Peer Support, Mental Health and Diabetes

Report from the

2017 Peer Support Research Conference of the UM-UNC Peer Support Core of the Michigan Center for Diabetes Translational Research

Michigan Center for Diabetes Translational Research

Peers for Progress
Peer Support Around the World
University of North Carolina at Chapel Hill

Peer Support, Mental Health and Diabetes: Report of a Working Research Conference

University of Michigan-University of North Carolina Peer Support Core Michigan Center for Diabetes Translational Research

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A. Introduction

In recent years there has been increased interest in and attention to the relationships among diabetes and other chronic diseases with varied mental health problems, including depression, anxiety disorders, personality disorders, and schizophrenia. At the same time, research on peer support (provided by community health workers, *promotores de salud,* health coaches, etc.) has shown broad effectiveness in diabetes, other chronic diseases, *and* mental health. Bringing these two trends together offers new directions for improving the care and lives of those with diabetes who often are doubly challenged by a range of psychological problems, from distress directly related to their diabetes, to co-occurring depression and other problems.

The University of Michigan-University of North Carolina Peer Support Core is part of the Michigan Center for Diabetes Translational Research (MCDTR) diabetesresearch.med.umich.edu/Cores_MCDTR.php. It includes Peers for Progress that has been developed at the University of North Carolina since 2008 (www.peersforprogress.org).

One of the Peer Support Core's aims is strengthening a national and international network of researchers developing and evaluating innovative peer support models to help prevent and

manage diabetes. To further this aim, each year it holds a research conference addressing key and emerging issues in peer support related to diabetes. For its 2017 and inaugural conference, we chose how peer support might address the co-occurrence and interplay among diabetes prevention and management and mental health.

Peer Support, Mental Health and Diabetes was organized as a working meeting of leading researchers interested in peer support for mental health problems in diabetes (including, of course, depression but also other mental health problems such as anxiety disorders and schizophrenia). The meeting convened leading experts in diabetes, peer support and mental health as well as representatives from the NIDDK-supported Centers for Diabetes Translation Research. A list of all attendees is included at the end of this report.

The focus of the meeting was to discuss research including dissemination and identify new research opportunities using peer support to address mental health issues across the diabetes care continuum, from primary prevention to advanced disease and complications. Participants met over two days to: 1) Share and discuss current work on mental health in diabetes and peer support to address mental health concerns; 2) Identify opportunities for research in the field; and 3) Identify and discuss collaborative opportunities among attendees.

The peer support workshop was held in conjunction with the annual meeting of the Michigan Center for Diabetes Translation Research in Ann Arbor, Thursday and Friday, May 11-12, 2017.

The Report includes presentations several participants made to introduce themselves and their work and which were especially pertinent to broad issues surrounding peer support, mental health, and diabetes (see Appendix). In addition to those presentations, the Report summarizes discussion of a variety of issues, culminating in research recommendations and opportunities for funding.

Notes from Peer Support Working Meeting

Conceptual Issues in Mental Health and Diabetes

Stage Setting – Critique of DSM-5

Ed Fisher presented a critical overview of current models for categorizing and diagnosing mental disorders as in the Diagnostic and Statistical Manual – 5th Edition of the American Psychiatric Association (DSM-5).[1] According to Fisher, problems with the DSM-5 include overlap among categories such that 50% of those who meet criteria for one category also meet criteria for another.[2] At the same time, categories are amorphous. For example, two people can both be diagnosed with Major Depressive Disorder yet share only one of nine features on which that diagnosis is based. From a cross cultural perspective, concerns have also been raised about validity. The categories may be *reliably* applied in different settings so, for example, investigators in diverse countries can agree on what meets and does not meet criteria for depression or schizophrenia. Reliability, however, does not necessarily confer validity. What is important about depression or schizophrenia in a particular cultural setting may be overlooked by the criteria that have been developed largely on the basis of US research and clinical practice.

Criticisms of DSM-5 have also emerged from more conceptual perspectives. In most categories, there are no identifiable diseases or disorders other than the cluster of symptoms defining them. There is no depression or schizophrenia to treat other than the symptoms that comprise depression and schizophrenia. Additionally, biological bases for disorders are assumed but with discounting of a variety of developmental, socioecologic and psychological determinants. This is naïve vis a vis the enormous amount of evidence that early and later experience influences neurobiology. Indeed, neurobiology may properly be seen as the mediator of environmental effects on behavior, rather than some *sui generis* basis for later behavior.

As an alternative to the DSM-5, Fisher proposed a focus on specific problems, e.g., low mood, disengagement in formerly enjoyable activities, confusing communications, suspiciousness and sensitivity to slights, etc. This would focus attention on specific problems, the level at which most interventions are planned and implemented. Cognitive behavior therapy for depression, for example, does not treat depression but, rather, treats separately the cognitive distortions, interpersonal problems, lack of enjoyable activities and other specific problems that are present in those labeled “depressed” but that vary widely in their presence and importance in individual cases. This would also “chunk” problems in terms more useful to clinicians. The diabetologist and certified diabetes educator are more likely to find useful consultation from a psychologist about a patient’s suspiciousness, hypersensitivity to criticism, and very labile attitudes toward their clinicians than trying to figure out how to treat a patients personality disorder.

Most pertinent to the meeting, problem solving has become recognized as a major theme of many psychotherapeutic approaches to mental disorders. This kind of problem solving is very similar to that which is routine in diabetes self management. This and similar approaches are clearly those that can be implemented by peer supporters. An example was evaluated in a cluster randomized evaluation of cognitive behavior therapy and problem solving for post-partum depression that was implemented by peer “Lady Health Workers in Pakistan.” The intervention reduced depression 12 months after delivery by 50% relative to usual care.[3] Thus, focusing on specific problems and problem solving and other therapeutic approaches to ameliorating them is something in which peer supporters may clearly play a substantial role.

Fisher's critique of the DSM-5 status quo is controversial, as was reflected in the notes from the discussion that followed.

What follows are notes from general discussion about mental health and diabetes and the roles that peer supporters might play in this area. The notes are left in "telegraphic" format to convey the immediacy and interactive nature of the discussion.

Discussion: Current Mental Health Care Paradigm

- It's real world problem-based. My job as a clinician is to identify the problem and deal with it. Does that make the DSM-5 redundant? Do I need that?
- If you take the DSM-5 for what it is, it's very broad categories for slicing up the pie. If someone has the label of depression, you have hunches about what will be useful that may not be useful for another label. Until you talk to them, you don't have a treatment plan. DSM-5 is okay for recordkeeping, a rough guideline, but it doesn't identify what specific treatment to use. The solution doesn't come from the guidelines.
- As a practicing clinician and psychiatrist, we've created a biological specialization. Not happy with psychiatry guild. I've come to emphasize collaborative care so that I can do whole patient care, otherwise you're doing biological psychiatry. Having team care is the solution. Otherwise things are very reductionist. Value-based care and risk contracts with ACOs have been a wonderful opportunity.
- A doctor once said, when I have a patient who's depressed and they become diabetic, I breathe a sigh of relief. When they're depressed, I have pills and good luck. When they're diabetic, they have a whole raft of self-management tools, classes, coaching, etc.
- I'm a big fan of the SCID (Structured Clinical Interview for DSM-5). I do not disavow admiration for DSM-5. I appreciate the presentation of an incorporative model and I agree with that.
    - Historically, we didn't have a concept of big science. Our guilds were tightly defined. Psychiatry was fighting for legitimacy. DSM-5 has helped bring legitimacy. Now we're in a different place.
    - I would not agree with throwing out the scaffolding that the DSM-5 created. DSM-5 is not meant to be a stopping point. It was always in the service of the medical model of finding the biological determinant. Don't need to have exclusivity where there is overlap of symptoms
    - In our history of research in diabetes and depression, we have 30 years of messy data. Having learned some of those lessons, I appreciate our systems of psychopathology. I don't think it's either/or.
- People have seized on the DSM-5 categories as identifying reality. I would really question whether we can understand relationships between diabetes and depression when we have such a broad categorization of depression. We probably have the same problem in diabetes. Two heterogeneous bundles.
- The scaffolding is helpful to use as an interview scaffolding. Is it stigmatizing? They can talk about the symptoms, weave in other things. There's a shared understanding of what depression is. We can follow these things in a "free flow." I'm not thinking about interventions around the DSM-5. But many people don't have the experience to "free flow" so the scaffolding is helpful.

Diabetes and Depression

- Treating depression and diabetes: depression gets better in 2-3 months, helping with habits and lifestyle. The focus shifts, deal with the depression first. Phasing, compartmentalizing, etc.
    - Many people don't recognize depression, want to talk about diabetes first
    - Distress is a great gateway to start talking about mental health
    - How to talk about depression without mentioning depression [Note: Rahman has written well on this development of a cognitive behavior therapy intervention into the "Thinking Healthy" protocol that avoids mention of depression.[4]]
    - How do you write that into a grant?
        - Depression symptoms and diabetes distress

Background Material: Peer Support Addressing Issues of Mental Health, Distress, Quality of Life, including Examples from Chronic Disease Management and Diabetes

(Drawn from: Fisher, E. B., Bhushan, N., Coufal, M. M., Kowitt, S., Parada, H., Sokol, R. L., Graham, J. T. (2018). Peer Support in Prevention, Chronic Disease Management, and Well Being. In E. B. Fisher, L. D. Cameron, A. J. Christensen, U. Ehlert, Y. Guo, B. Oldenburg, & F. J. Snoek (Eds.), *Principles and Concepts of Behavioral Medicine: A Global Handbook*. New York: Springer.)

Mental disorders may be seen as emerging from a complex of biological, developmental, psychological, social and economic disadvantages. Individuals who are disadvantaged with regard to a number of factors in this complex of determinants of mental disorders are at greatly increased risk to develop serious problems in these areas. Thus, an important strategy is to develop interventions that address this underlying complex in order to reduce unnecessary burden of disease and associated costs.[5,6]

There is much reason to think that peer support can be helpful in this. In addition to psychological problems complicating other health problems, they are also themselves the object of peer support. Both the social isolation or lack of a confidant that often accompany psychopathology and distress[5,6] and the general importance of simple social contact and emotional support[7] suggest that simple, frequent, affirming, and pleasant contact from a supporter may be especially helpful to those with emotional distress.

Data support this expectation. A meta-analysis by Pfeiffer, Heisler and their colleagues found a pooled, standardized mean difference between peer support for depression and usual care of -0.59 favoring the peer support.[8] The emotional benefits of peer support were illustrated in a study commissioned by the UK-based Stroke Association. Having a stroke can negatively impact on emotional wellbeing both in the immediate aftermath of a stroke, and in the longer term. In a small-scale study of the Stroke Association's peer support groups, some stroke survivors talked about "loss of the life and the person they were before their stroke." They highlighted significant changes to their personal and role identity, including a loss of independence, and reduced ability to do things they had previously done, including taking care of others in their lives. For these stroke survivors, attending a group alongside supportive peers had a positive impact on their mental wellbeing. This was variously attributed to being among friends, to the creation of a supportive and social group atmosphere and to groups creating a space in which people could make sense of the on-going emotional 'ups and downs' that can follow a stroke.

In a striking cluster randomized evaluation in Pakistan, "Lady Health Workers" implemented a cognitive-behavioral, problem-solving intervention for women who met criteria for major depression during the third trimester of their pregnancies. Relative to controls, the intervention substantially reduced depression 12 months *post-partum* ($p < 0.0001$).[3] In India, peer support for depression, anxiety and other mental health problems included education about psychological problems and ways of coping with them (e.g., deep breathing for anxiety symptoms) as well as interpersonal therapy,[9] all delivered by lay health counselors with back-up by primary care and monthly consultations from psychiatrists. Results included a 30% decrease in prevalence of depression and other common mental disorders among those meeting criteria at baseline, 36% reduction in suicide attempts or plans, as well as reductions in days out of work.[10]

A population based study in the US evaluated Medicaid enrollees who had made a claim for both community mental health and peer support services. A comparison group who had made only claims for community mental health services was matched by gender, race, age,

urban/rural residence, and principle diagnosis. Those who had received peer support were more likely (OR = 1.345) to achieve crisis stabilization than the comparison group, and those who did not achieve stabilization were still less likely to be hospitalized (OR = 0.766).[11]

Peer support also reduced distress and related hospitalizations among adults with diabetes in Hong Kong. The base of the program was, a standardized, systematic model of care[12,13,] incorporating many of the same emphases as Wagner's Chronic Care Model and the Patient Centered Medical Home, e.g., quarterly reports to patients providing appraisal of clinical status and self-management recommendations. In addition, half of participants were randomized to receive telephone based peer support provided by trained peer supporters.

Reflecting patterns familiar to most in health policy and services, patients with elevated levels of depression, anxiety and/or stress, were more likely to be hospitalized (34%) than those without distress (20%). Among the group with heightened distress, the peer support intervention improved distress scores relative to standardized, high quality care alone ($p = .03$) and reduced overall hospitalizations (relative risk = 0.15, $p < .001$), a reduction to the "normal" level of those low on distress measures.[14,15] That is, among the twenty percent of patients with high scores on distress and who account for greatly disproportionate hospital care, the addition of peer support to standardized, high quality clinical care reduced distress and lowered associated hospitalization rates to normal levels.

One of the striking aspects of these results of Chan and her colleagues in Hong Kong is that the peer support intervention was designed to assist diabetes management, not to reduce emotional distress. Yet it had substantial effects on distress and associated hospitalizations. Similar emotional benefits of peer support have been reported by Heisler and Oldenburg and their colleagues in the United States and Australia, respectively.[16] The provision of peer support *per se* may have emotional and quality-of-life benefits, regardless of the particular curriculum or behavior changes the peer supporter is promoting.

Discussion: Effective Practices in Addressing Issues of Mental Health, Distress, Quality of Life

- Integrative role for problem solving and activation for depression
    - Problem solving steps common in all behavioral disease self-management
- Self Control, Self Management, and Problem Solving came out of behavior therapy/behavior modification
    - Ironically, they have been abandoned by much of mental health practice while being widely adopted in chronic care, including diabetes management
- When interviewing peer supporters, test their preconceptions about the condition and what their role would be in that relationship. Process versus content questions. Can we develop better interview questions for interviewing peer supporters?
- Observations on Collaborative Care (e.g., as developed by Katon and his group.[17])
    - Just adding a care manager is a crapshoot. Doesn't always result in outcomes or triple aim.
    - Adding systematic case review reflects the clinical process. Identifying goals and "closing the loop" on a weekly basis promotes focused activities and clinical gains.
    - Collaborative care is a great way to address maladaptive attachment.
    - Peer support lends itself to a team-based approach, as in collaborative care. The team structure of collaborative care provides an organizational niche in which to place peer support.
- Case management benefits the 50% of diabetes patients who may dismiss or discount benefits of diabetes care or be fearful of it.

Discussion: Challenges in Peer Support and Mental Health and Good Practices for Meeting Them

- Loneliness can be fundamental
    - "Being there" is a fundamental value of peer support; it addresses loneliness
    - Peer support also provides a sense of belonging to community.
- Surveys of programs associated with Peers for Progress identified "bossiness" as a common problem and one which it is difficult to change.
    - Bossy, naggy peer supporters will fail
    - Emphasizing "being there" might be a strategy for discouraging "bossiness" among some peer supporters. Bossiness can result from a feeling of responsibility to "fix problems." Emphasizing "being there" might reduce the sense of responsibility to fix and the "bossiness" to which it may lead.
- There is value in an egalitarian peer support model (reciprocal peer support) in which peers both give and receive support.
    - Reciprocal peer support complements structured group activities
    - Does not work for everyone. Michele Heisler and colleagues reported success with those with diabetes[18] but not so with heart failure.[19]
    - Reciprocal support may require a level of energy that is not a problem for those with diabetes but is for many with heart failure

- Characteristics of successful peer support
    - Social comparison theory and peer coping models: People who have struggled do better as coaches.[20]
    - From perspective of modeling: "Peer Coping" model ("I struggled but I made progress") better than mastery model.[21]
- Importance of peer support being attractive to people. People don't want to go to a clinic for support services, they want peer support to be an enjoyabl experience.
- Challenge of ongoing support and follow up: how to sustain these efforts after the research team goes away.
- Recognize that all the content is behavioral skills. Sometimes clinicians ask for diabetes content and we provide that on the side. But no one is asking how the pancreas works.
- Great resource in sharing among peer supporters and program managers.
    - E.g., when one staff is much better at recruiting participants than others, get them together to share strategies
    - Bringing groups together to share both provides good ideas to programs and energizes and motivates the peer supporters and the managers
- Have to adapt US truisms about roles, autonomy, reciprocity, etc. to differing cultures.
    - For example, in India, people are used to didactic education system and power hierarchies.
    - If you don't respect the organizational structure, you will bump into it. You have to use the hierarchical structure as part of the intervention.
    - If they have a leadership position in the church or a management position in a workplace, they can't not be the leader or manager.
- Additional characteristics to be considered in maximizing reach and effectiveness of peer support:
    - Proactive outreach
    - Flexible and sustained follow up
    - Sound behavioral training and skill
    - Promote trust
    - Strong community presence and links across a range of health and community organizations

Discussion: Common Problems in Peer Support Interventions

- People with insecure attachment style are less likely to participate, but if you can get them to uptake, they benefit more from the intervention. Key may be consistency and not "getting ahead" of people by intensifying the relationship beyond what they ready to engage.
- Clinical inertia and the challenge of motivating individuals
- May intensify treatment now "as a bandaid" that we can remove later
    - Challenge of motivational strategies for patients that can fit into routine clinical encounters
- Changing how people think is the hardest thing.
    - E.g., around women's issues, "my husband doesn't let me go to the clinic because the doctor is a man"
    - Intimate partner violence; there may be limited or no awareness that this is not okay.
- Cost may or may not be a key factor for decision makers
    - With substitution of services and less utilization, costs of the program are trivial relative to overall system costs.
    - Present peer support as a way of making care management more efficient

Research Recommendations

Research questions and topics for investigation

1. Where does Peer Support best fit and how in the treatment of different mental health conditions? Does it vary by condition, and if so, how?
2. What are optimal combinations of different modalities of professional and peer support?
3. What is the comparative effectiveness of peer supporters compared with other care team members? How does this vary depending on role peer supporter plays and condition treated?
4. What is comparative effectiveness of different models of integrating peer supporters into the care team?
5. What are the mechanisms by which peer support may be effective for adults with diabetes and co-morbid mental health conditions? Again, does this vary by different condition? What are mediators and moderators of effectiveness?
6. Who benefits from different types of peer support models and combination of peer support with different types of care team and model?
7. What are characteristics of effective peer coaches and peer dyad matches in peer support models for diabetes and co-morbid mental health conditions? How are these the same or different from emerging evidence on this from current studies on peer support in diabetes?
8. Many current 'peer specialist' programs seek to match on mental health problems. How important is this?
9. How are peer supporters for adults with co-existing diabetes and mental health conditions best recruited and trained?
10. What are barriers and facilitators to and effectiveness of the implementation of peer support models in real-life clinical and other settings?
11. What is comparative effectiveness of different frequency and duration of peer supporter contacts?
12. What is comparative effectiveness of different modalities and combinations of modalities of peer support (e.g., face-to-face, phone, email, text, social media, web)
13. What is effectiveness of virtual forms of peer support?
14. What are ways to provide support for peer leaders/educators?

Evaluation tools and approaches

1. What are key processes and outcomes that should be measured across interventions?
2. What are best approaches to measure fidelity?
3. What are new technological approaches to assess fidelity to behavioral counseling approaches such as in motivational interviewing (e.g., technology that identifies whether peer support is using motivational interviewing tone, percentage of time talking)
4. How best to assess training, follow-up support, and fidelity to intervention?
    a. What is the balance between initial and follow up training?
5. What are the key outcomes that we should all be looking at?
    a. Need to compile and share measures of social determinant scales
    b. Need to develop an Inventory of validated patient-reported and other measures to make available and recommend to peer support researchers for Peer Support Core
6. Consider Research Domain Criteria, "endophenotypes" and other alternatives to DSM-5 in characterizing mental disorders for research purposes.

Directions for Funding

An aim of the Peer Support Core is to help applicants apply for grants if they are using peer support and evaluating outcomes. NIH is very interested in psychosocial behavioral issues and comparative effectiveness studies on how best to address these. Health equity, addressing disparities, advancing implementation science are strong interests. There are a number of NIH mechanisms to consider for applications:

Pamela Thornton presented an overview and answered questions regarding opportunities for research around peer support, mental health and diabetes.

- NIH is very interested in psychosocial behavioral issues
    - The topic is identified in various FOAs across Institutes
    - It is relevant to Dr. Thornton's portfolio that focuses on implementation science, health equity, disparities
- Practicality, innovation, and cost are important issues for translational and dissemination research
- Emphasis on integration of existing systems (staff, electronic records, etc.) in research proposals to promote rapid adoption and sustainability within the health care system after the funded project period
- Natural experiments are a growing interest at NIH and CDC
- The Time-Sensitive FOA involves a rapid peer review process by the NIDDK and represents an innovation because the time from submission to award is approximately 3-4 months
- What kinds of things have we been funding (examples):
    - Encouraging mail order pharmacy use to improve outcomes and reduce disparities
    - The Alabama Care Plan: Assessing the impact of regional care organizations on diabetes outcomes in a sample of Alabama Medicaid recipients
    - Large scale program to evaluate built environment on physical activity
- Implementation science, health equity, disparities and behavioral issues in diabetes are of interest for career development and training applications. However, currently, most applications submitted to NIDDK focus on basic science
- Question: What is the definition of pragmatic trials? Are large scale settings with large sample sizes required? These can be quite daunting for investigators.
    - Answer: Pragmatic trials must include integration within a healthcare system (making use of existing staff, resources, etc.) and testing the intervention in which it would be implemented. Using the healthcare system as a recruitment site only is not acceptable. Strong letters of support are encouraged from leadership within the healthcare system indicating the intervention will be adopted should the trial show positive findings. The Pragmatic Healthcare program includes an R18 (full scale trial) and companion R34 (pilot and feasibility trial to prepare for an R18). For the R18, samples sizes vary; however, a detailed power calculation must be provided. A fully-powered trial is not required for the R34.
- With particular reference to costs, effectiveness, adoption, there is growing interest in peer support.
- The R18 lends itself to peer support studies. The challenge is to show feasibility that the system would actually use peer support resources/intervention as part of sustainable staffing instead of an adjunct resource in the community that may or may not get utilized.

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