

Four Conversations: An online, personalized coping and decision aid for the metastatic breast cancer community

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## I. Structured Abstract

**Purpose:** Anticipating and making health care decisions about appropriate or preferred treatment around end of life (EOL) care is intellectually challenging and emotionally distressing for metastatic breast cancer (MBC) patients; new interventions are needed.

**Scope:** (1) To evaluate the impact of Four Conversations on completion of advance directives and decision-making and quality of life outcomes among MBC patients. (2) To demonstrate whether Four Conversations influences clinician EOL care knowledge.

**Methods:** Adult MBC patients and clinicians were recruited from the Duke Oncology Clinic and nationally via patient registries, social media, and organization listserv postings. Consenting patient participants were randomized 1:1 to receive Four Conversations versus usual care and completed REDCap surveys at Baseline and 4 weeks (post-intervention). Treatment arm and clinician participants accessed content online; web-based activities included viewing videos and completing documents including advance care directives and self-care plans. An independent-samples t-test was conducted to compare changes in decision-making and quality of life (QOL) outcomes in treatment and usual care conditions.

**Results:** Patient participants (n=252) were: mean age  $53.6 \pm 11.0$  years; 100% female; 88% white; 35% stage 4 at diagnosis. Clinician participants (n=40) were: 98% female; 90% white; 48% nurse. Among the treatment arm participants, most (94%) would recommend Four Conversations to others. Over half (54%) of treatment arm participants without an advance directive completed one by study end and most (62%) felt that Four Conversations helped them quite a bit or a great deal in making a better decision. Among the treatment arm participants, the change in decisional conflict from baseline to Week 4 was significant ( $p=.02$ ) and the change in decisional conflict scores for treatment conditions were marginally significant [ $t(247) = -1.8, p = .07$ ]. Among the clinicians, 82% felt that their participation in Four Conversations was meaningful and 92% would recommend it to others.

**Key Words:** metastatic breast cancer, shared decision making, advance directives, randomized control trial, eHealth intervention

## II. Purpose

The study purpose is to facilitate metastatic breast cancer (MBC) patient and clinician engagement in shared decision-making (SDM) around end of life (EOL) care planning. The long-term goal of this research program is to “design and implement programs (i.e., Four Conversations) that close clinical practice gaps (i.e., lack of SDM and EOL knowledge) and improve the quality of care for patients with MBC. Evidence of effectiveness from this demonstration study will be used to support an R01 application to conduct a larger, multisite dissemination and implementation study to inform best practice.

**Aim 1: To assess the feasibility of patient and clinician engagement in SDM through participation in Four Conversations.** We will examine the following process measures: 1) the MBC patient’s completion of the advance care directive and self-care documents; and 2) MBC patient and clinician program satisfaction.

**Aim 2: To demonstrate whether Four Conversations influences patient, caregiver, and clinician EOL care knowledge, SDM, and QOL.** We will analyze: 1) patient with MBC decision making preparedness and changes in decision making self-efficacy, decisional conflict, and QOL outcomes; and 2) clinician changes in EOL care knowledge.

## III. Scope

### Gaps in the Quality of End of Life Care

Because there is still no cure for MBC, health care professionals must inevitably address EOL issues with patients. Quality EOL care is increasingly recognized as an ethical obligation of health care providers, both of clinicians and organizations. Domains of quality EOL care include: receiving adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving a sense of control; relieving burden; and strengthening relationships with loved ones [1]. According to the American Society of Clinical Oncology, goals for EOL care for patients with metastatic cancer should include prioritizing QOL, ensuring that patients are well-informed about prognosis and treatment options including palliative care, having regular discussions with health care providers about options and preferences, and having the opportunity to die with dignity and peace of mind [2]. Certainly, anticipating and making health care decisions about appropriate or preferred treatment around EOL care is intellectually challenging and emotionally distressing for patients, families and friends, oncology clinicians, and other professional caregivers. However, there are many adverse consequences of failing to plan for EOL transition such as increased psychological distress, medical treatments inconsistent with personal preferences, utilization of burdensome and expensive health care resources of little therapeutic benefit, and more difficult bereavement [3].

Yet despite the evident need for quality EOL care and patient-provider discussion regarding EOL, “emerging evidence suggests that, too often, realistic conversations about prognosis, the potential benefits and limitations of disease-directed therapy, and the potential role of palliative care, either in conjunction with or as an alternative to disease-directed therapy, occur late in the course of illness or not at all [2].” Oncology providers often find it difficult to discuss these

issues with patients and assume that patients are reluctant to think about the issues involved. For example, one study found that there is a lack of explicit discussion regarding advance directives and patient preferences regarding EOL care, and concluded that facilitation of patient-physician communication is critical in providing quality patient care at EOL [4].

Similarly, another study found that most cancer patients/surrogates sign advance directives on the day of death, indicating delayed EOL palliative care and suboptimal patient-provider communication. The researchers concluded that their data underscored the importance of communication-training research tailored to improve EOL decision making [5]. Major findings from a systematic review reinforce these points, as it found that the presence of advance directives was associated with a decreased rate of hospitalization and the chances of dying in the hospital and decreased use of life-sustaining treatment; and increased use of hospice or palliative care [6]. Other studies focus on the risk for late or absent hospice referrals and assert the need to enhance EOL discussions and earlier referral to palliative care and hospice in order to improve care for patients with MBC. One of these studies found that one-third (33%) of MBC patients treated at a cancer center died without a hospice referral, and of those, only 7% had a documented discussion of palliative care as an option by the oncology team [7].

In addition to the effects these gaps in EOL communication and SDM have on patients' QOL, there are also financial consequences for patients and the health care system. As one MBC patient recently explained in an article published in the Washington Post, the current health care system often provides a lot of expensive critical care as people reach the EOL – care that people, if asked and engaged, might say they never wanted. For instance, the author of the article discusses how she chose to forgo more intensive treatments such as chemotherapy and surgery in exchange for a better QOL during the time she had left. She explains how without SDM and effective communication with her doctor, she would not have had the opportunity to make that choice, and purports that EOL discussions with her physician saved her life [8].

### **Current Evidence-Based Solutions to the Gaps in Quality EOL Care**

The evidence-based interventions that currently exist to address gaps in the quality of EOL care revolve largely around improving SDM via decision and communication aids. According to the Agency for Healthcare Research and Quality, “SDM occurs when a health care provider and a patient work together to make a health care decision that is best for the patient. The optimal decision takes into account evidence-based information about available options, the provider's knowledge and experience, and the patient's values and preferences [9].”

Evidence shows that SDM is effective in improving the quality of EOL care. This RFP discusses the importance of SDM and the role of decision aids in helping patients feel more informed about treatment options, reach decisions consistent with their values, and improve communications with their provider. Specifically, research on the impact of SDM interventions has found increased patient satisfaction and better health outcomes, more favorable outcomes such as decreased anxiety, quicker recovery and increased compliance with treatment regimens, and lower demand for health care resources [10]. One study implemented decision and communication aids (such as question lists) among breast cancer patients and found that they positively impacted factors such as knowledge, decisional conflict, preparation for decision-

making, satisfaction, and self-efficacy [11]. Another study concluded that decision aids, open communication, and involvement of supportive care specialists may improve emotional and existential distress associated with changing or stopping cancer treatment [12].

However, the research also shows that despite the benefits of SDM, it is still largely underutilized and suggests that there is a need for interventions directed at improving implementation and quality of SDM [13]. Another study found that question lists may be insufficient to bridge the divide between physicians and patient information needs in the setting of MBC, particularly regarding prognosis. The researchers there concluded that patients may need additional assistance defining question lists, and physicians may benefit from training in communication, particularly regarding discussions of prognosis and EOL [14]. Similarly, the Agency for Healthcare Research and Quality has posited that one key to success in SDM implementation lies in training physicians and other providers to help them understand how to facilitate the process and to “ensure that they appreciate the importance of respecting patient’s values, preferences, and expressed needs [10].”

### **How Four Conversations Can Help Close the Gaps in Quality EOL Care**

The Seven Pillars of Personal Strength™ is an evidence-based curriculum containing tools that have the ability to improve EOL care for patients with MBC by facilitating SDM and improving QOL. The Core Program, which has been tested and proven in multiple clinical settings, teaches individuals with cancer coping in an online group setting to reduce posttraumatic stress, depression, fatigue, and other QOL outcomes [15-18]. The proposed study will employ these same skill-building exercises through Four Conversations, an offshoot of the Core Program. Four Conversations has four modules, each of which consists of: 1) a series of interactive videos and workbook activities focusing on EOL reflections and wishes for “how one wants to live and die”; and 2) support from a specially-trained instructor called a Pillar Guide. Participants complete the activities in each module, and then communicated with a Pillar Guide in a live session or via email to practice and discuss what they’ve learned.

## **IV. Methods**

### **Design & Procedures**

This study employed the use of a randomized control trial of Four Conversations vs. standard or usual care. Patient participants were randomly allocated to the Four Conversations intervention or wait-listed usual care control group. Patients in the intervention group were asked to complete the baseline assessment and then begin Four Conversations, while those in the usual care group were wait-listed and asked to follow a data collection schedule that is identical to the intervention group. The effectiveness of Four Conversations is measured using validated instruments including the 16-item Decisional Conflict Scale [19] pre-intervention (baseline) and 4 weeks (post-intervention). Other outcome measures were administered to assess QOL and program satisfaction.

Four Conversations is delivered online and supported by a Pillar Guide who is employed by Pillars4Life Inc. in Los Angeles, CA. The Four Conversations intervention is a manualized

curriculum as described below; the Pillar Guide therapist supporting the intervention is a masters-prepared counselor specifically trained in the Four Conversations intervention.

Recruitment for this study occurred at the Duke Cancer Center, Duke Oncology Network, patient registries (i.e., Susan Love Army of Women, ResearchMatch.org), social media (e.g., Metavivor, Living Beyond Breast Cancer), and the Oncology Nursing Society and Association of Oncology Social Work listservs. At Duke, the principal investigator secured physician approvals in targeted clinics at the Cancer Center to grant permission to approach his/her patients in the clinics, treatment, and waiting rooms. The study team used DEDUCE to identify patients and then: 1) mailed a signed physician letter and followed up with a phone call prior to their next visit; or 2) presented the patient's name to the unit and asked either a provider to introduce them to the patient. Eligible patients provided informed consent by paper or via a secure, web-based electronic survey (i.e., REDCap). In terms of the patient registry recruitment, email blasts introducing the study were sent to the registry and volunteers were invited to register. Interested volunteers were emailed a link to the study website (hosted by the Duke Cancer Institute).

Eligibility criteria were as follows: age  $\geq$  18 years; MBC diagnosis; informed consent; reliable Internet access; and, ability to read/write English. Following informed consent, participants were randomized to the treatment or control group. Data collection surveys were administered to all study participants electronically at baseline and 4 (post-intervention) weeks using REDCap. No alternatives to electronic data collection such as paper surveys were needed since patients required online access as part of the study eligibility criteria. Waited-listed control group participants were offered the program following completion of the Week4 survey. Study participants received Amazon gift cards as compensation.

## Four Conversations Intervention

To address the issues experienced by MBC patients, we applied a manualized coping skills curriculum intervention that was modified for this population and has gone through an evolution of content and delivery the past decade (see Figure 1). Four Conversations is an evidence-based curriculum containing tools that have the ability to improve EOL care for patients with MBC by facilitating SDM and improving QOL.

The Core Program, which has been tested and proven in multiple clinical settings, teaches individuals with cancer coping in an online group setting to reduce posttraumatic stress, depression, fatigue, and other QOL outcomes [18-21]. Reimagine was most recently tested in a randomized controlled trial and found to be effective in reducing depression and fatigue among breast cancer survivors with chronic pain [22]. These same skill-building exercises are incorporated within Four Conversations as four modules, each of which consists of a series of interactive videos and workbook activities focusing on EOL reflections and wishes for "how one wants to live and die" (see Figure 2). Participants complete the activities in each module, and then communicate with a specially-trained "Pillar Guide" by email and/or telephone to discuss what they've learned over a four-week period. The web-based videos and exercises were available to the participants to access at any time (i.e., asynchronous).



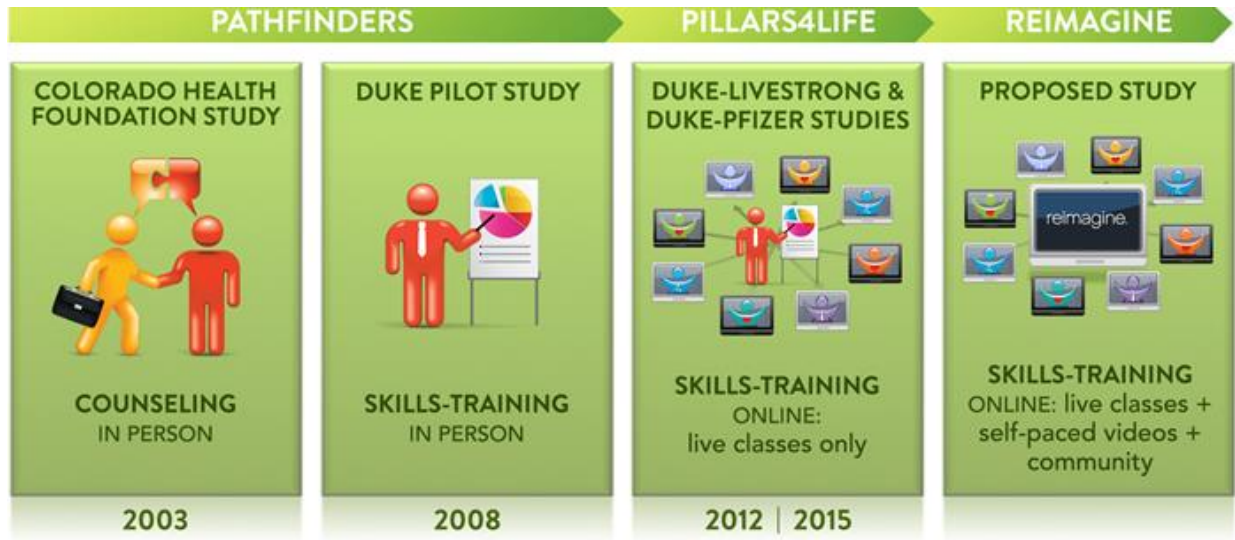



Figure 1. Progression of the original Pathfinders intervention


### The Four Conversations Trial

#### FOR THE METASTATIC BREAST CANCER COMMUNITY



*"This program helped me prioritize, simplify and accomplish those things that seemed too complicated and emotionally difficult to tackle."  
-B.C., Breast Cancer Patient*




The online Four Conversations™ program assists advanced disease care planning & decision making.



From the comfort of home, it helps you:

- **LEARN** skills to reduce stress & clarify your wishes;
- **UNDERSTAND** available treatment options, including palliative care & hospice;
- **SHARE** decision-making with your loved ones & healthcare providers;
- **TRANSFORM** fears into positive actions to improve quality-of-life & gain peace of mind.

**LEARN MORE. JOIN THE STUDY. >>**

### THE CONVERSATIONS

In each of the program's four modules, you will find brief videos & printable documents to help guide you through the topics.

- 1 An Informative Conversation with Healthcare Professionals
- 2 A Supportive Conversation with Family & Friends
- 3 An Inspirational Conversation With or About Spirit
- 4 An Honest Conversation with Yourself



### THE RESEARCH STUDY

Patients, caregivers & healthcare providers are eligible. You will be asked to take part in the online program & complete a few surveys. Participation lasts for two months, & you will receive monetary compensation for your time.

### TO ENROLL:

<http://dukecancerinstitute.org/fourconversations>  
 Email: FourConversationsTrial@duke.edu  
 Phone: 919-613-9444

### SUPPORTED BY

**PRO00070790**

Figure 2. Four Conversations recruitment brochure



## Data Analysis & Statistical Considerations

**Aim 1: To assess the feasibility of patient and provider engagement in SDM through participation in Four Conversations.** We hypothesize that, as compared to usual care, this intervention will lead to more frequent completions of advance directive documents. Descriptive analyses will be used to examine the following process measures: 1) the patient's completion of the self-care plan and advance care directive documents; and 2) patient and clinician program satisfaction.

**Aim 2: To demonstrate whether Four Conversations influences patient SDM and QOL, clinician EOL care knowledge.** We hypothesize that, as compared to usual care, Reimagine's Four Conversations intervention will effectively improve SDM and QOL among the patients. We will analyze changes in: 1) patient decision making self-efficacy, decisional conflict, and QOL; and, 2) clinician EOL care knowledge. We will also examine patient perceptions of intervention effectiveness on decision preparedness.

To assess SDM, the primary response variable will be a continuously scaled measure of decisional conflict, obtained from summing the 16 items of the Decisional Conflict scale, dividing by 16, and converting to a 0-100 point scale [19]. This outcome variable is measured at baseline and post-intervention. The most straightforward analysis is an independent samples t-test. Second, multiple regression will be conducted to estimate the relationships between the SDM variable and the outcome measures. Analyses of other outcome variables will proceed similarly. All outcome variables are measured at baseline and post-intervention.

To be conservative, a power analysis was conducted for the most complex statistical model (i.e., multiple regression of each outcome on all three SDM variables: preparedness, self-efficacy, and conflict), using G\*Power. The power analysis shows that for  $n = 100$  patients, the multiple regression will be able to detect a small to medium effect size ( $f^2 = 0.11$ ) and, for  $n = 40$  clinicians, the multiple regression will be able to detect a medium to large effect size ( $f^2 = 0.30$ ), both with a power of .80 at the significance level of .05.

## V. Results

### Main Findings

A total of 295 adults with MBC and 40 clinicians consented to participate in this study. There were 43 patient participants who withdrew (15%) following completion of the baseline survey; reasons included death, illness, and lost to contact. As shown in Table 1, patient participants were: mean age  $53.6 \pm 11.0$  years; 100% female; 88% white; 35% stage 4 at diagnosis. Clinician participants ( $n=40$ ) were: 98% female; 90% white; 48% nurse. Among the treatment arm participants, most (94%) would recommend Four Conversations to others. Over half (54%) of treatment arm participants without an advance directive completed one by study end and most (62%) felt that Four Conversations helped them quite a bit or a great deal in making a better decision. Among the treatment arm participants, the change in decisional conflict from baseline to Week 4 was significant ( $p=.02$ ) and the change in decisional conflict scores for treatment

conditions were marginally significant [ $t(247) = -1.8, p = .07$ ]. Among the clinicians, 82% felt that their participation in Four Conversations was meaningful and 92% would recommend it to others.

**Table 1. Patient Sample Characteristics**

| Demographics                    | All ( $N = 252$ ) |                    | Treatment ( $n = 110$ ) |                    | Control ( $n = 142$ ) |                    | $p^*$ |
|---------------------------------|-------------------|--------------------|-------------------------|--------------------|-----------------------|--------------------|-------|
|                                 | N                 | % or Mean $\pm$ SD | $n$                     | % or Mean $\pm$ SD | $n$                   | % or Mean $\pm$ SD |       |
| Female sex                      | 252               | 100                | 110                     | 100                | 142                   | 100                | .99   |
| White race                      | 222               | 88                 | 94                      | 86                 | 128                   | 90                 | .26   |
| College degree or higher        | 197               | 78                 | 88                      | 80                 | 109                   | 77                 | .54   |
| Married or partnered            | 168               | 67                 | 73                      | 66                 | 95                    | 67                 | .93   |
| Employed full/part time         | 84                | 33                 | 41                      | 37                 | 43                    | 30                 | .24   |
| Mean age                        | 252               | 53.6 $\pm$ 11.0    | 110                     | 52.7 $\pm$ 10.7    | 143                   | 54.3 $\pm$ 11.1    | .28   |
| <b>Clinical characteristics</b> |                   |                    |                         |                    |                       |                    |       |
| Stage 4 at diagnosis            | 88                | 35                 | 32                      | 29                 | 56                    | 39                 | .09   |
| Receiving treatment             | 241               | 96                 | 105                     | 96                 | 136                   | 96                 | .90   |
| <b>Mean baseline scores</b>     |                   |                    |                         |                    |                       |                    |       |
| Decisional Conflict             |                   | 31.6 $\pm$ 20.3    | 108                     | 31.5 $\pm$ 22.1    | 142                   | 31.6 $\pm$ 18.8    | .97   |
| Decision Self-efficacy          |                   | 81.7 $\pm$ 18.0    | 110                     | 81.9 $\pm$ 18.5    | 143                   | 81.4 $\pm$ 17.6    | .83   |
| PROMIS Physical                 |                   | 13.6 $\pm$ 2.9     | 110                     | 13.8 $\pm$ 2.9     | 143                   | 13.8 $\pm$ 2.9     | .22   |
| PROMIS Mental                   |                   | 13.0 $\pm$ 3.3     | 110                     | 13.4 $\pm$ 3.3     | 143                   | 12.8 $\pm$ 3.3     | .20   |

## Discussion

This study examined the efficacy of the Four Conversations program in addressing shared decision-making, EOL knowledge, and completion of advance care directives among a sample of MBC patients and clinicians. Over the 4-week study period, there were marginally significant differences in the reduction of decisional conflict scores among the MBC patient treatment and usual care groups ( $p=.07$ ). In addition, most (62%) felt that the program significantly enhanced their preparedness in making treatment decisions. Furthermore, over half of the sample who did not already have an advance care directive completed one during these 4 weeks. And, a large majority of patient and clinician participants would recommend the program to others (94% and 92%, respectively). However, there were no significant differences in the decision self-efficacy and QOL outcome scores between the treatment and usual care conditions. In addition, there were no significant differences in EOL knowledge between baseline and 4 weeks among the clinicians; however, their baseline mean score of 95/100 indicated that they were well versed in palliative care knowledge prior to the initiation of the intervention.

Study limitations include the higher attrition rate in the treatment versus usual care group that raises the possibility of bias (i.e., imbalance between the groups). Importantly, there were no differences among the groups at baseline in patient characteristics and outcomes. In addition, generalizability to MBC patients with less education is limited given that over two-thirds of our sample are college graduates. However, education level was not found to be associated with changes in decisional conflict scores in a correlational analysis. Third, several patients were lost

to follow-up despite multiple attempts to contact them, which could bias the findings. Despite these limitations, these findings provide support that the Four Conversations participants derive important benefits in advance care planning, decisional conflict, and decision-making preparedness.

### **Implications and Future Directions**

Despite these limitations, these data provide support that the Four Conversations participants derive important improvements in completion of advance care directives and decisional conflict. The findings from this study will be documented in two manuscripts. Given the different methods employed among the patient and clinician participants, the first manuscript will report on the results obtained from the MBC patient sample [20]. In addition, these data were presented at the ASCO Palliative Care Symposium and the Association of Oncology Social Work annual conference [21,22]. The second manuscript will report on the data collected from the clinician participants.

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