Kōkua Mau’s *Let’s Talk Story* Program
Analysis of an innovative and unique ambassador program
2017 review

**The Challenge:**
Many are not comfortable initiating conversations about care for loved ones or themselves should there be a diagnosis with a serious illness. As a result, those important conversations are avoided with no clear resolution. It usually takes a health crisis to bring these issues to the forefront, but this creates tremendous undue stress on families. At a time when the focus should be on providing the best quality of life for those with a serious illness, attention is often diverted to resolving personal differences that can often splinter families.

**The Solution:**
Kōkua Mau believes that advance care planning conversations should occur as early as possible, so there can be clarity about our wishes and values as well as those of our loved ones. These wishes must be documented and communicated to family members and healthcare providers to minimize the collateral effects of an illness on a family and bring greater peace of mind for everyone involved.

Initiating conversations about advance care planning is a challenge for a number reasons. There are cultural barriers and attitudinal differences about illness and death. Kōkua Mau’s *Let’s Talk Story* was originally launched as a Speakers Bureau and has evolved into a more substantive ambassador program designed to break down those barriers.

**Implementation:**
With the support of about 15 highly qualified volunteer representatives, Kōkua Mau has been able educate the public and professionals about advance care planning. Going to where “People Live, Work, and Pray,” our *Let’s Talk Story* program’s goal is to start the conversation in familiar settings, breaking the ice to get people to start talking about uncomfortable but important topics. These conversations encourage and empower people to take action on their own health care wishes.

The sessions are designed to be a catalyst for action by boldly raising the big taboo questions:

*If the unexpected happens, who will speak for you?*

*If you were facing serious illness, do your loved ones know your wishes?*

Revamped and expanded in 2016, the *Let’s Talk Story* program encourages groups to have two sessions. The two-step session approach ensures there is appropriate follow-up action to measure the effectiveness of the sessions. We continue to meet with groups that only request a single session and those results are found in the second part of this analysis.

In 2017, the Let's Talk Story Program did 45 community presentations to a wide variety of groups and reached more than 650 people where they live, work, and pray. Please see the attached complete listing of community presentations, professionals’ trainings and health fair participation.
FIRST SESSION
The first session uses the principles and content of The Conversation Project’s Starter Kit, an interactive tool to help people determine what matters most to them and how to have conversations about their end-of-life wishes with others. The attendees are encouraged to complete the Starter Kit and to bring their own completed advance health care directive as “homework” to the second session.

SECOND SESSION
The second session focuses on education and awareness of Advance Healthcare Directives (AHCD), POLST (Providers Orders for Life Sustaining Treatment), and the importance of sharing the information with loved ones, caregivers, and providers to ensure that one’s wishes for care and treatment are known, honored and respected.

Evaluation:
We have three parts to our evaluation strategy:
1. **Quantitative.** Metrics that include the number of attendees and number of sessions
2. **Qualitative.** Anecdotal indications of the readiness to have the conversation, and feedback showing increased preparedness and usefulness of the information
3. **Action Taken.** This focuses on actions taken between sessions 1 and 2, an added layer of information that began in 2017
   - b. Revised Advance Healthcare Directive
   - c. Located Advance Healthcare Directive
   - d. Discussed and shared Advance Healthcare Directive with loved ones
   - e. Discussed and shared Advance Healthcare Directive with health providers
   - f. Attended second scheduled Kōkua Mau session

At the end of the first session, our speakers ask the attendees to complete a short survey:
- Prior to today’s session, had you talked to your loved ones about your wishes for care?
- Do you plan to have the conversation within the next month?
- If you plan to have the conversation, do you feel prepared?
- Was the information presented useful?
- Any topics expected, but not included in the presentation?

At the end of the second session, attendees are asked to complete a second survey to measure effectiveness of the two-session approach:
- Was any action taken between the first and section session (9 options available);
- Do you plan to have the conversation within the next month?
- If you plan to have the conversation, do you feel prepared?
- Was the information presented useful?
- Do you have an AHCD?
- Any topics expected but not included in the presentation?

Community Engagement:
While continuing to offer single-session presentations, Kōkua Mau piloted the two-session approach with ten community groups in 2017.
Summary:
Those who completed two sessions pledged to have the conversations and felt more prepared than those who had a single session. They also took action in between the first and the second session.

Two-session approach more effective than single session approach

Second Session comparison

<table>
<thead>
<tr>
<th>Question</th>
<th>Session 1 “yes” answers</th>
<th>Session 2 “yes” answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1. I plan to have the conversation</td>
<td>97%</td>
<td>84%</td>
</tr>
<tr>
<td>Q2. I am prepared to have the conversation</td>
<td>68%</td>
<td>58%</td>
</tr>
<tr>
<td>Q3. I found the information useful</td>
<td>92%</td>
<td>93%</td>
</tr>
</tbody>
</table>

Note: 101 people attended the first session and 91 people attended the second session, for a 90% return rate.

Second Session Surveys:

Actions taken after first session:
After the last session with Kokua Mau I: (check all that apply)

- Completed an AHCD: 35 responses
- Talked with loved ones about my wishes: 14 responses
- Shared my AHCD with my loved ones: 19 responses
- Shared my AHCD with my doctor: 17 responses
- Located existing AHCD: 14 responses
- Completed TCP starter Kit: 14 responses
- Think about my wishes: 47 responses

To evaluate action taken after the 2nd session, we will adopt several approaches including revisiting the groups in person, sending email questionnaires when appropriate and telephone follow-up.
SINGLE SESSIONS

During 2017, eight groups requested a single session, reaching a total of 85 people. These groups had a variety of formats depending on the audience and length of the session (1-3 hours). Longer sessions covered the content of both sessions whereas shorter sessions necessitated a condensed version. With a single session, we are unable to measure action taken and, in the future, we will explore different ways to follow-up with participants.

TOTAL FROM EVALUATED SESSIONS

<table>
<thead>
<tr>
<th>Type of session presented:</th>
<th># of groups</th>
<th># of attendees</th>
<th># of surveys collected</th>
</tr>
</thead>
<tbody>
<tr>
<td>First session (1 of 2 presentations)</td>
<td>10</td>
<td>101</td>
<td>90</td>
</tr>
<tr>
<td>Second session (2nd of 2 presentations)</td>
<td>10</td>
<td>91</td>
<td>90</td>
</tr>
<tr>
<td>Single Session</td>
<td>8</td>
<td>85</td>
<td>85</td>
</tr>
<tr>
<td>Total</td>
<td>18 groups</td>
<td>277 attendees</td>
<td>265 surveys</td>
</tr>
</tbody>
</table>

LESSONS LEARNED

1. **Larger groups require a different type of evaluation and presentation.** We found that the large senior club with more than 100 people yielded incomplete evaluations completed. We also learned that many people who attend are there for a few hours of supervised activity so their caregivers can run errands and have a break. We feel that groups under 35 are the most effective and smaller groups allow more interaction. We also need to limit our outreach to groups in which people are cognitively competent.

2. **Meal sites should be avoided.** The second large group was a meal site and the vast majority of people did not listen fully to the presentation, participate in the discussions nor complete an evaluation. The meal sites may request education but we will avoid these groups.

FUTURE STEPS

The two-session approach is a more effective way of ensuring there are follow-up conversations and actions. Kōkua Mau recognizes this is a very preliminary data, and would like to formally incorporate the Let’s Talk Story ambassador program into the larger Let’s Talk Story communications and outreach program (worksite wellness). The built-in executive sponsorship and motivated employees who participate in worksite wellness programs will help to promote advance care planning conversations.

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