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Goldman, Matthew L

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Self-Management Peer Support for Low-Income Patients with Diabetes:  
A Qualitative Study of Peer Health Coaches' Perspectives

By

Matthew Louis Goldman

A thesis submitted in partial satisfaction of the

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Health and Medical Sciences

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University of California, Berkeley

Committee in charge:

Professor Stephen L. Eyre, Co-Chair  
Professor Thomas Bodenheimer, Co-Chair  
Professor Stephen M. Shortell  
Professor Colette Auerswald

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Self-Management Peer Support for Low-Income Patients with Diabetes:  
A Qualitative Study of Peer Health Coaches' Perspectives

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## Abstract

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by

Matthew Louis Goldman

Master of Science in Health and Medical Sciences

University of California, Berkeley

Professor Stephen L. Eyre, Co-Chair  
Professor Thomas Bodenheimer, Co-Chair

*PURPOSE:* Although self-management support (SMS) improves diabetes outcomes, it is not consistently provided in health care settings due to insufficient time. One solution is the use of peer health coaches (PHCs), patients trained to provide diabetes self-management support to other patients.

*METHODS:* A four-person focus group and seventeen qualitative semi-structured interviews were conducted with community-based PHCs in San Francisco. Transcripts were coded and analyzed using methods based on grounded theory to develop a theoretical model.

*RESULTS:* The qualitatively derived model for how PHCs function in practice defines three principal roles in providing peer SMS: advisor (teach, strategize), supporter (build trust, motivate), and role model (empathize, exemplify). While working with patients, PHCs had variable approaches to setting emotional boundaries and to allocating responsibility for implementing health behavior changes. PHCs were more consistent in seeking resources from providers. PHCs also became empowered to better manage their own diabetes.

*CONCLUSION:* PHCs are a highly motivated potential workforce that is uniquely positioned to teach and empower patients by building trust through shared experiences. The variability in PHCs' coaching styles suggests an inherent diversity among PHCs that must be accounted for in future strategies for design, recruitment, training, and oversight of peer coaching programs.

*This Masters thesis is dedicated to my Grandma and Pa,  
who have been there for me always;*

*and to Kevin Mack,  
who will forever be my guiding light.*

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## GLOSSARY OF ACRONYMS

CCM	chronic care model
CDSMP	Chronic Disease Self-Management Program
CHW	community health worker
HbA1c	glycosylated hemoglobin
HDL	high density lipoprotein
LDL	low density lipoprotein
PCMH	patient-centered medical home
PCP	primary care provider
PPACA	Patient Protection and Affordable Care Act
QALY	quality-adjusted life-year
RCT	randomized control trial
SMBG	self-monitoring of blood glucose
SMS	self-management support
WHO	World Health Organization

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**LITERATURE REVIEW & QUESTION FORMULATION**

## I. Introduction

Primary care providers (PCPs) have become so busy that their schedules limit their ability to give sufficient care to patients with chronic diseases. Studies have shown that preventive health education alone could take up 7.4 hours per working day,<sup>1</sup> and chronic care guidelines would demand 10.6 hours per working day of a PCP's time.<sup>2</sup> Richard Smith, the editor of the *British Medical Journal*, wrote an editorial that describes the current organization of primary care in the United States as "hamster health care."<sup>3</sup> With the development of managed care in the United States in the 1990s, PCPs were asked to do more work without getting paid more. As a result, PCPs were forced to increase their patient loads, which meant that they suddenly did not have enough time to cover all necessary topics with their patients. Low salaries and high stress have dissuaded medical school graduates from joining the primary care workforce, which has led to PCP shortages that further exacerbate the primary care system<sup>4</sup>—a vicious cycle of hamster wheels spinning faster and faster. The result has been a primary care system rendered unable to provide either efficient access for acute care or high quality chronic care.<sup>5</sup>

The need for reform continues to grow as the rates of chronic disease rise in the United States. For example, as of 2010, diabetes mellitus afflicted 10.9 million U.S. residents aged 65 years and older, or 26.9% of that population. About 1.9 million people aged 20 years or older were newly diagnosed with diabetes in 2010 in the United States. Furthermore, the rates of diabetes are disparate based on racial and ethnic groupings. Compared to non-Hispanic white adults, the risk of diagnosed diabetes was 18% higher among Asian Americans, 66% higher among Hispanics, and 77% higher among non-Hispanic blacks.<sup>6</sup> Diabetes is a particularly challenging disease to manage because, although clinical guidelines are well defined, there are multiple barriers to successful implementation of those recommendations, especially in minority and low-income populations.<sup>7,8</sup>

Two main models of reform have been discussed to address the challenges facing the management of chronic disease in primary care in the United States.<sup>9-11</sup> The first is the patient-centered medical home (PCMH) as a model for coordinating care for patients. The PCMH model calls for improvements in four of the fundamental tenets of primary care practice: 1) health information technology, 2) access and scheduling, 3) continuity of care, and 4) patient-centered care.<sup>12</sup> However, these changes must come as part of a larger system restructuring that includes payment reform and transformation of the primary care team.<sup>13</sup>

The other main focus of reform is to transform and expand the primary care team to better implement the chronic care model (CCM), including offering self-management support (SMS) to patients with chronic illness. The CCM was developed at the Group Health Cooperative of Puget Sound to improve primary care for patients with chronic illness by addressing the need to expand the clinical team to include non-PCP providers of SMS.<sup>14</sup> The parallel approaches of the PCMH and the CCM, to enhance both the organization and the delivery of primary care, are two of the pillars of health delivery reform in the United States.

This literature review explores the background of this qualitative thesis, which aims to better understand the experiences of diabetes peer coaches, patients trained to provide SMS to other patients. First, the general concepts of both the CCM and behavior change theory are discussed. Next is a description of the main patient-centered models for implementing SMS for diabetes, including related quantitative studies of efficacy and qualitative studies of patient

perspectives. Finally, the relevant cost-effectiveness literature is summarized, and current developments in SMS are discussed.

## **II. Theoretical background**

SMS represents a convergence of two major theories. The first is the chronic care model (CCM), which is a matter of health care policy and practice reform, and requires a systemic implementation by primary care providers. The other is behavior change, which is an approach to clinical practice that requires on-the-ground training of individual health care workers. In order to contextualize the need for SMS in management of chronic diseases, both the broader implications of CCM and the specific adoption of behavior change techniques must be addressed.

### *Chronic Care Model*

Of the many models that emerged in the 1990s to improve chronic care in the United States, one of the most enduring has been the CCM. The conceptual framework for the CCM was developed at the MacColl Institute for Healthcare Innovation at Group Health Cooperative of Puget Sound. Based on an examination of leading organizations' chronic illness programs, MacColl Director Edward Wagner sought to create a guide for provider organizations desiring to improve the care of chronic illness. The CCM exemplifies a healthy and iterative relationship between theory and practice: Theory (the model) grows from practice (and from study of scientific evidence), feeds back to improve the practice, which in turn feeds back to modify and improve the theory.<sup>15</sup>

The CCM addresses six fundamental and interrelated components of chronic care management: 1) self-management support, 2) decision support (clinical practice guidelines, clinician education), 3) delivery system redesign (planned visits, group visits, case management, primary care teams), 4) clinical information systems (registries, clinician feedback, reminders), 5) health care organization, and 6) community resources.<sup>9</sup> 32 of the 39 studies reviewed by Bodenheimer and Wagner showed that implementing CCM practices led to improvements in at least one process or outcome measure for diabetic patients.<sup>10</sup> The CCM has therefore become one of the core tenets of primary care reform.

One of the most challenging aspects of the CCM is self-management support (SMS). As Holman and Lorig explain, there are many responsibilities of the patient in the presence of chronic disease.<sup>16</sup> Patients must use medications properly, change behaviors to improve symptoms or slow disease progression, adjust to social and economic consequences, cope with emotional consequences, and interpret and report symptoms accurately. These challenges therefore require unique interventions.

### *Behavior change theory*

In order to address the challenges faced by patients with chronic disease, health care providers must be able to engage and empower patients in order to convey strategies for self-management. The theoretical foundation of SMS is known as behavior change.

Providers must consider many factors that mediate a patient's ability to manage his or her disease, including: 1) predisposing factors such as a patient's coping style and prior attempts at

change; 2) a patient's needs, as evaluated by both the clinician and by the patient him or herself; 3) a patient's intention and readiness to change; 4) precipitating cues that indicate disease status, such as hypoglycemic and hyperglycemic symptoms; and 5) the presence of both resources and barriers that affect patient experience, including personal, social, and community factors.<sup>17</sup>

To address these aspects of living with diabetes, specific interventions have been identified for each. For example, didactic education can provide knowledge about the risks and benefits of self-care, while demonstration and feedback can help build skills and correct errors. Setting goals can help establish specific and appropriate objectives that are ambitious but realistic for the patient, and problem solving can help patients find ways to overcome barriers. Lastly, support and counseling can help patients maintain positive emotional well-being.<sup>17</sup> These specific educational targets have resulted in behavior change techniques that may be used in clinical management of chronic illness.

A review by Goldstein seeks to develop several principles and strategies for delivering behavior change interventions in primary care.<sup>18</sup> One example is the "5A's" construct: assess, advise, agree, assist, and arrange-follow up. Goal setting is another practice that has been developed for clinicians to effectively work with patients.<sup>19</sup> Additional techniques include shared decision-making, motivational interviewing, and assessment of readiness to change.<sup>19</sup> Unfortunately, despite these data showing the efficacy of the "5 A's" and motivational interviewing, a large majority of PCPs remain unaware of these behavior change techniques.<sup>20</sup>

Alternatively, the Diabetes Initiative of The Robert Wood Johnson Foundation proposes an "ecological perspective" aimed at positioning diabetes SMS in the context of social and environmental influences.<sup>21</sup> By articulating SMS from the perspective of individuals' needs, the following key resources and supports are highlighted: 1) individualized assessment, 2) collaborative goal setting, 3) skills enhancement, 4) follow-up and support, 5) access to resources, and 6) continuity of quality clinical care. All of these approaches emphasize identification of goals, teaching of skills, and facilitation and reinforcement of those skills.

Unfortunately, the state of patient-physician communication has deteriorated in tandem with the diminishing time for preventive health education. One study by Michelle Heisler's group at the University of Michigan highlighted the importance of physician communication and participatory decision-making by demonstrating that these aspects of clinical care are directly related to patient understanding in diabetes.<sup>22</sup> Nevertheless, although patients have been shown to retain as little as half of what PCPs convey during an outpatient encounter, many PCPs neglect to test their patients' comprehension.<sup>23</sup> These are only some of the reasons that patients and providers struggle to reach clear agreements on their goals, which may lead to worse health outcomes,<sup>24</sup> especially for those with poorer health status and non-health competing demands.<sup>25</sup> Such barriers further indicate the need for SMS in primary care.

### *Bringing together CCM and behavior change*

In order to realize the aims of SMS, clinicians must be willing to prioritize behavior change both in terms of clinical practice and organizational capacities. However, many obstacles remain, including lack of access to SMS programming, and even physician resistance.<sup>26</sup> Nevertheless, given that PCPs do not have sufficient time to practice behavior change techniques themselves, it has become necessary to innovate new ways of increasing the capacity and efficiency of the primary care team to include SMS. The following section describes models for

expanding the clinical team in order to incorporate SMS and behavior-change counseling in primary care practice.

### III. Self-Management Support

The relationship between a SMS intervention and a patient's health outcome is a multifactorial process that varies depending on the setting, participant characteristics, length of intervention, and many other factors. In order to demonstrate the potential for SMS in primary care, a vast array of randomized control trials (RCTs) have measured the health outcomes of various intervention models in a wide range of patient populations. This section first explains the unique challenges of chronic management of diabetes, then aims to give a brief overview of the literature on SMS in diabetes, and finally focuses on the role of peers in SMS.

#### *Difficulty of managing diabetes*

The enormous prevalence of diabetes is particularly disconcerting given how complicated it is to manage. Many of the papers discussed in this literature review introduce the topic of diabetes SMS by stating that diabetes is a chronic condition that requires patients to actively participate in their management of the disease.<sup>27</sup> Yet beyond the basics of improving diet and exercise, there are multiple obstacles to improving their self-management, including psychosocial and medical complications.

The first step in diabetes self-management is for the patient to understand the disease. Studies have shown that self-monitoring of blood glucose (SMBG) may lead to improved glycemic control, but only in the context of appropriate education.<sup>28</sup> Low health literacy in SMBG<sup>29</sup> and in interpreting blood glucose lab values such as glycated haemoglobin (HbA1c)<sup>30</sup> are significant barriers to effective self-management that disproportionately affect underserved populations. This lack of understanding can lead to poor adherence to medication regimens,<sup>31</sup> a problem further exacerbated by high medication costs for patients<sup>32</sup> as well as insufficient intensification of treatment plans by clinicians.<sup>33</sup>

Beyond the immediate effects of hyperglycemia lies a multitude of comorbidities,<sup>34</sup> including cardiovascular complications, chronic pain, and depression. Although diabetic patients should be actively engaged in treatment decision-making and monitoring as a strategy to improve their hypertension outcomes,<sup>35</sup> studies have shown that knowledge of blood pressure targets is low among diabetics.<sup>36</sup> Chronic pain is prevalent among diabetes patients as well, and can be a major limiting factor, both physically and psychologically, in a patient's ability to manage his or her diabetes.<sup>37</sup> Finally, the adverse effects of depression on energy, motivation, concentration, self-efficacy, and interpersonal interactions are also believed to negatively affect self-management of diabetes.<sup>38,39</sup> The presence of comorbidities creates competing demands for diabetic patients, which complicates both treatment and SMS strategies.

Finally, psychosocial factors such as family dynamics play a role in a patient's diabetes self-management. Family members are often highly involved in patients' self-care, particularly with patients who have low health literacy.<sup>40</sup> However, one study found that children of diabetes patients have roles that are both supportive and undermining to the goals of their parents.<sup>41</sup> Interventions should therefore help patients overcome family barriers by helping families use positive and effective support techniques.<sup>40</sup>

Patients who receive diabetes SMS have been shown to have a good gauge of their disease status, which backs the notion that education and support can improve diabetes management despite the challenges listed above.<sup>42</sup>

### *Overview of SMS in diabetes*

Commonly used outcome measures for studies of SMS in diabetes include HbA1c, as well as measures of comorbidities such as blood lipid levels (including LDL, HDL, and total cholesterol), blood pressure, and body weight. Some studies assess for diabetes knowledge, while others examine factors such as self-reported changes in SMBG, food intake, and physical activity, although such results are prone to over- and under-reporting.<sup>43</sup> Finally, many studies discuss measures of feasibility, including economic assessment of cost-effectiveness and qualitative evaluation of patient acceptance of the intervention.

A number of review articles have attempted to distill the breadth of topics covered in these studies. For example, a systematic review found that SMBG may only be effective in improving glycemic control if patients receive education or are able to self-adjust their treatment.<sup>28</sup> A meta-analysis of 18 randomized educational and behavioral interventions ranging from 1 to 19 months in length found a mean decrease in HbA1c of 0.43%.<sup>44</sup> Another meta-analysis of 31 studies found that self-management education improves HbA1c by 0.76% immediately after interventions and by 0.26% after 1-3 months of follow-up.<sup>45</sup> They also found that improvements in glycemic control increase with the amount of time that patients spent with educators, suggesting a dose-dependent response.<sup>45</sup> Lastly, a Cochrane review of group-based diabetes programs demonstrated improvements in HbA1c, fasting glucose, diabetes knowledge, body weight, blood pressure, and need for medications.<sup>46</sup>

Other reviews explore some of the theoretical aspects of why SMS may lead to improved health in patients with diabetes. Brown, for example, takes a historical perspective to establish that diabetes education and behavioral interventions are effective in improving psychosocial and health outcomes.<sup>47</sup> Another review takes a closer look at the link between SMS and self-efficacy, saying "the goal for educating people with diabetes is to improve their individual self-efficacy and, accordingly, their self-management ability."<sup>48</sup>

### *Overview of Peer SMS in diabetes*

SMS may be provided by trained health care workers such as registered nurses, pharmacists, medical assistants, or other non-clinicians, but it may also be offered by lay people, often referred to as peers, who are patients trained to provide diabetes education and support to other patients.<sup>49</sup> Peers may play a unique role in SMS. For example, in an early qualitative study that used focus groups to study the challenges of behavior change, an incidental finding was that clients were interested in spending time with other people who have diabetes because they learn from one another.<sup>50</sup>

A handful of review articles have been written about peer SMS in general, including a Cochrane review of peer SMS in a wide variety of chronic conditions.<sup>51</sup> The authors found that, similar to non-peer SMS, there have been only modest short-term benefits due to peer SMS interventions. However, physiologic benefits were potentially confounded by the breadth of diseases included in the analysis. A disease-specific review of peer SMS aimed at improving psychosocial adjustment in cancer patients found that there was a high level of satisfaction with



peer SMS programs; however, evidence for psychosocial benefit was mixed.<sup>52</sup> The results were more straightforward in a review of peer SMS in heart disease, which demonstrated positive effects such as higher levels of self-efficacy, improved activity, reduced pain, and fewer emergency room visits.<sup>53</sup>

Although peer SMS in diabetes is still an emerging field of research, a couple reviews have attempted to compile relevant studies and reports. A 2009 review by Brownson and Heisler focuses on the six essential roles that peers play in SMS: 1) access to regular, high-quality clinical care; 2) an individualized approach to assessment and treatment; 3) patient-centered collaborative goal setting; 4) education and skills training; 5) ongoing follow-up and support; and 6) linkages to community resources.<sup>54</sup> It is worth noting that it is these characteristics of an intervention that best define a peer SMS program, given that the terminology for peers remains unstandardized in the literature, as suggested by a World Health Organization consultation from 2007:

Lack of specificity in terminology has led to some degree of confusion about the effectiveness of peer support interventions. The published literature contains a range of terms for peer support interventions, including for example: diabetes education and self-management; expert patient programmes; lay health workers in primary and community health care; and self-management education programmes by lay leaders.<sup>55</sup>

Finally, a systematic review by Funnell in 2010 begins by discussing some of the behavior-change strategies mentioned above, and then provides examples of their use in peer-based SMS programs in diabetes.<sup>56</sup> She finds that, with proper training in communication and behavioral health strategies, peers can fill the need for SMS both effectively and economically. That said, she acknowledges the variability in intervention outcomes, which may be the result of the lack of understanding about which models of peer SMS are most effective and whether strategies are more effectively implemented by professionals or peers. The differences between countries and cultures further complicate the findings of studies of peer SMS. Lastly, she acknowledges the lack of consensus about the behavioral strategies used by peers, as well as the training and supervision of peers. The training of peer educators is further elaborated in an overview of training curricula for peer community health workers.<sup>57</sup>

The following section describes some of the innovative models of peer SMS currently in development and presents studies that have begun to elucidate the different options for primary care clinicians as they seek to integrate peers into their practice.

#### **IV. Models of peer SMS in diabetes**

The following section describes each of the leading models for integrating peer SMS into primary care, as well as study results that back peer SMS as a viable, low-cost intervention with the potential of helping individuals with diabetes. Peer SMS models include one-on-one meetings with peer coaches, face-to-face support groups, community health workers, and remote programs via telephone, web, or email.<sup>58</sup> While professionally-led group meetings can provide a forum for patient-patient interaction and SMS, this paper will focus on the programs that require training of peers.

## *Peer coaches*

One of the earliest descriptions of peer coaching equates chronic care coaches to coaches in sports, music, and the arts, and argues that healthcare is a fitting context for such a one-on-one approach.<sup>59</sup> In fact, the idea of training diabetes patients to offer one-on-one advice to other patients dates back as far as the early 1980's; however, "society at large was not prepared to accept the use of lay advisors."<sup>60</sup>

Times have changed. Peer coaches, also known as peer advisers, counselors, or mentors, represent one of the most exciting models for peer SMS, and they are the focus of this thesis. Preliminary studies in the U.S. have shown that peer coaching may be especially well suited to minority groups, who may have a mistrust of mainstream health systems.<sup>55</sup> As Heisler explains in her review, peer coaches offer

a more informal, flexible means of providing peer support for patients with diabetes and other chronic conditions.... Peer coaches meet one-on-one with other patients to listen, discuss concerns and provide support. Peer coaches are usually individuals who have successfully coped with the same condition or surgical procedure and can be positive role models. These coaches usually receive from 8 to 32 hours of initial training. The training focuses on communication skills, including empathic listening, helping participants clarify their values and life goals, problem solving and assertiveness. Teaching the skills necessary to support patients is emphasized, rather than having the mentor try to assume the role of a health care provider.<sup>61</sup>

According to the same review by Heisler, there are very few rigorous published evaluations of peer mentor programs in general, and no studies to date have rigorously evaluated the effect of peer coaching on health outcomes in adults with diabetes.<sup>61</sup> This relative absence of peer coach studies in the literature is also described in a review that aims to determine if peer coaching assists diabetes patients to make the correct diet and activity choices.<sup>62</sup> They report that peer SMS is indeed helpful for people who are struggling to cope with diabetes, and that a structured follow-up program should follow.

Peer coaching for diabetes patients has not been studied in an RCT, although some studies in the context of other chronic illnesses have demonstrated the potential utility of peer coaches. An RCT of the effect of peer counselors on smoking cessation among pregnant mothers, for example, showed a decrease in number of cigarettes smoked and subsequent improvement in birth weight.<sup>63</sup> Peer coaches in congestive heart failure were able to improve self-care in the intervention group, although there were no differences in readmissions, length of stay, or cost.<sup>64</sup> Additionally, an RCT of peer mentors discussing end-of-life decision-making for dialysis patients showed improvement among African-American patients (but not whites) in completing advanced directives, as well as improving the participants' well-being and anxiety.<sup>65</sup> These results demonstrate the social importance of one-on-one interactions, and they suggest that cultural differences may affect approaches to specific populations (i.e. oral tradition may be more effective among African-Americans, while written materials may be more effective for whites).

Additional related research includes a mixed-methods study showing benefits of peer-led dancing on HbA1c, blood pressure, and body fat.<sup>66</sup> Focus groups done as part of that study

described peer support as a source of “camaraderie, enjoyment, and laughter,” which fostered attendance. Another RCT of peer coaches compared to specialists found that trained patients were as effective in imparting knowledge to their peers as specialist health professionals.<sup>67</sup> Finally, an RCT by Heisler et al. examined reciprocal peer support, which involves pairing a diabetes patient with another age-matched peer patient, and training both of them to offer peer SMS to each other.<sup>68</sup> Compared to nurse care management, reciprocal peer support resulted in a 0.81% improvement among patients with a baseline HbA1c greater than 8%, although no differences were seen in blood pressure, self-reported medication adherence, or diabetes-specific distress.

Despite all of the evidence that supports peer coaching, this model is often discussed as the unproven model in the literature.<sup>55</sup> Therefore, the peer coaching study coming from Heisler’s group is highly anticipated, as its pilot study showed that it is feasible to train coaches.<sup>69, 70</sup> Peer coaching is also the focus of the Peers for Progress program undertaken by the UCSF study associated with this thesis.<sup>71</sup>

### *Peer-led group programs*

In her review of models for peer SMS, Heisler describes face-to-face group SMS as

programs that combine discussion on key self-management issues participants are facing, peer exchange and support and behaviorally based approaches to strengthen participants’ diabetes care self-efficacy, problem solving skills and efforts to set and follow through on specific behavioral goals.... In these programs, the leader serves primarily as a facilitator with participant-defined agendas.<sup>61</sup>

One of the pioneers of peer-based SMS is Kate Lorig, who runs the Chronic Disease Self-Management Program (CDSMP) at Stanford. The CDSMP is a peer-led group education program for diabetes, as well as multiple other chronic diseases. A longitudinal 2-year follow-up of an RCT of the CDSMP showed that diabetes patients had improved perceived self-efficacy to manage their disease, as well as decreased hospital and emergency room visits.<sup>72</sup> A subsequent study at the CDSMP was an RCT for diabetes, as well as heart & lung disease, which showed that at both 4 months and 1 year after the intervention, participants demonstrated improved health status, health behavior, and self-efficacy.<sup>73</sup> More specifically, an RCT of the CDSMP peer-led groups showed improvement at 6 and 18 months in HbA1c, health distress, hypo- and hyperglycemia symptoms, and self-efficacy.<sup>74</sup> This study also showed improved patient communication with physicians.<sup>74</sup> Most recently, the CDSMP diabetes peer-groups showed improvements at 6 months in depression, hypoglycemia symptoms, physician communication, healthy eating, reading food labels, patient activation, and self-efficacy, but not HbA1c.<sup>75</sup>

Additional studies have corroborated the findings at the CDSMP. A review of peer-led group-based training for diabetes self-management strategies shows that this model is effective in improving fasting blood glucose levels, HbA1c, and diabetes knowledge and reducing systolic blood pressure, body weight and the need for diabetes medication.<sup>46</sup> Specific examples include an informal case study of a volunteer peer group program for diabetes at Leesburg Regional Medical Center in Florida, which shows improved HbA1c as well as better adherence to daily SMBG, annual lipid profiles, and annual foot and eye exams.<sup>76</sup>

However, some less encouraging findings have been published as well. For example, an RCT of peer groups in Ireland found no significant changes at two years in HbA1c, blood pressure, total cholesterol, or well-being.<sup>77</sup> This conflicting data demonstrates the importance of further studies, such as the RCT of a peer group intervention aimed at assessing health outcomes, cost-effectiveness and qualitative data,<sup>78</sup> and the peer group program in English and Spanish for a diverse, urban, low-income population.<sup>79</sup>

### *Community health workers*

Community health workers (CHWs), also known as *promotoras*, are one of the better-described models of peer SMS. Heisler describes them as follows:

CHWs are community members who work as bridges between their ethnic, cultural and geographic communities and health care providers to promote health, usually among groups that have traditionally lacked access to adequate health care. Community health workers traditionally have not necessarily had diabetes or other chronic conditions themselves, but have been peers to the populations they serve in other important respects: They often speak the language, share the culture, and come from the same communities as the patients with whom they work. Some populations are more likely than others to turn to informal health care systems, and the community health worker model may fit these populations best.<sup>61</sup>

A recent review describes the roles played by peer CHWs as supporter, educator, case manager, advocate, and program facilitator.<sup>80</sup> The programs evaluated in this review led the authors to conclude that these multidimensional peer CHWs provided culturally appropriate interventions, and they were able to link community with healthcare providers. A RCT of the peer CHW component of Project Dulce, which is a model for culturally sensitive, peer-led education for Mexican-American patients, showed that patients in the intervention group had improved HbA1c, blood pressure, and cholesterol when compared to the control group.<sup>81</sup>

A separate study describes integration of peer-led SMS into a federally qualified health center, which allowed for continual improvements of SMS services in response to patient needs. This resulted in a system of referral, follow-up, feedback, and documentation that produced consistently high-quality clinical care.<sup>82</sup>

### *Remote peer support programs*

To circumvent distance barriers, outreach via telephone, websites, and email may be an effective and cost-efficient extension of clinic-based diabetes services and face-to-face SMS training, particularly as follow-up to in-person programs.<sup>61</sup>

Telephone-based interventions are a relatively recent model for remote peer SMS, and the results of telephone-based peer SMS alone are not promising. Interviews with participants in a peer SMS telephone-based program found that interactive voice response technology is feasible and acceptable to patients.<sup>83</sup> However, Dale et al. later wrote a review of peer SMS via telephone calls, which suggests that there is a need for further studies to clarify the cost and clinical effectiveness of this model.<sup>84</sup> An RCT of telephone peer support by the same group

showed no statistically significant improvements in self-efficacy scores, HbA1c, or other secondary outcome measures.<sup>85,86</sup> There was evidence of a high level of acceptability, but some patients stated that they would have valued more information and advice. A program called New DAWN, a culturally sensitive, church-based diabetes self-management education program for African Americans, carried out an intervention with peer telephone coaches.<sup>87,88</sup> The RCT showed that short-term HbA1c was improved at 8-months, although not at 12-months, and that the intervention was well received by participants. A mixed-methods study of another peer-led telephone counseling intervention showed that physical activity behaviors remained relatively constant over the 12-week program, with only slight improvements in self-efficacy.<sup>89</sup>

Although telephone-based interventions are desirable due to their low cost, this record of poor efficacy suggests that it is not viable as a stand-alone model. Instead, it is possible that telephone calls could be better used as a follow-up strategy for a different peer SMS model. For example, further information may be gathered in an ongoing RCT of a cardiac and diabetes (non-peer) SMS program coupled with peer coach follow up via weekly phone calls.<sup>90</sup>

As an alternative to telephone-based programs, the internet is a possible forum for remote peer SMS. Lorig et al. carried out an RCT of peer internet-based coaches, which showed that at 1 year, the intervention group had significant improvements in health status compared with usual care control patients, and comparable results to the in-person peer group model.<sup>91</sup> Furthermore, the same group performed a separate RCT of peer-facilitated internet-based intervention that showed it is an acceptable model among patients, and led to improvements at 6 months in HbA1c, patient activation, and self-efficacy.<sup>92</sup>

In contrast to these findings, an early RCT of peer-led internet chat-groups showed that this forum for peer support did not improve health outcomes at 10-month follow-up.<sup>93</sup> Furthermore, an additional RCT of non-peer internet-based SMS by the same research group found that, while the minimal intervention improved healthy eating, fat intake, and physical activity, these results did not translate into changes in biological outcomes during the 4-month study period.<sup>94</sup>

### *Complex interventions*

While many studies attempt to isolate a single model of peer SMS, many interventions combine more than one feature of the models described above. For example, the program known as "The New Leaf ... Choices for Healthy Living With Diabetes" consists of recruiting and training peer coaches who partook both in peer-led group sessions and peer telephone calls aimed at increasing physical activity among diabetic patients.<sup>95</sup> Participants found this program to be culturally relevant and acceptable. An RCT of this program compared the peer group and peer telephone intervention plus 6-month reinforcement to a minimal intervention, and found that the program led to improvements in physical activity.<sup>43</sup> The program was viewed as feasible and acceptable to participants, and led to improved diabetes knowledge, mental well-being, and diabetes-specific health status. However, patients in all groups gained weight, there was little observed effect on glycemic control, and dietary intake results were undependable due to underreporting.

Another peer SMS program is called Project Dulce, which combines nurse case management with a peer-led group.<sup>96,97</sup> RCTs for Project Dulce demonstrated improved HbA1c, LDL cholesterol, total cholesterol, and blood pressure. The cost-effectiveness data for this program are extensive, and are described below.

### *Challenges of measuring outcomes*

It should be noted that many of these papers and reviews conclude with calls for further research due to uncertainty about study efficacy. For example, Brown's review of literature concludes that diabetes education and behavioral interventions are effective in improving psychosocial and health outcomes, but that more research is needed on how best to achieve these improved outcomes.<sup>47</sup> A meta-analysis of the effect of behavioral interventions on body weight and glycemic control found that modest improvements have been made in glycemic control, but that interventions and methodology need to be improved.<sup>44</sup> In a review of studies focusing on older, African-American, or Latino patients, the researchers again found that more large scale clinical trials are needed.<sup>98</sup>

This recurring theme may be due in part to the fact that SMS interventions are large-scale, complicated projects that require tremendous time and resources. Additionally, the multifactorial nature of this work makes it difficult to measure a clear cause and effect. As suggested in the systematic review by Norris, many studies may have had methodological issues that threatened internal validity, such as:

1. Lack of blinding of the assessor
2. Infeasibility of blinding study subjects
3. High attrition
4. Contamination of the control group
5. Unintended cointerventions
6. Lack of detail on allocation concealment
7. Response-set bias whereby intervention group participants report dietary and other habits that match the goals of the intervention rather than actual behavior
8. Deficits in the reliability and validity of the instruments used to measure knowledge, self-care, and dietary habits

Furthermore, it appears that program evaluations have focused too narrowly on commonly used outcome measures such as diabetes knowledge and HbA1c. It would be worthwhile to reassess how SMS is studied in order to include more process and mediating variables such as self-efficacy, problem-solving, and coping skills, as well as quality-of-life measures.<sup>99</sup>

### **V. Qualitative research**

In addition to the quantitative RCTs described above, many qualitative questions emerge. A recent systematic review of the literature of SMBG found that the qualitative literature in diabetes SMS is limited.<sup>28</sup> The following section explores the qualitative research related to diabetes, SMS and peer SMS, and gives a rationale for the choice to interview the peer coaches, rather than patients, for this thesis.

#### *Qualitative studies of SMS in diabetes*

The barriers to successful diabetes SMS are often difficult to characterize in RCTs. One study used focus groups of patients with diabetes to ask them about lifestyle changes they have

had to make, in order to better understand differences in diabetes-related problem solving. The focus group was comprised of patients who had good control over their disease described a generally positive outlook on diabetes SMS and problem solving, as well as a rational problem-solving process and a positive transfer of past experience. The group with poor control of their diabetes, on the other hand, had an overall negative impression of SMS, were careless and avoidant at problem solving, and had negative transfer of past learning to new situations. These findings, while seemingly intuitive, capture data that is relevant to shaping future clinical practice. Rather than seeing people with poor control as if they were incapable, it is important to consider each patient's background, which is one of the main challenges in SMS.<sup>100</sup>

Another important use of qualitative research is revealed in the longitudinal, in-depth interviews with 20 diabetes patients about taking oral glucose-lowering agents.<sup>101</sup> Patients themselves are best at describing their barriers to medication adherence, and unanticipated adverse effects are often identified through qualitative research. In a study of the perception of SMBG measurements, for example, two rounds of in-depth interviews with 40 patients found that performing regular SMBG revealed to patients that their diets directly affected their disease.<sup>102</sup> The authors therefore concluded that the patients' sense of success or failure may have been amplified based on their SMBG results, and that negative results could result in feelings of guilt and anxiety, thereby negatively influencing a patient's desire to continue their self-management. An additional study by the same researchers found that SMBG did not necessarily encourage patients to act on their results due to a lack of education.<sup>103</sup>

Other qualitative studies have been used as evaluations of programs. For example, interviews with 32 patients assigned to non-peer health coaches said that the coaches had enhanced their SMS by fostering caring relationships and investment in the program.<sup>104</sup> Similarly, in a non-peer CHW program with both one-on-one support and group SMS sessions, participants said that they were more confident in the patient-doctor relationships in addition to improving their diabetes self-management.<sup>105</sup>

### *Qualitative studies of peer SMS in diabetes*

Qualitative studies have been important in the development of peer SMS as well. As described earlier, in an early qualitative study that used focus groups to study the challenges of behavior change, an incidental finding was that clients were interested in spending time with other people who have diabetes because they learn from one another.<sup>50</sup> Participants in earlier stages of their disease were exposed to others who were in the maintenance phase, which led the research team to develop a peer coaching intervention to further foster such interactions. An additional qualitative study of this subsequent intervention by Joseph et al. used focus groups to assess the experiences of patients who worked one-on-one with peer coaches.<sup>106</sup> They found that participants had a positive experience from having an "outside" person take an interest in them. These results demonstrate the advantages of the accessibility and availability of peers with regard to important face-to-face contact (especially initially), checking in regularly, and learning about behavior change strategies. The coaches were also pleased to help others with diabetes.

Heisler et al. provide an additional example of a qualitative study of peer SMS. Semi-structured interviews were conducted with 40 African-American and Latino adults in Detroit who participated in a diabetes self-management program with both one-on-one support and group self-management training sessions conducted by CHWs. The study examined both the general gaps in diabetes care identified by participants, as well as how the program influenced

participants' diabetes self-management. By focusing specifically on any gaps in care that were addressed by this program, the Heisler study found that peer SMS interventions are effective in promoting more effective diabetes care and patient-doctor relationships, and may help to mitigate racial and ethnic disparities in diabetes care and outcomes.<sup>105</sup>

In addition to more standard interviews and focus groups, a wide range of qualitative methods have been employed to evaluate peer SMS in diabetes. First, open-ended interviews were combined with a phenomenologic approach to look at 4 peer facilitators of group meetings of American Indians, which found that their cultural knowledge helped them teach about type 2 DM in a culturally sensitive way.<sup>107</sup> Next, semi-structured interviews were conducted with program managers of CHW programs in order to accompany a literature review that demonstrates the benefits of CHWs.<sup>108</sup> Another study of diabetes patients helped by CHWs utilized a combination of descriptive quantitative data and qualitative interviews and found that patients viewed their CHWs as helpful in demonstrating how to incorporate diabetes self-management into their daily lives.<sup>109</sup> Patients also said that a personal connection, along with availability and provision of key resources and supports for self-management, made the CHW-patient interaction successful. Lastly, two focus groups for post-intervention data were conducted to complement an RCT about diabetes education by CHWs, which elucidated the increases in participants' perceived SMS competence, as well as the positive influence of CHWs on participants' compliance with the program.<sup>110</sup>

#### *Qualitative studies showing effect of training on providers*

While these patient perspectives are crucial, this qualitative thesis project focuses on the experiences of peer coaches themselves. As has been demonstrated by multiple recent studies, qualitative interviews with health workers have provided important insight into their experiences in training programs. Recent examples from the literature include an antibiotic prescribing intervention for general practitioners<sup>111</sup>; an essentials of critical care orientation program for nurses<sup>112</sup>; and a depression training program for caregivers of elderly care recipients.<sup>113</sup> Furthermore, the qualitative literature includes many recent studies that assess quality of the programs themselves, including a cultural competency workshop for occupational therapists<sup>114</sup>; gerontological competencies for social workers<sup>115</sup>; an externship program for nursing students<sup>116</sup>; and a breastfeeding peer counselor program that focuses on both peer counselors and participants.<sup>117</sup> These studies have provided insights into improving these training programs, which suggests that there is a clear role for qualitative assessment of peer coaching.

## **VI. Cost effectiveness**

In 2007, the estimated diabetes costs in the United States were \$174 billion, including direct medical costs (\$116 billion) and indirect costs (\$58 billion) due to disability, work loss, and premature mortality. After adjusting for population, age, and sex differences, average medical expenditures among people with diagnosed diabetes were 2.3 times higher than what expenditures would be in the absence of diabetes.<sup>6</sup> Furthermore, the mean cost of diabetes-related hospitalizations per patient was \$2,792 among those with mean HbA1c of < 7% and \$6,759 among those with mean HbA1c of  $\geq 10\%$ .<sup>118</sup>

As Bodenheimer et al. explain in their 2002 article about the chronic care model, in the case of diabetes, “programs that improve diabetic glycemic control would be expected to show



savings only throughout the long term, with reduced vascular complications”.<sup>10</sup> Nevertheless, they go on to say that “some studies have shown that improved diabetes care can save money in the short run.” Additionally, in adults with diabetes, comorbidities such as heart disease, hypertension, and depression, more strongly predict future costs than the HbA1c level.<sup>119</sup> Therefore, management of these comorbidities is necessary to control health care costs in adults with diabetes.

SMS is a cornerstone of diabetes maintenance and prevention of complications. This section aims to summarize the cost-effectiveness arguments for SMS in general, and then focus on the studies of peer SMS that included a cost-effectiveness component.

### *Cost-Effectiveness of SMS*

A recent review of economic benefits and costs associated with diabetes education shows that a majority of current research associates diabetes education and SMS with decreased cost<sup>120</sup>. They go on to say that overall, the benefits associated with education on self-management and lifestyle modification for people with diabetes are positive and outweigh the costs associated with the intervention. Nevertheless, more research is needed to validate that diabetes education provided by diabetes educators is cost-effective.

In one study of cost-effectiveness, a simulation model was used to estimate the long-term effects of self-management interventions in real-world community primary care settings.<sup>121</sup> The intervention was estimated to reduce long-term complications, leading to an increase in remaining life-years and quality-adjusted life-years (QALYs). The incremental cost-effectiveness ratio was estimated at \$39,563/QALY, well below a common benchmark of \$50,000/QALY for cost-effectiveness. Although a reduction of \$3385 in treatment and complication costs was more than offset by the \$15,031 cost of implementing and maintaining the intervention, it was the projected QALYs that predicted acceptable cost-effectiveness ratios for these diabetes SMS programs. These findings suggest that SMS programs for diabetes are cost-effective from a long-term health systems perspective, and therefore justify increased reimbursement for effective SMS programs in diverse settings.

Lastly, a study of Medicaid recipients found that group SMS resulted in an estimated savings in diabetes-related cost over 3 years of \$415 per program participant.<sup>122</sup> They go on to suggest that SMS can reduce health care use among Medicaid recipients with diabetes within one year, and that further reductions in costs may be associated with lower long-term utilization of health care. Similarly, an RCT of a telephone SMS program led by nurse care managers within a population of Medicare Advantage users found that the intervention group had decreased all-cause hospital admissions, diabetes-related hospital admissions, and all-cause and diabetes-related emergency department visits.<sup>123</sup> This resulted in a decrease in all-cause total medical costs of \$984.87 per participant per year compared with a \$4547.06 increase in the comparison group.

### *Cost-Effectiveness of peer SMS*

Many of the efficacy studies of peer SMS described above include basic descriptive data about the costs of the models, but rigorous cost-effectiveness analyses of peer SMS are limited. The results presented here focus on the peer group model, which is the only peer SMS model to

have substantial data on cost-effectiveness. Just as with the general studies of SMS, there have been multiple measures used to assess the economic benefit of peer SMS.

In the program at Leesburg Regional Medical Center in Florida, cost containment results show that total professional costs are approximately \$27 per participant for services provided over the 3-year intervention.<sup>76</sup> In another RCT of a lay-led self-care group for patients with a wide range of self-defined long-term conditions, the intervention group experienced better patient outcomes at slightly lower cost than the control group, as measured by improved QALY.<sup>124</sup> These findings suggest that peer groups would be considered very likely to be cost effective when compared with treatment as usual.

The Project Dulce program, which combines nurse case management with peer groups, showed that expenditures were increased overall due to higher pharmacy utilization and program expenditures, but that hospital and emergency room expenditures were lower due to decreased admission.<sup>97</sup> An additional study of Project Dulce found that QALYs were improved and diabetes-related complications were decreased, which may be particularly effective in low-income populations.<sup>125</sup>

Lastly, in the case of the CDSMP at Stanford, Lorig et al. report basic cost-effectiveness measures by using hospital and emergency room visits as a proxy for health care expenditures. In the longitudinal follow-up study, reduced ER and outpatient visits resulted in two-year savings of \$590 per participant, which exceeded the program cost of \$70 to \$200 per participant.<sup>72</sup> The subsequent RCT of diabetes, heart and lung disease showed that at both 4 months and 1 year after the intervention, participants had fewer emergency room visits.<sup>73</sup> The most recent study also found that at 6 and 18 months, participants had fewer emergency room visits.<sup>74</sup>

## **VII. Conclusion**

The potential for widespread implementation of SMS programs continues to grow as research studies further validate its efficacy. As demonstrated by the quantitative, qualitative, and cost-effectiveness literature described above, the effects of peer SMS have been studied extensively, save for a couple of missing pieces such as an RCT of peer coaching. Collecting these results is fundamental to the goals of encouraging adoption of the CCM among providers, as well as bringing effective behavior change programs to patients with chronic illness.

Expanding these disease management programs and strengthening primary care are crucial to reducing healthcare expenditures, particularly because these cost containment measures connect closely with physicians themselves, who should play a central role in addressing the cost crisis in the U.S. health care system.<sup>126</sup> For now, the ball is in the court of the medical establishment to implement these programs, for it is the responsibility of providers to educate and activate their patients about their disease.<sup>14</sup> Physician-led solutions in primary care redesign, such as implementing the PCMH and the CCM, can lay the foundation for broader systemic reforms aimed at transforming the organization and delivery of health care in the United States.<sup>127</sup>

Fortunately, research continues to move forward as peer SMS becomes more politically relevant. The Patient Protection and Affordable Care Act (PPACA) of 2010 endorses peer-support programs by including CHWs among the integral components of the nation's health care workforce.<sup>128</sup> Section 399V of the Act approves "grants to promote positive health behaviors and outcomes for populations in medically underserved communities through the use of community health workers."<sup>129</sup>

This funding source coincides well with the call to arms by the W.H.O. in their report on peer support programs in diabetes.<sup>55</sup> This W.H.O. consultation resulted in Peers for Progress, a global initiative of the American Academy of Family Physicians aimed at promoting best practices in peer SMS on an international scale.<sup>130</sup> The four papers published in the journal *Family Practice* in 2010 lay the groundwork for peer SMS,<sup>56,60,130,131</sup> including Fisher's piece about challenges to, and strategies for, implementing peer SMS programs internationally, given different cultural considerations. Multiple studies are ongoing in pursuit of the better defining strategies for peer SMS as outlined by the Peers for Progress initiative.<sup>132</sup>

In the Bay Area, the Center for Excellence in Primary Care at the UCSF Department of Family and Community Medicine has implemented the Peers for Progress program in order to fill the gap in the research with regards to an RCT on peer coaching. A peer coaching program was established in which approximately 25 peer coaches were paired one-on-one with 150 patients during a six-month-long intervention. Clinical values (HbA1c, LDL cholesterol and blood pressure) and self-reported diabetes self-efficacy and self-care activities were measured at baseline and after 6 months for coaches and patient participants, in addition to 150 patients in a control group. The primary outcome is change in HbA1c, while secondary outcomes include change in systolic blood pressure, body mass index, LDL cholesterol, diabetes self-care activities, medication adherence, diabetes-related quality of life, diabetes self-efficacy, quality of life, and depression. Changes in hospital admissions and emergency room visits are used as a measure of cost savings.<sup>71</sup> The quantitative data for this study are forthcoming.

The Peers for Progress study at UCSF is also the subject of this thesis, which focuses on the qualitative analysis of peer coaches' perspectives. Given the well-established qualitative literature focusing on patient experiences in peer SMS interventions, the study team decided to focus on the perspectives of the peer coaches themselves, given their unique and previously undocumented perspectives as both providers of SMS and as patients. These semi-structured interviews are aimed at revealing peer coaches' views on program efficacy, challenges to success, the role of the peer coach with regard to patients and to the clinic team, and feedback on the training curriculum. The results of this qualitative study are described in the original research section to follow.

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**ORIGINAL RESEARCH**

## Introduction

Peer coaching has gained acceptance as a potential solution for improving diabetes self-management. The World Health Organization (WHO) recently endorsed further development of diabetes peer coaching programs as part of a global initiative called Peers for Progress.<sup>1</sup> This momentum is based on evidence that self-management support (SMS) can improve diabetes outcomes,<sup>2</sup> yet is not consistently provided by primary care clinicians due to insufficient time.<sup>3</sup> SMS may be provided by trained health care workers such as registered nurses, pharmacists, medical assistants, or other non-clinicians, but SMS can also be offered by lay people, often referred to as peers, who are patients trained to provide diabetes education and support to other patients.<sup>4,5</sup> Patients with diabetes are motivated to interact with other diabetes patients because they can learn from one another, which creates a unique role for peers in SMS.<sup>6</sup>

The Peers for Progress initiative promotes one-on-one meetings between patients and peer health coaches (PHCs).<sup>7</sup> PHCs are also known as peer advisors, counselors, or mentors. They can meet with fellow patients in the community or in the clinic to discuss shared experiences of living with diabetes, and to give advice about diet, exercise, stress reduction, and medication adherence. However, a fundamental question about diabetes peer SMS remains unanswered: *what exactly does a PHC do in practice?*

PHCs in other diseases have been studied,<sup>8-10</sup> as well as non-PHC diabetes peer SMS programs such as reciprocal peer support,<sup>11</sup> community health worker activities outside the medical practice,<sup>12</sup> and remote programs via telephone,<sup>13</sup> web, or email.<sup>14</sup> However, no studies have quantitatively evaluated the effect of one-on-one peer coaching on health outcomes in adults with diabetes.<sup>15</sup> Furthermore, a literature review has found that previous qualitative studies of peer-based diabetes SMS have focused on patient participants but not on the perspectives of the peers themselves.<sup>16-18</sup> While many qualitative studies have characterized the motivators and challenges to success among PHCs,<sup>16,19-21</sup> qualitative methods have not been used to develop a model for the roles and interactions of PHCs in practice.

Due to this lack of qualitative research on diabetes PHCs, the roles for PHCs have been described from the perspectives of researchers. For example, a literature review of peer SMS by Brownson and Heisler found six essential roles assigned to peers: access to regular, high-quality clinical care; an individualized approach to assessment and treatment; collaborative goal setting; education and skills training; ongoing follow-up and support; and linkages to community resources.<sup>22</sup> Dennis' concept analysis of peer SMS in health care settings recognizes three main types of support: informational, emotional, and appraisal.<sup>23</sup> These roles are prescribed duties assigned by researchers rather than the PHCs' own descriptions of their activities.

This study proposes a qualitatively derived model that gives insight into the experiences of PHCs working in a low-income community-based setting. By learning from the perspectives of PHCs, this primary care innovation may be better implemented in the future.

## Methods

### *Description of the intervention*

This peer coaching program was developed at the Center for Excellence in Primary Care in the UCSF Department of Family and Community Medicine in conjunction with the Peers for Progress WHO global initiative.<sup>7</sup> The study protocol of this randomized controlled trial (RCT),

comparing peer coaching with usual care for patients with diabetes, is described elsewhere.<sup>24</sup> PHCs were low-income English and Spanish speaking patients who receive primary care at one of five San Francisco Department of Public Health clinics. Patients who were candidates to be trained as PHCs needed to have a HbA1c less than or equal to 8.5 percent, considered the cutoff for good glycemic control. They were referred to the study by their physicians or the clinic diabetes team. Candidate PHCs underwent a 36-hour-long training session about diabetes SMS techniques. Those passing the course were considered to be PHCs. PHCs met monthly with the program director (AG) to discuss problems and receive refresher training during the course of the study. Patients randomized into the peer coaching group chose their PHC out of a photo book. PHCs were expected to meet with patients once every two months during the 6-month intervention and to make phone contact every other week. PHCs were also required to attend at least one physician visit with each patient. PHCs were compensated \$150 for completing the training and \$25 per month for each patient they were actively coaching (maximum of seven patients at any one time). Approval to conduct this study was granted by the Committee on Human Research (Institutional Review Board) at the University of California, San Francisco.

### *Participants*

Eligible participants were the 21 PHCs who passed the training and who were assigned patients prior to the interviews. The four most experienced English-speaking PHCs were purposively recruited for the focus group. Four PHCs dropped out during the course of the study; all of the remaining seventeen PHCs, including three of the four PHCs from the focus group, were purposively recruited to participate in the qualitative interviews. Two of the PHCs who were interviewed dropped out of the study later on.

### *Data collection*

An open-ended focus group of four PHCs was held to reveal general attitudes and to inform the development of the interview guide. Semi-structured interviews, between 35-75 minutes in length, were then conducted with seventeen PHCs in English or Spanish. After each interview, the interview guide was revised in an iterative process. The interview guide included questions about how PHCs define SMS; the PHCs' roles with regard to the patients and the clinical team; and how participation in the program affected the management of their own diabetes. There was sufficient commonality in the data to indicate that thematic saturation had occurred (i.e. no new themes were identified). PHCs were compensated \$20 for their participation in the qualitative study. Sociodemographic data were collected with a quantitative survey as part of the RCT.<sup>24</sup> To reduce social desirability bias, the interviewer (MLG) was not involved in the RCT study, and the PHCs were assured that their responses would remain anonymous.

### *Data analysis*

The focus group and interviews were audio recorded and transcribed. Spanish interviews were analyzed in Spanish and translated only for publication. Using methods based on grounded theory, transcripts were encoded with AtlasTI qualitative data analysis software. A preliminary round of descriptive coding was performed inductively to develop a basic vocabulary of the data

and to identify major themes, as outlined by Miles and Huberman.<sup>25</sup> Interrelations were then conceptually mapped to develop the theoretical model. The codebook and model were workshopped during meetings between MLG and the other authors. The codebook was also presented to the PHCs as a way of verifying the analysis. Quotations are presented without specific demographic characteristics in order to protect anonymity.

## Results

### *Description of the sample*

The mean age of the group of PHCs was 60 years (range 47-80, SD=8.5). Additional demographic data are presented in Table 1. Only one of seventeen PHCs had not yet met with any patients at the time of the interview. Among the other sixteen PHCs, the mean length of time from the first patient assigned to a PHC to the time of the interview was 120 days (range 55-229, SD 50.8), and the mean number of patients that each PHC had been assigned was five (range 1-9, SD 2.4).

### *Qualitatively derived model*

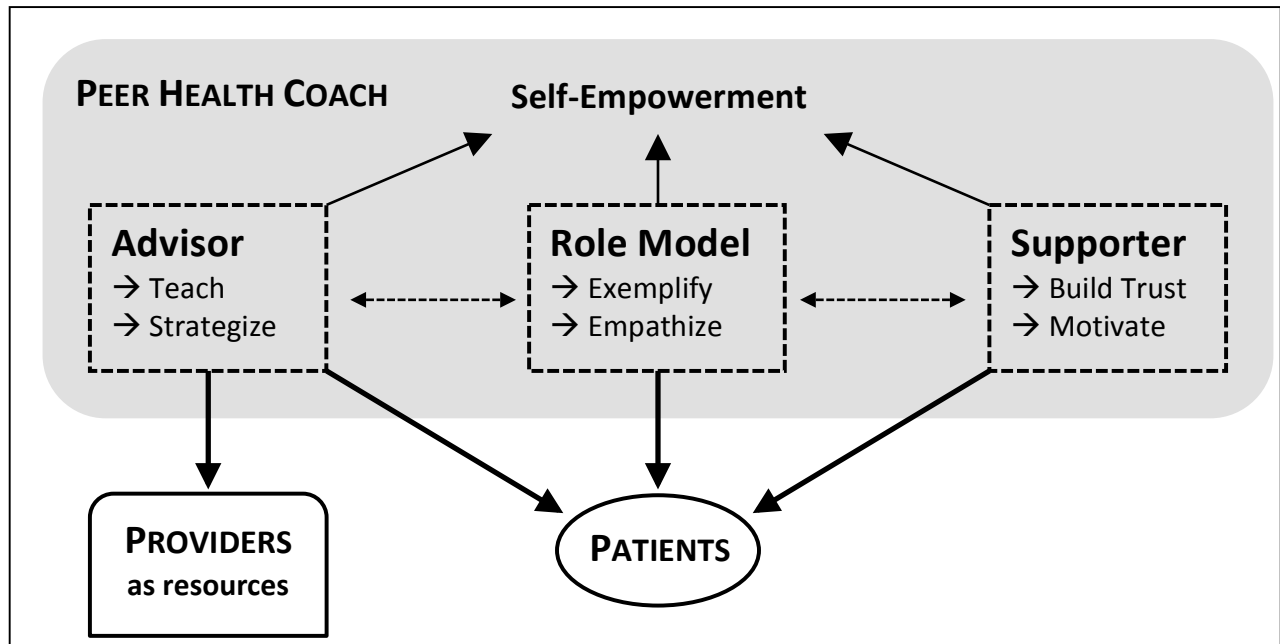
The following model represents the roles and interactions of diabetes PHCs working with patients in a community-based primary care setting (Figure 1). We begin by defining the three principal PHC roles based on the PHCs' descriptions of their activities.

Next, we present how PHCs interacted with patients and providers within these roles. Finally, we demonstrate how these experiences led the PHCs to become empowered in managing their own diabetes. These roles and interactions are explained below with illustrative quotations from the PHC interviews.

**Table 1.** Peer health coach demographics.

	Number of PHCs	%
<b>Sex (n=17)</b>		
Male	5	29.4
Female	12	71.6
<b>Self-reported race/ethnicity (n=17)</b>		
White/Caucasian, non-Hispanic	3	17.6
Latin/Hispanic	6	35.3
Black/African-American	5	29.4
Asian/Pacific Islander	1	6.9
Native American	1	6.9
Multiracial	1	6.9
<b>Education level (n=17)</b>		
Did not graduate high school	2	11.8
High school graduate or "GED"	4	23.5
Some College	4	23.5
College graduate	7	41.2
<b>Employment status (n=17)</b>		
Full-time paid (>30 hours/week)	3	17.6
Part-time paid (<30 hours/week)	3	17.6
Retired	6	35.3
Unemployed	3	17.6
Disabled	2	11.8
<b>Annual income (n=16)</b>		
Less than \$5000	5	31.3
Between \$5000-10,000	2	12.5
Between \$10,000-\$20,000	7	43.8
More than \$20,000	2	12.5





**Figure 1. Qualitatively derived model for functions of PHCs in practice.** The main roles of PHCs (in dotted boxes) include an advisor who teaches and strategizes, a supporter who builds trust and motivates, and a role model who incorporates personal experience in order to exemplify and empathize. PHCs had variable approaches to setting boundaries with patients in their roles as advisor and supporter with regard to health behaviors and emotional issues, respectively. PHCs were more consistent in how they sought resources from providers. PHCs became self-empowered to better manage their own diabetes during their work.

*PHC roles*

The PHCs described activities that fell into three principal roles in their provision of SMS: *advisor*, *supporter*, and *role model*. The advisor role focused on patients' health behaviors in order to implement diabetes self-management. The supporter role encompassed the emotional aspects of connecting to patients. As role models, the PHCs incorporated their personal experience into their interactions with patients.

ADVISOR

Among many duties that PHCs fulfilled, the advisor role encompassed the aspects of their work related to modifying health behaviors. *Teaching* activities included providing medical knowledge, answering questions, and referring patients to resources. *Strategizing* focused on how PHCs actually implemented SMS techniques in their patients' lives.

All seventeen of the PHCs said that they spent time teaching. A majority of PHCs shared information about medications with their patients, and many taught about diet and blood sugar—both self-monitoring of blood glucose and the meaning of HbA1c. Other topics included exercise and diabetes risk factors such as high cholesterol, high blood pressure, and stress.

*I'd be like a teacher, an instructor, teaching them the good things about the diabetes and the bad, and helping them also with their menus, their food choices. Tell them what is good and what is bad and how big the portions should be.*

The other aspect of the advisor role was the time many PHCs took to strategize about how to incorporate these lessons into their patients' lives. Some of the main strategies from the training were described, including making an action plan, using medication reconciliation, planning for future doctor visits, and checking in with patients to track progress.

*A peer coach is someone who assists you with working out your challenges with your diabetes. So - getting you an action plan and helping you learn your medications, your exercise, and your diet.*

In acting as advisors, PHCs dealt with the informational and practical elements of providing SMS to their patients. These health behaviors were the focus of the training curriculum, and there was a consensus among PHCs that advisory functions were a core tenet of their work.

#### SUPPORTER

While the advisor role focused on health behavior change, the supporter role encompassed the emotional aspects of PHCs' interactions with patients. In order to make patients feel comfortable enough to discuss their diabetes, many PHCs felt it was necessary to *build trust* with patients by cultivating rapport and fostering friendship. PHCs also tried to *motivate* patients by giving reassurance and empowering them to use self-management techniques independently.

Almost all of the PHCs said that they began most interactions by discussing their patients' personal lives, which was the principal way of building trust.

*The first thing you have to do is try to earn their friendship, their trust ... so that they feel confident in you. They can reveal everything, because when they don't have trust, they don't see the coach as a friend, and they're not going to come out with everything.*

The PHCs said they were able to establish rapport with patients by listening carefully, being honest, staying positive, and showing compassion. Many PHCs said that their availability was important in building trust, especially since most doctors cannot be so openly accessible.

*We can develop a relationship with and sit with them, where when something happens that may be hurting them, with that problem, they can call us where they wouldn't call the doctor.... So that's a thing we can do that makes us - as far as I'm concerned - invaluable. Because if I had a peer coach thirteen years ago, I'd probably be cured.*

With regard to motivating patients, many PHCs said it was important to encourage patients to follow through on their strategies for diabetes self-management. There was a broad range of tactics that PHCs employed to motivate their patients, such as emphasizing that it is possible to live with diabetes for a long time, and staying optimistic and persistent.

*To make them aware that it's a disease that can be taken care of, I tell my patients, "Look, you have to learn one thing: That those who are diabetics can last a long time if we are obedient about our medications and diet."*

Additionally, some PHCs stressed that the knowledge that patients gained from coaching was itself a form of empowerment.

*Lack of knowledge makes a man ignorant. So if he knows how to do a certain thing and doesn't do it, that's on him. But after he learns how to do something, and he follows the directions and he sees the results, he can live like this for the rest of his life and never worry about that anymore.*

By engaging with patients on an emotional level to varying degrees, many of the PHCs felt they were more successful at providing support.

## ROLE MODEL

While many PHCs described their activities in terms of lessons and techniques acquired during their training, they also brought personal experiences to their work in these advisor and supporter roles. As role models, PHCs *empathized* with patients by sharing their experiences and lessons learned. They also *exemplified* their own healthy behaviors by demonstrating self-management strategies that have worked for them.

A majority of PHCs said they empathized with patients by bonding over shared experiences and by understanding their patients' struggles.

*Sometimes I tell them about my disease – I tell them that I also have diabetes, and that I also do the same things that I'm explaining to them... that I'm like them. Then they say, "Oh good," and they say, "That's good because this way we can gain your experience."*

Although many experiences were mutual, some PHCs acknowledged that they did not necessarily have the same experiences as their patients. The few PHCs who went so far as to exemplify healthy behaviors would exercise or share foods with patients, with many saying they were motivated to "practice what you preach."

*Someone asked me, say, "Why are you walking so much?" I said, "Because I'm gonna practice what I'm gonna be preaching. I'm not gonna tell some guy to walk three days a week if he can make it to that, and I can't walk three." You see? I want to be able to do what I'm telling you to do.*

## *Dynamics of PHC interactions*

Within these primary roles, PHCs interacted with both patients and providers. Each PHC independently determined the dynamics of these interactions. With patients, the PHCs varied in the extent to which they were *setting boundaries*, both in their advisor and supporter roles. In contrast, the PHCs were consistent in how they depended on *seeking resources* from providers when their patients needed assistance beyond their expertise. Finally, many PHCs said their experiences initiated a process of *becoming empowered* to better manage their own diabetes.

## SETTING BOUNDARIES

PHCs differed in their approach to setting appropriate boundaries with patients. In their capacity as advisors, there was a wide range of how much responsibility the PHCs allocated to their patients versus to themselves towards the goal of keeping their patients engaged in the process of health behavior change. Some PHCs tried actively to convince patients to adhere to their plans, while other PHCs maintained that diabetes is a self-help disease.

*Diabetes is primarily a self-help disease. The doctor can only tell you what you should do. He can't do it for you. I can only tell you what you should do. I can't do it for you. Ultimately it's all up to you. Either you do it or you don't.*

When acting as supporters, PHCs varied greatly in their openness to discussing emotional issues with their patients, with some avoiding such private matters and others becoming deeply invested in their patients' lives. A majority of PHCs said they were open to personal topics.

*And tell them a little bit about yourself, so that ... you build up a friendship with this person. But you gotta know where the line is ... where it's not too personal, but personal enough. That's the key thing.*

Conversely, some PHCs said they were not sure how to deal with emotional issues that arose, or they avoided them altogether.

*I'm not used to being around anybody who's depressed.... What are you gonna do? Cause that's something above and beyond what we get any kind of training.*

Each PHC had their own style of coaching, as can be seen in their different approaches to acting as advisors and supporters while interacting with patients. Despite sharing an identical training curriculum, this lack of consensus suggests that personal factors play an important role in coaching dynamics.

## SEEKING RESOURCES

In contrast to their work with patients, the dynamics of the PHCs' interactions with providers were mostly consistent throughout the group. Providers included the patient's or the PHC's physician and clinical care team, as well as the Peers for Progress program staff. Many PHCs expressed caution about only sharing information in which they were confident, stating that when they did not know how to answer a question or how to approach a situation, they would ask for help or refer patients to their providers.

*I shouldn't be able to do more than what they trained me to do.... So certain things I just refer them to the clinic, or to the advice nurse, or check on it for you and get back with you. I don't go farther than what I know.*

Furthermore, there were a couple of cases in which the patient's personal issues went beyond the scope of the PHC's training, and professional help was sought.

*One of my clients ... was real depressed.... And I contacted [the social worker] at our clinic ... and I said, "I don't know what to do, she is so depressed." And I had asked my client, "Do you need someone to talk to besides me?" And she told me, "Yes."*

The PHCs' consistent approach to contacting providers suggests that they maintained a sense of the limits of their knowledge and abilities, which was emphasized during their training.

## BECOMING EMPOWERED

In addition to motivating their patients, PHCs themselves were empowered by their work. They were motivated to join the program by multiple factors, including altruism.

*I gave them tools they needed, and I've seen their enthusiasm.... It made me feel proud.... This is my passion, doing this! So it makes me very fulfilled.*

PHCs also had a personal interest in learning more about diabetes.

*And it helps me, too, to also know more correct information, because even now I don't know everything about it. I learn things about myself even on it.*

Most of the PHCs said that being in the program led to an improvement in their diabetes self-management, while a couple said their health declined due to personal circumstances.

*I have some pretty good clients. They help me, too, you know. I'm telling you, it works both ways. Whether they know it or not, they're peer-coaching me, too.*

Thanks to becoming empowered, many of the PHCs drew upon their training with family and friends, as a community resource, and with patients beyond the completion of the program. Some PHCs even described ambitions to expand the program.

*Being a peer coach, I think, is a great thing. I think some of the other diseases also need coaches - like people with high blood pressure .... If I'd had a coach from the very beginning, when I got the diabetes, I would have been able to control mine much better.*

## Discussion

In this qualitative analysis, PHCs' descriptions of their experiences with patients and providers give insight into working as a PHC. In addition to answering the question of *what* PHCs do, this model begins to explore *how* the PHCs acted in their roles as advisors, supporters, and role models. For example, each PHC had a different style of engaging patients as advisors. PHCs differed in whether they interpreted SMS as allocating responsibility more to their patients or to themselves. Some PHCs assigned most of the responsibility to their patients to implement their health behavior changes, while others regularly contacted their patients and urged them to succeed. These findings point to the inherent variety of personalities among peers, which may introduce both desirable diversity and complicated inconsistencies into peer coaching programs.

Similarly, in dealing with emotional issues while acting as supporters for patients, a majority of PHCs were willing to engage because they saw these topics as an opportunity to build trust. Nevertheless, a few PHCs did not feel comfortable discussing personal matters. The

interpersonal challenges of peer SMS in diseases other than diabetes are well known,<sup>19-21</sup> but the variability within this small group of diabetes PHCs, all of whom received the same training, suggests that personal preferences are an important factor, albeit an unpredictable one.

In contrast to their interactions with patients, the PHCs described less variability with regard to providers. Previous studies have raised concerns regarding the extent of a PHC's role, stating that peer providers of SMS are not professionals and should not dispense medical advice.<sup>3,26</sup> The analysis of the dynamics of interactions between PHCs and providers found that PHCs were well aware of their limitations and that they were careful to seek resources from providers whenever necessary.

The PHCs' descriptions of becoming empowered were overwhelmingly positive. As with PHCs providing SMS for heart disease,<sup>19</sup> these PHCs were highly motivated by a spirit of altruism. They benefitted from health education that they had never received as patients, resulting in their feeling more confident about managing their own diabetes. They then shared their lessons not only with the patients assigned by the study, but also with their families and communities.

### *Limitations*

Although all PHCs active at the time of the study participated in the interviews, this study did not include a later cohort of three PHCs as well as the four PHCs who dropped out prior to the interviews and may have had negative experiences in the program. Social desirability bias may have been a factor in the PHCs' responses. Finally, these findings are specific only to this group of diabetes PHCs working in a low-income primary care setting and cannot be generalized to all peer coaching contexts.

### *Implications*

Figure 2 suggests that many people on the spectrum from layperson to provider can fill some of the PHCs' main roles, but that only PHCs seem to satisfy all three at once. In order to reincorporate SMS into primary care, PHCs can fill this gap in the health care team.

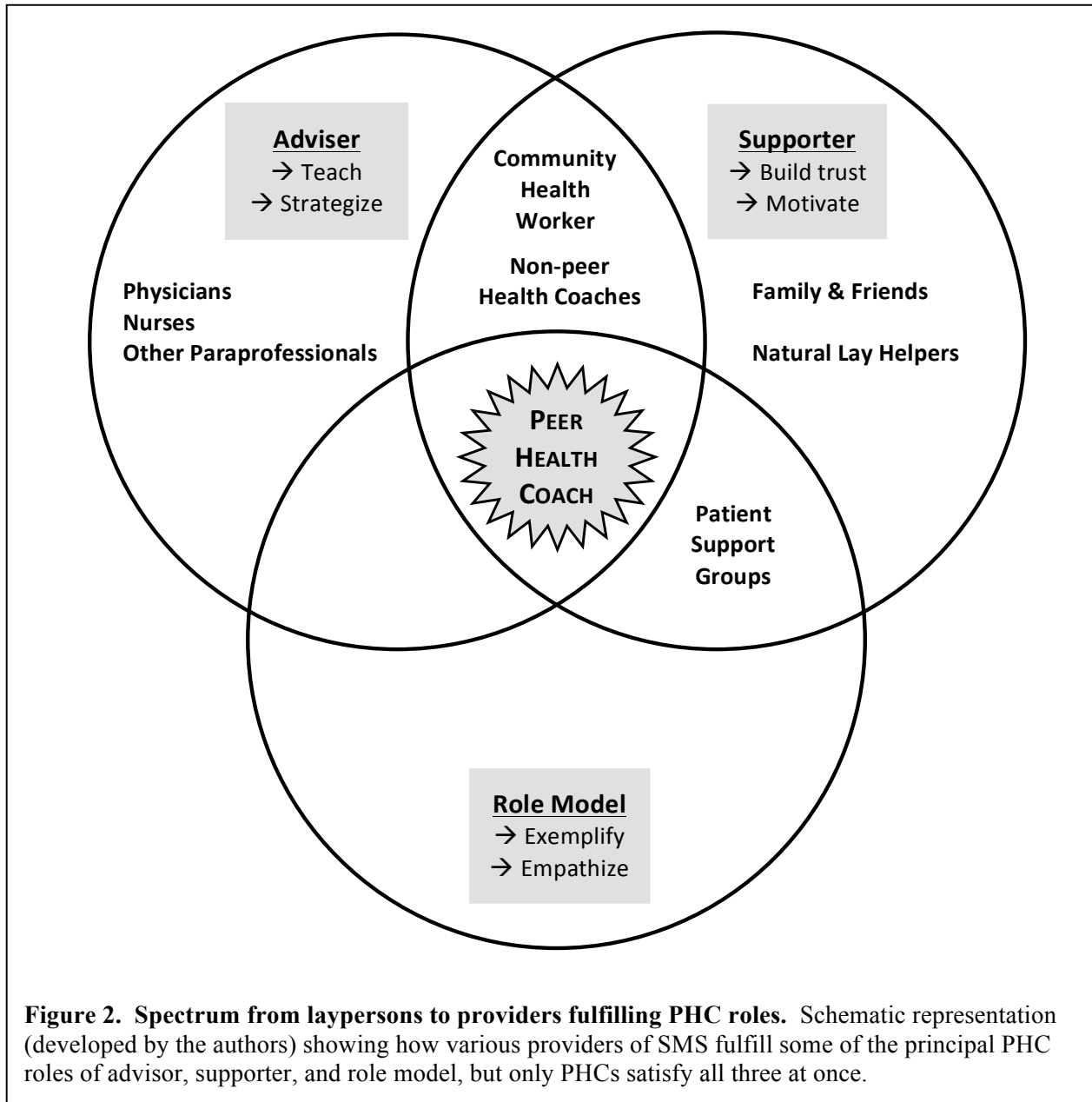
This qualitatively derived model assists in the implementation of future peer coaching programs in the following ways:

- Recruitment for this study depended on the recommendations of the PHCs' physicians or the clinic diabetes team, but factors such as personality and openness were not assessed prior to training the PHCs. Future programs should use entrance interviews to assess each candidate's potential coaching style in order to invest in PHCs who are likely to work well with a diverse group of patients. Once recruited, PHCs should be encouraged to learn various approaches to working with patients in order to adapt to each patient's preference.
- Training curricula should define acceptable limits for PHCs given that they have individual preferences for how they interact with patients and providers. For example, while setting boundaries with patients in their advisor role, program staff may recommend that PHCs neither pressure their patients to adopt new health behaviors, nor remain so hands-off as to render themselves ineffectual.
- Oversight of future peer coaching programs should maintain available resources and ensure access to providers given that PHCs consistently seek advice about health

behaviors or emotional issues when they are confronted with a situation that goes beyond their knowledge and abilities.

*Conclusion*

Diabetes SMS is lacking in primary care,<sup>3</sup> and primary care physicians no longer have time to provide this essential component of chronic disease management.<sup>27</sup> PHCs are a vast and highly motivated potential workforce for providing one-on-one SMS. This qualitative model shows that PHCs are uniquely positioned to teach and empower their patients by building trust through shared experiences.



**Figure 2. Spectrum from laypersons to providers fulfilling PHC roles.** Schematic representation (developed by the authors) showing how various providers of SMS fulfill some of the principal PHC roles of advisor, supporter, and role model, but only PHCs satisfy all three at once.

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