DISSEMINATING THE RESULTS OF A DEPRESSION MANAGEMENT STUDY IN AN URBAN ALASKA NATIVE HEALTH CARE SYSTEM

Lisa G. Dirks, MLIS, MAdm; Jaedon P. Avey, PhD; Vanessa Y. Hiratsuka, PhD, MPH; Denise A. Dillard, PhD; Karen Caindec, BSBA; and Renee F. Robinson, PharmD

Abstract: Increased attention to diagnostic accuracy in depression screening and management within primary care has demonstrated inadequate care when patients prematurely discontinue recommended treatments such as medication and counseling. Decision-support tools can enhance the medical decision-making process. In 2010, the Southcentral Foundation (SCF) Research Department developed a stakeholder-driven decision support tool to aid in depression management. This paper describes feedback from attendees at SCF's 2016 Alaska Native Health Research Forum (Forum) regarding a dissemination product highlighting the aforementioned study. Forum attendees participated in a small group discussion and responded to a brief survey using the audience response system. Thematic analysis was conducted on data from the small group discussion. Overall, Forum attendees responded favorably to the dissemination product. Most agreed the presentation was clear, the amount of information presented was appropriate, and that results were presented in an interesting way. Small group discussion participants provided constructive feedback about why depression-related research results should be shared; how they believed results should be best shared; who results should be shared with; when and where results should be shared; and what level of research results should be shared. The stigma associated with depression treatment may be assuaged if results are shared in a way that normalizes support for depression treatment. Community member involvement in disseminating results has potential to make information more acceptable and meaningful.

The purpose of this pilot project was to determine if a co-developed depression management tool improved depression management, health care decisions, and health outcomes in Alaska Native and American Indian individuals who received services at Southcentral Foundation's (SCF) primary care center. The current article describes the pilot project and the feedback from attendees at SCF's 2016 Alaska Native Health Research Forum regarding a dissemination product highlighting the study.

INTRODUCTION

Behavioral health disorders in primary care are prevalent and potentially costly to patients and the health care system (Goldman, Wise, & Brody,1998; Greenberg, Fournier, Sisitsky, Pike, & Kessler, 2015; Kaufman, Beals, Croy, Jiang, & Novins, 2013; Kurian, Grannemann, & Trivedi, 2012; Miranda, Hohmann, Attkisson, & Larson, 1994; Ormel et al., 1994), yet these disorders are often under-recognized and, accordingly, untreated (Mulrow et al., 1995; Swartz & Rollman, 2003; Williams, Kerber, Mulrow, Medina, & Aguilar, 1995). Limited evidence indicates that depression is at least as common (if not more common) among AN/AI people than the general US population (Duran et al., 2004). Nationally, only half the people who meet the criteria for a depressive disorder are ever treated, resulting in unnecessary suffering and financial cost to affected individuals, their families, employers, and the health care system (Berardi et al., 2005; Broadhead, Blazer, George, & Tse, 1990; Duncan, Best, & Hagen, 2010; Greenberg et al., 2015). Over the past two decades, increased attention to depression screening diagnostic accuracy and management within primary care has demonstrated less than optimal care, with patients prematurely discontinuing recommended treatments, such as medication and counseling. One-third of patients discontinue treatment within 1 month and one-half within 3 months (Almanzar et al., 2014; Frank, Huskamp, & Pincus, 2003; Seelig & Katon, 2008).

Historically, clinical practice guidelines have been designed to provide the best evidence for health care professionals' decisions about patient health care, not necessarily for advancing patient involvement in the decision-making process. These one-for-all practice guidelines and recommended management strategies thus do not take into account the differences in conceptualizing causes, treatment preferences, and medical needs of the individual or community, suggesting a demand for more flexible guidelines and accompanying decision-support tools that facilitate patient involvement in clinical decision making (Barry & Edgman-Levitan, 2012; Eddy, 1991; Gilmore, 1993; Krahn & Naglie, 2008; Mahone et al., 2011; McCormack & Loewen, 2007; Mistler & Drake, 2008; Nease & Owens, 1994). Clinicians have been working towards more patient-centered approaches to developing clinical practice guidelines and are engaging stakeholders in that process (Bennett et al., 2017; MacLennan et al., 2017). Decision-support tools offer providers and patients an expedient method of sharing knowledge and individualized health care information to help make decisions around health care. Decision-support tools can enhance the medical decision-making process; improve patient-

provider communication; inform options for treatment; provide a balanced, value-neutral presentation of the advantages and disadvantages of each option; and help patients clarify their preferences and values about treatment. These processes support patient involvement and participation in achieving ownership of their treatment and well-being.

Evolution of Depression Management at Southcentral Foundation

In 2001, SCF's Anchorage Native Primary Care Center (ANPCC) collaborated with SCF's Behavioral Services Division to increase access to behavioral health-related services for AN/AI people (Dillard & Christopher, 2007). Through this effort, an annual depression screening using the nine-item Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001) was implemented within SCF's ANPCC (Dillard & Christopher, 2007). Although the implementation of depression screening identified more individuals with depression seen at the ANPCC that had not previously been diagnosed, the loss to lack of follow-up when patients were referred to specialty behavioral health services (i.e., individualized therapy, group counseling) remained high. In 2003, SCF initiated another improvement effort to better integrate behavioral health services in the ANPCC by creating a behavioral health consultant position on each integrated care team; however, gaps in screening and treatment still remained (Driscoll et al., 2013). The two areas for improvement related to depression management that remained were: 1) some individuals chose not to fill or refill their antidepressant prescriptions, and 2) few individuals referred by primary care providers to a behavioral health provider ever completed the referral and had a behavioral health-related visit (Dillard & Christopher, 2007). The SCF Research Department subsequently approached clinical, administrative, and tribal leadership about engaging stakeholders to develop a decision-support tool to facilitate discussions between providers and patients who screened positive for depression on the PHQ-9. The SCF Research Department hypothesized that the reason patients were not filling prescriptions or following through with referrals was because they were not ready to choose an intervention, or recommendations from providers were not in line with patient values and preferences. Their solution was to create a stakeholder-driven depression management decision support tool that took these factors into consideration and could conceivably measure a reduction in the number of unfilled prescriptions or unfulfilled referrals to behavioral health. These discussions resulted in the submission of a pilot project proposal to the Patient Centered

Oriented Research Institute (PCORI). In 2010, the SCF Research Department received funding from PCORI to involve community members in a collaborative research study to develop a stakeholder-driven decision support tool to aid patients, providers, health care administrators, and tribal leaders to improve depression management at SCF. In 2013, PCORI provided additional funds to SCF through an Engagement Award Initiative Notice (EAIN) to augment disseminating research results to patients and providers. This paper describes a Depression Management Decision Support Tool (DM-DST) with particular emphasis on a product called a "rack card," a two-sided, half-page handout placed in exam rooms and clinic lobbies in display racks, which was shared with SCF's Alaska Native Health Research Forum (Forum) attendees.

Background

The "Engaging Stakeholders to Improve Depression Management in a Tribal Health System" pilot project was designed to determine if a co-developed depression management tool improved depression management, health care decisions, and health outcomes in AN/AI individuals who received services at the SCF ANPCC. The aims of the study were to: 1) identify SCF leader, provider, and patient priorities or needs that influence depression management decisions in AN/AI individuals who receive services at the ANPCC; 2) develop a decision-support tool to help translate and integrate SCF leader, provider, and patient priorities or needs into depression management decisions; 3) evaluate the effectiveness and cultural appropriateness of the decision-support tool for AN/AI individuals who receive services at the ANPCC; and 4) determine if the decision-support tool improves depression management, health, and economic outcomes.

Semi-structured interviews and focus groups were used to obtain feedback from SCF patients, providers, and leaders on concerns and preferences for depression management and treatment. Results from this process were subsequently used to develop an iPad-based DM-DST, a patient-centered tool designed to translate preferences for depression management and evidence-based care into practice at SCF (Starks, Shaw, Hiratsuka, Dillard, & Robinson, 2014). Results suggested that discussions about depression treatment should begin by normalizing depression and acknowledging individual patient's life events. Patients preferred having a tool that: 1) facilitated shared terminology to simplify treatment discussions with providers, 2)

allowed the opportunity to describe their personal views about the causes of their depression, and 3) communicated depression management preferences with their provider (Starks et al., 2014).

With these preferences in mind, the DM-DST was developed and pre-tested with 20 patients with depression symptomology and five providers. The DM-DST was subsequently revised with data collected during the pre-test and feedback from an 11-member project steering committee consisting of individuals from the SCF research and data services staff, SCF primary care and behavioral services leadership, information technology leadership, and a national expert in AN/AI behavioral health. After revisions, the DM-DST was piloted with a larger sample of patients using a randomized cluster design. The intervention group consisted of 131 AN/AI adults who screened positive for depression and agreed to participate. Of these, three withdrew after the DM-DST malfunctioned, one withdrew because of fatigue, one did not consent to electronic health records review, and 14 were excluded from analyses because they were determined to be ineligible after the study had begun. The resulting intervention group consisted of 112 participants (88 women) with mean (SD) age of 40.7 (SD = 16.2) years. Nearly three quarters (74%) were unmarried and had a median annual income of $50,000 to $59,000. The control group consisted of the 263 AN/AI adults who screened positive for depression in the treatment-as-usual condition during the same period. Demographic information about control participants was not calculated. The total sample size for the pilot was 375 individuals.

Pilot Study Results Summary

Pilot results suggest that the DM-DST helped providers and leaders enhance their understanding of the subjective experiences and depression management preferences of patients with depression within SCF's health system. Patients who used the DM-DST were more likely to select physical and emotional symptoms of depression than cognitive ones. They were most interested in pursuing counseling and medication management and were least interested in peer-support groups, herbal remedies, and spirituality. They were also generally supportive of, but undecided about, stress reduction training and education on healthy eating.

Implementation Guidance and Results Dissemination Before the Alaska Native Health Research Forum

After the pilot study, the SCF Research Department received a PCORI EAIN award to disseminate pilot study results and examine implementation of services informed by the study

results. The project steering committee reviewed the results of the study and requested guidance on disseminating and implementing the results of the DM-DST. The steering committee also recommended that materials discern between informative and actionable results to help implement the DM-DST. Dissemination activities were tailored to reach specific stakeholder groups: the SCF quality improvement committees, six primary care clinics, obstetrics/gynecology providers, pediatrics providers, certified medical assistant supervisors, and patients. SCF leaders and different health care providers then reviewed information about the pilot study and provided guidance about how best to implement the use of the DM-DST within primary care, as well as how to disseminate information to both health care providers and patients. Depression treatment preference and symptom information collected in the pilot provided practical advice about depression management and patient needs to tribal leadership and health care providers. Engaging patients and other stakeholders helped shape plans for using the DM-DST in primary care clinics and to establish project result dissemination plans. As expressed in these plans, study staff worked with the SCF Public Relations Department to create a toolkit to disseminate pilot summary results to patients and the health care system. A multi-tiered approach was used to share study information, which included:

- An article in SCF's quarterly community newspaper (*Anchorage Native News*);
- An article in SCF's weekly, internal electronic newsletter (*SCF Communicator*);
- Print infographic of select pilot study results shared with SCF providers;
- SCF Facebook post that highlighted the pilot study results; and
- The display of a rack card (promotional brochure) that highlighted select study results, in exam rooms and clinic lobbies.

Although various materials were generated to share results of the project, only one product was highlighted at the Forum. SCF Research Department staff worked with the SCF Public Relations Department to create a promotional rack card (see Figure 1) as a method of sharing results of the pilot study. Rack cards are often used in marketing to display information, are typically 4" x 9," and may contain information on one or both sides. Rack cards are usually found in business or medical offices and are typically located in waiting areas or other high traffic areas. More often, rack cards are used in the tourism industry in hotels, airports, or visitor centers to promote tours and attractions for visitors. They are designed to visually attract a person's attention and are typically printed on glossy, colorful, high quality card stock that

contains images. The rack card was selected by an SCF Research Department workgroup to highlight during the Forum as a new method of disseminating results, and the Forum provided an opportunity to obtain patient feedback on this method.

PowerPoint Presentation

The Forum PowerPoint presentation consisted of 10 slides and a 12-minute oral presentation about the development of the DM-DST and pilot study results. The presentation began with a brief five-minute background about the study purpose and rack card design, followed by a 15-minute small group discussion. After the small group discussion, attendees responded to three questions using the Audience Response System (ARS) to determine whether the information on the rack card was clear, accurate, and interesting. (The ARS is described elsewhere in this special issue; see Hiratsuka et al., 2018, "Approach and Methods"). The presenter devoted 10 minutes informing attendees about the study, including the overall goal of the study, methodology for the different aims of the study, and lessons learned from each aim of the study.

RESULTS

Data Analysis

Detailed information about data analysis methodology can be found elsewhere in this special issue (see Hiratsuka et al., 2018, "Approach and Methods"). Qualitative themes were coded by each of the primary discussion questions: *Why should results be shared? How should results be shared? Who should hear about the results? What results should be shared? Where should results be shared? When should results be shared?*

Audience Response System Results

After the background presentation about the purposes of the rack card and study, Forum attendees responded to three questions about the rack card (Table 1). Overall, Forum attendees responded favorably. Most of the respondents (78%) agreed that the presentation was clear. Even more (85%) agreed that the amount of information presented was about right. More than three-quarters (77%) agreed that the results were presented in an interesting way.

Table 1
Participant's Evaluation of the Rack Card Publicizing the Depression Management Tool

Survey Response	N	%
The presentation about the results was clear.	28	100
Strongly disagree	0	0
Disagree	6	22
Agree	13	46
Strongly agree	9	32
The amount of information was about right.	27	100
Strongly disagree	0	0
Disagree	4	15
Agree	17	63
Strongly agree	6	22
The results were presented in an interesting way.	30	100
Strongly disagree	1	3
Disagree	6	20
Agree	14	47
Strongly agree	9	30

Small Discussion Group Results

Why Should Results be Shared?

Participants in each group suggested that sharing results could help normalize depression by making it okay to talk more openly about it. Some mentioned that many people suffer from depression, and people may participate in research studies on depression if they see results have been shared. Another said that sharing the information "helps so others experiencing depression [can] relate and help them feel more open to seeking help." Participants were also asked to consider why results should be shared using a rack card format. Participants highlighted the rack card's inclusion of treatment and prevention options. People liked seeing different categories of depression treatment options in the rack card, and some stated that they may not have realized that options were available or useful for depression management, such as stress management or traditional healing. Others thought the rack card could be a good way to share information about resources with friends or family members as they could easily take the rack card home. One person mentioned that some people do not necessarily like participating in small discussion groups, such as the discussion they were participating in at the Forum, so they would likely prefer written results like the rack card.

How Should Results be Shared?

Many participants had suggestions for improving how results could be disseminated. Some participants reported that they felt the rack card contained the right amount of information;

others wanted more information; still others felt there was too much information. The title of the rack card, "Depression iPad Application Study" was confusing to some. One person mentioned that they thought the rack card did not apply to them because they do not have an iPad. Attendees suggested that the title be changed to "Depression Management Study" as the study was more about depression management than iPads. The small groups also discussed formatting. Several groups commented that the text was too small and difficult to read, particularly for elders. Participants suggested the use of a tri-fold brochure format, so text can be made larger and more information can be included in the brochure. Some people liked the rack card format and referred to it as "catchy," "trendy," "colorful," and "bright." The small groups specifically discussed the brochure's infographics, which were the pictures that corresponded to the data categories on the charts. For example, on the treatment preferences graph, printed beside the "exercise" treatment preference category there is an icon of someone running. Some infographics were well received, but others were not. Rather than using the image of an iPad, attendees suggested using an image of a person. Participants also recommended that results be framed in a more positive way by emphasizing what helped people with depression. A suggestion was made to provide an explanation about how to read graphs depicted in the rack card, as not everyone is familiar with interpreting data in graph-format. Some people suggested including contact information for SCF behavioral health-related services, such as behavioral health consultants and learning circles (group therapy) in addition to the study results. The groups also discussed methods of sharing information, other than the rack card. People mentioned disseminating results using social media (e.g., Facebook), local radio talk shows, and presentations like the Forum.

Who Should Hear About the Results?

All groups recommended that the results, in general, be shared with patients. Some suggested they be shared specifically with people who receive behavioral-health-related services. One group stated that more studies about depression need to occur in rural Alaska. Some recommended sharing study results with the local Elder's program and another with youth. Participants also suggested that the rack card specifically be shared with family members of people with depression and providers so that family members and providers understand the preferences for depression treatment that people in the study shared.

When Should Results be Shared?

Overwhelmingly people suggested that results for depression studies should be shared on an ongoing basis: before data collection, during data collection, and after the research is done. Participants did not specifically discuss when to share results using the rack cards.

What Results Should be Shared?

Although some participants thought only key points about the depression study should be shared, many also wanted more nuanced detail. For example, some said more information about the methods for obtaining the results, the length of the project, and more context about the study, particularly the link between the iPad application and depression, should be included in the rack card. Some attendees wanted additional background about who was doing the research included in the brochure. Participants said that because SCF has a good reputation for research, the rack card should emphasize that the study results came from a credible source and that credibility should be highlighted in all results made available through SCF. Participants also liked seeing, in the rack card, the percentages of research participants in the study who used SCF services; one person suggested that the percentages be a different color to help them "pop" rather than blending in with the rest of the rack card. Another reason mentioned for using the rack card was that it could be helpful to people who are experiencing depression and are not ready to talk about it with others. The rack card could potentially inform people to become more ready to discuss depression with family, friends, or providers, without having to interact with someone in person to receive the initial information.

Where Should Results be Shared?

One suggestion was to place rack cards in the lobby at the ANPCC to make them more accessible to patients. Suggestions for other locations to disseminate the rack cards across the Alaska Native Medical Center campus included locations easily accessible to patients such as the cafeteria, pharmacies, by the front entrance to clinics, in clinic exam rooms, and at clinic front desks.

Participants also discussed how results about depression studies in general should be shared. One group recommended using television screens in clinic lobbies, also known as passive education panels, to share all of the SCF Research Department's study results, not just for this study, as reporting on one study would get repetitive. Discussion groups also acknowledged that some people do better hearing and seeing results rather than just reading them

in print. Others suggested that results be shared in print in the SCF community newspaper, the *Anchorage Native News,* or the regional newspaper, the *Frontiersman*. Several participants suggested that depression-related results be shared with youth at both schools and programs in the community. Other public community locations were also proposed, such as homeless shelters, bus stations, public libraries, youth-serving agencies (i.e., Boys and Girls Club), and bulletin boards around town, airports, and coffee shops. There were also suggestions that the results be shared at special community events like the annual Alaska statewide conference of the Alaska Federation of Natives, the annual Anchorage-based SCF Gathering, and various SCF sponsored patient walk/run events.

DISCUSSION

Feedback provided by Forum participants is useful to consider for results dissemination in general, but also for disseminating results specifically concerning depression. Screening regularly for depression in primary care, similar to routine blood pressure or cholesterol screenings, has been suggested as a way to destigmatize and normalize depression (Starks et al., 2014). Forum attendees also commented that normalizing depression symptoms and treatment options could reduce any stigma associated with seeking depression treatment. Some attendees suggested that seeing the high percentages of specific symptoms of depression (i.e., loss or gain of sleep) was something they could relate to and make them feel less alone. The value of knowledge-sharing through local initiatives similar to this one has the potential to decrease stigma about depression and other behavioral health conditions, by showing people that others may have similar experiences, thus breaking down stereotypes (Byrne, 2000).

The formatting and extent of information included in dissemination materials, such as rack cards, should be considered carefully. In a review concerning formatting, Versloot et al. (2015) suggest that the more vivid, intuitive, and visual a document is, the more likely it will be read, remembered, and used. Although many discussion group members found the rack cards to be interesting and visually stimulating, some brought up the importance of creating dissemination materials that can easily be seen by anyone, with a special mention for elders or others who may have poor vision. This suggestion highlights the notion that using multiple channels for disseminating results is essential to expand the reach to accommodate various recipients. Participants provided guidance on where to disseminate research results, including the

Alaska Native Medical Center campus and the larger Anchorage community. Sharing results outside of SCF using a rack card format has potential challenges. In particular, contextual factors familiar to patients and SCF staff may not be readily apparent to a broader audience and may require more description and background than a rack card offers. Contextual factors may be partially addressed through disseminating research results using a variety of methods. Participants suggested other ways of sharing the results of the depression management study that benefit different methods of delivery, including face-to-face (i.e., presentations), social media (i.e., Facebook), and audio (i.e., radio talk show).

Community member involvement in disseminating results has potential to make information more acceptable and meaningful, especially in AN/AI communities (McShane, Smylie, Hastings, & Martin, 2006; Rivkin et al., 2013; Smylie, Kaplan-Myrth, & McShane, 2009). During the Forum, attendees were asked to suggest who in the community should receive study results. Most participants suggested that patients in general and behavioral health providers be given the results. Some recommended that results be shared specifically with youth and elders. In one research project that examined disseminating results in an Inuit community, community members suggested integrating dissemination strategies with existing information sources, which included elder's advice (McShane et al., 2006). Incorporating research information dissemination into pre-existing local approaches can help ensure that results are shared in a way that reaches more community members (McDonald et al., 2016).

Opportunities for Improvement

Although the Forum provided meaningful insight, some limitations are worth noting. There were only 31 attendees at the forum, and only 29 participated in the discussion groups; therefore, results shared in this study should not be viewed as representative of all SCF patients. Furthermore, as most attendees were women over 40 years old, there was limited information about male preferences. The same can also be said regarding younger participants: only one-third of participants were less than 40 years old. Younger people may have other perspectives on sharing results related to depression management. Although the presenter prefaced the ARS questions by asking attendees to focus their response only on their reaction to the rack cards, some also responded to content about the study purpose and rack card introduction that was shared during the oral presentation prior to the discussion groups.

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ACKNOWLEDGEMENTS

AUTHOR INFORMATION

Lisa G. Dirks is a researcher in the Research Department at Southcentral Foundation in Anchorage, Alaska. Drs. Jaedon P. Avey and Vanessa Y. Hiratsuka are senior researchers in the Research Department at Southcentral Foundation. Dr. Denise A. Dillard is the director of the Research Department at Southcentral Foundation. Karen Caindec serves on the Board of Directors for Southcentral Foundation. Dr. Renee F. Robinson is a senior researcher in the Research Department at Southcentral Foundation.

Figure 1. Rack Card Shared with Alaska Native Health Research Forum Attendees