

# Voluntary Organizations and Community Groups as New Partners in Diabetes Self-management and Education

## A Critical Interpretative Synthesis

### Purpose

The purpose of this study is to critically review the literature on the role and work of voluntary organizations and community groups and volunteers in diabetes self-management programs. It seeks to explain how these organizations are located and could be integrated further within a broader system of support.

### Methods

A critical interpretative synthesis of the literature was undertaken as part of the conceptual development of a European research project. Evidence (2000–November 2014) was searched in databases, with the use of key terms, and limited to the languages of the participating countries. This was supplemented by an additional hand search and snowballing technique. A total of 21 articles were included in the review.

### Results

Evidence regarding the involvement of voluntary organizations in diabetes self-management programs mainly related to: the nature and remit of their work, responsibilities, and attributes; key strategies of programs accounting for success; motivations/barriers for engaging in volunteering participation; relationships between volunteers and users; and connections/tensions with formal services.

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## Conclusions

This review has uncovered a range of facets of voluntary organizations and community groups relevant for supporting diabetes self-management such as the context within which they act and the nature of relationships developed with community and health services. The principles of “assistance, support, sharing, and link” seem essential for this voluntary initiative in self-management to establish effective reciprocal collaboration with health professionals.

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**D**iabetes is a chronic condition (CC) that has rapidly spread in the Western world and become highly prevalent among low- to middle-income countries.<sup>1</sup> Consequently, diabetes and its associated comorbidities place some countries’ financial sustainability in jeopardy, especially where social and health care infrastructural support is deficient.<sup>2</sup>

A response to this situation has been the proliferation of self-care and self-management strategies that have progressively gained in presence and salience in education, research, health policy, and services in Europe and other Western countries.<sup>3</sup> These strategies promote the active involvement of patients in the decision-making and education process and include the roll out and implementation of complex interventions to promote the collaboration of health services and the third sector resources like voluntary organizations and community groups (VOCGs)<sup>2</sup> in lay-led programs.<sup>4</sup> Although it cannot be obviated that there are differences between European countries and also between Europe and other continents like America in relation to how the third sector is defined and what its legal requirements are, a common characteristic can be found for all organizations, advocacy groups, or charity organizations included in the third sector, which lies on a “non-for-profit” regulation.<sup>5</sup> According to the Sandwell Metropolitan Borough Council,<sup>6</sup> the community and voluntary sector, or third sector,

includes a very diverse range of organizations including some or all of the following components: voluntary organizations, community groups, tenants and residents groups, faith groups, housing associations, most co-operatives and social enterprises (provided all profits

are retained for the benefit of the members or community served), most sports organizations, grant making trusts and private clubs.<sup>6</sup>

More concretely, Sandwell<sup>6</sup> defines a *voluntary organization* as “a formal organization run by a management body made up of volunteers who are engaged in that activity for environmental, economic or social good” and a *community group* as “a less formally organized body run by a management body made up of volunteers who are engaged in that activity for environmental, economic or social good.”

In this respect, bottom-up initiatives involving networks of lay people who share ideologies and life and diabetes experience are emerging in the Western world not only on behalf of the patient with a CC but also in part to serve a systemic imperative of rescuing financially exhausted health care systems.

At present, VOCGs are recognized as having importance for the promotion of quality of life and seen as an element in the range of services available to support the health and well-being agenda within local and national contexts.<sup>5,7</sup> Furthermore, VOCGs have been shown to have capacity to reach people who are frequently excluded from traditional health services (eg, asylum seekers or ethnic minority populations).<sup>8</sup> This is of great relevance in diabetes care at times of increasing social inequality and poverty.

However, the emerging emphasis on the role of VOCGs has affinities with contradictory political and policy imperatives such as patient empowerment, improvements in resource use and allocation for people with CCs, and the weakening of the welfare state through the downward transfer of responsibilities. Consequently, despite their growing significance in diabetes self-management programs, it still remains unclear what are the work and roles of VOCGs, how the relationships between organizations are built to foster diabetes self-management, and what is the role they can play within a broader health policy agenda.

Therefore, this article aims to critically review the existing literature on the role and work of VOCGs in diabetes self-management programs and explain how they are or could be integrated within a broader system of support. The following review questions will be answered:

*Question 1:* What is the role that VOCGs play in diabetes self-management programs, and in what ways do they meet the needs of patients?

*Question 2:* How are they associated/integrated with formal services?

## Methods

This review of the literature is part of the conceptual work of a European research project (EU-WISE; <http://www.eu-wise.com>), which aims to describe and analyze the support mechanisms that operate on the macro, meso, and micro levels that promote the implementation of self-management strategies with people with CCs. This European project involves 6 countries including Bulgaria, Greece, Norway, Spain, the Netherlands, and the United Kingdom.

## Critical Interpretative Synthesis

A critical interpretative synthesis (CIS) was chosen as a review method since it can be used to inductively analyze, interpret, and synthesize different forms of evidence, leading to the generation rather than testing of theory,<sup>9-11</sup> which was considered to match with the objectives of this article.

## Parameters of the Review

### Data Sources and Search Strategy

Several databases were searched: MEDLINE (Pubmed), CINAHL, EMBASE, Proquest: Dissertations and theses, Biblio Map EPPI-Center database of health promotion research, Social Care Online, PsycINFO, and Web of Science. Furthermore, the authors applied a snowballing technique and consulted the websites of voluntary organizations related to diabetes mellitus, healthy lifestyle, and well-being.

Moreover, to increase the sensitivity of the literature searches and minimize retrieval bias of the databases,<sup>12</sup> the authors undertook hand searches of issues of the past year (2014) of the following journals: *Nonprofit and Voluntary Sector Quarterly*, *Voluntary Sector Review*, *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, *Canadian Journal of Volunteer Resources Management*, *Chronic Illness*, *The Diabetes Educator*, and *Diabetes Care*.

### Key Terms

As it is depicted in Table 1, 3 main facets were developed that encompassed the key elements of our research questions: terms related to the type of patients; terms related to VCOGS, third sector, and social action sector; and finally, terms related to educational interventions (eg,

Table 1

### Search Strategy: Key Terms<sup>a</sup>

Terms Related to the Type of Patients	Terms Related to Voluntary Organizations and Community Groups, Third Sector, or Social Action Sector	Terms Related to the Intervention/Focus
Chronic*	Associat*	Self management
Chronic illness*	Societ*	Self-care
Chronic disease*	Group*	Self care
Chronic condition*	Faith based	Self-management
Long term	organization*	
condition*	Religious	
Diabet*	organization*	
Type 2 diabet*	Foundation*	
DM	Federation*	
DM2	Charit*	
	Platform*	
	Institution*	
	Club*	
	Social	
	organization*	
	Reference group*	
	Social support	
	Support group*	
	Social network	
	Peer support	
	Self-help group	
	Lay health	
	Volunt* corporate	
	Non-governmental	
	Non-profit	
	Social regional	
	Local	
	Communit*	
	Regulat*	
	Framework*	
	Polic*	
	Law*	
	Legal	
	Legislation	
	Funding	
	Typolog*	
	Function*	
	Structur*	
	Origin	
	Statutes	
	Rol*	
	Campaign*	

<sup>a</sup>The asterisk indicates the possible endings of some words.

self-management). The review team tried different combinations between the terms of each facet to enhance relevant papers' retrieval and used acronyms and truncations (asterisk to indicate the possible endings of some words) when relevant.<sup>13</sup> The booleans OR and AND were used to combine terms within each column and between columns, respectively. Not all terms were used and combined simultaneously in all databases.

### Search Limits and Inclusion and Exclusion Criteria

A number of preestablished limits were used to search the databases such as Language: English and language of the countries participating in the European project and Year of Publication: 2000 to November 2014. Furthermore, the following inclusion and exclusion criteria were set initially.<sup>11</sup>

Inclusion Criteria	Exclusion Criteria
<p><b>1. Empirical studies (qualitative/quantitative or mixed-method, combined designs) and reviews</b> about the topic that provide information to answer the review questions.</p> <p><b>2. Descriptive papers</b> that deal with information that could answer the review questions.</p> <p><b>3. Other documents:</b> grey literature, policy/organizational documents, unpublished scientific documents, conferences, abstracts as long as they provide information to answer the review questions.</p>	<p>1. Articles/documents exclusively focused on other disorders than type 2 diabetes.</p>

Three reviewers performed the selection of articles, and the review team discussed decisions at all stages of the review. A total of 136 papers (Figure 1) were included from the databases after reading title and abstract and 8 papers from other sources (hand search and snowballing technique). After applying the inclusion/exclusion criteria, a total of 75 papers were selected from the databases. At the beginning, the sampling of evidence was purposive

and afterwards theoretical to achieve theoretical saturation.<sup>11</sup> Through the theoretical sampling, qualitative and mixed-method papers (n = 21) were included and reviewed until theoretical saturation was achieved and no more themes were emerging from the analysis and concepts were well developed.<sup>11</sup> Although quantitative evidence and grey literature were also reviewed, these were not included in the final analysis of review findings because they did not provide sufficiently relevant information on the topic.

### Quality Appraisal of Evidence

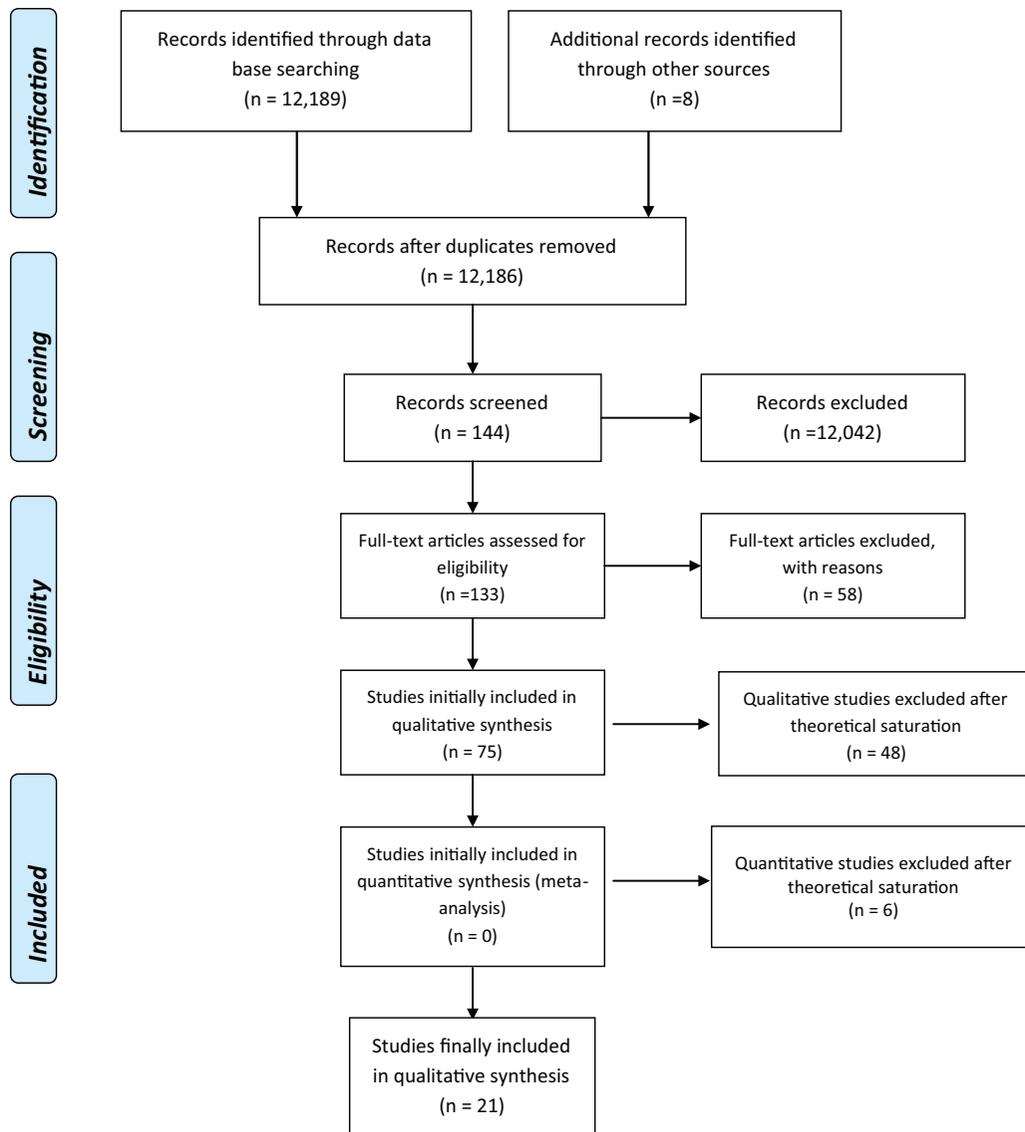
Following Dixon-Woods et al's<sup>10</sup> recommendations, 5 prompts (Figure 2) were applied to identify fatally flawed empirical papers. Two reviewers developed the validation of the process (M.C.P., E.R.) and consulted the rest of the team to achieve consensus where needed. After considering this, the conceptual relevance of the evidence and other methodological rigor issues were analyzed.<sup>9,11</sup>

### Synthesis, Analysis, and Data Extraction of the Articles

Of the 21 papers included in this review, 15 were qualitative papers (3 case studies and 12 qualitative descriptive papers), and 6 applied a mixed-method methodology. Contextual data of each reviewed studied were extracted and presented in Table 2 for the description of the studies.

The final aim of a CIS is to generate theory through the development of well-defined categories and the summary of evidence. The *synthesizing argument* started with an initial step where 2 reviewers (M.C.P., E.R.) undertook, individually, the complete analysis and synthesis of 3 papers.<sup>14-16</sup> Findings were discussed with all the members of the team to find connections between emerging concepts. After completing this initial review, themes were discussed and validated in group sessions with the rest of the team.<sup>17,18</sup>

After this initial step, our analysis of the evidence continued as follows: study findings (labeled as results or findings) of the reviewed papers were coded inductively (n = 324) to describe each sentence of the findings of the reviewed papers. Also, concepts were translated from one study to another, using descriptive codes or creating new ones, starting the process of critical synthesis. After this, grouped codes turned into more descriptive themes that represented findings from a wider perspective. A



**Figure 1.** Adapted PRISMA flow diagram (review parameters and track of hits) to critical interpretative synthesis methodological steps.

total of 7 data-driven themes were created at this stage<sup>18</sup> and are presented in the results section.

The final stage of the CIS in which the creation of the synthesizing argument took place involved the integration of the reviewed evidence into a comprehensive theoretical framework, which showed the relationship between the emerging themes.<sup>11</sup> More concretely, group discussion of the findings of the review took place, and the descriptive themes were analyzed and their content abstracted and transformed in a new conceptual form, which increased the understanding of the phenomenon of self-management of diabetes and the implication of

VOCGs. As a result of this process, a total of 2 synthetic constructs were created to determine the implications for the development of interventions that could foster self-management in diabetes and could be promoted by VOCGs.

## Results

In this section, a description of the 7 data-driven themes and the 2 synthetic constructs emerging from the synthesizing argument is presented. Some original quotes (Q) and text fragments (T) from the reviewed articles are

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
3. Do the researchers provide a clear account of the process by which their findings were reproduced?
4. Do the researchers display enough data to support their interpretations and conclusions?
5. Is the method of analysis appropriate and adequately explicated?

**Relevance:** Are the research questions addressed in the reviewed literature?

**Rigor:** Does the literature have methodological credibility to address the research questions?

**Figure 2.** Five prompts to identify fatally flawed papers.<sup>11</sup>

shown in Table 3 to illustrate this analysis and increase the transparency of the process involved.

As it can be seen in Table 2, 8 articles reported on studies taking place in Europe (mostly the UK), 7 on studies from US, 3 on studies from Australia, 2 on studies from Asia (Thailand and Sri Lanka), and 1 on a study from Canada.

Most reviewed articles focused on the contribution of voluntary roles to CC self-management (mainly diabetes programs) and 3 of them on partnerships between volunteers and health services. Furthermore, several articles reported on studies taking place with vulnerable populations (deprived people, people at risk of isolation, and ethnic groups). Details are found in Table 2.

## Data-Driven Themes

### Nonprofessional/Voluntary Roles in the Community: Their Work and Responsibilities

Several nonprofessional roles can be found in the community to promote individuals' health in CC and diabetes self-management programs. As it will be shown in the following, although the available empirical evidence mainly refers to individual roles of volunteers within the workforce in VCOGs,<sup>19-30</sup> 2 articles<sup>32,33</sup> presented research findings from an organization point of view.

Individual and organizational perspectives of the roles of volunteers in self-management programs can be found in the literature. With regard to the individual point of view, it is important to highlight the existence of Community Health Workers (CHWs) who, according to

the definitions found in the US literature, are trained lay individuals perceived by community members who are willing and able to provide instrumental, emotional, social, and informational support and to facilitate the access to health care services<sup>19</sup> (Table 3, T<sub>1</sub>). Under this umbrella term, other figures such as Lay Health Advocates,<sup>19</sup> Family Health Advocates (FHAs),<sup>20</sup> or *Promotoras*<sup>21</sup> seem relevant in self-management programs in the US. More concretely, FHAs are CHWs who are assigned to adults with diabetes to promote healthy lifestyle and diabetes self-management behaviors. Furthermore, they help participants navigate the health care system and be more active in clinic visits<sup>20</sup> (Table 3, Q<sub>1</sub>). The *Promotor/a* is a CHW who belongs to the same community in which they serve.<sup>22</sup> "A *Promotor/a* is a CHW who represents the population he/she serves ethnically, linguistically, educationally, culturally and economically. . . . *Promotoras* tend to be natural helpers who are intrinsically motivated to help their community."<sup>21</sup>

Another particular role in voluntary self-management initiatives in the US is the Church Pastor, who has been found to have a very relevant role when it comes to African communities in the US and is considered a leader who transmits messages from the pulpit in order to generate healthy behaviors in parishioners. At the same time, Church Pastors are seen as an example or role model to follow,<sup>14,23</sup> as evidenced in the testimony presented in Q<sub>2</sub> in Table 3. Finally, Lay Health Workers (LHWs) and Peer Supporters, like CHWs, play an intermediary and complementary role between individuals and community or health services<sup>16,20</sup> (Table 3, T<sub>2</sub>) and are relevant in European countries like the UK or France (see Table 2).

The reviewed evidence on community self-management programs shows that nonprofessional roles are undertaken by people living with a CC, who are trained to help other people under similar circumstances.<sup>19</sup> In general, the characteristics of the work of the figures described previously include:

- Acting as intermediaries in order to bring users to the health system and other community services,<sup>16,20,22,24</sup> listening to clients, and signposting them to other services or sources of information<sup>16,25,26</sup> (Table 3, Q<sub>3</sub>).
- Supporting community health services participating in health programs and strengthening health professionals' recommendations<sup>20,24</sup> (Table 3, Q<sub>4</sub>).
- Complementing the professionals' role, helping people understand healthy life recommendations,<sup>16,20,24,27</sup> facilitating

Table 2

## Critical Appraisal and Further Content of the Studies

Type of Evidence	Document/Paper Reference (Authors, Year, Country)	Dixon-Woods et al's <sup>11</sup> Appraisal Prompts for Informing Judgments About Quality of Papers/Documents					Relevance/Rigor	Study Design	Methodological Strengths	Focus	Specific Roles	Impact on Disease Self-management
		1	2	3	4	5						
Qualitative	Atkinson et al (2009) <sup>14</sup> US	Y	Y	Y	Y	Y	Yes/yes	Descriptive study Focus groups	Well-described data collection and analysis procedures	African American churches Diabetes prevention programs Deprived people	Church leaders	Motivation and relationships Increasing health awareness and diabetes control
	Boyle et al (2003) <sup>33</sup> Australia	Y	Y	Y	Y	Y	Yes/yes	Case study Face-to-face and telephone interviews	Well-described aims and participants	Partnerships between GPs and VOGOes	No one specific role SHOs	Helping people to cope with CCs and increasing social support and increasing community resources Linking with community resources
	Catalano et al (2009) <sup>31</sup> Australia	Y	Y	Y	Y	Y	Yes/yes	Descriptive study Semi-structured interviews	Well-described participants, sampling procedure, and interview protocol	Volunteers as program leaders in combination with HPs Chronic disease self-management programs (diabetes and others)	Peer leaders	Facilitating people with chronic conditions to develop self-management skills and behaviors
	Cherrington et al (2008) <sup>13</sup> US	Y	Y	Y	Y	Y	Yes/yes	Descriptive study Semi-structured interviews	Well-described key informants access, data collection, and analysis procedures	Community Health Workers in diabetes management Deprived people	Community Health Workers	Linking with community resources Increasing social support and helping people to improve diabetes control
Qualitative	Ferrand et al (2008) <sup>28</sup> France	Y	N	Y	Y	Y	Yes/yes	Descriptive study Semi-structured interviews	Measures to ensure data credibility	People with type 2 diabetes who belong to a patients' association	Peer Supporters	Promoting relationships Motivation and relationships factors Increasing healthy lifestyle and social support
	Heisler et al (2009) <sup>20</sup> US	Y	Y	Y	Y	Y	Yes/yes	Descriptive study Semi-structured interviews	Well-described data collection and analysis Theoretical saturation Findings validated with participants	African American community Disadvantaged people Diabetes self-management program	Family Health Advocates	Helping people to improve diabetes control Linking with community resources
Qualitative	Hipwell et al (2008) <sup>34</sup> UK	Y	Y	Y	Y	Y	Yes/yes	Qualitative descriptive study In-depth interviews	Well-described sample and analysis	People with CCs (diabetes and others) and ethnic disparities	Lay Health Workers	Helping people to better manage their long-term condition
	Holmes and Joseph (2011) <sup>35</sup> Sri Lanka	N	N	N	N	N	Yes/no	Case study Focus groups	Provides quotes that reflect the results	Older people with chronic conditions (diabetes and others), limited access to health services, and at risk of isolation	Peer Supporters	Facilitating access to services, increasing healthy lifestyle, and social support
	Kennedy et al (2005) <sup>35</sup> UK	Y	N	Y	Y	Y	Yes/yes	Descriptive study Semi-structured interviews	Well-described subjects	Self-management trainers for people with long-term conditions	Lay Health Workers	Motivation and relationships Linking with community resources Increasing chronic condition control and stimulating people to be a trainer for others
	Kennedy et al (2008) <sup>36</sup> UK	Y	Y	Y	Y	Y	Yes/yes	Qualitative analysis of postings to the discussion of online classes	Well-described aims, methods, and analysis	People with long-term conditions (diabetes and others) and at risk of social deprivation	Lay Health Workers	Motivational and relational factors Engaging people in self-management
	Scarpello et al (2013) <sup>29</sup> UK	Y	Y	Y	Y	Y	Yes/yes	Descriptive study Focus groups	Well-described sampling, setting, and analysis	People at risk of type 2 diabetes	Peer Supporters	Motivational factors to reduce the risk of type 2 diabetes
	South et al (2008) <sup>15</sup> UK	Y	Y	Y	Y	Y	Yes/yes	Case study Semi-structured interviews	Well-described methods and objectives	Social prescribing as an innovative approach to promote voluntary sector Disadvantaged people	No one specific role Social Prescribing	Promoting healthy life styles Increasing social support, helping people to cope with long-term conditions, and reducing health inequalities

(continued)

Table 2 (continued)

Type of Evidence	Document/Paper Reference (Authors, Year, Country)	Dixon-Woods et al's <sup>11</sup> Appraisal Prompts for Informing Judgments About Quality of Papers/Documents					Relevance/Rigor	Study Design	Methodological Strengths	Focus	Specific Roles	Impact on Disease Self-management
		1	2	3	4	5						
Qualitative	South et al (2010) <sup>16</sup> UK	Y	Y	Y	Y	Y	Yes/yes	Qualitative study Interviews	Clear description of data collection and analysis Inductive approach to analysis	People in the community with direct experiences of voluntary services Deprived population	Lay Health Workers and Peer Supporters	Motivation and relationships Increasing healthy lifestyle and social support Linking with community resources
Mixed- method	Torres and Ingram (2009) <sup>21</sup> US	Y	Y	Y	Y	Y	Yes/yes	Qualitative study Interviews	Well-described procedures and program	<i>Promotoras</i> and the spirituality in diabetes self-management Rural areas Deprived people	<i>Promotoras</i>	Increasing social support and engaging in diabetes self-management Promoting relationships Linking with community resources
Mixed- method	Young et al (2010) <sup>32</sup> Australia	Y	Y	Y	Y	Y	Yes/yes	Qualitative study Semi-structured interviews	Well-described analytical process	Partnerships between GPs and VCOGs Related to people with CCs	No one specific role CHOs	Helping people to cope with long-term conditions and increasing social support Linking with community resources
Mixed- method	Austin and Claborne (2011) <sup>23</sup> US	Y	Y	Y	Y	Y	Yes/yes	Mixed-method (community-based participatory research)	CBPR resulted in an adequate design to implement the program	Different cultural backgrounds African American churches Deprived people with type 2 diabetes	Church Leaders	Helping people to improve diabetes control Promoting healthy lifestyles
Mixed- method	Blickem et al (2013) <sup>30</sup> UK	Y	Y	Y	Y	Y	Yes/yes	Integrative and collaborative approach Focus groups and interviews	Well-described data collection and analysis procedures	People with CCs (diabetes and others) and at risk of social deprivation	Peer Supporters	Increasing social support and helping people cope with long-term conditions Promoting healthy lifestyles Promoting relationships
Mixed- method	Collinsworth et al (2013) <sup>24</sup> US	Y	Y	Y	Y	Y	Yes/yes	Mixed-method study Semi-structured interviews	Well-described approach, sample, setting, and data analysis	Self-management in type 2 diabetes Deprived people	Community Health Workers	Linking with community resources Increasing social support and improving diabetes care Promoting relationships Linking with community resources
Mixed- method	Johnston et al (2012) <sup>36</sup> Canada	Y	Y	Y	Y	Y	Yes/Yes	Mixed-methods Focus groups	Well-described methods and analysis	Impact of a group self-management program for people with CCs (diabetes and others)	Peer Supporters	Facilitating people to develop healthy lifestyles and skills to cope with chronic illness Linking with other community resources
Mixed- method	McCleskey et al (2011) <sup>22</sup> US	Y	Y	Y	Y	Y	Yes/yes	Mixed-methods Interviews	Well-described program, method, and analysis	Rural and urban centers <i>Promotoras</i> , community partners, and health care providers in diabetes self-management programs for people with diabetes and racial disparities	<i>Promotoras</i>	Motivational and relational factors Improving diabetes control Promoting relationships Linking with community resources
Mixed- method	Sukwataneer et al (2011) <sup>27</sup> Thailand	Y	Y	Y	Y	Y	Yes/yes	Participatory action research Focus groups and observations	Well-described participatory action research process	Disadvantaged people with type 2 diabetes Elderly people	Peer Supporters	Motivation and relationships Helping elderly people to self-care and try to improve their quality of life Promoting healthy lifestyles Linking with community resources

Abbreviations: CBPR, community-based participatory research; CC, chronic condition; CHOs, consumer health organizations; GPs, general practitioners; HPs, health professionals; SHOs, self-help organizations; VCOGs, voluntary organizations and community groups.

Table 3

Quotes and Text From Findings: Reviewed Papers<sup>a</sup>

Data-Driven Themes	Quotes and Text From Findings
1. On professional/voluntary roles in the community: their work and responsibilities	<p><b>Q<sub>1</sub></b>: "I thought my doctor had explained what we needed to do and what we shouldn't do, and basically we were doing a pretty good job but . . . [REACH] just painted a clearer picture in your mind what you had to do and what you must do if you wanted to live longer and better . . . we learned a lot of things that I guess you could say the doctor didn't have time to sit down and explain to us." (20, p. S275)</p> <p><b>Q<sub>2</sub></b>: "Well, our pastor is diabetic. . . . He encouraged a lot of people to start watching their diets and kind of looking after your health." (14, p. 267)</p> <p><b>Q<sub>3</sub></b>: "We have people who have diabetes. They come to the office but still don't have health care. And with the Family Support component of the program, we can help them to get the health care." (22, p. S85)</p> <p><b>Q<sub>4</sub></b>: "The patients call me if they have questions about the next appointment, labs, or how to take their medicines. They [physicians] ask me to explain to the patient about things such as medicine and insulin." (24, p. 796)</p> <p><b>Q<sub>5</sub></b>: "If you have any 'out of the usual' symptoms the best thing is to go to your GP. I'd go back every few days, at least then it is being noted how you are and how your problem is manifesting itself. I'd also ask to be referred back to your specialist . . . after all they know the best about the course of your condition." (26, p. 6)</p> <p><b>Q<sub>6</sub></b>: "She will help coach them in ways that they can make changes in their diet and exercise habits. She can teach them how to understand diabetes better and functions of the medicines." (24, p. 795)</p> <p><b>Q<sub>7</sub></b>: "The first is compassion, empathy, understanding my community, understanding where I live, understanding cultural diversities, and understanding illnesses, whether they be mental, physical, or emotional." (22, p. S85)</p> <p><b>Q<sub>8</sub></b>: "We can work side by side, like GPs try to educate, encourage, instruct, coach, but likewise in slightly different ways than the medical relationships, the support groups give peer support, encourage and coach from other people's stories." (32, p. 262)</p> <p><b>T<sub>1</sub></b>: "Over half of the programs expected their CHWs to provide self-management guidance, facilitate medical follow-up and help identify resources. Half described social support as a main CHW responsibility. Just under a third of the programs have CHWs engaged in some sort of medical management, including reviewing medications and monitoring for diabetes complications." (19, p. 829)</p> <p><b>T<sub>2</sub></b>: "They also reported learning how to access neighbourhood resources (e.g., locations for better deals on medications and affordable eyeglasses, grocery stores with discounted produce, and exercise classes)." (20, p. S274)</p> <p><b>T<sub>3</sub></b>: "The groups were described as a 'safe place' where members could share meals with others or engage in social interaction. . . . Groups also provided an access point to a range of everyday support such as transport, home help or advice about benefit entitlement." (30, p. 52)</p> <p><b>Q<sub>9</sub></b>: "My fear from joining any walking group was holding people up, 'oh no here she comes' and there is none of that in this group and [name] makes sure that everyone is comfortable about the pace that we are going at, so you don't feel like a nuisance if your slower than the rest." (16, p. 663)</p> <p><b>Q<sub>10</sub></b>: "I met Franck and Marion. They gave me confidence through their words, their competence and their accessibility. I appreciate the usefulness of the information obtained and their listening when I talk. They are trustworthy persons." (28, p. 516)</p> <p><b>Q<sub>11</sub></b>: "Such a good positive feeling being able to say you are comfortable in the path your life has taken. Use that positivity to work for you and am sure you will be pleasantly surprised where the path takes you. Confidence builds self-esteem and that is something we all need loads of. Keep smiling and you use far less muscles to smile than you do to frown." (26, p. 5)</p> <p><b>Q<sub>12</sub></b>: "[Name] knows about [Asian] community and our culture and our religion and she gives advice on things like food and what's good to eat and what's not because sometimes things aren't good." (16, p. 663)</p>
	<i>(continued)</i>

Table 3 (continued)

Data-Driven Themes	Quotes and Text From Findings
3. Key strategies of success for VOCs' program	<p><b>Q<sub>13</sub></b>: "We were looking for people who really had the commitment to work in the community, to do this kind of out reach in the community. [“are you looking to give back to your community?”] Kind of looking for their motivation and not necessarily their skills.” (19, p. 829)</p> <p><b>Q<sub>14</sub></b>: “I think it’s absolutely vital. I really do. I think that, even for people who are carers of people who have long-term chronic conditions, still there’s some kind of barrier there. I think if you can talk, when you talk about fatigue or depression, or whatever you’re talking about, you know, waiting rooms and consultants, and that kind of stuff, you can . . . just sharing a bit of that story you’re not talking down to people—you actually understand on some level.” (25, p. 433)</p> <p><b>Q<sub>15</sub></b>: “The CHW is from the community, so what she says holds more weight. Especially with what to eat, how to diet, how to exercise. [The CHW] may understand better where the patients are coming from and what some of the common myths [concerning diabetes] are and be able to challenge them in a way that the doctor in the white coat is not going to be able to challenge them.” (24, p. 796)</p> <p><b>Q<sub>16</sub></b>: “I think that we’re not fully aware of their cultural needs. I think it would be helpful to be more aware, and not find out when you put foot in it and have done something you shouldn’t.” (24, p. 285)</p> <p><b>Q<sub>17</sub></b>: “When you hear it from the pastor it gives it a little more credence, a little more impact.” (14, p. 267)</p> <p><b>Q<sub>18</sub></b>: “I was very surprised when I learnt that most of us with chronic conditions suffer from this unpredictability, I had thought it was only those with my condition. It’s a big help to me to know this, I then think just how many thousands of us are having this problem, and most are managing well, and then, so can I!” (26, p. 4)</p> <p><b>Q<sub>19</sub></b>: “I think the thing that I would probably say, especially if you’re starting a project, do not underestimate the time you have to spend in the community.” (19, p. 829)</p> <p><b>T<sub>4</sub></b>: “Both CHWs and PCPs acknowledged that it took time to develop comfortable working relationships and that observed improvements in patient outcomes helped foster acceptance of the CHW role in primary care clinical teams.” (24, p. 797)</p> <p><b>T<sub>5</sub></b>: “The value of working relationships between HPLs and PLs was that this combination enhanced the sustainability of the approach. Through pairing with HPLs, PLs had greater access to resources that they would not have had otherwise (e.g. networks to recruit participants, telephone access, access to venues, administration support).” (31, p. 109)</p>
4. Motivations for and barriers to volunteer participation	<p><b>Q<sub>20</sub></b>: “I realized that, although I’d hit such a low level, it wasn’t my fault. And I learned to hand that back. I was other people’s problems; if they couldn’t cope with somebody . . . that was their problem, not mine. And then, just by chance I saw—I was looking for employment—and I saw the advert for this programme. And I just felt it was fate.” (25, p. 433)</p> <p><b>Q<sub>21</sub></b>: “Walking is not my primary leisure activity so I’m active in other ways in the community with museums, with local neighbourhood societies and with things that are across the city, so I’m not going to volunteer to lead a walk, if somebody else does it then I’ll go. And it’s a very delicate thing about getting, at what point people take responsibility for whatever activity in the community and in a voluntary way, it’s different for each person.” (16, p. 665)</p> <p><b>Q<sub>22</sub></b>: “Well I’ve considered it [being a walk leader] but I wouldn’t be one because I am a fair-weather walker, if it’s going to pour with rain I don’t want to know. Also because of health issues sometimes I’m just not able to do it and I don’t want to be put in a position where I’m letting people down. Having said that I’m happy to help, taking the back post of the walk and stuff and making sure everybody is alright, I’d quite like to help and I’ll quite happily communicate things but I wouldn’t particularly want to be a leader.” (16, p. 665)</p> <p><b>Q<sub>23</sub></b>: “So that we lost a couple people just because they found higher paying jobs. For example, one of our CHWs actually took a job driving a truck, because that paid more than you know, what we could play.” (19, p. 830)</p> <p><b>Q<sub>24</sub></b>: “There was one of them that just recently resigned, probably 2 months ago, but you know, resigned because he had some family issues, you know had a child who died and all this stuff. Another one of our mates actually passed away himself. And then another one, he resigned early on in the project.” (19, p. 830)</p> <p><b>T<sub>6</sub></b>: Motivations for volunteering included altruism—“putting something back,” recognition of the need for extra assistance to run activities and the social benefits from increased contact. (16, p. 665)</p>

*(continued)*

Table 3 (continued)

Data-Driven Themes	Quotes and Text From Findings
5. Relationships between volunteers and users	<p><b>Q<sub>25</sub></b>: "I just feel that [name] loves walking anyway, he walks outside of this group, he is a great outdoors-ey person, that he does it for the love of it rather than someone who is just paid to do it and I just feel that someone that is doing it for nothing who absolutely loves it will somehow bring another dimension to our walks, rather than someone who is paid to do it whether they want to or not." (16, p. 664)</p> <p><b>Q<sub>26</sub></b>: "I can practice and talk to my friends about my problems at the same time. We frequently laugh and gossip. I think that it is important that they encourage me, help me when I am not well. They convince me to put everything behind me." (28, p. 516)</p> <p><b>Q<sub>27</sub></b>: "He's not just a good communicator but he has got good people skills, and also he is friendly, warm and hospitable and he is aware of every one space. My fear from joining any walking group was holding people up, 'oh no here she comes' and there is none of that in this group and [name] makes sure that every one is comfortable about the pace that we are going at, so you don't feel like a nuisance if your slower than the rest." (16, p. 663)</p> <p><b>T<sub>1</sub></b>: "The exercise classes . . . seemed situated within a familiar and comfortable environment where participants were doing enjoyable, every-day things. Hence, familiarity with the surroundings and the other people involved appeared to create an encouraging atmosphere for participants to take part in exercise." (30, p. 53)</p>
6. Connections and tensions between VOCGs and formal services	<p><b>T<sub>8</sub></b>: "Promotoras emphasized that spirituality is essential in helping people deal with crises." (21, p. 122)</p> <p><b>Q<sub>28</sub></b>: "If there were no benefit for the patient I would not be using the SHO." (33, p. 77)</p> <p><b>Q<sub>29</sub></b>: "[Physicians] do not know too much about what [programming] is going on in the vicinity." (36, p. 5)</p> <p><b>Q<sub>30</sub></b>: "[Two HPL] provides a very balanced . . . professional . . . credible [course] . . . it carries more weight with people if you do have two people from different disciplines. . . . Because it's backed by, 'the Physio said . . .'" (31, p. 111)</p> <p><b>Q<sub>31</sub></b>: "I've done a couple [of courses] with lay people [ie, PLs] and I wouldn't do them again. But that was the particular lay people. I think if you get a good layperson you're fine. If you don't, then they can actually pull a group down. And the one [PL] we had did pull the group down and I wouldn't do it again with a layperson." (31, p. 110)</p> <p><b>Q<sub>32</sub></b>: "With some of them [CHO], I'd probably make sure I'd told them [patients] to be careful of the information that they'd received as some people may get led astray and start getting some ideas about, you know about multiple chemical sensitivities or something and they may not even have it. But I wouldn't say don't go, but I think I would, I guess, caution some people to try and have balance, just like if I send people to the internet for some stuff, I just say be careful about the quality of what you're reading." (32, p. 264)</p> <p><b>Q<sub>33</sub></b>: "People who are struggling and need extra, I might mention it again and again you know, I might push harder for those who may need extra support from that side of things." (32, p. 264)</p> <p><b>Q<sub>34</sub></b>: "But I think a lot of the challenges are going to be around how much to pay, funding our big problem was that we could not get the institution to maintain this. They were looking to cut back on the diabetes clinic." (19, p. 830)</p> <p><b>T<sub>9</sub></b>: "The CHWs said they felt comfortable interacting with PCPs as part of a care coordination team and worked with providers to provide patients with high-quality care. They explained that they know the scope of their role and when they should alert PCPs to potential patient problems." (24, p. 797)</p> <p><b>T<sub>10</sub></b>: "The CHWs indicated that the PCPs value them and often request their help with patients." (24, p. 797)</p> <p><b>T<sub>11</sub></b>: "The evaluation later found that health professionals felt comfortable referring patients due to high levels of trust and confidence in the CHAT worker's ability to find appropriate voluntary services." (15, p. 313)</p>

(continued)

Table 3 (continued)

Data-Driven Themes	Quotes and Text From Findings
7. Outcomes: benefits of VOCGs programs	<p><b>Q<sub>35</sub></b>: "The [CHWs] takes a lot off of our hands. She is able to spend a lot more time on those areas that necessitate a lot of time and education from the patient standpoint that in no way would be efficient for the physician to handle in depth." (24, p. 796)</p> <p><b>Q<sub>36</sub></b>: "It's a good combination, one of each [HPL and PL]. . . . [Course participants are] getting two slightly different perspectives . . . that's an advantage. They know that one person has experienced similar things to what they're experiencing . . . the other person knows more about the health system." (31, p. 109)</p> <p><b>Q<sub>37</sub></b>: "My relationship with my doctor is better because now I have more confidence. Before I just went and they checked me and gave me papers and that was it. I didn't say anything to my doctor, but in they told me I have to ask questions and make requests, like to ask him to check my feet or to tell me how much I weight, so now I ask. I have to go there with a clear mind and ask the doctor everything. [My FHA] helped me see that when you ask questions, nothing bad happens." (20, p. S277)</p> <p><b>Q<sub>38</sub></b>: "I'm not the only one with diabetes. I have friends with diabetes. It's our group and we share willpower with one another. I'm not the only one with high blood sugar. Other people in the group also have the same thing. We motivated one another on limiting our eating of sweet snacks." (27, p. 227)</p> <p><b>Q<sub>39</sub></b>: "I do all the minor repairs in the church . . . I enjoy it, working for people, helping people." (30, p. e53)</p>

<sup>a</sup>Reference number, page number in parentheses. CHAT, community health advise team; CHO, consumer health organizations; CHW, community health worker; GP, general practitioner; HPL, health professional leader; PCP, primary care provider; PL, peer leader; Q, participants' quotes in the studies; REACH, Racial and Ethnic Approaches to Community Health; SHO, self-help organizations; T, text in findings sections.

medical follow-up, and providing self-management guidance<sup>19,24,28,29</sup> (Table 3, Q<sub>1</sub>, Q<sub>5</sub>, and T<sub>1</sub>).

- Having a social role and seeking social cohesion, creating social networks in the community,<sup>16,30,31</sup> and providing social and emotional support<sup>19,20,30</sup> for people with diabetes.

When it comes to a more organizational point of view of the voluntary activities in self-management programs, evidence from Australia focuses on Consumer Health Organizations (CHO)<sup>32</sup> or Self-Help Organizations (SHO),<sup>33</sup> which contribute to patient care by providing practical, psychosocial, and informational support; communicating experiential knowledge; and teaching coping methods in a variety of ways (telephone counseling, exercise classes, newsletters, websites, workshops, online forums, and peer support groups). Although the services provided are practically the same, the main difference between the individual or organizational volunteering initiatives of self-management programs lies on the fact that the reach, workforce, and diversity of support is wider in organizations.

### Nonprofessionals'/Volunteers' Attributes

Apart from the main characteristics of the work non-professionals/volunteers involved in VCOGs developed, there is evidence that identifies some attributes that define their personality but also the type of relationship they normally establish with users, which is the backbone of the education and support they provide.

According to the literature, volunteers in diabetes self-management programs are described as good people who create a *collaborative and harmonious atmosphere* in the group while implementing health activities.<sup>16,20</sup> This is illustrated in Table 3 (Q<sub>9</sub>). *Being trusted* is another important quality that stands out in the literature for volunteers<sup>21,24,28</sup> in diabetes self-management programs. Having experiential knowledge about a CC like diabetes<sup>26,31</sup> helps create a trusting relationship, as we can see in Q<sub>10</sub> (Table 3).

Apart from trust and needing to be *accessible*, a key feature of volunteers in these self-management programs is having the capacity to exchange knowledge and beliefs. The literature refers to volunteers maintaining a positive attitude that enables people to feel good about themselves and to continue to cope with diabetes<sup>26</sup> (Table 3, Q<sub>11</sub>). In addition to this, *empathy* is said to emerge from sharing feelings and experiences between volunteers and people

participating in programs.<sup>26,31</sup> This along with *cultural identification* are described not only in terms of mutual understanding but also in relation to gaining health information and access to other resources.<sup>16,22,24</sup> Finally, volunteers are sometimes part of the communities they work with, and therefore, effective 2-way communication channels seem developed in most cases<sup>16,19,20,21</sup> (Table 3, Q<sub>12</sub>).

### Key Strategies of Success for VCOGs' Programs

Many key strategies to ensure success of CCs or diabetes self-management programs led by VCOGs can be found in the literature. These mainly relate to how volunteers are recruited and trained and how relationships between volunteers and target communities and volunteers and formal services can be promoted.

According to the literature, volunteers' recruitment is based on some eligibility criteria that could vary depending on the communities or populations the programs are to be implemented in. Common criteria across programs are having good interpersonal skills or willingness to learn.<sup>19</sup> However, more specific criteria lie on having a strong connection and sense of belonging to the target community<sup>14,19</sup> and having personal experience of a CC,<sup>19,25,29</sup> as shown in Q<sub>13</sub> through Q<sub>15</sub> in Table 3. Furthermore, other studies highlight that cultural,<sup>27,34</sup> gender,<sup>28,34</sup> and ethnicity identification<sup>19</sup> and credentials of lay educators<sup>14,23</sup> are other relevant elements for successful recruitment.

The target population and communities of diabetes programs also determine the type of training volunteers receive. The literature states that training courses mainly focus on health-related technical skills, self-management and behavior change strategies, and resources and referrals procedures.<sup>19</sup> Hands-on exercise, didactic lecture, practice teaching/role playing, interactive discussion, and informal one-on-one are some methodological techniques used for the training.<sup>19</sup> Furthermore, other abilities in relation to social support, culture, religion, effective communication, and problem/conflict solving need to be developed. For example, a voluntary Expert Patient Program tutor of one of the reviewed studies expresses the need for cultural competency in Q<sub>16</sub> in Table 3. In this regard, the involvement of interpreters in multi-ethnic programs to solve cultural problems seems an adequate solution.<sup>34</sup> Notwithstanding, this training seems sometimes limited by the low educational level of some of the volunteers.<sup>34</sup>

Strategies for promoting people's health awareness and engagement in diabetes self-management programs are also reported. Dissemination and public participation in the programs is encouraged through formal communication, reminders or exhortations from the pulpit (church-based organizations mainly), and newspapers and flyers in churches or community businesses.<sup>14,23</sup> In addition, the literature suggests that the way messages are transmitted is crucial and thus should be carefully planned with reference to role modeling. For instance, identifying leaders or successful people as examples to follow, who can provide evidence of positive life changes is a recurrent strategy found in the literature,<sup>14,26</sup> as Q<sub>17</sub> in Table 3 illustrates.

Furthermore, reviewed evidence shows that stimulating people to share their experiences in the group, emphasizing the commonality of problems and feelings, and providing positive reinforcement for people with CCs help set short- and long-term goals (Table 3, Q<sub>18</sub>).

Finally, there is evidence of more successful community and peer-supported programs in which health care providers accept and collaborate<sup>24</sup> with volunteers, raising public awareness and participation in the programs consequently.<sup>22</sup> A collaborative plan between lay educators and health care providers seems to have many benefits for participants and enhances programs sustainability,<sup>22,24,31</sup> as illustrated in T<sub>4</sub> and T<sub>5</sub> in Table 3.

### Motivations for and Barriers to Volunteer Participation

The reviewed literature mainly highlights barriers to volunteer participation. There are only 2 articles that showed why volunteers are motivated when participating in these self-management programs. Their reasons mainly relate to feelings of altruism<sup>16</sup> or the need to be involved in activities after retirement.<sup>25</sup> The need to feel useful and the ability to put the problems back makes people with CCs become volunteers to help others, as can be seen in Q<sub>20</sub> and T<sub>6</sub> in Table 3.

By contrast, many barriers are described by participants in the reviewed studies when it comes to participating in self-management programs as volunteers. These disadvantages are main causes of the low attrition rate of volunteers in these programs and the lack of commitment and changes in personal preferences (Table 3, Q<sub>21</sub> and Q<sub>22</sub>). Another important barrier is the lack of or poor remuneration of nonprofessional posts as shown in Table 3, Q<sub>23</sub>. Moreover, other individual circumstances such as physical and health limitations, bureaucracy, cultural

issues, or the pressures of family commitments are also identified in the studies as barriers to volunteering<sup>16,19,35</sup> (Table 3, Q<sub>24</sub>).

### Relationships Between Volunteers and Users

Volunteers' attributes mentioned before seem to allow them to build relationships with users based on confidence<sup>11,24,28</sup> and make them a significant source of motivation for people's self-esteem. According to the literature, this has a positive impact on the adoption of healthy lifestyles in terms of exercise or diet.<sup>16,28,30</sup> Also as illustrated in Q<sub>26</sub>, Q<sub>27</sub>, and T<sub>7</sub> in Table 3, community groups are described as a "safe place" where members can share their experiences<sup>30</sup> and social and personal network sources.<sup>16,28,32</sup> The fact that volunteers belong to the same community where programs are implemented<sup>16,35</sup> allows them to have a better understanding of users' and community cultural needs.<sup>16,24</sup>

In relation to diabetes or other CCs education, volunteers are distinguished from professionals from formal services because they do not only teach what but also how to do something.<sup>20</sup> Volunteers provide informational support about practice services through effective communication, understandable terms, and spending more time with people.<sup>16,28,32</sup> Similarly, according to the literature, users could identify volunteers' commitment to the community, which distinguishes them from the professionals care providers<sup>16,20,30</sup> (Table 3, Q<sub>25</sub>).

### Connections and Tensions Between VOGs and Formal Services

According to the literature, relationships and partnerships between VOGs and health services can be positive or negative in relation to self-management programs.

With regard to positive experiences, several studies have been found that show good collaborations of VOGs and health professionals in daily practice related to self-management,<sup>16,24,30,32</sup> which is perceived in successful management of cases and research results.<sup>33</sup> There is evidence that when nonprofessionals and the health system collaborate in health programs, the former feel comfortable and valued<sup>24</sup> (Table 3, T<sub>9</sub> and T<sub>10</sub>). Likewise, professionals consider programs led by volunteers to be a good strategy in order to reinforce their recommendations to patients<sup>22</sup> and recognize patient improvements and self-management benefits<sup>22,24,32,33</sup>

(Table 3, Q<sub>28</sub>). In response to the need for collaborative relationships between the voluntary sector and formal services to implement successful self-management programs, South et al<sup>15</sup> advocate “social prescribing” as a strategy to improve connections between health services and community organizations. This initiative links people using primary care with support available in the community and aims to improve physical and psychosocial status of individuals<sup>15</sup> (Table 3, T<sub>11</sub>).

In contrast, tensions between volunteers and health professionals in CC self-management programs have also been reported. According to the literature, professionals are not always aware of the range of services offered by the community to help people in self-management<sup>15,35</sup> (Table 3, Q<sub>29</sub>), and they do not fully trust the information and support that lay educators give patients.<sup>32</sup> They value more positively their own contribution and knowledge in contrast to volunteering, as stated in Q<sub>30</sub> in Table 3. Furthermore, 1 of the reviewed studies reflects that professionals do not sometimes want to work with volunteers,<sup>32</sup> mainly because they consider volunteers a burden, due to the time and efforts required to be spent in order to support them and for cases that had bad previous experiences. Also, they reported that finding individuals who have good skills is a great challenge (Table 3, Q<sub>31</sub>).

For these reasons, volunteers may feel demotivated and dissatisfied, which may lead to negative consequences for the programs.<sup>31</sup> In addition, practitioners who are closely connected to traditional care approaches tended to identify more barriers to integrate voluntary services into daily practice.<sup>32</sup> In consequence, based on the findings retrieved from this review, it can be suggested that patients’ referral to VO CGs seems to be conditioned by personal and professional practitioners’ interests rather than by the program or organization characteristics; credibility, education, or information provided to patients; and patients and illness characteristics<sup>32,33</sup> (Table 3, Q<sub>32</sub>, Q<sub>33</sub>). Another tension between VO CGs and health services lies on the economic sustainability of diabetes self-management programs as formal services may not always fund VO CGs (Table 3, Q<sub>34</sub>).

### Outcomes: Benefits of VO CGs’ Programs

Voluntary services emerge as a good resource for CCs’ self-management education and support,<sup>15,20,24,31,33,36</sup> as reflected in Q<sub>35</sub> in Table 3 in terms of patients’ learning

and autonomy gaining, financial outcomes, coordination between community and formal services, and personal networking.

First, collaborations between the voluntary sector and formal services can result in more effective self-management of the illness due to training based on skills, expertise, and knowledge<sup>31,33</sup> (Table 3, Q<sub>36</sub>). Moreover, the involvement of volunteers in the implementation of diabetes self-management programs leads to improvements in users’ knowledge and skills about their disease and greater feelings of security and sense of illness control and empowerment. This consequently fosters patients’ acceptance of the illness and reactivity in the control of their lives, as stated in the literature.<sup>23,24,27,30,36</sup>

In terms of financial outcomes and coordination between community and formal services, working with nonprofessionals can save time and money to health systems<sup>26</sup> because the limitations professionals face to tackle nonphysical issues or the lack of time to access resources for education could be overcome. Nonprofessionals working with health practitioners can enhance the sustainability of the programs<sup>31</sup> because their initiatives could be integrated in the health policy agenda.

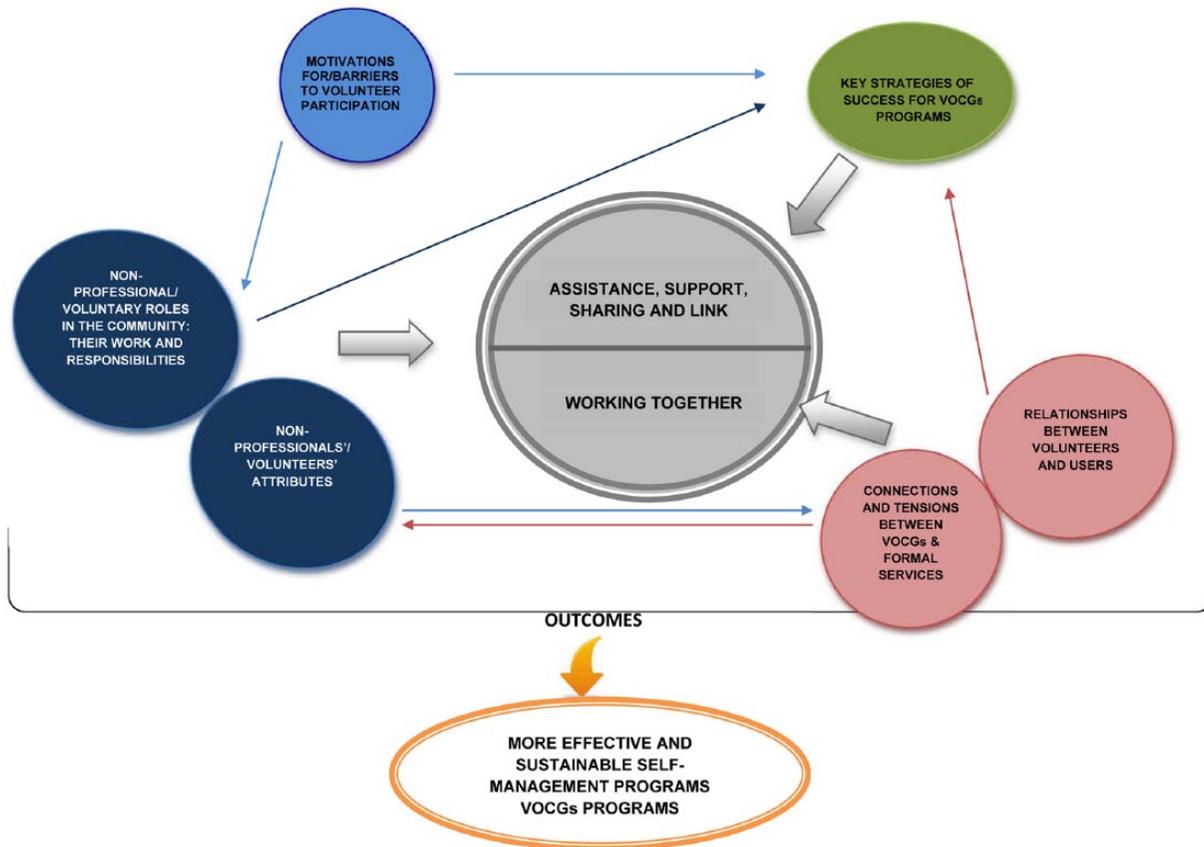
In addition, belonging to a group where people with CCs can share their own experiences and listen to others with CCs can help people normalize the challenges of CCs.<sup>26,28,30,31</sup> This sense of belonging to a group and the volunteers’ attributes reported previously become key elements in the process of change of behavior, improvement of the perception of social support, and adoption of healthy lifestyles<sup>27,28,30,35</sup> (Table 3, Q<sub>38</sub>).

Finally, active user participation takes place in voluntary initiatives and community groups in relation to diabetes self-management as patients adopt active roles and develop complementary and supportive activities such as providing mutual support,<sup>16,20</sup> sharing their experiences,<sup>16,20,26,28,30</sup> involving in organization<sup>16,26,30,35</sup> or planning new activities for the group<sup>16,30,35,36</sup> (Q<sub>39</sub>, in Table 3).

### Synthetic Constructs

Considering the aim of this review, 2 synthetic constructs have emerged from the synthesizing argument,<sup>11</sup> as it is represented in Figure 3.

Following the results of the *synthesizing argument* of this CIS, Figure 3 shows the relationships between the data-driven themes emerging from the analysis of the literature and the synthetic constructs. This figure also



**Figure 3.** The contribution of voluntary organizations and community groups (VOCCs) to providing successful self-management support.

illustrates the transformation of the evidence in a more conceptual form.

Different strategies are needed to develop and implement successful self-management support when voluntary or community groups are involved. In this sense, some predefined success criteria need to be determined and considered so that recruiting and training of people with appropriate qualities and attributes to perform their roles and responsibilities take place safely. This is also essential when it comes to the development of successful relationships between users and volunteers and between volunteers and formal health and social services.

In this sense, motivations for and barriers to volunteering should be also taken into account when recruiting volunteers as these clearly influence how volunteers play their roles and the success of these programs.

Similarly, relationships and relationality between users and volunteers and between VOCCs and formal services determine how they perform their roles and take

advantage of their attributes and again, the success of the programs.

This aforementioned process when developed safely would have positive outcomes as presented previously for both users and health services. Furthermore, this process needs to be ruled by the principles of assistance, support, sharing, and link, which emerged in the literature as the 4 pillars integral to self-management interventions undertaken and promoted by VOCCs. The VOCCs assist people in the management of the diet, physical activity, or medication to cope with CCs; provide support at emotional and social levels, increasing social cohesion; share gender, culture, illness, and life experiences with users; and also are the link between users and community resources and the health care system, guaranteeing the success of the programs.

Finally, working together with other organizations as part of a network to minimize isolation will enable increased dissemination and uptake of programs. Future

programs and research should promote relationships between VOCGs and health systems based on reciprocity in preference to hierarchical relationships or delegation as an essential aspect for successful development of programs.<sup>8,31</sup>

## Conclusions

This CIS provides further evidence of the potential value of VOCGs as partners in the provision of diabetes or other CCs' self-management support based on a synthesizing argument. The small number of papers reviewed and the fact that only qualitative and mixed-method empirical evidence was analyzed could seem a limitation of this review. Notwithstanding, following the CIS method,<sup>11</sup> evidence was included and analyzed until theoretical saturation was achieved.<sup>11,18</sup> Also, some of this qualitative and mixed-method evidence reported on the evaluation of some self-management programs, and the process of review and thematic analysis was continuously validated by the research team.

As stated in this review, nonprofessionals play an important role in improving the quality of life for people living with diabetes or other CCs by providing assistance and support and bridging the communication gap between communities and their health care providers.<sup>19,24,29</sup> This assumes special relevance when it comes to communities where access to health services is limited.<sup>15,20-22</sup> In addition to this, these results are in line with other studies that affirm that the voluntary and community sector plays an important role in the provision of health and social care services for these groups and adds value to health professionals in terms of the resources they offer and the procedures they employ.<sup>8,37,38</sup> In dealing with populations that might have limited access to resources and more generally with the social determinants that might be at the root of those inequalities, a call has been made for intersectoral action with the involvement of government sectors, formal organizations, and nongovernmental players, including informal community groups.<sup>39</sup> The health care sector has been identified as having a role in advocating, monitoring, and mobilizing communities; providing technical support and training; and giving voice to marginalized people<sup>40</sup> so that they could gain autonomy and feel part of a network. In order to fulfill those roles, the collaboration between health professionals and VOCGs would be vital. As a first step in building that collaboration, health professionals should be aware

of the existence and potential contribution of VOCGs to the provision of successful diabetes or other CCs' self-management as suggested by the present review. Furthermore, further organizational and policy support is required to formalize these volunteering initiatives.

Furthermore, this review has uncovered other relevant issues in relation to voluntary roles, the context where they act, and their relationships with the community and health services. More concretely, an unnecessary variety of different names to denominate similar nonprofessional roles has been detected as the goals and work of volunteers seem alike. This could pose a problem not only in identifying evidence to develop diabetes lay-led self-management programs but also when these programs are implemented and evaluated, leading to confusion in professionals and users and to unclear role boundaries at the volunteers–health professionals sphere. A clearer and concise typology of these VOCGs and individual volunteers' roles is needed, as stated by others,<sup>37,41,42</sup> to ensure the transferability of interventions<sup>43</sup> and define and structure their training.

As in previous studies,<sup>24,30,32,44</sup> this review emphasizes that when relationships between VOCGs and health services are built collaboratively, numerous benefits have been identified for both community members and health professionals, particularly where health inequalities exist.<sup>45</sup> Consequently, a horizontal participation in patient care and an equal distribution of responsibilities (patients, volunteers, and health care providers) when designing and implementing lay-led self-management programs are needed. On the other hand, no evidence has been found that shows collaborations between different VOCGs to tackle diabetes challenges. Flanagan and Hancock<sup>8</sup> stated that there are a number of positive aspects in working in partnership, and it seemed to be a priority for a number of the organizations due to the multidimensional and holistic nature of users' needs. Therefore, more research is needed in this area.

Another important issue is the sustainability of voluntary-led diabetes self-management programs. Several studies have shown the effectiveness of voluntary-led diabetes self-management programs.<sup>4,46-48</sup> Moreover, other studies show that the sustainability of these programs could be favored by the development of health policies that ideologically and financially support them.<sup>19,32,43</sup> In this regard, further research is needed to prove how referral pathways can be built between formal services and different types of VOCGs and that one size

does not fit all when it comes to CCs and self-management programs.

## Implications for Diabetes Educators

Implications are that future interventions for the promotion of self-management of patients with diabetes or other CCs need to involve VCOGs. This could make a difference in how diabetes education is delivered rather than in what is transmitted. When it comes to cooperation between formal services and VCOGs in self-management initiatives, volunteers could lead aspects related to the use of resources, practical advice, emotional support, motivation, and socialization, which are also essential to sustain self-management long-term positive biomedical outcomes.

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