

COMMUNITY AND SCHOLARS UNIFYING FOR RECOVERY

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A convergence of events led to a remarkable partnership. It began in 2001 when The University of Texas Health Science Center at San Antonio School of Nursing (UTHSCSA-SON) demonstrated its dedication to developing young researchers by creating a Research Scholars seminar. This seminar is held Fridays at noon at the School of Nursing with research scholars and research faculty joining in discussions, presentations, and instruction in current research projects, themes, and conference preparation. In its fourth year, this seminar became a learning environment for Community-Based Participatory Research (CBPR) and Student Service-Learning. The purpose of this paper is to share with you the steps we took on this journey in creating a project partnership among the Research Scholars and the Prosumer Group. It is our hope to provide an example of a successful partnership that began with a foundation built on mutual respect, trust, integrity, and honesty.

In 2005, the School of Nursing opened its doors to the Prosumer Group, a group of people diagnosed with psychiatric disorders that are proactive in their recovery and are giving back to their community. The

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monthly three-hour Prosumer meeting starts with a seated lunch where members exchange information in order to establish natural supports in the community. Information exchanged includes things like where to find a dentist that uses a sliding scale, who is up at 2:00 in the morning and doesn't mind phone calls, how to access social services that really make a difference, and so forth. The group becomes "family" by celebrating birthdays and other events. The group then moves into the main room, and for the next two hours participates in an empowerment meeting designed to build resilience in life. The subjects range from learning about making choices, to the benefits and practice of laughing, to the interconnectedness of all. Sometimes there are guest speakers, such as the state representative who shared how to talk with legislators, the medical director for the state, and the chair of psychiatry at the University of Texas Health Science Center at San Antonio. Participants are strongly encouraged to vote, to take a stand on issues, and to speak out about their experiences. Speaking out about thoughts and experiences is incredibly empowering.

The Prosumers meetings and the Research Scholars Seminar both meet at noon on Fridays in the School of Nursing. Janna Lesser, Ph.D., R.N., is a faculty member involved with the Research Scholars who saw an opportunity for mutual benefit through a research partnership between UTHSCSA-SON and the Prosumers. Dr. Lesser and other faculty serving as mentors for student research scholars asked the question, Could the coincidence of meeting time and place make it logistically possible to develop a partnership of students, faculty, and Prosumers that would support the research capacity building goals of all groups? Prosumer directors were invited to attend a research seminar, and following introductions and a brief presentation of content the question was posed. The content defined research capacity building, CBPR, and service learning. The resulting discussion led to the formation of a partnership between the Research Scholars and the Prosumers. The project that evolved from this partnership is "Exploring the recovery outcomes of an empowerment approach to peer support among Prosumers." This project utilizes CBPR in combination with Student Service-Learning; Janna Lesser is the sponsor of the Prosumers UTHSCSA-SON partnership.

COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

Community-Based Participatory Research, is defined by Israel, Shultz, Parker, and Becker (as cited in Blundo, 2004) as:

a collaborative, partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process.

Partners contribute their expertise and share responsibilities and ownership to increase understanding of a given phenomenon, and incorporate the knowledge gained with action to enhance the health and well-being of community members. (Israel, et al. 2001, p. 184) Participating research differs from community-based research in that it involves the community partners at all levels, whereas community-based research merely refers to research conducted in the community.

The CBPR approach to research provides an opportunity to take academia to the community and bring the community to academia. The community benefits from research technology and rigor brought to bear on its endeavors, and academia benefits from the reality of settings that are not controlled environments. This approach also eliminates the lag time between research and community implementation.

STUDENT SERVICE-LEARNING

Student Service-Learning is “a teaching and learning approach that integrates community service with academic study to enrich learning, teach civic responsibility, and strengthen communities” (National Service-Learning Clearinghouse; NSLC, 2004). While service-learning is beneficial to the students involved, this unique combination of service-learning and CBPR is meaningful and valuable to all partners. The partners must learn to work together as a team to incorporate academia with community service in a way that is mutually beneficial.

Service-learning is highly effective in that it incorporates all of the learning styles—auditory, visual, and kinesthetic—we have as human beings, which ensures that the students internalize a lasting body of knowledge and experience. It provides the rich and dynamic aspects of research with the traditional theory and methodology learned in settings that are more traditional. It also provides a platform for exploring the myriad ways nursing interfaces with communities and enriches their health outside of the traditional clinical setting.

THE PROSUMER PROGRAM

The Prosumer Program is a result of the remarkable resilience and creativity of Janet Paleo and her struggle to recover from her mental illness. After a two-year hospitalization at the age of 29, her life seemed over. She was told she would never work, never go to school, never be able to raise her daughter, never have a significant other, and never hold a baby—never, never, never. These same things are told to consumers

of mental health services all the time. For nine years, Janet confined herself to her home as much as she could to avoid further hospitalization. During that time, in spite of having multiple hospitalizations, she continued to be highly suicidal. Janet began volunteering at her local community center and began to learn more about the public system and recovery. She started speaking out about the experiences of people diagnosed with a psychiatric disorder on local advisory committees and boards. In the process, Janet gained recovery and a passion that fuels her life. She traded her suicidal ideations for advocacy. As she rose as an international speaker, she found that other consumers in recovery had similar experiences. One of the key concepts was that of giving back. Volunteering to help others, getting outside one's self, changing one's focus toward the world outside, these were experiences shared by all the consumer survivors with whom she spoke. This also was Janet's experience, but as she looked at the mental health system in Texas, nowhere did she see anyone encouraging people to volunteer or to give back. So she started a group she called Prosumers: People who wanted to be in recovery by giving back to others. Being a Prosumer is what you do, not who you are.

In a short three years, the Prosumer Group has grown to over 300 members with 50–70 attending the monthly meetings. The most common reason that people stop coming is because they have gone to work or returned to school. The demand is high for an evening Prosumer meeting so that working Prosumers can continue to participate in the meetings. The Prosumers have experienced firsthand that "Recovery is Possible!"

THE PROSUMER-RESEARCH SCHOLAR PARTNERSHIP PROJECT

The specific aims of The Prosumer-Research Scholar Partnership Project are: (1) to describe the dynamics of the group, (2) to identify patterns of information dissemination and mutual peer support, (3) to monitor and record the self-reports of recovery and well-being from the participants, and (4) provide content summary of presentations and any perceived effects on the participants.

This research study uses the ethnographic strategy of participant observer methods. Trained Research Scholar students and Prosumer group members are actively participating in and observing the Prosumer Meetings. Participant observation is a method in which a researcher takes part in the daily activities and events of a group of people as one of the means of learning the explicit and tacit aspects of their life routines and of their culture (DeWalt & DeWalt, 2002).

Field observations are recorded on site onto templates and, within 24 hours, input into computer files for later data analysis. Content analysis techniques are used for the coding of categories and the identification of themes. Field-note data are read and reread, coded, and broken down into data segments. These data segments are then sorted into clusters and according to the emerging categories, reexamined and combined into themes. The Prosumers verified the validity of the data.

During the preliminary observations of the group processes during the Prosumer meetings, Research Scholar faculty identified that the program philosophy is congruent with the theoretical framework of Aaron Antonovsky, who coined the term salutogenesis. Salutogenesis is derived from the Greek “salut” (health) and “genesis” (origin). Salutogenesis focuses on factors that support human health, well-being, and the origin of health rather than the origin of illness and disease. Antonovsky described health as a movement in a continuum on an axis between total ill health (disease) and total health (health-ease). Key elements of salutogenesis are “the orientation towards problem-solving and . . . the capacity to use the resources available” (Lindstrom & Eriksson, 2005, p. 440). A person who has this ability to take in the whole situation and move towards the health-ease end of the continuum is seen as having a Sense of Coherence, a sense of comprehensibility, meaningfulness, and manageability. According to Antonovsky, salutogenesis is not “limited by the disciplinary borders of one profession but rather an interdisciplinary approach and a question of bringing coherence between disciplines . . . it is not only a question of the person but an interaction between people and the structures of society” (Lindstrom & Eriksson, 2005, p. 440). This framework of salutogenesis is evident in the meetings and the outcomes of the Prosumers. The voices of the Prosumers give an idea of the salutogenic nature of their recovery:

“They have the ability if they enter that program . . . to understand that they will be able to help themselves through helping others; it does work because I’ve seen it work.”

“People trusted me even though I had a diagnosis.”

“That’s the best medicine there is, support and love.”

“I’ve never heard an unkind word said at a Prosumer meeting to anyone or about anything; it’s been very, very positive.”

“The Prosumers are there with you to go forward. They help me and they are also helping themselves. I like that!”

“Recovery is possible!”

These words of the Prosumers are just a few examples of the evident Sense of Coherence that is displayed by the members during the

meetings, during their recovery, and during their empowerment of each other.

It is important to emphasize that in the Prosumer-Research Scholar Partnership Project the community partners have been fundamentally responsible for the research design. They are full participants in the collection of data as participatory observers, along with Research Scholar participants, and they are researchers as well as participants in the study. This means that they actually conduct and inform the research at every stage through Prosumer representatives actively involved in each process, including data coding and analysis. Additionally, the group as a whole will be instrumental in interpreting the data.

COMMUNITY PARTNER EXPERIENCE

Initially, the Prosumer Group representatives were wary of the proposal to do research with the group. It was explained that people diagnosed with psychiatric disorders have the experience of being watched, prodded, and studied all the time, and that the Prosumer Group exists, among other reasons, to redress some of the damaging effects of the objectifying experience they have with health professionals. Given this underlying trepidation, it was extremely important that the faculty and the students build relationships with the Prosumers. One of the conditions the community partners put on the relationship was that those involved in the research from the School of Nursing would become members of the group and fully participate in their monthly meetings. Over time, the Research Scholars began interacting in the meetings as full members. During this process, the Prosumer representatives continued participating in the Research Scholars' classes and began developing a relationship based on mutual respect and admiration. In order to address some of the concerns about being part of a research project, the partners agreed to have one of the Prosumer leaders be the primary investigator for the project with one of the faculty as co-investigator to facilitate interactions in the academic setting. Additionally, the methodology was developed to include full Prosumer participation in determining data collection, data coding, and data analysis.

This structure addressed the concerns voiced by the Prosumers and had the added effect of solidifying the full partnership of the parties. A collegial relationship arose based on mutual respect and understanding. This goes a long way in building research capacity within the community as it shifted their perception of both research and researchers.

STUDENT EXPERIENCE

This journey has been a one-of-a-kind experience for the Research Scholars and has been a springboard for their inner growth. The following are some of the insights students gained from this endeavor as they relate to academics, civic responsibility, career goals, and their personal viewpoints:

Through this Service-Learning/community partnership, I was introduced to a different way of learning in which the information that would normally be taught and read was, instead, heard and seen. It was reality; it brought everything into perspective for me.

During the long road to IRB approval, many of the research scholars used the time to gain entry and familiarize themselves with the group by attending the monthly Prosumer meetings.

Through Service-Learning, we, the scholars, have entered a path to becoming competent investigators, while at the same time, developing better communication and social skills with vulnerable populations.

This experience has ignited something within me that can only be defined as civic responsibility. Not only has this experience woven my desire to help people on a large scale with my newfound love for research, but it has also brought me closer to a level of self-actualization. I envision myself utilizing nursing research to contribute to the well-being of many people living with chronic illnesses.

This experience has reinforced the power of community support. What a blessing it is to be surrounded by those that are committed to making a difference in the lives of others! It makes me remember Margaret Mead's famous quote, "Never doubt that a small group of committed citizens can change the world; indeed, it is the only thing that ever has."

I've always wanted to be a servant of the public in my profession. Being a nurse will allow me this opportunity, and this experience with our community partners has made me proud of my decision.

I feel that being a part of the research scholars has opened my eyes to the need for more nurses to work with vulnerable populations, such as the Prosumers, to provide for a better community.

These student reflections are indicative of the gratitude felt for being fortunate enough to be a part of this Student Service-Learning-CBPR experience. This experience has broken through the stigma our society

has for persons living with a mental illness. The students involved represent typical members of society, and they have come to realize that persons living with a mental illness are just people, people with hopes, dreams, and the right and will to live their lives just as everyone else. This lesson learned is indeed valuable and will be carried forward by all students involved, in their lives and careers.

IMPLICATIONS FOR NURSING RESEARCH, EDUCATION, AND PRACTICE

In working with communities, it is important to recognize the importance respect and trust play in forming collaborative research partnerships. The communities should be involved in every aspect of the research process, from beginning to end. Furthermore, the partnership detailed here demonstrates the positive impact this model can have on the overall training of nursing students. It allows them to take what they learn in an academic setting and immediately apply it to the communities they will work in. This leads to internalizing what they learn through practice, while realizing the benefit of working in the community.

CONCLUSION

Though the study is still in progress pending further data collection and data analysis, it is evident that there have already been noteworthy and lasting effects on the parties involved. From our early interpretation of this ongoing study, we believe integrating Student Service-Learning and Community Based Participatory Research is mutually beneficial to students and community partners alike. What is even more important is what we have derived thus far from the experience, that is, establishing trust and partnership, mutual care and respect, and enrichment of all involved. These are essential in creating a rich environment for learning and service in academia and the community.

In our estimation, what has been proven by this research project is that Student Service-Learning combined with CBPR yields a better-equipped and transformed nurse. Additionally, it yields a community empowered to show efficacy and equipped with tools to provide ongoing development and improvement through research. In the end, we are all just people trying to survive in a world filled with stigmas, stereotypes, and disparity. What we hope is that we can make a difference by working together, learning from each other, and by respecting and embracing all

that makes us who we are. Through partnership and learning, we will make that difference.

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