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Partnership with consumers to improve research dissemination

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Abstract

Evidence-based treatments are often poorly integrated into community care because of challenges with research dissemination and implementation. This article reviews barriers to research dissemination and describes the leading theoretical frameworks and strategies to encourage active dissemination. The growing role of consumers in healthcare is examined along with the importance of consumer feedback and collaboration; the potential benefits of consumer leadership roles in the dissemination process are highlighted. The concept of patient-centered care and research is introduced as a model to promote researcher-consumer collaboration. The article describes approaches and strategies to develop a meaningful partnership with consumers to improve research. Lastly, we present examples of lessons learned from a patient-centered research project involving the partnership between mental health researchers and parent consumers of mental health services. We provide details on the collaborative process relating to project planning and implementation and offer recommendations about how to strengthen this type of collaboration.

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1. Introduction

There are considerable barriers to clinical research dissemination. Research funding prioritizes treatment discovery over strategies to improve treatment dissemination and implementation, and traditional dissemination strategies are generally passive (e.g. presentations at scientific conferences) and ineffective (Glasgow et al., 2012). The recent shift in health care and clinical research towards "patient-centered" approaches offers opportunities to engage and partner with consumers in the dissemination process. This article provides an overview of leading theoretical frameworks to enhance active dissemination as well as a discussion of the challenges and barriers to this process. Strategies to collaborate with consumers on research dissemination are discussed, and collateral benefits of empowering these stakeholders in this process are highlighted. Finally, we present on "lessons learned" about collaboration with consumers from completing a Patient-Centered Outcomes Research Institute (PCORI) funded study involving a research partnership with parent consumers of child mental health services.

2. Challenges to dissemination of evidence-base treatments

Dissemination refers to "the targeted distribution or spread of information and interventions to specific public health and clinical practice settings." (Tinkle et al., 2013) Dissemination and implementation strategies are needed not just for new treatments but also to improve utilization of existing treatments for common conditions. For example, only about half of individuals with hypertension are being successfully treated, despite extensive evidence-based treatment options to manage this condition (Glasgow et al., 2012). Community stakeholder involvement is strongly recommended to enhance dissemination (Brownson et al., 2013), although consumer involvement is often overlooked or added late in the process.

There are several challenges to dissemination of clinical research in community care settings. Evidence-based treatments may be perceived as inflexible and overly complex (Nelson et al., 2006), and both providers and patients may have concerns that strategies used in research studies are not practical or effective in community care. Introduction of new clinical approaches or treatments may also require considerable investment of time and resources for implementation. For example, strategies to improve care with electronic medical records (e.g. implement flags/alerts to address unmet health needs) may require system-wide changes, including performance measurement systems, focused strategies to address specific patient populations, and consultation with clinical researchers to study outcomes of changes (Kupersmith et al., 2007). Finally, there may be very different perspectives between researchers and consumers of community care in terms of their preferences for care and how they assess quality of treatment. For example, researchers may prioritize specific patient outcomes to judge quality of care (e.g. measurement of symptom reduction) whereas consumers may prioritize outcomes related to the doctor-patient relationship (e.g. "more attentive care is better care") (Carman et al., 2010).

3. Theoretical framework for active dissemination

The US National Institutes of Health (NIH) funded 76 dissemination and implementation projects from 2005 to 2012, and the two theoretical frameworks most commonly cited in funded projects are the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) and the Rogers' Diffusion of Innovations models (Tinkle et al., 2013).

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The RE-AIM model was first described by Glasgow et al. in a 1999 publication. The first component, Reach, measures individual-level participation of a defined population. This model emphasizes the importance of studying non-participants as well as participants in order to better understand how dissemination can be adapted and enhanced. Adoption refers to the "proportion and representativeness of settings" (e.g. number of clinics) that utilize a new treatment. Again, the authors emphasize careful attention to non-participating sites to identify barriers to dissemination. In addition to emphasis on effectiveness and implementation of treatments, the model underscores the importance of monitoring sustainability by long- term maintenance of behavior changes. Although the RE-AIM approach is cited in grant applications, the developers of this approach point out that research protocols often do not include attention to all five elements, highlighting the challenges in developing comprehensive dissemination strategies (Kessler et al., 2013).

The Rogers' Diffusion of Innovation Theory groups individuals in a society based on their attitudes towards a new process, idea, or technology; namely innovators, early adopters, earlier majority, later majority, and laggards (Zhang et al., 2015). The stages of diffusion at the individual level are characterized as knowledge, persuasion, decision, implementation, and confirmation (Doyle et al., 2014). The process of adoption is conceptualized as occurring through an initiation phase (agenda setting), decision, and implementation phase (Doyle et al., 2014). In the final stage, there is an opportunity to further redefine changes and shift to routinizing or fully incorporating a change in a system.

4. The role of consumers in supporting dissemination strategies

There are several advantages of engaging and collaborating with consumers in the dissemination process. Traditional research tends to focus on narrowly defined questions developed by academicians that do not necessarily address the needs or concerns of community care stakeholders (Kuo et al., 2015). Consumers can support dialogue on the relevance of new discoveries to local communities and additionally help to adapt evidence-based treatments to be "culturally relevant" before implementation occurs (McDavitt et al., 2016). Consumers can also help develop and provide feedback on dissemination materials to ensure that communication is clear and addresses the priorities of patients.

Changes in the research process are needed to support a stronger partnership with consumers in dissemination. First, consumer input optimally should begin at the level of research design. Consumer feedback and collaboration at these early stages of investigation can help support researchers to develop questions that are relevant to patients. This partnership requires opportunities for cross talk between researchers and consumers/consumer representatives, a cultural shift in which patients are valued collaborators rather than simply consumers of research findings, and training of both researchers and patients so that they have a shared language and process how to discuss research. Sacristan et al., (2016) advocate for greater transparency of the research process and findings to consumers, and suggest that information for consumers should be available in the same vehicles that are utilized by academic scientists (e.g. consumer information in medical journals).

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5. Patient-centered approach

Engaging and collaborating with consumers on the dissemination process is part of a larger movement to amplify the voice of patients in shaping healthcare. The concept and definition of a "patient-centered" approach continues to evolve for clinical care and research. Bardes (2012) reviews the history of the term "patient-centered medicine" and identifies this term was first used in 1969 to describe a new psychotherapy intervention that was framed in contrast to the traditional approach of "illness-oriented" care. One influential report by the Institute of Medicine (2001) entitled "Crossing the Quality Chasm: a new health system for the 21st century" defines patient-centered care as "care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." Berwick (2009) identifies three maxims for "patient-centeredness" as "The needs of the patient come first;" "Nothing about me without me;" and "Every patient is the only patient." These statements reflect a considerable shift from a more traditional view in which the expert provider has sole authority and control over care. The European Association on Communication in Health Care and the American Academy on Communication in Healthcare have been instrumental in developing resources to improve training of clinicians on patient communication strategies in the context of this new approach (King and Hoppe 2013).

Consumer engagement in research is a process with the ongoing goals of 1) developing a collaborative relationship with researchers and other related professionals; and 2) improving patient care (Carman et al., 2016). Community-based participatory research structures the dissemination process with a meaningful "two-way dialogue" between consumers and researchers about research findings (McDavitt et al., 2016). McDavitt et al. (2016) advocate that consumer engagement should be a thoughtful and active process that should include planning, outreach, content development, interactive presentations, and follow-up.

The definition of patient-centered research has recently been shaped by the enactment of the Patient Centered Outcomes Research Institute (PCORI) by the Affordable Care Act. PCORI defines patient-centered outcomes research as investigation which "helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options," and identifies 4 key patient-centered questions that address the individual patient e.g. "what are my options for care, and what are the potential benefits and harms of these options?" as well as healthcare systems e.g. "how can clinicians and care delivery systems…help me to make the best decisions about my health and healthcare?" PCORI also developed methodological standards for this type of research (www.pcori.org/research-results/patient-centered-outcomes-research; accessed 2-15-17).

6. "Lessons learned" from consumer partnership in research

Our research team completed a PCORI-funded study entitled the Family VOICE (Value of Information, Community Support, and Experience) study (Reeves et al., 2015). This study is a collaboration between clinical child mental health researchers and parent consumers of child mental health services. These consumers collaborated closely with the research team on all phases of research, including design, implementation, and dissemination.

Consumer partnership has been a highly valued and beneficial component of this

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study. "Lessons learned" from this collaborative process relate to planning, implementation, and feedback. Planning: Training of both research and consumer team members can be very beneficial prior to beginning a research study because these different stakeholders may enter this collaboration with a very different language and perspective. Researchers may benefit from training on consumer experience and strategies used for networking, outreach, and advocacy to a specific patient population. This discussion can inform development of consumer valued research questions, strategies to implement the study, and development of early dissemination approaches. Consumers may also benefit from training to provide basic research skills (e.g. discussion about the rationale for randomization and other aspects of study design) and discussion to clearly address protection of human subjects concerns and related matters (e.g. confidentiality). Consumers may have questions about how their role will be different compared to other roles they have had in the community. For example, in our research study, we had several discussions with our consumer partners to consider and plan appropriate boundaries between consumers research team members and research participants. Our consumer research team members opted to restrict any social media contact with study participants after we had discussions about confidentiality and privacy issues in research. This boundary was in stark contrast to their experience engaging with community members in their advocacy work, where social media contact was highly encouraged.

Planning can also address how to discuss research ideas so different members of the research team feel comfortable speaking up and sharing their ideas. Consumer members who have more leadership experience with advocacy and outreach may be more comfortable serving initially to represent consumer input in discussion, but ideally each member of the team should be provided opportunities to participate in the discussion and encouraged to provide feedback.

6.1 Implementation: Implementation strategies can greatly benefit from a hands-on role by consumer partners. In our study, parent consumers implemented a parent peer support program by telephone to other parents of youth with special mental health needs. Parents were very receptive to speaking with peers, and our study retention rate was higher than anticipated. Consumers provided essential feedback on written materials, the structure of contact with research participants (e.g. ad-hoc availability for telephone support instead of just scheduled contact), and the informed consent process. This feedback allowed us to structure the study so that it would be relevant and feasible for our study population of interest, i.e. busy and often overwhelmed parents.

6.2 Feedback: Relationship building requires an interest and openness to ongoing feedback. If there are no formal structures or processes for bi-directional feedback between researchers and consumers, there is limited opportunity to enhance the collaborative relationship. In our study, we had a weekly conference call meeting with researchers and parent consumers who were implementing the peer support intervention. This meeting included an opportunity for ongoing case supervision, and consumers were encouraged to share their observations about the study and experience collaborating with researchers. The product of this discussion helped our team to identify specific research training needs (e.g. learn more about how outcomes of the intervention and participant satisfaction are measured), develop an open forum where consumer input was highly sought and valued in an ongoing way, and also to learn from

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consumers on how to improve the study. For example, our consumer research team members identified that even though the focus of the intervention was on improving access to child mental health services, they were concerned that parents of low-income families often have more urgent priorities for access to food and stable housing. This feedback from our consumer partners allowed us to recognize a blind spot in our intervention and expand the types of resources we offered families.

6.3. Comparing patient-centered dissemination with traditional dissemination strategies: Compared to traditional dissemination strategies, patient-centered approaches re-position consumers from a passive role of receiving information to a leadership role of utilizing information to address consumers to address unmet needs of in community care. The "lived experience" of consumers is valued as a research expertise because consumers can help develop research questions relevant to the community population that the study serves. The bi-directional communication between researchers and consumers, in contrast to a one-directional researcher to consumer communication allows opportunity for feedback and learning in the collaboration that can shape future studies.

7. Conclusion

Consumers are key stakeholders to improve the research dissemination process. The patient voice and their experience can be critical to shape not only how research findings are conveyed and adopted in community care, but also how future research questions are structured to be the most relevant to the needs and values of consumers. Given the gap between treatment discoveries and treatment utilization and the limited history of collaboration between consumers and researchers, it is important to actively consider and address potential barriers to partnership in the planning process. Further research on emerging strategies and theoretical frameworks to support consumer-researcher collaboration are needed to optimize and expand this partnership and maintain its influence on improving healthcare systems.

Disclosure

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