

Introduction

For patients with serious, life-limiting illness and their loved ones, the healthcare system is a perilous place, with risks of getting unwanted care, too little care, or the wrong care. Getting just enough of the right care requires making decisions in the moment based on values, goals, and preferences that a patient may not yet have figured out. Preparing for those decisions before they must be made maximizes patients’ opportunity to receive the care they want and avoid care that will not benefit them. Preparing requires that health professionals, patients and family members have a serious illness conversation (i.e. talk to each other about prognosis, values, goals, worries, etc.) before they are in crisis.

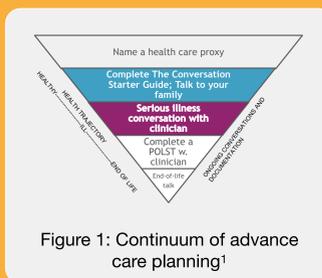


Figure 1: Continuum of advance care planning¹

Advanced Care Planning (ACP) is a continuous process that involves ongoing conversations with a patient and their clinician that begin well before the end of life (Figure 1) and continues along their health trajectory¹.

At Ariadne Labs, the Serious Illness Care Program offers clinicians evidence-based, tested tools and training to guide better serious illness conversations with their patients². The Program’s mission is to make these highly valuable conversations into the standard of care for all patients with serious illness. Our prior work focused on preparing clinicians and the health care system to have serious illness conversations³.

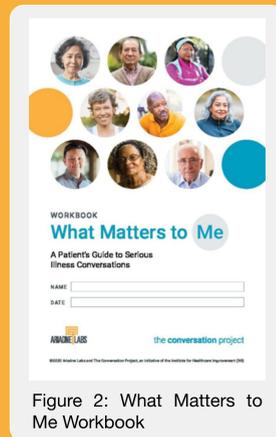


Figure 2: What Matters to Me Workbook

The What Matters to Me Workbook (Figure 2) will help patients and their caregivers for these crucial conversations about their goals, values, and preferences for care. It will help prepare patients to get the most out of serious illness conversations with their clinicians. The overall objective for this project is to develop a tool that patients and caregivers find acceptable, easy to use, and useful and that is safe, i.e. any potential unintended harms are identified and addressed.

Methods

Participants eligible for the study were defined as Seriously Ill (subjects affirm that they have a serious illness such as metastatic cancer, chronic kidney disease on hemodialysis, chronic lung disease, cirrhosis requiring medical management, congestive heart failure, etc) and will affirm that their illness significantly impacts their quality of life or function. Caregivers were defined as a friend or family member of a person with a serious illness (as defined above) who is routinely involved in conversations with their health professionals (more than once and at least once in the past 12 months). We enrolled patient-caregiver dyads with the exception that if a patient wishes to participate in the study but does not have a caregiver, he/she was still allowed to participate. Caregivers whose patient did not want to participate were not enrolled. All participants must be 18 years or older and be English speaking (plans to translate the workbook into Spanish is in the process which will allow for Spanish speaking participant recruitment).

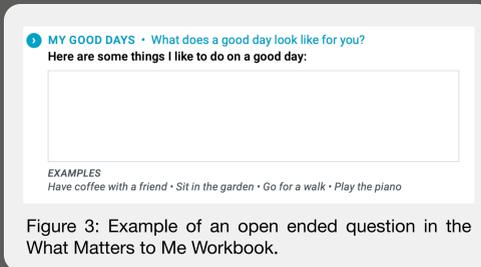


Figure 3: Example of an open ended question in the What Matters to Me Workbook.

In the first part of the study, we asked patients and caregivers to complete the Workbook and discuss their answers with each other. Figure 3 and 4 demonstrate examples of open ended and sliding scale questions from the What Matters to Me Workbook. After completing the workbook each dyad, patient and caregiver, completed an online quantitative survey, which took an estimated 15-20 minutes. The third and final part of the study, patients and caregivers participated in a focused recorded qualitative interview over Zoom lasting approximately 1 hour. During the interview participants were asked to speak over their experience in completing the workbook. For example, patients and caregivers were asked to elaborate over emotions, difficulties and impact discussing the workbook with one another. Participants who completed the study received a \$25 gift card.

All interviews will be transcribed and coded, and data will be analyzed for common themes using qualitative description. The lessons learned will inform any changes needed to the workbook’s content or format. We used the net promoter score, investigator-authored survey questions, and qualitative analysis of in-depth interviews to assess the four dimensions of acceptability, ease-of-use, safety, and usefulness, with an eye towards improving the Workbook. Thus far, we have recruited patients and caregivers through Ariadne Labs’ colleagues and community contacts. We have also used purposive sampling to try to recruit participants from underrepresented and marginalized communities.

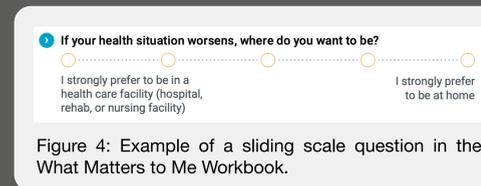


Figure 4: Example of a sliding scale question in the What Matters to Me Workbook.

Results

This is an interim analysis of the first 16 (30 planned) participants. Our initial reports indicated most participants have completed quite a bit of ACP. Preliminary demographics demonstrated 6 patients, 8 caregivers and 2 experts. Of the initial participants 8 completed college, 7 completed graduate or professional school and 1 completed some college. Participants ranged from the Midwest (1), Northeast (8), South (3) and West (4).

Overall, ratings were very positive with a Net Promoter Score of 50 (excellent - 50% promoters, no detractors). They rated the Workbook as safe (4.96/5), acceptable (4.82/5), easy-to-use (4.43/5) and useful (4.14/5). Qualitative data revealed that the workbook’s usefulness was somewhat limited by many of the participants’ extensive prior advance care planning experience. Minority participants noted that, while the Workbooks’ acceptability was very high, that depended on it being introduced in the right way by a trustworthy health professional.

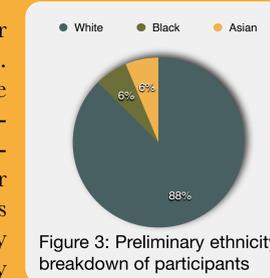


Figure 3: Preliminary ethnicity breakdown of participants

Conclusion

While these participants rated the Workbook very highly, we are seeking to increase the diversity of our sample to include more people from under-represented and marginalized communities that we would expect to be less positive about the Workbook. If it’s presented in the right way by a clinician they trust, the What Matters to Me Workbook can help patients and caregivers clarify and refine their understanding of their goals and preferences and make serious illness conversation more efficient.

Future Goals

Mass General Brigham has made major efforts to build routine serious illness conversations into the structures and processes of care in many clinical settings. Various clinical units are currently implementing some version of Serious Illness Communication. The lessons learned from the project will inform any changes needed to the workbook and represent a valuable addition to these programs.

References:

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3. Lakin, Joshua R et al. “A Systematic Intervention To Improve Serious Illness Communication In Primary Care.” Health affairs (Project Hope) vol. 36,7 (2017): 1258-1264. doi:10.1377/hlthaff.2017.0219

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