

## **PREPARE-ing South Dakota Farm and Ranch Women for Advance Care Planning**

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### **Abstract**

**Purpose:** Evaluate the impact of an advance care planning (ACP) educational session utilizing PREPARE for Your Care for South Dakota farm and ranch women and its ability to increase engagement in ACP and documentation of medical wishes in the form of an advance directive.

**Sample:** A convenience sample of women (n = 23) represented members of the farm and ranch community in South Dakota who were participating in the Power of Women as AgVocates Conference. Inclusion criteria for this study included being 18 years old or older, female, and conference participation. Exclusion criteria included men and those under the age of 18.

**Method:** This was a cross-sectional investigation, consisting of three phases, and included comparisons of the same sample population before and after an ACP intervention at different time intervals (baseline, 1 week after the educational session and 3 months after the educational session). Increased engagement in ACP was evaluated using a pre-test, post-test design and utilized

the 15-item Advance Care Planning Engagement Survey. Demographic information including age and highest level of education completed was collected.

**Findings:** In total, 23 women participated in the education session. The median age range was 35-44 years of age. There were statistically significant increases in self-efficacy and readiness to complete ACP reported by participants. The objectives of this education session were met. Per the participants, this was an effective format for ACP. Advance directive completion rates did not increase.

**Conclusions:** The use of PREPARE for Your Care during an education session on ACP can increase self-efficacy and readiness to engage in ACP. The format of this program is appropriate for future use in community settings with the farm and ranch population.

*Keywords:* Advance Care Planning, farm and ranch women

### **PREPARE-ing South Dakota Farm and Ranch Women for Advance Care Planning**

The Institute of Medicine (IOM) recommended that care at the end-of-life (EOL) include person-centered, family oriented, and evidence-based approaches (Institute of Medicine [IOM], 2015). To achieve this goal, advance care planning (ACP) conversations and written documentation regarding a person's EOL wishes are needed. These ACP conversations and associated written documents are imperative in order to avoid costly care inconsistent with the patient's wishes (Heyland et al., 2013).

Advance directives (ADs) are patient-initiated documents and include living wills and documents naming a healthcare agent (IOM, 2015). These documents may include an individual's wishes related to medical treatments and procedures. Advanced care planning is an extension of ADs and includes the completion of AD documents in combination with discussions of EOL care (IOM, 2015). Conversations involving ACP are not a one-time event, but instead a part of a process

which occurs on a continuum (Sudore, Lum et al., 2017a). Advance care planning provides a focus on preparing patients and decision makers with the skills needed to identify and communicate which treatments align with the patient's goals of care in relation to the specific circumstances experienced by the patient.

### **Importance of ACP and ADs in South Dakota**

Despite national recommendations, a gap exists in establishing and meeting the goals of care of American adults, particularly among ethnic minorities, veterans, the disabled, and those living in geographically isolated regions (Wicks et al., 2018). As an example, the number of adults living in South Dakota that have an AD reflect the national rates. A statewide sample of 2,533 adults completing a survey in the, "South Dakota's Dying to Know" initiative, revealed that only 35% had completed some form of AD (Schrader et al., 2009). More recently, the South Dakota Department of Health (2015), through the Behavioral Risk Factor Surveillance System, also reported that only 31% of South Dakotans stated they had an AD.

A recent survey conducted by the Conversation Project indicated that 32% of American adults have had EOL conversations ("The Conversation Project," 2018). Even though 90% of American adults think it is important to have such discussions, 68% of Americans have not participated in these conversations ("The Conversation Project," 2018). In South Dakota, 89% of individuals noted that they were somewhat or very comfortable discussing dying, but preferred the conversations be initiated by family or professionals such as healthcare providers or clergy (Schrader et al., 2009).

Lack of knowledge is a significant barrier to ACP for many (Rao et al., 2014), thus, education on the topic is one approach to helping people take steps towards engaging in ACP. Education,

particularly in the community setting before a crisis, provides an opportunity with minimal capital expenditures.

### **Rural Context**

A variety of definitions reflect the diversity of rurality. The U.S. Census Bureau definition of rural guided this project with rural defined as, “all population, housing, or territory not included within an urban area” (U.S. Census Bureau, n.d.). In South Dakota, approximately 43.3% of the 814,180 residents lived in a rural area in 2010 (U.S. Department of Commerce, 2012).

The number one industry in South Dakota is agriculture. Of the farms in South Dakota, 98% are family owned and operated (SD Department of Agriculture, n.d.); therefore, changes in health status for farmers and ranchers can impact the sustainability of farm and ranch operations. With the high percentage of South Dakotans participating in farming and ranching, the importance of ACP is paramount. Farming and ranching livelihood increases work hazards related to heavy machinery and livestock (SD Safety Council, n.d.). This hazardous work environment can lead to life-altering and life-threatening accidents and can increase the need for ACP, especially in younger populations.

### **Purpose**

This program evaluation study included the development and implementation of an education session entitled, “Conversations that Matter: Advance Care Planning for Rural Women” during a conference for South Dakota women in agriculture called The Power of Women as AgVocates Conference. The session included the use of the evidence-based program “PREPARE for Your Care” (also referred to as “PREPARE”). The Institutional Review Boards at South Dakota State University and Loyola University Chicago reviewed this project. Both institutions deemed the project exempt.

The purpose of this project was to evaluate the impact of an ACP educational session for South Dakota farm and ranch women and its ability to increase engagement in ACP and increase documentation of medical wishes in the form of an AD. The program was also evaluated for future use with South Dakota State University (SDSU) Extension for ACP.

Three objectives guided this project: develop and implement an ACP educational session with rural farm and ranch women; evaluate the ACP educational session for increased engagement in ACP and documentation of medical wishes and EOL wishes by rural farm and ranch female participants; and, evaluate the educational session at three time points.

The Power of Women as AgVocates Conference is presented annually by SDSU Extension and Annie's Project. As a land grant university, South Dakota State University's mission is focused on teaching, research and extension. South Dakota State University Extension is the link between university researchers and county extension agents to aid in the dissemination of information to the community (National Research Council, 1995). Annie's Project- Education for Farm Women, is one of the many educational programs provided through SDSU Extension. Annie's Project is designed to provide education to strengthen the role of women in modern farm enterprises ("Annie's Project," n.d.). Annie's Project provides educational opportunities through 6-week workshops throughout the state as well as this annual conference.

### **Theoretical Framework**

The model chosen to guide this project was the Transtheoretical Model. The model identified behavior change, much like ACP, as a process. A person moves through six different stages when attempting to change a behavior: precontemplation, contemplation, preparation, action, termination, and maintenance (National Cancer Institute, 2005).

Prochaska et al. (2015) identified an individual moves through multiple stages when making a change. Initially, an individual does not have enough information to change (precontemplation). As an individual gains information, the process of behavior change begins: the individual acquires information, contemplates the change, prepares for the change, acts, and maintains the change (Prochaska et al., 2015).

### **Evidence-Based Intervention**

#### **PREPARE for Your Care**

PREPARE for Your Care is a patient-centered, step-by-step web-based guide that is used to teach people the skills needed to identify life goals and medical care preferences within their current context and communicate these wishes to surrogate decision makers and providers (Sudore, Knight et al., 2014). The program has five steps: Choose a Medical Decision Maker, Decide What Matters Most in Life, Choose Flexibility of Your Decision Maker, Tell Others About Your Wishes, and Ask Doctors the Right Questions. This program has been used independently and in group settings and includes written and video information and scenarios with interactions between actors demonstrating the steps of ACP. For use in group settings, PREPARE includes a workbook which allows participants to write down their answers to the questions presented within each scenario. Previous research has indicated increased engagement in ACP overtime along with higher rates of AD documentation with the use of PREPARE (Cresswell et al., 2018; Sudore, Boscardin et al., 2017b; Zapata et al., 2018).

#### **Advance Care Planning Engagement Survey**

Development and documentation of an AD has been the gold standard for determining the success of ACP interventions (Howard et al., 2016; Sudore, Stewart et al., 2013). However, ACP is a process, meaning ADs alone are not enough to evaluate ACP interventions. The Advance Care

Planning Engagement Survey (ACPES) was developed to measure the impact of ACP interventions on engagement by measuring changes in behavior (Howard et al., 2016). Engagement in ACP is affected by behavioral change processes. Engagement in these processes (knowledge, contemplation, self-efficacy, and readiness) leads to actions in ACP. Based on this information, the ACPES has two sections: process and action measures (Sudore, Stewart et al., 2013).

The original 82-item ACPES has demonstrated reliability and validity along with strong psychometric properties, however the length of the survey decreases its utility in research and clinical settings. Five shorter versions of the survey were created. Each of the shorter versions is focused on process measures only. The 15-item survey, which was used for the current study, had a Cronbach's alpha of 0.92 (Sudore, Heyland et al., 2017c).

Responses to questions on the ACPES are on a 5-point Likert scale and measure readiness for change and self-efficacy. Readiness questions correspond to the person's stage of change in relation to the Transtheoretical Model. Self-efficacy questions measure a person's confidence in themselves related to certain ACP behaviors. Scores on the survey are reported as an average for each question, each domain (medical decision maker, what matters most in life, flexibility for surrogate decision making, and asking questions of medical providers), and each process measure (readiness and self-efficacy).

### **Design and Methods**

This was a cross-sectional investigation, consisting of three phases, and included comparisons of the same sample population before and after an ACP intervention at different time intervals (baseline, 1 week after the educational session and 3 months after the educational session). Increased engagement in ACP was evaluated using a pre-test, post-test design and utilized

the 15-item ACPES. Along with the ACPES, participants were asked, “Have you signed official papers to put your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life? These forms are sometimes called an advance directive, durable power of attorney for healthcare, or living will.” Demographic information including age and highest level of education completed was collected at the education session.

The setting for this study was the Power of Women as AgVocates Conference held in January 2020 in South Dakota. This community setting engages women in agriculture in South Dakota who come together to learn about issues including estate and transition planning along with advance care planning. The registration fee for participants was \$50.

A convenience sample of women (n = 23) represented members of the farm and ranch community in South Dakota who were participating in the conference. Inclusion criteria for this study included being 18 years old or older, female, and conference participation. Exclusion criteria included men and those under the age of 18. This ACP education session was a part of a larger conference. Recruitment for the conference was completed through SDSU Extension. The conference was advertised at different events throughout the state, through e-mail lists of past Annie’s Project participants, information on the SDSU Extension website, and media releases to newspapers and radio stations. The conference was also promoted on the SDSU Annie’s Project Facebook page.

As mentioned previously, the study consisted of three phases. Phase 1 included the collection of baseline data. After registration ended for the conference, each participant received an e-mail asking her to complete the ACPES prior to conference attendance. Participants could choose not to complete the survey. Participants had four weeks to complete the survey prior to conference. The participants received four reminder e-mails.

Phase 2 consisted of the education session “Conversations that Matter” at the conference. This session was an hour and a half in length. The participants viewed the videos for Steps 1-3 of PREPARE (Choosing a Medical Decision Maker, What Matters Most in Life, Choose Flexibility for Your Decision Maker). Participants were encouraged to write their answers down to each question during each module in the companion workbook to keep for use after the conference. After each step, participants had the opportunity to ask any questions related to the step. Upon completion of Steps 1-3 participants were introduced to the topics covered by Steps 4 and 5 and how to access them online, but they were not covered during the program due to time constraints. Sample AD forms were provided for each participant. The process for filling out an AD form was reviewed with participants. Participants then had the opportunity to ask any remaining questions. Immediately following the completion of the program, participants were asked to complete the educational session evaluation form.

Phase 3 consisted of data collection after the conference. One week after the education session, participants were e-mailed and asked to complete the ACPES. Participants had one week to complete this survey and participants received two reminder e-mails. Three months after the education session participants were again emailed to complete the same survey. Participants had one week to complete this survey and received two reminder e-mails.

To encourage participation in each survey, the participants had the opportunity to register for one of two \$20 Visa gift cards after each survey, with a total of 4 opportunities. When completing the online survey, the last question asked if the participant wanted to be registered for the drawing. If the participant answered yes, she would be taken to a separate survey to complete contact information. This was to ensure anonymity. For the program evaluation survey, participants were

asked to put their name on an index card and place in a box and two winners were chosen at random.

### **Data Collection and Analysis**

Data collection at baseline, 1 week and 3-month follow-up occurred via the use of QuestionPro surveys. QuestionPro is web-based software that is used for the creation and distribution of surveys (QuestionPro, n.d.). Data collection immediately after the educational session occurred using paper and pencil. Responses to the QuestionPro surveys were automatically tabulated and reviewed by the project coordinator.

Statistics Kingdom and SPSS software were used for analysis for the data from the ACPES. For statistical procedures, the level of significance was set at 0.05. A Mann Whitney test was used to analyze survey results comparing baseline data to one-week after the education, baseline data to 3 months after the education, and one week after to 3 months after the education.

Participants completed the program evaluation form immediately following the session. Participants answered questions regarding if the three program objectives were achieved using a 4-point Likert scale (To a great extent = 4, To a moderate extent = 3, To a slight extent = 2, Not at all = 1). Teaching expertise/effectiveness of the presenter using a 4-point Likert scale (Excellent = 4, Good = 3, Fair = 2, Poor = 1) was also evaluated. Effectiveness of delivery format and relevance of content to the participant and her family was evaluated with yes or no responses. Demographic information was collected. Participant names were not collected. Each evaluation form was given an identification number.

Program evaluation form data were entered into an Excel spreadsheet by the project coordinator. The average and standard error of each of the three objectives and review of the presenter were calculated using Excel. Responses for the format and content were tabulated. Age

and education level were classified using age range and degree level. The data were stored on a laptop that could only be accessed by the project coordinator via password. The project coordinator is the only one that had access to the raw data. The evaluation forms were stored in a locked filing cabinet and will be kept for five years, after which the documents will be destroyed.

## Results

### Demographics

In total, 23 women participated in the Power of Women as AgVocates Conference and the Conversations that Matter session; 22 women answered the demographic questions on the evaluation form. Participants ages ranged from the 18-24 years age group to the 65 years and older age group. The median age range was 35-44 years of age. Of the participants responding to the demographic questions (n = 22), 95% (n = 21) had completed at least some college. See Table 1 for additional demographic information.

**Table 1**

*Demographic characteristics of Power of Women as AgVocates Conference participants.*

| Age in Years                                    | N = 22 | Percent |
|---|--------|---------|
| 18-24   | 1      | 4.55%   |
| 25-34   | 3      | 13.64%  |
| 35-44   | 7      | 31.82%  |
| 45-54   | 3      | 13.64%  |
| 55-64   | 7      | 31.82%  |
| 65 or older                                     | 1      | 4.55%   |
| <b>Highest Level Completed / Highest Degree</b> |        |         |
| Less than high school degree                    | 0      | 0       |
| High school degree or equivalent                | 1      | 4.55%   |
| Some college but no degree                      | 3      | 13.64%  |
| Associate degree                                | 3      | 13.64%  |
| Bachelor's degree                               | 9      | 40.91%  |
| Graduate degree                                 | 6      | 27.27%  |

### Program Evaluation

Overall, participants (n = 23) agreed the three objectives of the conference session were met. All participants responded that each objective was either met to a moderate extent or to a

great extent. See Table 2 for additional information. The majority of participants rated the teaching expertise/effectiveness as excellent (n = 22; 96%) while one participant rated teaching expertise/effectiveness as good (n = 1; 4%). The majority of participants agreed the format of the session was effective for ACP (n = 18; 78.3%). One participant did not find the format effective (n = 1; 4%) while four participants did not respond (n = 4; 17.4%). The majority of participants found the program relevant for themselves and/or family (n = 21; 91.3%). There were two participants that chose not to respond to the question (n = 2; 8.7%).

**Table 2**

*Achievement of program objectives*

| Objective Description   | Mean<br>(N = 23) | Standard Error |
|---|------------------|----------------|
| Describe the importance of choosing a medical decision maker      | 3.96             | 0.043          |
| Identify what matters most in life and for my medical care.       | 3.78             | 0.879          |
| Determine how much flexibility to give my medical decision maker. | 3.82             | 0.080          |

Rating scale used: To a Great Extent = 4, To a Moderate Extent = 3, To a Slight Extent = 2, Not at All = 1

**Advance Care Planning Engagement Survey**

Participants were asked to complete the ACPES prior to the conference as a baseline, one week after the conference, and three months post-conference. Completion rates declined with each survey; 100% (n = 23) of participants completed the baseline survey while 52% (n = 12) and 22% (n = 5) completed the one-week post-conference and three-month post-conference respectively. Comparisons were made between the baseline survey and one-week post-conference, baseline and three months post-conference, and one-week post-conference to three months post-conference.

**Individual Questions**

Using a Mann Whitney test, from baseline to one-week after the conference, the question, “How ready are you are talk to your decision maker about how much flexibility you want to give them?” showed statistical significance. At baseline, the average score for this question was 2.8 (n = 20) and the average at one-week was 4.1 (n = 11) (U = 58.5, z-score = -2.1573, p = 0.0155).

From baseline to 3 months, the question, “How confident are you that today you could talk to your doctor about how much flexibility you want to give your medical decision maker?” showed statistical significance. At baseline, the average score for this question was 3.7 (n = 21) and the average at three months was 5 (n = 3) (U = 12, z-score = -1.7649, p = 0.00388). No questions showed statistical significance when comparing one-week and three-months post-conference.

### ***Domains and Process measures***

From baseline to one-week post conference, there was statistical significance for the domains of what matters most in life and flexibility. For what matters most in life, the average score for questions in this domain was 3.5 at baseline and at one-week as 3.9 (U = 2754.5, z-score = -1.7655, p = 0.0388). For flexibility, the average score for questions within the domain was 3.2 at baseline and 4.0 at one-week (U = 1472, z-score = -2.5688, p = 0.0051). There was no difference in any domain from baseline to 3 months or one-week post-conference to three months post-conference.

The process measures of readiness and self-efficacy were measured by the ACPES. There was an increase in self-efficacy from baseline (average = 3.8, n = 23) to one-week post-conference (average = 4.3, n = 12) as well as baseline to three months post-conference (average 4.3, n = 5). These increases were statistically significant (U = 4114.5, z-score = -2.2395, p = 0.0126; U = 1228, z-score = -1.8721, p = 0.0306). An increase in readiness was seen from baseline (average = 3.0, n = 23) to one-week post-conference (average = 3.6, n = 12). This was statistically significant (U = 8181.5, z-score = -2.6984, p = 0.0035). Statistically significant differences were not seen for the other time intervals.

### **Advance Directives**

Along with the ACPES, participants were asked if they had completed official paperwork documenting their medical wishes. At baseline, 22 women responded to this question. Of the

respondents, the majority did not have official paperwork (n = 13, 59.1%) while 8 participants stated they had official documents (n = 8, 36.4%), and 1 participant was not sure (n = 1, 4.5%). One week after the education session, of the 12 responses to the survey question, 5 participants had official documents (n = 5, 41.7%) and 7 did not (n = 7, 58.3%). Three months after the education session, 4 participants responded to this question on the survey. Of the 4 participants, 0 (n = 0, 0%) had official documentation of medical wishes.

### **Discussion**

This project sought to determine if an education session on ACP at a conference for women who farm and ranch would increase engagement in ACP along with documentation of ADs by comparing the results of the ACPES at baseline, one-week, and three months after implementation. This study demonstrated the use of PREPARE during a session of a larger conference has potential to increase self-efficacy and readiness (both parts of engagement), although further studies are needed. Increases in self-efficacy and readiness were seen one week after the conference indicating that, at least in the short term, this program increased engagement in ACP in terms of process measures. At three months, increases in self-efficacy remained, while increases in readiness did not increase significantly. After the completion of the conference, the only communication with the participants was via e-mail requesting completion of the follow-up surveys. Engagement increased in the time shortly after the conference, but then was not maintained three months after the conference. This could indicate the need for continued follow-up with the conference participants.

Annie's Project, one of the many programs provided through SDSU Extension offers 6-week workshops for women in agriculture. Participants in these workshops meet weekly for six weeks which would provide more frequent interaction and follow-up with participants. Based on the

program evaluation, participants agreed the format was appropriate for the topic of ACP and that the objectives of the session were met. Therefore, this is a program that could be implemented through SDSU Extension in the future. However, the recommendation would be to include further follow up with participants.

While an increase in engagement for readiness and self-efficacy was apparent, there was not an increase in AD completion at either time point after the conference. There could be several reasons for this. First, low response rates to the surveys after the conference could impact results. Those that have completed ADs might not have completed the follow-up surveys. Second, the focus of the PREPARE steps 1-3 were more focused on process measures (readiness and self-efficacy) rather than taking the action of completing an AD.

### **Implications**

Limited research has been conducted on ACP in farm and ranch communities. This project sought to add to this body of knowledge and determine if the PREPARE intervention was an appropriate initiative for a rural population. Detering et al. (2010) found those who participate in ACP conversations are three times more likely to have their wishes for end-of-life known and followed. Improving ACP in the rural population has the potential to improve the care provided at the end-of-life and assure the care provided aligns with the patient's wishes.

It is important to note that rural dwellers are considered self-reliant and tend to resist help from "outsiders" and will seek needed healthcare from informal systems instead of formal systems when able (Long & Weinert, 1989). Major sources of support and information in rural communities include family, friends, and neighbors, particularly those with a healthcare background (Wathen & Harris, 2006). As a trusted source, the rural nurse has an opportunity to

support community members in the process of ACP. PREPARE is a program that could be used by nurses in rural communities to have conversations related to ACP.

By providing education in the community setting to a group of women they could participate in patient activation. Patient activation is defined as, “patients’ willingness and ability to take independent actions to manage their health and care” (Hibbard & Greene, 2013, p. 207). As a part of patient activation, the patient understands her role in her care and has the knowledge, skills, and confidence to manage that care. Many organizations do not have the resources (financial, time, manpower) to provide detailed ACP education to patients and this program is a way to bring this information into the community and support patient activation. With increased patient activation there is potential to improve patient outcomes and healthcare experiences while decreasing the cost of care (Hibbard & Greene, 2013).

### **Limitations**

Although the Power of Women as AgVocates Conference had a capacity of 75 participants, only 23 participants signed up for the 2020 conference. While the reason for the small group is not known, it has been suggested that the unpredictable January weather may have kept some participants away. The weaker farm economy has been suggested as a reason for poor attendance as participants paid a registration fee as well as transportation and lodging, if necessary.

Because of the low conference attendance, there was a small sample size when this study started. While all participants completed the ACPES prior to conference attendance, there was limited survey completion one week after the conference (n = 12) and at three months after the conference (n = 5) despite reminder e-mails and the gift card incentive. The three-month post conference follow-up survey occurred in April 2020. During this time, COVID-19 was impacting the daily lives of many Americans, including those in South Dakota. The current literature is sparse

on the impact of this pandemic on survey response rates, but this could have impacted the survey completion during this time period. Within the surveys which were completed, there was missing data which can impact the value and the interpretability of the data (Mercieca-Bebber et al., 2016). Therefore, with such a small sample size, the results should be viewed with caution.

### **Conclusion**

This study focused on the need for ACP education for the South Dakota farm and ranch population using an evidence-based ACP intervention. The use of PREPARE for Your Care during programs provided by SDSU Extension for women who farm and ranch has potential to increase engagement in ACP. The education session was relevant to participants and was an appropriate format for providing information on ACP. This program could be easily adapted to other programs offered by SDSU Extension, including Annie's Project workshops. By providing education in a community setting, ACP education and conversations can be initiated and continued in the healthcare setting. Further research is needed on this topic and should be focused on evidence-based interventions to continue to increase engagement in ACP with the farm and ranch population. Even though there were limitations to this study, this education session format provided relevant information to South Dakota women who farm and ranch.

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