



Peer Support for Type 2 Diabetes Brief

Introduction

Peer support is defined as emotional, informational or practical support provided by one individual to another, usually in a voluntary and non-professional capacity. It can be provided on a one-to-one basis, in a small group, or in a large network. Peer networks have long been formed around health issues. Cancer support networks are common, as are mental health and addiction support networks. Peer networks can be formal, funded and managed such as those offered by health authorities and Self-Management BC, or informal, such as many available on social media sites. Such informal offerings may be completely self-initiated and perpetuated or they may be funded and supported directly or indirectly by a particular private marketing interest.

In the past, peer networks often met at places of gathering such as community centres and churches. However, over the past few decades peer support is increasingly moving online, where social media platforms like Facebook, Instagram, Twitter, and Reddit have removed traditional barriers to the administration of peer networks.

With the proliferation of virtual support networks, there has been a large increase in options for those living with type 2 diabetes who are seeking peer support. The purpose of this brief is to review the evidence related to peer networks, to provide a summary of how they are used in the chronic disease space, and to identify and discuss opportunities to scale their use to improve the lives of those living with type 2 diabetes.

How much do those living with chronic conditions want to participate in peer support?

There is substantial evidence that those living with chronic conditions want to participate in peer support. According to a Pew Research survey, 1 in 4 of those living with a chronic illness have gone online to find others living a similar experience.ⁱ For young people, this number is even higher, with 51% of those 18 to 22 years old saying they have looked online for people with health concerns similar to their own.ⁱⁱ The Pew survey also showed clearly that while patients want to turn to health care professionals for information about things like prescription drugs, for practical advice about coping with day-to-day situations patients want both the support of peers as well as health professionals. When it comes to who is more helpful for providing emotional support, 59% of patients say fellow patients, friends and family are more helpful compared to only 30% who say health professionals.ⁱⁱⁱ

The proliferation of peer-to-peer groups on social media sites also demonstrates a demand for peer connection and support. While Facebook does not publish the total number of groups on the site, an official company press release claims there were over 70 million admins and moderators actively

running Groups with more than 1.8 billion total members.^{iv} Reddit boasts over 100,000 active communities administered and moderated by community members.^v

Finally, many communities have been developing specialized health websites and mobile app ecosystems. A survey of those using the PatientsLikeMe platform, which matches patients to others like them, found 72% of them found the platform helpful for learning about their condition.^{vi}

Can peer support improve the lives of those living with a chronic condition?

As a result of our desire for social connection, most of those living with a chronic condition receive peer support at some point in their journey, and many of them will provide it to others living a similar experience. Peer support and peer networks are also often integrated with the formal health care system, such as cancer support groups operated by BC Cancer.^{vii}

A paper from *Peers for Progress* provides an overarching evidence review of the space and outlines the case for peer networks. It claims that social support has strong evidence as a protective factor in health, and that social isolation has a clear link to morbidity and mortality. It notes that a “one size fits all approach” is not appropriate, supporting the use of networks for niche interests and needs. While overall it is very positive about peer support, it notes that many studies lack the ability to measure the actual impact of peer support.^{viii}

Peers for Progress has been funding research in this space to close this knowledge gap. One such study of peer support for those living with type 2 diabetes found large improvements in 5-year cardiovascular risk factors. The intervention was found to be feasible, acceptable and effective, with 94% of participants stating the program helped them manage their diabetes on a day-to-day basis.^{ix}

Outside of publications led by *Peers for Progress*, researchers and advocates paint an unclear picture of the impact of peer support. While some experts portray peer support in a very positive light, there is also quite a bit of research demonstrating mixed or negative results.^x A large systematic review looking at 25 studies for peer support in diabetes, including 14 controlled trials, found very few of them generated positive results. Only 3 of the 14 trials demonstrated improvements in glycemic control, and few found improvement for other biomarkers. There were a few positive areas. For instance, 4 of 6 studies that measured it found reduced depression among participants, suggesting positive emotional outcomes were more likely than positive clinical outcomes. The authors of this review found that while peer support can help some type 2 diabetes patients, more research is needed to make any recommendations in the space.^{xi}

Peers for Progress were critical of this review. Their key point is that almost all the trials included in the analysis suffered from low participation and engagement of participants, leading to an underestimation of the impact for those who actively participated and received significant “doses” of peer support. This points to a concern that we raise in our type 2 diabetes environmental scan – those interventions help those who are actively engaged, but that many participants fail to engage and many who are eligible completely opt out.

Another systematic review that looked at 13 studies trying to determine if peer support reduced diabetes distress in those living with type 2 diabetes also produced negative results. The authors found that the overall quality of the studies was poor, and a meta-analysis demonstrated that peer support did

not significantly reduce patient distress.^{xii} Additionally, a study looking at a formal type 2 diabetes peer support network including 395 patients found no statistically significant improvements in A1C or other biomarkers at 2-year follow-up, with the authors concluding that at least some patients are unlikely to benefit from peer support.^{xiii} A similar study looking at 337 patients found a 24-month peer support program did not lead to any significant improvement in patient outcomes.^{xiv}

Looking outside of type 2 diabetes, the mental health space is the most developed in terms of both the use of peer support and associated research. Here we again find mixed results. One large literature review found that the literature supports the use of peer support across a wide array of mental health conditions,^{xv} and a systematic review of digital interventions in the space found that most virtual interventions demonstrated acceptability and feasibility and showed some preliminary positive patient outcome for both synchronous and asynchronous virtual networks.^{xvi}

However, two recent large systematic reviews including meta-analyses of peer support in mental health found less evidence to support its use. A 2020 review of the effectiveness of one-to-one peer support in mental health found that while some programs improved psychosocial outcomes, they were unlikely to improve clinical outcomes.^{xvii} A 2021 review looking at group peer support found little evidence they improve clinical outcomes and concluded that widespread integration of these programs into mainstream mental health services could not be recommended.^{xviii} Both reviews noted the poor quality of studies in this space.

Alcoholics Anonymous (AA) is the largest and probably the most widely known peer support program in world. According to the organization, there are over 100,000 Alcoholics Anonymous support groups and more than 2 million global members.^{xix} Because of its incorporation of faith-based elements, AA has historically been seen skeptically by many health professionals. However, it was the peer support program we found with the most evidence of its effectiveness. According to a Cochrane systematic review, 24% of AA participants achieve sustained alcohol abstinence compared to only 14% of those who participate in substance abuse cognitive behavioural therapy. The review also found a nearly 50% reduction in health care costs for those in the program. The authors note that the evidence supports AA's effectiveness across different age and ethnic populations. The authors of an article discussing the implications for clinicians note that such strong evidence of effectiveness for any other program would almost certainly be heralded as a major breakthrough in standard of care.^{xx}

Another specific methodology with supporting evidence is the Stanford self-management model. In this model trained peer facilitators lead individuals through structured, multi-week programs. Studies have found these programs lead to small but statistically significant improvements in chronic disease outcomes including pain, disability, fatigue, depression, health distress and quality of life. They can also lead to increased healthy behaviours and self-efficacy.^{xxi xxii} A meta-analysis looking specifically at type 2 diabetes self-management programs found improvements in glucose control.^{xxiii} However, one systematic review of the space notes these programs are less effective in type 2 diabetes populations with low socioeconomic status.^{xxiv}

While the virtual peer support space is relatively new, we found two relevant reviews looking specifically at virtual networks for chronic disease. The first, a systematic review including 42 studies of social media for chronic disease management, found that 48% indicated some benefit, 45% were neutral and 7%

suggested harm. They found groups focused on social, emotional and experiential support were generally more effective than those focused on patient education, disease modification/management and diagnosis.^{xxv} The second review looked specifically at chronic disease Facebook Groups. It found that research in this space is in its infancy, and that it is not a good fit with traditional research and evaluation methods. The authors conclude much more research is needed to determine if these groups are effective.^{xxvi} A look through the references of these reviews, which we scanned for relevant studies, demonstrates just how little research has been published in the space.

There is some relevant qualitative research in the virtual peer network space. One recent study looked at interactions between peers in virtual health networks to determine how peers were supporting each other. They found that emotional support was by far the most common, but that conversations that began as emotional support often turned to more tangible support.^{xxvii} Another recent study looking at the potential of Facebook to implement chronic disease programming for South Asian British Columbians found that delivery of health information over Facebook is feasible and acceptable for those who are comfortable with social media.^{xxviii}

Finally, one study looked at the space from a different angle and explored how leading a peer support group impacted the peer leaders, who themselves were living with type 2 diabetes. They found being a peer supporter led to much more stable glucose control at both 6 month and 4 year follow up, with the effect growing over time. The authors concluded that the knowledge and accountability associated with being a peer leader resulted in better outcomes for these individuals.^{xxix}

What innovative practices are happening in the type 2 diabetes peer support landscape?

A large part of the push towards digital peer networks has been led by Facebook. We found dozens of Facebook groups related in some way to type 2 diabetes. Many of them are very active. For instance, the *Type2diabetes.com* group has over 100,000 members and hundreds of new posts every day.^{xxx} Other large groups include *Reversing Diabetes Type 2 Support Group* (26k members), *Type 2 Diabetes - Diet Support – Canada* (smaller with 1.6k members but still very active) and *Winning Type 2 Diabetes Together* (40k members). Some of the Facebook groups are private, requiring completion of a questionnaire to join, whereas others are open to anyone wishing to participate. The most common topics discussed in these groups are diet and exercise. Sharing of diabetes-friendly recipes is very popular in most of the groups. Some of the groups provide general advice, whereas others are topic specific, such as helping those with type 2 diabetes adhere to low carbohydrate diets. Some of the groups are operated by vendors and used as promotional channels, whereas others appear to be independently moderated.

Other social media sites such as Reddit and Twitter are also home to type 2 diabetes networks. On Reddit, the largest type 2 diabetes sub we found was *r/diabetes_t2*, with over 14,000 members and dozens of topics discussed every day. As with many Reddit subs, discussion generally takes the form of one member posting a question and other members answering it (as opposed to large Facebook groups in which moderators generally choose topics). Diet and pharmacotherapy appear to be the most popular topics. In addition, Reddit also hosts many other communities in which type 2 diabetes is commonly discussed such as *r/intermittentfasting* and *r/keto*.

On Twitter, networks are much less structured, but we found a number of active related hashtags including #type2diabetes and #T2D. Conversations on Twitter tend to focus on thought leaders in the space, and topics include everything from recipes to clinical trials. The Diabetes Social Media Advocacy account hosts weekly chats about different diabetes topics.^{xxxix}

Outside of social media, there are a host of websites offering type 2 diabetes peer networks. The largest we found is *www.diabetes.co.uk*, a global diabetes community based in the UK that includes both type 1 and type 2 diabetes. The network includes resources, information and an online forum. It has hundreds of thousands of members and is connected to a large Facebook page.^{xxxix}

Beyond Type 2 is based on the very successful *Beyond Type 1* network. It offers a place where those with type 2 diabetes can share their stories, get connected to the community and find resources.^{xxxix} Other websites that promote peer networks include *Diabetes What to Know*^{xxxix}, *Take Control of Your Diabetes*^{xxxix}, and *Diabetes Care Community*.^{xxxix}

There are also hundreds of mobile applications offering chronic disease peer networks. A great example is *Curatio*, a Vancouver-based company that provides peer networks and chronic disease programs led by health professionals. *Curatio* includes a type 2 diabetes reversal program designed in partnership with local BC clinics.^{xxxix} There are also a number of business to business (B2B) service providers in the space such as *Responsum Health*, which provides a platform to create custom peer health networks.^{xxxix}

In terms of what these networks offer, we found a qualitative study looking specifically at the content of diabetes Facebook groups. They found that most posts were associated with sharing of diabetes management strategies and/or providing emotional support. They also troublingly found that 27% of posts were promotional in nature, often providing clinically inaccurate recommendations in promotion of “natural” remedies. We should note that this study was completed in 2010, and we anecdotally saw less promotion on the Facebook Groups we explored.^{xxxix}

Discussion

It is clear that many living with type 2 diabetes seek out and enjoy participating in peer support. While there is some evidence that peer support can help provide emotional support, it remains unclear if peer support can be structured to consistently lead to better health outcomes. Because of the rapidly changing landscape focused on virtual support, it will likely be some time before the true impact of modern peer support can be established. We also don't have a good sense of the financial, social, language and cultural barriers some may face in participating in such on-line communities.

One big challenge is that while most peer networks are informal social media networks, studies tend to focus on formal programs run by health professionals. Formal programs are much easier to evaluate, but we know that people recruited to participate in these studies likely do not have the same motivation as those that seek out programs on their own. Moreover, peer support is necessarily more popular among those who are already motivated to change, and it is difficult to measure the impact on these individuals because establishing a representative control group is very challenging.

In the absence of evidence, we must turn to what experts deem to be best practice, and here *Peers for Progress* appear to be leaders in the space. They suggest that peer networks should be standardized based on function rather than content, and that key functions include:^{xl}

1. Assistance in applying disease management or prevention plans in daily life
2. Emotional and social support
3. Linkages to clinical care such as patient navigators
4. Proactive, ongoing support

While there has been much written about the dangers of virtual peer networks in the health space, such as networks of COVID deniers, we thankfully found type 2 diabetes networks to be generally (though not exclusively) based on good faith attempts to follow evidence-based medicine. This seems to mirror the quality of cancer networks, demonstrated by a study that showed an online cancer forum contained only a tiny fraction of posts that were false, and that false posts were almost always corrected by other members.^{xli} Still it should be noted that Facebook, in response to the misinformation in other unrelated health networks, has changed their algorithm so that it no longer recommends Groups that focus on giving people health advice. It is unclear what impact this will have on the membership of Facebook-based health networks moving forward.

Conclusion

This brief looked at the type 2 diabetes peer support landscape to identify what is available to those living with type 2 diabetes, and how peer support can improve their lives. We found a flourishing space in which the evidence has not yet caught up to the scale it has achieved. It is likely that peer support makes those living with type 2 diabetes feel better, but whether participants experience better clinical outcomes remains an open question. The complex nature of type 2 diabetes management means that peer support in the space may never achieve the same results it has in other health conditions like addictions treatment. We conclude that type 2 diabetes peer support should be seen as a tool to supplement, rather than replace, other proven interventions.

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