

Peer Support Group Model Improves Glycemic Control and Social well being in Type 1 Diabetes Mellitus in India

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Abstract

Aims: The aim of this study was to design, implement, and evaluate the effectiveness of a novel peer support intervention addressing the social needs of individuals with Type 1 diabetes mellitus (Type 1 DM) living in settings where diabetes-related stigma is prevalent.

Methods: A longitudinal cohort study examining 50 participants diagnosed with Type 1 DM was carried out for 36 months at Christian Medical College in India. Participants attended peer support sessions facilitated by a diabetes nurse educator to discuss topics in diabetes management and emotional well being. To assess the glycemic and social impact, HbA_{1c} was measured periodically and a questionnaire was administered.

Results: Mean \pm SEM HbA_{1c} decreased from 86 ± 5 mmol/mol ($10.0 \pm 0.4\%$) at initiation of the study to 63 ± 2 mmol/mol ($7.9 \pm 0.2\%$) at 36 months. 90% of participants noted that the topics discussed were useful and 76% disclosed feeling comfortable informing others about their experience with diabetes. 75% reported believing that diabetes would not prove a hindrance to their educational or work performance.

Conclusions: This study demonstrated a markedly positive improvement in glycemic control and social well-being compared to previous studies featuring similar models of peer support applied in Western settings. This suggests that the setting in which this intervention takes place is critical to its success. Further research into the efficacy of peer support programs implemented in such settings will allow for a more accurate consensus regarding the clinical usefulness and applicability in promoting greater positive outcomes for people with Type 1 DM.

Keywords: Peer support, Type 1 diabetes, India, Social support, Peer group

Introduction

Diabetes has emerged as a major healthcare problem in India with a prevalence reaching epidemic proportions. According to the Diabetes Atlas published by the International Diabetes Federation (IDF), there were an estimated 69.2 million persons with diabetes in India in 2015, and this number is predicted to rise to almost 123.5 million by 2040 [1]. While the majority of new cases are due to Type 2 diabetes mellitus (Type 2 DM), available data suggest that the prevalence and incidence of Type 1 diabetes mellitus (Type 1 DM) are also on the rise, with a 3-5% increase per year [2,3]. Worldwide, one in five children diagnosed with Type 1 DM are of Indian nationality, and within India itself, the prevalence of Type 1 DM ranges from 3-18 per 100,000 children between the ages of 0-14 [4]. This incidence is increasing by 3% per annum especially in younger children [5].

Living with Type 1 DM may be challenging in any country, but particularly so in low and middle income countries, akin to India, where resources are scarce and numerous factors exist that can hinder diabetes management, such as low socioeconomic status, a significant illiteracy rate of more than 25%, and inaccurate perceptions of non-communicable disease management [6-14]. The negative social appraisal is one major obstacle in the management of diseases in many Asian countries, including India. Diabetes-related stigma is particularly severe since Type 1 DM is a chronic and life-threatening condition that can impact numerous important components of a person's life, including dignity, social status, employment opportunities, marriage prospects, family relationships, and friendship [15]. The culmination of these factors profoundly affects not only the physical well-being of individuals with Type 1 DM, but their psychosocial wellbeing, as well. According to the Cross-National Diabetes Attitudes, Wishes

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and Needs Study, of the thirteen countries examined, people with diabetes in India reported the lowest measures of psychological wellbeing, as well as a one of the highest self-reported measures of diabetes-related distress [9]. Of note, people from India reported the lowest adherence to their care regimens. Such low measures of psychological well-being may be detrimental, since good psychosocial health is vital for proper diabetes self-management [16,17].

In recent years, members of the Indian medical community have increasingly recognized this problem, although addressing it has proven to be challenging [18]. One promising concept that has evolved is peer support. Peer support was defined by Dennis et al. As “the provision of emotional appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behavior or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person” [19]. One type of peer support model recognized by the World Health Organization (WHO) is a health worker-led group with peer exchange, in which a group of people with similar health conditions meet together on a regular basis with a healthcare professional to attain unmet social support and educational needs [20,21]. The WHO expressed a need for further research to determine the efficacy of peer support for people with diabetes across different populations, particularly those in low- and middle-income countries, and in fact a number of studies have been published recently that aim to identify best practices in peer support, particularly in Western settings such as in North America or Europe [20,22-24]. However, little research exists that measures the social impact and glycemic efficacy of peer support for people living in settings outside of the West, such as India, where negative social appraisal against diabetes makes it difficult for people to seek support from others and openly follow optimal management guidelines.

We noted poor glycemic control in patients with Type 1 DM attending our clinic and also identified unmet educational needs during individual counseling sessions with diabetes nurse educators. Hence we felt a need to develop an intervention that has shown some impact on improving clinical outcomes of patients with Type 1 DM. We derived inspiration from peer group support models of other chronic diseases with stigma like HIV, etc. This article describes the design, implementation, and evaluation of the first-of-their-kind pilot health worker-led support groups featuring peer exchange for people with Type 1 DM at Christian Medical College (CMC), Vellore, a multispecialty tertiary care academic medical center located in Southern India.

Methods

In this prospective longitudinal cohort study, 50 participants with Type 1 DM above the age of 14 years and who had at least 4 to 6 outpatient Diabetes Clinic visits in the preceding year were recruited from June 2011 onwards. This study was approved by the Institutional Review Boards (IRB) of Christian Medical College, Vellore, [IRB Min no: 9072 (RETRO) dated 24.09.2014] and the Albert Einstein College of Medicine, New York, U.S.A.

The inclusion criteria consisted of the following characteristics: Type 1 DM subjects above the age of 14 years, who have attended at least 4-6 outpatient visits to the adult young diabetes clinic in the preceding year of recruitment, and who have attended peer

group sessions. The following subjects will be excluded: Non Type 1 DM subjects, those with psychiatric illness, and those who attended less than 4 outpatient visits to the adult young diabetes clinic in the preceding year. The sample size in this pilot study was based on the existing patient pool in our clinic.

Group design

Group demographics: The action committee used a registry of people with Type 1 DM to identify potential participants. There were 73 subjects attending the clinic at that time, but 23 patients did not have regular follow up visits and hence were excluded.

Peer groups were formed based on the participant's life stage specific concerns and social needs, as expressed during an initial interview, to ensure that participants could relate to one another and provide emotional support. The groups were characterized as follows: those consisting of students, those seeking employment, those searching for a spouse, those married and awaiting conception, and those married with children.

Session facilitator: A multi-lingual diabetes nurse educator was present at every session to serve both as a facilitator as well as an interpreter for participants that spoke different regional languages. As a facilitator, their role was to maintain the group's structure, promote dialogue among participants, and provide expertise when requested by the participants.

Group location and date: To ensure regular attendance, group sessions were conducted at the CMC Department of Endocrinology, Diabetes, & Metabolism on the morning of the Type 1 DM outpatient clinic. Participants from each group were scheduled to come in for their clinic appointments on the same day, so that members of the same group could be present to attend a peer support session afterwards. Each session was of 70 minutes duration with structure as described in Table 1.

Session topics: A curriculum for the first five sessions was created based on the educational needs of the participants. Each session focused on a singular topic, which were as follows: 1) What is Type 1 DM and why do people with Type 1 DM need to take insulin injections for the rest of their lives?; 2) Nutrition; 3) Physical activity and foot care; 4) Maintaining a logbook of blood glucose, diet, and activity; 5) Social wellbeing. A PowerPoint presentation containing pictorial depictions of these topics was created to accompany each session. Once the initial five sessions were completed, then further sessions were scheduled in which additional life stage specific issues, such as those regarding employment, marriage, and children, were discussed.

Timeline

The study took place over the course of 36 months. A group

Time	Task
5 minutes	Settling in
5 minutes	Introduction
15 minutes	Icebreaker activity
5 minutes	Presentation of case scenario
30 minutes	Group discussion of session topic
5 minutes	Review of main points
5 minutes	Thank group members for attending & evaluation forms
Total: 70 minutes	

Table 1: Peer support group session structure.

session was held approximately every 4-6 weeks, which was the amount of time between participants' appointments at the clinic. The initial five sessions were carried out in the first 12 months of the study; afterwards, additional unstructured sessions were held where participants were free to discuss additional psychosocial issues.

Session structure

Set-up: The participants were invited to be seated in the conference room. The facilitator explained that the purpose of the group session was to provide participants with Type 1 DM the opportunity to meet other people with Type 1 DM, and to share their experiences and ideas about diabetes-related topics in the hope that they could provide educational, social, and emotional support for each other. The facilitator emphasized that all participants would have the opportunity to express their thoughts, and that anything said would remain confidential.

Icebreaker activity: An icebreaker activity was performed during the first group session. Participants were requested to introduce themselves with their name, age, place of residence, how long they have had diabetes, and their hobbies.

Case scenario and discussion: The sessions were intended to be interactive and engaging. Facilitators used a PowerPoint presentation containing images and diagrams relating to the pre-designated topic for that session to guide the meeting. Participants were asked to initiate discussion by first recounting a problem involving diabetes self-management he or she faced recently. Other group members would then provide ideas on how to resolve the issue, leading to a discussion. The facilitator promoted dialogue by periodically asking open-ended questions intended to encourage members to participate and provide their own perspectives. The facilitator also used case scenarios at times to promote dialogue between participants who may have felt uncomfortable talking about themselves.

Conclusion: At the end of each session, the facilitator reviewed the key points for that session's topic, and thanked the participants for attending. Anonymous evaluation forms were given to the participants to provide feedback about their experience that day. During the last session at the end of the 36 month period, an additional questionnaire was administered to assess the overall social impact of these group discussions.

Glycemic impact

(Glycated hemoglobin) was measured using the ion-exchange base High Performance Liquid Chromatography (HPLC) assay method (Bio-Rad Variant II turbo glycated haemoglobin (HbA_{1c}) analyser; CV: 2.6%) to determine the glycemic impact of the peer support groups. The mean HbA_{1c} of the preceding year prior to study initiation was taken as the baseline value, and glycemic status were periodically assessed throughout the study itself by measuring HbA_{1c} levels once every 3-6 months.

Statistical analysis

Statistical analysis was performed with SPSS version 16. The main outcome variables were glycemic impact assessed by serial changes in HbA_{1c} and social support as perceived by the patients at the end of the study [36 months]. Repeated measures ANOVA was used to assess the significance of serial changes in

HbA_{1c} from initiation of the study to 18 months and 36 months following the peer support groups, respectively.

Results

Demographic data

The baseline characteristics of the participants are described in Table 2. The mean age of the participants was 24.4 years (range 14-43 years); with a man to woman ratio of 29:21. The mean duration of diabetes was 12.2 ± 6.5 years. The mean distance travelled by the participants to reach the health center was 45 kilometers (range 3 to 300 km), with an average travel time ranging from 30 minutes to 7 hours.

Three participants voluntarily withdrew by 18 months, and a further five withdrew by the end of 36 months. The predominant reason participants reported for withdrawing was financial constraints that made travelling to attend the support groups every 4-6 weeks difficult. Of the eight participants who withdrew, five remained for HbA_{1c} follow-up at 36 months, while three were lost.

Glycemic status

The mean ± SEM HbA_{1c} at initiation of this study was 86 ± 5mmol/mol (10.0 ± 0.4%). HbA_{1c} decreased significantly to 70 ± 2mmol/mol (8.6 ± 0.2%) at the end of 18 months, and decreased further to 63 ± 2mmol/mol (7.9 ± 0.2%) at 36 months (p<0.005, repeated measures ANOVA) (Table 3). The mean HbA_{1c} at baseline of those that withdrew was 87 ± 11mmol/mol (10.1 ± 0.6%) (n=8), and remained high at 81 ± 14mmol/mol (9.6 ± 1.3%) (n=5) when they participated in a follow-up after the completion of the study.

Response: Feedback at the end of sessions

Most participants provided a positive assessment following the support group sessions. Overall, about 90% of participants felt that the topics discussed during each session were useful and that they enjoyed the introduction and ice-breaker activities.

Characteristics	N (%)	Mean (SD)	Minimum	Maximum
Age, years	50	24.4 (6.8)	14	43
≤15	3 (6)			
16-25	29 (48)			
26-35	14 (28)			
36-45	4 (8)			
Gender	50			
Female	21 (42)			
Male	29 (48)			
BMI	47	20.7 (3.6)	13.7	30
HbA_{1c} at Baseline, mmol/mol (%)	50	10.0 (2.9)	48 (6.5)	162 (17)
43 (6.1) - 53 (7.0)	3 (6)			
54 (7.1) - 64 (8.0)	12 (24)			
65 (8.1) - 75 (9.0)	6 (12)			
7.6 (9.1) - 86 (10.0)	11 (22)			
> 86(10.0)	18 (36)			
Duration of Diabetes, months	50	135.6	40	341
Dec-60	12 (24)	-79		
61-120	11 (22)			
121-180	10 (20)			
≥180	17 (34)			

Table 2. Baseline participant characteristics.

Peer group	Group Concern	Mean HbA _{1c} , mmol/mol (%) ^a				Percentage Change (%) ^b
		Age in yrs Mean±SD [Range]	HbA _{1c} ^a Study Initiation	HbA _{1c} ^a 18 months	HbA _{1c} ^a 36 months	
Whole group			86 ± 5 (10.0 ± 0.4)	70 ± 2 (8.6 ± 0.2)	63 ± 2 (7.9 ± 0.2)	-27 (-21)*
Group 1 [n=12]	Student	17.91 ± 2.7 [14-23]	102 ± 11 (11.5 ± 1.0)	74 ± 5 (8.9 ± 0.5)	74 ± 8 (8.9 ± 0.7)	-27 (-23)
Group 2 [n=8]	Employment	20.12 ± 2.42 [17-25]	107 ± 13 (11.9 ± 1.2)	79 ± 6 (9.4 ± 0.6)	72 ± 7 (8.7 ± 0.6)	-33 (-27)
Group 3 [n=11]	Awaiting marriage	23.64 ± 2.91 [18-29]	73 ± 5 (8.8 ± 0.5)	69 ± 3 (8.5 ± 0.3)	56 ± 6 (7.3 ± 0.5)	-23 (-17)
Group 4 [n=8]	Married with no children	26.12 ± 5.11 [20-36]	68 ± 8 (8.4 ± 0.7)	61 ± 3 (7.7 ± 0.3)	57 ± 3 (7.4 ± 0.3)	-16 (-12)
Group 5 [n=11]	Married with children	33.36 ± 5.43 [26-43]	80 ± 9 (9.5 ± 0.8)	67 ± 5 (8.3 ± 0.4)	63 ± 6 (7.9 ± 0.5)	-21 (-17)
Withdraw n [n=8]			87 ± 11 (10.1 ± 0.6)		81 ± 14 (9.6 ± 1.3)	-7 (-5)

^aData are presented as mean ± SEM

^bValues represent differences between mean HbA_{1c} at study initiation and at 36 months post study initiation.

Statistical analyses were performed on HbA_{1c} data using repeated measures of ANOVA *P<0.005

Table 3. Percentage change in mean HbA_{1c} measurements over 36 month period.

No.	Questions	Response	Percentage
		Yes	%
1	Are you comfortable to ask for diabetes support from your nurse educator?	35	70
2	Do you have a relative/friend to ask for diabetes support?	29	58
3	Are you comfortable talking about diabetes with other people?	38	76
4	Have you told a friend that you have type 1 diabetes?	43	86
5	Do you think that diabetes will affect your ability to do well in school/work?	13	26

Table 4. Assessment of social support at the end of 36 months.

Assessment of social support

A questionnaire was administered at the end of the 36 month period to assess the social impact of the peer support group sessions. Given the participants' initial reticence to disclose their diabetes diagnoses, it is remarkable that 76% now reported that they felt comfortable talking to others about diabetes, and that 86% had informed a friend that they had Type 1 DM. Seventy percent of participants felt comfortable obtaining support from the diabetes nurse educator; and about 58% indicated that they now had a friend or relative who could provide diabetes support. Almost 75% of the participants believed that diabetes would not be a hindrance to their performance in academics or at work (Table 4).

Discussion

Different models of diabetes education programs exist that aim to tackle the issues and concerns people face in diabetes self-management. Peer support is a particularly unique concept due to its emphasis on improving psychosocial wellbeing, something that most models of diabetes education programs do not take into consideration. Peer support provides people the opportunity to openly engage with others who are facing similar difficulties in self-management, as opposed to other models that include only one-on-one discussions with healthcare workers. This permits people to find, and in turn provide, support that will allow them to address their psychosocial needs and in the process improve their Type 1 DM management and quality of life.

Data from this pilot study support this notion. Following months of peer support, the mean ± SEM HbA_{1c} of participants

decreased significantly, from 86 ± 5mmol/mol (10.0 ± 0.4%) to 63 ± 2mmol/mol (7.9 ± 0.2%) by 36 months. This marked improvement in HbA_{1c} closely approximates that achieved in the EDIC cohort [64 ± 11mmol/mol (8.0 ± 1.0%)] [25]. While all groups showed benefit, groups with the highest initial HbA_{1c} (students and unemployed) demonstrated the greatest improvement in glycemic control. Since unemployment negatively affects the wellbeing and quality of life of those with Type 1 DM, thereby hindering the attainment of glycemic goals, such individuals may benefit disproportionately from this peer-support intervention [26].

In terms of social impact, at the end of 36 months, 76% of participants noted that they felt comfortable talking to others about living with diabetes (Table 4). Additionally, 86% of participants had informed a friend of their diagnosis, suggesting that they had overcome their apprehension and fear of others knowing about their condition. Interestingly, although 70% of participants felt at ease receiving support from a diabetes nurse educator, only 58% believed they could receive diabetes support from a family member or friend.

Feedback collected at the end of each meeting provided insight into how participants felt about the content and structure of the group sessions. A few participants noted that, initially, they did not feel comfortable sharing their own personal diabetes-related experiences when prompted. They preferred the use of a case scenario instead as a vehicle through which to approach various topics in diabetes care management. Case scenarios allowed participants to share their experiences vicariously

through the fictitious individuals introduced in the scenario. As group sessions progressed, participants began to feel sufficiently comfortable to incorporate their own first-hand experiences into the discussion. In addition, having the discussions moderated predominantly by the participants, rather than the facilitator, increased participation, enhanced self-reflection, and helped participants feel empowered. Patient empowerment has been found to be critical to successful diabetes self-management by allowing people to better maintain the lifestyle changes necessary for improving glycemic control and preventing negative health outcomes [27,28]. These findings support numerous calls for action for the advancement of psychosocial support for individuals affected by diabetes [9,11,17].

Data from this study suggest that peer support may be a promising intervention with the potential to significantly improve both diabetes management and social wellbeing of people with Type 1 DM. However, results from past research investigating the efficacy of peer support for people with diabetes are conflicting and inconclusive, often suggesting that peer support is ineffective in improving glycemic control. A review by Dale et al., which looked at several studies investigating the use of peer support for people with diabetes, noted that only a few studies demonstrated statistically significant improvements in glycemic control. Of the small number of studies that measured perceived psychosocial support and depression, only about half saw a statistically significant improvement following the use of peer support. Dale et al. concluded that while peer support may have a positive impact on certain individuals, inconsistencies and limitations in the results make it difficult to definitively determine its effectiveness as an intervention for people with diabetes [23].

It is important to note, however, that all the studies presented in the review were carried out in Western settings, namely the United States and the United Kingdom. It is possible that the reason our study demonstrated such overwhelmingly positive outcomes compared to previous research was due to the non-Western population featured, which suggests that the degree of effectiveness of peer support is contingent on the setting in which it is applied. Peer support may be particularly effective in settings in which negative social appraisal against diabetes is prevalent, as is the case in certain areas of India. This type of environment makes it difficult for people with diabetes to openly talk to others about their experiences and the challenges they face, potentially leading to feelings of isolation and shame that can have detrimental repercussions on psychosocial wellbeing. Peer support can prove particularly effective in fulfilling the social needs of people with diabetes by providing emotional support and the opportunity to openly discuss diabetes-related issues, both of which may be lacking in the society which they inhabit. Since diabetes is much less stigmatized in Western settings, people they're likely do not face these types of problems; consequently, they may benefit less from peer support compared to people elsewhere who contend with such societal obstacles. This may explain why past studies focusing predominantly on Western populations have been unable to reach a consensus regarding the effectiveness of peer support. Additional studies focusing on non-Western populations may gather results more in line with our own.

Furthermore, not all of the studies featured in the Dale et al. review utilized a model of peer support featuring face-to-face interactions amongst participants. Peer support models varied

and included the following scenarios: a group of individuals meeting in person, postings on online forums, phone calls with a peer counselor, online group conference calls, and real-time live chat. In addition, not all studies involved a specialist health professional, such as a diabetes specialist nurse or health educator, to facilitate discussions amongst participants; instead, peer leaders or counselors were chosen to moderate sessions. We believe that this life stage based peer support model consisting of face-to-face interactions in the presence of a healthcare worker allowed for a higher degree of interactivity than could have been achieved in other models. This may have helped them meet their social needs better, resulting in significant improvement in glycemic control and social satisfaction that were observed.

Challenges encountered during this study provided an opportunity to strategize ways to improve the organization and effectiveness of peer support models for individuals with Type 1

DM in India. First, given the busy schedules of healthcare workers and participants alike, ensuring the consistent and long-term sustainability of peer groups was a challenge. To address the issue of group attendance, meetings were scheduled on the same day that participants were scheduled to come in for their appointments, thereby sparing participants the need to travel to the hospital more than strictly necessary. Additionally, participants in the same group were scheduled to come in on the same day for their appointments to ensure that all group members could be present at the same time. Furthermore, the design and structure of the groups were allowed to evolve over time to suit the needs of group members; one example of this is how topics discussed during group sessions following the initial five were chosen entirely in accordance with input from participants. Travel was another challenge, particularly for participants who did not live nearby. A few participants were unable to attend all group meetings due to financial constraints that made frequent visits to the hospital difficult to accomplish. A few other participants moved to a different region in India halfway through the study due to marriage, school, or employment; they then occasionally missed subsequent sessions because it was no longer as feasible for them to travel. The problem of irregular attendance could be addressed through expanded access to peer group programs, which would allow participants to join groups closer to where they live, thus alleviating them of the financial and temporal burden imposed by frequent long-distance traveling to distant sites. A third challenge faced was that of language barriers and illiteracy. India is a nation in which several languages are spoken and where a significant portion of the population is illiterate [8]. Our study participants predominantly spoke four languages (Tamil, Telugu, Hindi, and English), and several were illiterate. Due to this linguistic diversity, we took care to find nurse educators who were at least bilingual to lead the group sessions. However, it was difficult to provide written take-home materials summarizing the session's key points in all four languages. It is critical to develop multilingual educational resources so that all participants can have access to written materials, both at group sessions and at home, that they can refer to and use to reinforce what they learn. Lastly, evaluation of the success of these programs remains a challenging endeavor. A written questionnaire was provided at the end of the study to gauge participant feedback on the program, but due to the lack of access to translation services, it was administered in only two languages (English and Tamil).

The facilitator assisted participants who did not speak either of those languages by administering the questionnaire to them verbally. However, this could have led to possible inaccuracies in some of the data gathered. Tools for accurate feedback collection need to be developed in order to better gauge the impact of group meetings.

The results from our pilot program implemented at Christian Medical College suggest that peer group support has the potential to significantly improve social wellbeing and diabetes management of people with Type 1 DM. Combined with an appropriate insulin regimen, a motivated healthcare team, and sufficient organizational and financial resources, peer support can likely prove highly promising, especially when applied to participants living in settings where prevalent negative social appraisal against diabetes makes it difficult for them to otherwise meet their social needs. We believe that our initiative will serve to motivate other health centers to take steps towards implementing similar peer support group models as a tool for empowering their patients and helping them to more successfully manage living with diabetes.

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Novelty Statement

- There is a paucity of research into the effectiveness of peer support for people with Type 1 diabetes mellitus living in non-Western settings where diabetes-related stigma is prevalent
- This is a first-of-its-kind pilot study in which a peer support intervention was designed and provided to patients with Type 1 diabetes mellitus in India in order to evaluate its effectiveness
- Our data suggest that peer support may significantly improve their social wellbeing and glycemic control
- May be reproducible for people with Type 1 diabetes mellitus in low- and middle-income countries.

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