process in which a problem is identified, solutions to address it are developed within the context of the community's existing resources, interventions are implemented, outcomes are evaluated according to what is essential in the eyes of participants, and interventions are modified in accord with new information as necessary; 4) project members' humility and flexibility to accommodate changes as necessary across any part of a project; and 5) recognition that community-based participatory research can be a slow and messy process, especially during its initial phases.

The Citizen Health Care Model

Tables 1 and 2 outline the main principles and strategies of Citizen Health Care. The model aims to access a resource that is largely untapped in our contemporary health care system: the knowledge, lived experience, wisdom, and energy of individuals, families, and communities who face challenging health care issues in their everyday lives. This is different from the conventional way of perceiving an activated patient who becomes a responsible agent for his or her own health. The notion of 'citizen' refers to people becoming activated along with their neighbors and others who face similar health challenges in order to make a difference for a community. Ordinary citizens become assets in heath care as they work as co-producers of health for themselves and their communities. They no longer assume passive roles whereby they are simply consumers of services looking out for their own health and that of their immediate loved ones (Doherty & Mendenhall, in press).

Reflecting the public work and community organizing elements in Citizen Health Care, this model calls for a bold vision about making a difference in the community and the world – not just designing and delivering 'volunteer services'. The language of citizenship and 'we the people' thereby permeates Citizen Health Care initiatives, as does the vision of each small project working locally but contributing to a broader movement towards reclaiming health care as work by, for, and with citizens.

Table 1 Citizen Health Care Model: Core Principles

1	The greatest untapped resource for improving health care is the knowledge, wisdom, and energy of individuals, families and communities who face challenging health issues in their everyday lives.
2	People must be engaged as co-producers of health care for themselves and their communities, not just as patients or consumers of services.
3	Professionals can play a catalytic role in fostering citizen initiatives when they develop their public skills as citizen professionals in groups with flattened hierarchies.
4	If you begin with an established program, you will not end up with an initiative that is 'owned and operated' by citizens. But a citizen initiative might create or adopt a program as one of its activities.
5	Local communities must retrieve their own historical, cultural, and religious traditions of health and healing, and bring these into dialogue with contemporary medical systems.
6	Citizen health initiatives should have a bold vision (a BHAG – a big, hairy, audacious goal) while working pragmatically on focused, specific projects.

We have done 12 projects in Citizen Health Care and the larger Families and Democracy Project (in which this work is positioned) since 1999 (Doherty & Carroll, 2002; Doherty & Mendenhall, in press; Mendenhall & Doherty, 2003, 2005, in press). Core elements of these projects apply across a diversity of socio-economic and ethnic groups, and their implementation differs across different communities and problem areas.

Partners in Diabetes

Partners in Diabetes (PID) is a health care initiative that was designed and implemented through a collaborative and democratic partnership among patients, families, and providers in primary care. Fourteen PID 'support partners' (representing both patients and spouses) were nominated by their physicians to receive training and then reach out to other patients and families (called 'members') across a variety of contexts, including home-visits, restaurants, over the telephone, and on clinic grounds. Support partners represent a range of ethnic and socioeconomic diversity, as does PID's patient community.

Support partners are purposively connected with members who have struggled with diabetes for some time (e.g. three consecutive A1c tests of >9%) or who are in the initial phases of adjusting to their diagnosis. They commit at least two hours per week to the project, and maintain active contact with one to five members at any given time. While further detail regarding the content and nature of the support that support partners provide is outlined below, foci within PID support partner/member meetings are remarkably varied – encompassing a broad range of disease management strategies and educational topics. Similarly, the

Table 2 Action strategies for Citizen Health Care

1 *Get buy-in from key professional leaders and administrators.*
   These are the gatekeepers who must support the initiation of a project based on its potential to meet one of the goals of the health care setting. However, we have found it best to request little or no budget, aside from a small amount of staff time, in order to allow the project enough incubation time before being expected to justify its outcomes.

2 *Identify a health issue that is of great concern to both professionals and members of a specific community (e.g. clinic, neighborhood, cultural group in a geographical location).*
   Stated differently, the issue must be one that a community of citizens actually cares about – not just something we think they should care about. And the professionals initiating the project must have enough passion for the issue to sustain their efforts over time.

3 *Identify potential community leaders who have personal experience with the health issue and who have relationships with the professional team.*
   These leaders should generally be ordinary members of the community who in some way have mastered the health issue in their own lives and who have a desire to give back to their community. 'Positional' leaders who head community agencies are generally not the best group to engage at this stage, because they bring institutional priorities and constraints.

4 *Invite a small group of community leaders (3–4 people) to meet several times with the professional team to explore the issue and see if there is a consensus to proceed with a larger community project.*
   These are preliminary discussions to see if a Citizen Health Care project is feasible and to begin creating a professional/citizen leadership group.

5 *This group decides on how to invite a larger group of community leaders (10–15) to begin the process of generating the project.*
   One invitational strategy we have used is for providers to nominate patients and family members who have lived expertise with a health issue and who appear to have leadership potential.

6 *Over the next six months of biweekly meetings, implement the following steps of community organizing:*
   • *Exploring the community and citizen dimensions of the issue in depth*
   • *Creating a name and mission*
   • *Doing one-to-one interviews with a range of stakeholders*
   • *Generating potential action initiatives, processing them in terms of the Citizen Health Care Model and their feasibility with existing community resources*
   • *Deciding on a specific action initiative and implementing it*

7 *Employ the following key Citizen Health Care processes:*
   • *Democratic planning and decision-making at every step*. As mentioned before, this requires training of the professionals who bring a disciplined process model and a vision of collective action that does not lapse back into the conventional provider/consumer model, but who do not control the outcome or action steps the group decides to take.
   • *Mutual teaching and learning among community members*. Action initiatives consistent with the model first call upon the lived experience of community members, with the support of professionals, rather than recruiting community members to support a professionally created initiative.

Table 2 cont.

- *Creating ways to fold new learnings back into the community.* All learnings can become 'community property' if there is a way for them to be passed on. Currently we have vehicles for professionals to become 'learning communities', but few vehicles outside of Internet chat rooms for patients and families to become learning communities.
- *Identifying and developing leaders.* The heart of community organizing is finding and nurturing people who have leadership ability but who are not necessarily heads of organizations with turfs to protect.
- *Using professional expertise selectively – 'on tap', not 'on top'.* In this way of working, all knowledge is public knowledge, democratically held and shared when it can be useful. Professionals bring a unique font of knowledge and experience – and access to current research – to Citizen Health Care initiatives. But everyone else around the table also brings unique knowledge and expertise. Because of the powerful draw of the provider/consumer way of operating, professionals must learn to share their unique expertise when it fits the moment, and to be quiet when someone else can just as readily speak to the issue. A community organizing axiom applies here: never say what someone in the community could say, and never do what someone else in the community could do.
- *Forging a sense of larger purpose beyond helping immediate participants.* Keep the Big, Hairy, Audacious Goal (BHAG) in mind as you act in a local community. Citizen Health Care is not just about people helping people; it is about social change towards more activated citizens in the health care system and larger culture. This understanding inspires members of the Citizen Health Project about the larger significance of their work. It also attracts media and other prominent community members to seek to understand, publicize, and disseminate Citizen Health Care projects.

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nature and intensity of the support that support partners offer also varies – with some members simply needing a single 'pep talk' and others requiring several in-person and telephone meetings over several months.

As an established program, PID represents a supplement to patients' standard care, and is thereby an optional resource that is available above and beyond what patients are entitled to as members of the clinic. Providers not directly connected to PID are not privy to the details of meetings between PID support partners and patient members beyond what the patient chooses to share. Case or meeting notes are not logged into patients' records, and time spent with PID support partners is not billed for.

Providers who are involved in PID, itself, participate in the monthly meetings between support partners and other involved professionals to discuss challenges that support partners have experienced, develop solutions to issues warranting attention, learn about new information or advancements in diabetes-related knowledge (broadly defined), and further-assign new members to support partners in accord to support partners' availability (i.e. current case loads) and appropriate 'match' considerations (e.g. a female patient member who wishes to connect with a female support partner, a patient and spouse who wish to visit

with a support partner 'couple team' that synchronously includes a person with diabetes and his/her supportive spouse). In a similar manner to aforementioned efforts to honor patients' rights to confidentiality, information exchanged in these meetings is not relayed back to patients' primary physicians/providers or recorded in a medical chart.

The confidential and 'out-from-underfoot' nature of patients' involvement in PID is a reflection of the professionals' and support partners' (patients plus family members) views about what was the best way to arrange the program. Providers introduced to PID see the program as helping them in their work, and integrating it into patients' treatment plans does not require additional efforts or time (by the primary provider). Patients are still able to access high quality standard care, and at the same time are able to access high quality community support in a manner that feels welcoming and non-pressured or stigmatizing.

Method

Partners in Diabetes has involved all project members (patients, spouses, providers) throughout its development and implementation, embracing their unique lived experiences and respective wisdom. Designed to improve the lives of a community that is touched by diabetes, PID is overtly oriented to change. The project's self-evaluative and flexible nature has been demonstrated repeatedly as problems have been identified and solutions implemented. While the guiding model of PID has been presented elsewhere (Doherty, 2000; Doherty & Carroll, 2002; Doherty & Mendenhall, in press) this is the first study examining how it is implemented in practice.

Study design

While quantitative measures can be made to assess impact on a dependent variable that is easy to measure (e.g. metabolic control, or A1c), the community-based participatory research process represents a moving target that is better captured through the subjective experiences, voices and observations of key participants. Accordingly, qualitative analyses were carried out in this investigation, and multiple sources of data were employed to further augment the validity of findings (Hagey, 1997; Lindsey & McGuinness, 1998; Nichols, 1995; Razum, Gorgen & Diesfeld, 1997).

Sources of data

Partners in Diabetes process notes (covering 49 meetings across more than three years) are detailed minutes that capture both the process and content of PID

assemblies. Process notes recount each person's ideas, words, and phrases, as well as the manner in which the group interacted. As a result, process notes are quite lengthy (2000+ words per entry). The first author recorded the majority of these notes, which were then perused and verified by other PID participants. See Appendix 1 for an example of process notes recounting a PID meeting.

Key informant interviews were conducted with select participants who have been actively involved in PID. Participants included four professionals (one physician, two nurse educators, one administrator) and six support partners (four patients, two spouses). Interviews followed a semi-standardized format, which permitted probes for elaboration while gathering information relevant to a structured set of questions about participants' involvement with PID, challenges that PID has faced, and overall perceptions of the program. Interviews were conducted by the first author and a research associate not involved with PID, and were transcribed verbatim.

Data analysis

Analyses of interview transcripts and meeting process notes followed an iterative data reduction method in which information is extracted and orchestrated into patterns, categories and themes that emerge from the gross data base (Crabtree & Miller, 1999; Creswell, 2003; Kvale, 1997). The sequence of this method involves the following steps:

1   Get a sense of the whole; read through several of the documents carefully and record initial ideas for categories and themes.
2   Pick one document and peruse it again, recording thoughts about its principal substance.
3   Repeat Step 2 several times with other documents, and then begin a list of all topics and themes identified. Cluster similar topics together. Place these groupings into columns that might be arranged as major topics, unique topics, miscellaneous.
4   Revisit the data. Abbreviate topics as codes and record the codes next to the appropriate segments of the text. Modify and add new topics and themes if they emerge.
5   Find the most descriptive wording for topics and turn them into categories. Reduce the total list of categories by grouping topics that relate to each other.
6   Assemble the data belonging to each category and assimilate the categories into a comprehensive picture.

For the purposes of augmenting the validity of findings, analyses of Partners in Diabetes process notes and interviews were conducted by the authors and a research associate not involved with PID. Following the methodological sequence outlined above, these analyses encompassed a lengthy process of perus-

ing, taking apart, and consolidating data in a manner that captured the evolutionary process and development of this complex initiative. We first read through hundreds of pages of text to facilitate an introductory impression and understanding of PID's overall progression from its early beginnings to the present time. General topics and themes were identified, and groupings of topics were consolidated as repeated passes through the data were made. Topics that were conceptually similar were merged under broader conceptual categories and themes, and unique themes were identified in their own right as stand-alone topics. Descriptive wording consistent with the evolutionary nature of respective themes was developed, and categories were grouped together according to overall thematic foci. Regular meetings for consultation and discussion of data analyses were held throughout this process to deliberate coding and resolve coding differences – from the initial identification of categorical topics to the assembly of multiple categories into larger and more inclusive themes.

Results

Eleven major themes were identified as relevant to the process and evolution of Partners in Diabetes (see Appendix 2). While all of these themes were supported by both process notes and interview sources, some of the sub-categories subsumed within these major themes were only supported by one data source. This is more a reflection of the data source than it is a reflection of a finding's validity, however, because some data were more readily available from process notes (e.g. accounts of discussions that occurred three years ago) or interviews (e.g. overall personal reflections about PID), respectively. It is also important to note that the themes overlapped in terms of temporal occurrence. That is, while results are presented below across the general sequence through which PID developed, individual themes did not occur in chronological isolation from other themes.

Space limitations prohibit comprehensive attention to all of the themes identified in this investigation. Results are reported here according to the authors' sense of what is most important in describing Partners in Diabetes' developmental evolution, with particular attention to how providers – and then support partners – internalized the guiding Citizen Health Care Model and worked together in a democratic fashion to create, implement and maintain PID. Key points of difficulty and lapses from the guiding model are also highlighted, and serve to illustrate how initiatives like PID do not develop in a linear and trouble-free fashion.

Providers learn a different way of working

Early discussions with clinic staff centered on providers' frustrations with how the current medical system is 'maxed out', and how traditionally doing something

'new' entails doing something 'more' (thereby requiring increased staff time and energy). For example, providers described previous attempts with focus groups as frustrating because patients asked for more services (e.g. weekend clinics) that staff could not offer. The second author framed these experiences as consistent with traditional models of care that position providers solely as a source of services that patients passively consume. The Citizen Health Care Model was put forth as a solution because it facilitates a productive role for patients, and with this, providers became increasingly enthusiastic about PID. One noted:

> What we've done with chronic care [and] diabetes . . . is that we've tried to convert that into a series of acute visits . . . [In PID] the patients became more and more empowered . . . [we are] moving care . . . outside of the boundaries of it having to all be done by the medical professionals . . . it does break outside of the institutional walls and starts to show people that health care has to be done out in the real world on a day-to-day basis.

Overt affirmations of this type of initiative were evidenced in a number of intentional efforts made by providers to embrace patients' experiences and resources. A provider remarked that:

> We wanted to try to create a health care activity that was more patient-organized and directed . . . The clinic very intentionally stimulated this thing, but . . . it's really an activity that's patients caring for patients . . . It's a very collaborative thing that is directed . . . by the patients, themselves.

Beyond providers' stance that PID is a novel supplement to standard care, overt activities further affirmed buy-in on an institutional level. PID's primary clinic, for example, has incorporated Partners in Diabetes into its standard diabetes care plan. Anyone who is initially diagnosed with diabetes, or who maintains A1c > 9%, is introduced to PID.

Patients learn a different way of working

An unexpected early experience was that patients tended to function in the passive consumer role of the conventional medical model even when efforts by providers to work democratically were put forth. Initial meetings (which included between 15 and 25 patients and three to five providers) often digressed to customary question-and-answer exchanges with patients, for example, about diet or exercise. One provider recalls how continued redirections were necessary:

> It's back to that active/passive thing. I think . . . it's fair to say it took several months [before] the patients gradually got the idea . . . we had to just keep saying, you know, 'we aren't going to make these decisions for you' . . . [we] didn't want this to be just the same-old, same-old.

As patients came to understand that PID was not going to function as a conven-

tional educational forum, several dropped out. As more attention was paid to facilitating an understanding regarding PID's dissimilarity to conventional provider-led initiatives, a more discriminating selection of patients and significant others (*n* = 14) emerged and administrative endorsement returned.

As patients' participation increased in partnership with providers, they became further aware of their potential to contribute through their lived experiences and wisdom. One recalls realizing that 'I had some influence as a person with diabetes . . . Maybe not a "knowledge expert", but a "life expert"'. Another recalls being excited by the process of everyone (providers, patients, spouses) contributing to PID's development:

> It's like having a jigsaw puzzle . . . You have a few pieces, but once you get all the pieces, you've got the whole picture . . . It's like putting a recipe together . . . You throw in the mixture and it comes out great when you get done.

As PID has evolved into its current state of functioning, decisions continue to be made collaboratively and with all participants' involvement.

Evolution of leadership

As mentioned before, providers evidenced a shift from hierarchal to collaborative functioning before patients did (probably because providers were introduced to the PID idea first). As patients became increasingly oriented to the model, their confidence as contributors to PID grew. This first began as providers and patients brainstormed a mission statement and outlined respective participants' roles. Even the terms 'support partner' and 'member' were developed with the model in mind, chosen over other labels that suggest hierarchy (such as diabetes 'coach', 'mentor', 'client', or 'patient'). By the time the group began to design the curriculum for PID's training, everyone involved represented a perspective with equivalent voice. One support partner maintained that 'it's a joint effort . . . we've got the bottom, the middle, and the top all mixing together and getting it solved'.

Providers, too, no longer struggled to elicit patients' active contribution. Having earlier felt pressure to simply answer questions and lead the process, one provider reflected: 'I had my medical training and experience . . . [but] there came a point where my doctor cap was almost off and I was just . . . another member of the group.'

Designing the PID training curriculum

As patients and providers met to discuss the role of a PID support partner, they identified important areas of training to prepare for this role. Support partners thought about what members would want to know, for example, up-to-date information and available resources. They also recognized the need for training in handling distressed members, for example, support skills, listening, and reflect-

ing. Providers identified topics crucial to any health care or volunteer initiative, for example, confidentiality, ethics, and safety.

Training for Partners in Diabetes was organized into the following sequence: 1) Living with Diabetes; Support Skills; 2) Medical Information, Giving Advice versus Providing Support; 3) Psychosocial Issues; 4) Boundaries and Self-disclosure; and 5) Resources, Confidentiality, Logistics. A graduation ceremony was held at the conclusion of this training, in which support partners received certificates recognizing their participation.

Implementing Partners in Diabetes

Process notes and interview transcripts reveal that the case-specific challenges that support partners encounter are as diverse as the patient members they connect with. From listening empathically and validating members' frustrations and confusion about diabetes, to assisting members in finding out how to update their blood glucose measuring technology, support partners' work is remarkably varied. One support partner recollected how he worked with someone who was uncomfortable with giving herself injections:

> [Member] wasn't giving herself injections . . . she refused . . . and I tried different techniques. We would go out to lunch . . . so that she could see me take my injection before I go in and eat and [I tried] to give examples of different techniques for giving the injections, different locations, that might be more comfortable for her.

Another support partner recalls how surprised she was when:

> [Member] announced almost when I got . . . into the apartment, she announced, 'Well, you know, I never eat breakfast'. And I thought, and my mind was just screaming, 'You never eat breakfast?! What's the matter with you?'

Support partners clearly connect with members in a way that providers cannot. The member described above began eating breakfast. Many other members – patients who providers had long since identified as 'non-compliant' and destined to manage their diabetes poorly – met with support partners and evidenced significant change. One woman who never exercised began walking with a support partner as they discussed new recipes that were both good-tasting and diabetes-sensitive. Another who never checked her blood sugar consistently began doing so after a support partner shared easy ways to incorporate this into an otherwise busy schedule that he (the support partner) had figured out, himself.

> We met, went out for coffee, called on the phone . . . she was having problems with checking her blood, and I got her where she was doing that better, actually, pretty well . . . her A1c's have been good [and] . . . overall she's doing okay.

One support partner, in recounting how she struggled so much with initially joining and assisting a member, shared that:

> It went well! Despite all odds . . . I just love her . . . It's turned out to be a challenge to work with somebody who has a personality that is so polar-opposite to me . . . [and] it's really gotten kind of fun.

Sometimes members simply need a pep talk, and may visit with a support partner just once on the telephone. Other times members and support partners meet regularly for several months. Whatever is the best for members receiving support is negotiated and arranged with the support partners, and while happy endings are not universal, the majority of PID connections that are made are described by support partners as successful.

As with any action research initiative, the work of the support partners encountered a number of challenges that were addressed and negotiated along the way. For example, issues regarding the telephone were particularly difficult, for the reason that the HMO's policy was that volunteers should not give their home telephone numbers to those receiving support. This required support partners to block their numbers when calling (to evade caller-ID technology), which often led to members refusing to answer for fear that they were about to be solicited by a telemarketer. Other members felt put off after a satisfying initial connection that was followed by a support partner refusing to give out his/her telephone number. The PID group dealt with this issue in a variety of ways, for example, using workplace or cellular phones (which cannot be connected to a home address), using PID providers as contact liaisons. Related to this difficulty, support partners frequently struggled with reaching patients (e.g. patients would not return calls or arrive at scheduled meetings). This issue was discussed in a PID forum and the group decided that after three unsuccessful attempts to connect with a potential patient member that the support partner will discontinue attempts and then be referred to another member.

A number of the support partners experienced frustration with having to explain Partners in Diabetes from scratch to each potential member receiving support, and providers and support partners alike maintained that the process of providers identifying recipients of PID support on an individual (one-at-a-time) basis was not a particularly efficient way to promote understanding and awareness of this resource. The group decided to develop an informational pamphlet that highlights PID as a unique opportunity to connect with someone who has personal experience with diabetes (either as a patient or the spouse of a patient), supplemented with training regarding up-to-date information, diabetes-relevant resources, and support skills. The pamphlet enables patients to self-identify as potential recipients of support, and this is beheld as a better way to ensure that their participation is founded in their own interest as opposed to going along with something their provider has suggested. One support partner reflected that '[The pamphlet will] get more information to potential [members]. There is a sheet on the back that they can send in, so it's more volunteer. They don't feel pressured

into it.' Another said that, 'I don't think that we're touching enough people . . . the brochure . . . will touch more people'.

Personal ownership in Partners in Diabetes

From early tasks that were accomplished in a spirit of egalitarian collaboration, to later tasks of problem-solving and self-definition, it became increasingly clear that support partners maintained a personal stake in PID. For example, after devising key points to communicate for the pamphlet discussed above, a draft was created and reviewed by the group. A discussion ensued about the weight that providers had placed on PID's training versus support partners' sense that the most important characteristic of PID is that the volunteers have lived experience with diabetes. It was decided that although training should be mentioned to augment credibility, support partners' experience should be disproportionately highlighted. This decision reflected the willingness of support partners to challenge providers on behalf of PID's guiding model.

As providers and support partners look into the future, they show a strong belief in the utility of developing similar initiatives, and even transporting PID's philosophy to other conditions. One provider maintained that, 'I think it should [expand]. I think it's a great resource. I believe that it has potential and is the future of diabetes care.' A support partner echoed this enthusiasm, saying that, 'I . . . hope it keeps going, and can get to the point where it spreads out all over the place. I really, truly think . . . if you can do it for diabetes, you can do it for all kinds of other diseases.'

Lapses in Partners in Diabetes' development: Contradictions to the guiding model

Consistent with the notion that action research encompasses slow and messy processes of successes and failures, PID has experienced a number of setbacks. These setbacks tended to involve sequences that contradicted tenets of PID's guiding Citizen Health Care Model, and serve to illustrate potential pitfalls to avoid.

The first major lapse occurred during planning efforts to invite patients and their families to clinic-sponsored forums that were designed to recruit participants in the development of PID. While a number of issues were confronted and resolved democratically, a misstep occurred when providers, concerned about logistical challenges, reversed a group decision in between meetings and sent out invitations without the appealing envelopes and physicians' signatures that support partners had articulated were necessary. The turnout for the forum was disappointing.

A second lapse occurred shortly after PID's training phase. When training began, a necessary shift occurred whereby those providing the training were

positioned as experts. The group, however, did not spontaneously return to its pre-training state of collaborative functioning when training concluded. Support partners seemed to be reporting to the first author, rather than to the whole group, about their efforts. The first author was functioning as an expert 'troubleshooter', without a sharing of input and ideas among support partners. He then worked to de-center his role and facilitate support partners' engaging one another in a democratic dialogue and problem-solving regarding their work.

Discussion

Partners in Diabetes' guiding model emphasizes that citizens work within the unique challenges and resources of their local communities. Because no two communities are entirely alike, the results from this study cannot be generalized to every site invested in initiating a similar project. Initiatives in community-based participatory research have been similarly cited for this limitation, with the trade-off gain of having created something with immediate relevance for a particular community (McKibbin & Castle, 1996). Nevertheless, lessons learned through PID's course can be helpful to inform future efforts and avoid potential pitfalls (see Table 3).

Engaging stakeholders through self-interests

It is important that citizen initiatives engage people through their self-interests in synchrony with interests of the community, and this was evidenced in PID on a number of counts. Early administrative endorsement was given with the notion that a frustrating health care problem that is expensive was going to be addressed. Providers saw PID as an alternative to conventional provider/consumer dynamics that position patients in passive roles. Patients and family members discussed how providers' lack of personal experience with diabetes limits providers in terms of empathy and influence, and were highly invested in supporting fellow patients from a position that is missing in standard care. Support partners also gained from the fulfilling sense of helping others, as well as having regular access to up-to-date information.

Issues of replication

Many one-of-a-kind initiatives are never replicated, and it is important to consider how Partners in Diabetes stands in terms of this risk. First, PID uses the existing resources of its established clinics and participants, rather than relying on external grants or funding. This is important because external funding tends to bring with it the expectation of specific 'outcomes' (defined by funders) accord-

Table 3 Partners in Diabetes and Citizen Health Care Projects: Lessons Learned

1	This work is about identity transformation as a citizen professional, not just about learning a new set of skills.
2	It is about identifying and developing leaders in the community more than about a specific issue or action.
3	It is about sustained initiatives, not one-time events.
4	Citizen initiatives are often slow and messy during in the gestation period.
5	You need a champion with influence in the institution.
6	Until grounded in an institution's culture and practices, these initiatives are quite vulnerable to shifts in the organizational context.
7	A professional who is putting too much time into a project is over-functioning and not using the model. We have found the average time commitment to be in the order of 6–8 hours per month, but over a number of years.
8	External funding at the outset can be a trap because of timelines and deliverables, but funding can be useful for capacity building to learn the model, and for expanding the scope of citizen projects once they are developed.
9	The pull of the traditional provider/consumer model is very strong on all sides; democratic decision-making requires eternal vigilance.
10	You cannot learn this approach without mentoring, and it takes up to two years to get good at it.

ing to a preset schedule. This can undermine the democratic process of developing a project through citizenship participation. Furthermore, projects supported by external funding are generally difficult to replicate without similar funding. Second, provider concerns about time commitment are important to consider. Citizen Health Care projects like PID require time commitments that are more longitudinal than intensive, averaging six to eight hours per month over a period of years (Mendenhall & Doherty, in press; Morrison & Lilford, 2001). Providers involved in PID participated without additional compensation, framing this time as within their job descriptions.

Limitations of this investigation

In addition to issues of generalizability, there are other limitations of this study. To begin, the first author recorded the majority of PID's process notes. While these documents were perused and revised by other PID participants, they may reflect some personal biases. Second, the first author conducted half of the key informant interviews. Because he was an active participant in PID, it is possible that interviewees presented more positive accounts than they would have with a stranger. However, interviews conducted by the authors' research associate (who

was not involved in PID) did not differ appreciably in their content or tone. Third, the first author participated in the conduct of qualitative analyses (on process notes that he recorded and interviews that he conducted). While his intimate familiarity with these data is a strength, the first author's closeness to PID could have colored his perceptions of identified categories and themes. Open discussions between the first author, his research associate, and the second author regarding data analyses were useful in addressing this, and consistent agreement in conclusions were drawn.

Future directions

Anecdotally, many patients have benefited from their involvement in Partners in Diabetes. As outlined above, patients who had long since been given up on by their providers as 'non-compliant' and destined to manage their diabetes poorly have evidenced considerable change. Patients who were not exercising are exercising. Patients are eating better, and they are losing weight. Providers enthusiastically refer patients to PID, maintaining that the opportunity for patients to talk with other patients about managing their disease facilitates a tapping of lived experience and wisdom that they – as providers – do not possess. The clinic has even incorporated PID into its standard protocol for diabetes care, based on the argument and belief that the program offers patients a valuable resource in disease management while synchronously reducing care burden on providers and related clinic resources.

While these anecdotal accounts are encouraging in regard to PID's potential effectiveness and utility as a program, evidence-based outcome research stands as a benchmark for credibility in medicine and behavioral science. Investigative efforts that assess empirical quantitative data are thereby requisite to evaluate PID's effects, and in justifying its expansion. Future efforts in this regard can be done through single-group repeated-measures designs (to elicit pilot, quantitative data) that will build the case for large subsequent randomized controlled trials wherein patients receiving standard care plus support through PID are compared to patients receiving standard care only, or standard care plus other interventions (e.g. psychoeducation, group clinics). Consistent with existing literature that has tested the efficacy of individually oriented and family-based interventions, researchers should assess outcomes across the following dependent variables: 1) physical and biological (e.g. A1c, BMI, weight); 2) psychological (e.g. perceptions of life quality, depression); 3) diabetes-specific knowledge (e.g. regarding diet, exercise, blood testing); and 4) behavioral (e.g. exercise, complying with medical regimens). Additionally, researchers should assess family and social outcomes (e.g. perceptions of disease co-ownership, diabetes-specific support), because strong associations exist between these systemic characteristics and diabetes

management and control. We are currently seeking funding to conduct scientific studies that test these outcomes empirically.

Finally, it is worth returning to the greater vision for Partners in Diabetes: to create a model of health care as work by and for citizens, with all stakeholders – including patients, their families, physicians, and other providers – working as active contributors. Participants in PID show a sense of doing work of profound significance, and they are energized by this broader vision. At an early meeting when the second author maintained that these efforts are about changing how health care is done in the United States, a support partner interrupted him and asked, 'What about the world?' As future efforts in PID and other citizen initiatives proceed, this vision of transforming health care will serve as a sustainer of energy and commitment in the face of this formidable but inspiring task.

Appendix 1: Exemplar of process notes from a Partners in Diabetes (PID) meeting

> Dear Colleagues: I thought this was our best meeting of the community activation team (CAT) group. Everyone was engaged and on task, and there was a real egalitarian spirit of decision making across professionals and [clinic name] members. The content was noteworthy for a searching discussion of what to call the peer outreach folks and those who are being reached out to. We wanted to avoid traditional terms such as 'volunteer' and 'patient'. We are moving ahead to plan a Diabetes Partners Support Program featuring 'partners' who will be trained to do peer outreach, and 'members' who ask for this outreach. The democratic theory underlying this program calls for opportunities for members to become coaches, coaches to become trainers of the next cohort of coaches, and trainers to become clinic leaders. That's the bold vision. For now, the group is working on launching the Diabetes Partner Support Program as soon as [clinic name] is finished with its transitions. Thanks again to Tai for his superb minutes. Comments welcome from the silent folks who are on the 'copy' list for these notes.
>
> Bill Doherty

Partners in Diabetes: community action team notes

The Community Activation Team (CAT) assembled on 13 October at 5:30 pm. Bill Doherty (BD), Tai Mendenhall (TM), Mary Bloom (MB), Ann Bukoskey (AB), Valerie Fox (VF), Debra English (DE), and four patients were present (MP, DP, BM, and BL).

Pre-meeting

The evening began by patients filling out nametags as they arrived and visiting with each other and staff. The atmosphere felt casual as a variety of topics were given attention. TM tried to write the CAT mission statement ('A community of people working together to promote the well-being of patients and families at Physicians Clinic who are touched by diabetes') on the white board with a permanent marker and ran out of space. The rest of the group, lead by BD, made sure that TM did not live this down.

Meeting

BD began the meeting by welcoming all present, and asked CAT members to introduce themselves to the group as a means of reorientation and because DE was new to the assembly (and BM was not at the last CAT meeting). BM affirmed her interest in being a part of the CAT's community-outreach initiatives. DE identified herself as [clinic's] volunteer coordinator. TM, AB, BL, BD, MP, and DP all disclosed their interest in activating patients and families in collaboration with health care providers in novel and effective ways.

BD then clarified our goals for the evening as encompassing key initial planning for the diabetes-coaching project that we discussed at the last CAT assembly. This program will represent a new and exciting way of reaching out to patients with diabetes and their families that is both collaborative in nature and empowering for patients (volunteers and recipients alike). BD wrote a list on the white board of six things we need to work through over the next few meetings. The list was as follows: (1) Project Name, (2) Names of Roles, (3) Job Description, (4) Recruitment, (5) Training, (6) Clinic Coordination and Support.

BD suggested that we start with (2) Names of Roles. Beginning with naming the role for the patients doing the outreach, several group members offered suggestions, for example, 'coach', 'mentor', 'visitor', 'leader', 'helper', 'teacher', 'partner'. AB asked members if they liked 'mentor', to which BM, BL, and MP responded negatively. Mentor implies a hierarchy that we do not wish to imply – as do 'leader', 'helper', and 'teacher'. BD suggested that we preface role names with the word 'peer', for example, 'peer mentor', 'peer leader', 'peer helper', etc. Reactions were mixed. BD and TM noted that 'coach' and 'mentor' have been the terms that we have used the most frequently so far.

VF entered the meeting at this point. She is from RFP and is interested in initiating a CAT-like initiative at her site with TM and others. BD quickly brought her up to speed and explained today's tasks within the larger context of collaboration.

The group resumed its discussion regarding names of roles. 'Visitor', 'leader', 'helper', and 'teacher' were all crossed out as members maintained that

an unwanted hierarchy – with or without 'peer' prefacing the term(s) – was communicated with these terms. After narrowing down the options to 'supporter' and 'partner', the group struggled for several minutes with further reducing of the list because both of these terms capture what we are trying to do. BD suggested combining the terms into 'Diabetes Support Partner'. All present liked this term and approved it.

Having constructed this label, AB suggested that the (1) Project Name could fit this idea, as well. She suggested 'Diabetes Peer Support Program'. The group discussed whether 'project' should be used instead of 'program', and collaboratively decided that 'program' communicates a stronger sense of permanence than 'project'. All agreed and approved 'Diabetes Peer Support Program'.

BD then brought us back to (2) Names of Roles in regard to persons asking for the support. 'Partner' was suggested, to which TM responded with concern that this term could get mixed up with the peers doing the outreach. All agreed. BD asked the group how we can capture the notion that persons asking for support are not simply passive recipients of that support. AB maintained that 'patients' and 'clients' are, indeed, asking for support – but that it is important to not demote this role. TM and VF suggested 'team member' and 'team player'. BD suggested narrowing this down to 'member'. The group dialogued regarding 'member', and decided that this is an excellent way to demarcate this role.

We then moved on to (3) Job Description. Members felt that 'job' denoted a provider–customer dichotomy. BD suggested 'task' description. Members agreed. AB asked to hear the CAT's mission statement again. BD read it to the group. We then began discussing the task description of the Diabetes Support Partner. The following are what the group collaboratively identified as what the support partner role encompasses: source of reassurance, connect members to resources, listen, share experiences (e.g. coping strategies, recipes, stress reduction), support, exercise (advice or even an exercise partner), motivation tips, affirmation (universality of the experience), helping family members to support without nagging, sharing strategies for working with health care professionals. BD queried the group, 'What will the partners get out of doing all of these things?' BL responded, 'The same things!' All agreed. BD paralleled this to peer tutors in school, who often report getting even more out of tutoring than the students tutored.

DE made the case that we must make these benefits clear to potential partners; otherwise, they might not think that such benefits exist (unless they possess previous experience volunteering). BD said that partners will also be getting more information from ongoing interactions with health care professionals via special training (yet to be discussed). BL emphasized that different people 'do change' differently; partners must be aware of this across work with different members. BD returned to the final (above) task description, 'sharing strategies for working with health care professionals' as an interesting one. The group discussed how

some professionals are more and less collaborative and empathic to patients' experiences, and that sharing with members sundry ways to cope with and effectively negotiate patient–provider interactions is definitely indicated.

AB asked 'Where will all of this happen?' Several options were identified, for example, in the home, at the clinic, on the telephone, on the www, and at a neutral place (restaurant, mall, etc.). BL maintained that the telephone should not be used beyond initially scheduling visits until a working relationship has been developed. All agreed. In regard to working in homes, MB expressed reservations. AB said this could be negotiable. DE discussed telling members what to expect, setting minimum requirements (e.g. time), and training of risk-management. BD concluded that 'where' will remain a flexible, but not in the clinic.

AB asked 'When?' DE said that usually there exists a range of patient requests, and that schedules will have to be coordinated accordingly.

BD brought up the issue of time. AB maintained that partners should expect 16–24 hours of training. In regard to program commitment, the group decided that a tentative time commitment to be involved of two years was acceptable (and certainly negotiable). A minimum of two hours per week with members should be expected. Partners will start with one member, and increase from there depending on their availability. AB emphasized that partners will need to be encouraged to set clear boundaries when they are too busy.

BD noted that members will hopefully become partners and partners will hopefully become trainers to future partners-in-training, and perhaps eventually clinic leaders. All agreed, and maintained that transitioning from a member to a partner helping other members could potentially be an empowering experience for members.

BL suggested that another thing partners can do is connect two-plus members to each other for ongoing support, and thereby release the partner to work with other members. All agreed that this could be potentially helpful.

AB suggested that the guideline of working with a member for one to six months be set and made known to members from the outset. Continuing partner–member work will be renegotiated every one to two months. All agreed.

BM said that we should set time limits for each visit, too. The group dialogued and agreed to set each visit to approximately one hour. BD said that he would draft a sentence to describe explicitly what partners do.

We then moved on to (6) Clinic Coordination and Support. MB said that Physicians Clinic just hired a new RN, but that she will not be 'up to speed' for a few months. BD asked if she could be at the next CAT meeting. MB said, 'maybe'. BD emphasized that we really need this RN to be on board. AB asked when we will start this in coordination with the clinic. BD said that we can have another Event in [year].

In regard to (4) recruitment, the [year] Event will facilitate this. The last Event went well, and the next one will be modeled after [year's] Event. We will

include an educational component, a panel of patients, providers, and family members, and can recruit partners and members on this day. AB indicated that we should make sure that partners are aware that training will take up to two months to complete. All members and partners should have some connection with [clinic]. AB and MB also noted that with new physicians (from Pediatrics) coming in April, there may be more opportunities for parent–parent and adolescent–adolescent connections. VF maintained that we should match partners and members according to whether they possess Type 1 or Type 2 diabetes. All agreed.

BD suggested that we further discuss training at our next meeting. He encouraged all present to be thinking about what the training needs of partners encompass. AB encouraged all present to be thinking about ongoing support mechanisms for partners, for example, opportunities for partners to get together and support each other and share experiences, etc. BD liked this point, and maintained that we should incorporate time necessary for this into partners' time commitments when they decide to assume partner roles. AB said that we should also consider ongoing, continuing education for partners.

BD thanked everyone for coming, and emphasized how he sees the process of collaboratively dialoguing between patients and professionals as a very useful and exciting process of building something new – something that will benefit everyone involved. All enthusiastically agreed. The group confirmed its next meeting as 3 November at 5:30 pm, and adjourned.

Appendix 2: Developmental evolution of Partners in Diabetes (PID): Summary of findings

Gaining entry

- Activities/recognition of the importance of administrative endorsement
- Endorsements by administrative leadership
- Activities that elicit (initial) buy-in to PID
- Problems with gaining and maintaining buy-in/entry

Providers learn a different way of working

- Recognize and express dislike for conventional paradigm
- Position new paradigm as a solution
- Activities that overtly affirm buy-in to new paradigm (in-thinking)
- Activities that implicitly affirm buy-in to new paradigm (in-action)
- Activities that overtly affirm buy-in to new paradigm (in-action)

Early challenges related to public launching events

- Logistics[a]
- Evaluation[a]
- Purposive actions that align with model
- Maintaining momentum
- Not over-burdening clinic resources[a]
- Recruiting support partners

Patients learn a different way of working

- Activities by providers that share or illustrate the novel model
- Activities by support partners that illustrate the novel model
- Reflections by support partners that illustrate the novel model

A second clinic is incorporated into PID

- Discussions of expanding PID to other clinics[a]
- Declarations of interest by 2nd clinic
- 2nd clinic as a solution to problems at 1st clinic
- Partnership of two clinics

Designing the PID training curriculum

- Activities/processes in planning/designing that were democratic
- Confidentiality and ethics
- Demarcate arenas of expertise
- Co-ownership of PID's future[b]

Evolution of leadership

- Clinic leaders endorse PID
- Providers explicitly attempt to employ new model
- Leadership and facilitation during PID meetings
- Active collaboration between patients and providers
- Overall reflections regarding changes in leadership activity[b]

Personal ownership in PID

- Collaborative/democratic task-accomplishment and decision-making
- Frank discussions and feedback sequences
- Comfortable atmosphere is highlighted
- Expanding/Replicating PID

Implementing the PID initiative

- Confidentiality and boundaries
- Case consultation; diverse foci
- Follow-up and maintaining contact
- Describing PID to new members; PID pamphlet
- Easy references regarding diabetes resources
- Ongoing education
- Logistical challenges with support partners
- Success stories (case-specific)[b]
- Struggles (case-specific)[b]

Characteristics of PID participants

Characteristics of PID providers

- Recognition of providers' empathy for support partners
- Providers show humbleness
- Providers reflect and self-critique
- Use of humor

Characteristics of PID support partners

- Support partners reflect and self-critique
- Empathy towards members and/or patients with diabetes
- Satisfaction and pride with PID[b]

Lapses in Partners in Diabetes' development: Contradictions to the guiding model

- Providers overrule group planning regarding invitations to launching event[a]
- Participants temporarily maintained hierarchical functioning following training[a]
- Providers temporarily stopped checking-in at ongoing meetings[a]

Other categories/thematic patterns

- Diversity of patients, PID support partners, and members
- Normalization of messy processes
- Importance of family
- Support partners benefit from participating in supportive role
- Support partners remark regarding PID's risk and uniqueness[b]

[a]Supporting data from PID process notes only; [b]Supporting data from interviews only.

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