Canadian Dementia Learning and Resource Network (CDLRN)

Share and Solve Event Summary: Tips and Strategies for Interviewing and Videotaping People with Lived Experience of Dementia

Background

On Tuesday, October 19, 2021, David Harvey from the ***Dementia Dialogue Podcast Network*** project, and Kayla Regan and Dr. Laura Middleton from the Dementia Resources for Eating, Activity, and Meaningful Inclusion ***(DREAM)*** project shared lessons learned from their own approaches and strategies for interviewing and videotaping people living with dementia and care partners. Members of other Dementia Community Investment (DCI) projects were invited to ask questions or share their own strategies.

Dementia Dialogue is an initiative that aims to raise awareness of dementia and reduce stigma using a podcast platform where people living with dementia and care partners are able to tell their stories. As a facilitator and producer of the podcast, David has recorded dozens of interviews with people living with dementia as well as care partners. David has also trained and provided guidance to people living with dementia as they took on the role of interviewer. Over 40 episodes have been released to date, with 30 alone in the past 18 months.

The *DREAM* project works closely with people living with dementia, care partners, and community partner organizations to develop and deliver dementia inclusion training related to physical activity, healthy eating, and wellness programs. This includes education for

providers as well as key resources for people living with dementia and their families. During the Share and Solve session, Laura and Kayla were joined by Carole, who is living with dementia and is on the DREAM steering committee, and has also been part of the team on other research projects. Carole was also interviewed for a Dementia Dialogue episode.

The summary below outlines three key themes that emerged from the discussion: Preparation as a Key for Success, Maximizing Comfort, and Reducing Stigma. A tip sheet follows with tips and strategies for interviewing and videotaping people living with dementia and care partners.

Key Themes and Recommendations

Theme 1: Preparation as a Key for Success

It is important to help people know what to expect from the interview process. This will help them be as comfortable as possible with the experience, whether they have dementia or not. The Dementia Dialogue and DREAM projects discussed a number of strategies and approaches they have used. These include sending participants interview questions in advance and, where possible, talking through questions ahead of time to provide an opportunity to clarify what is being asked and why.

The DREAM project noted that allowing participants to ask clarifying questions was especially important if participants feel unsure about how they might answer a question during the interview. They also suggested these conversations can be used for the interviewers to adjust the questions so that they are personally relevant to the interviewee. Questions that the interviewee feels are personally relevant allow for more natural responses. Both projects emphasized the importance of the story being led by the person being interviewed.

The Dementia Dialogue project further highlighted the importance of doing one's research in advance, if the interviewer is less familiar with the area, as well as engaging participants in an open-ended "pre-interview". This can help to get to know the person, become more familiar with their story, and build their comfort in answering questions. From this pre-conversation, the Dementia Dialogue team creates an informal interview guide with 5-6 points they would like to cover in the episode. Dementia Dialogue will also use open-ended questions to start a conversation with the participant. Interview questions focus on who the person is, what they are interested and involved in, the purpose of this work and how others can contribute.

Theme 2: Maximizing Comfort

When interviewing and recording participants with lived experience, it is important to help them feel as comfortable as possible. This will help them feel confident in sharing their stories and their experiences. Carole noted it was helpful when interviewers asked questions slowly and allowed ample time for her to respond. Another strategy shared by both projects is reminding participants that they are welcome to pause an interview, restart a thought or ask for a question to be repeated as needed, since pauses or interruptions can be edited from the final product.

Other strategies that create comfort and confidence in interviews include sharing meals together and connecting with people with whom you have an existing relationship.

Theme 3: Reducing Stigma and Showcasing Varied Lived Experience Perspectives

Dementia Dialogue and DREAM aim to reduce the stigma of dementia by showcasing the lives and contributions of people living with dementia. David noted that the Dementia Dialogue podcast interviews themselves challenge stigma, as they demonstrate that people who are living with dementia have rich insights and contributions. The guests discuss and share insight into their challenges and how they address them. Podcasts showcasing the problem-solving approaches used by people living with dementia and their successes have proved helpful for others who are newly diagnosed with dementia.

The DREAM project team shared about their use of a participatory approach to engage early and ongoing with exercise providers, healthcare professionals, persons living with dementia, and care partners to identify what knowledge and messages needed to be shared. These include de-stigmatization of dementia by countering negative stereotypes, sharing about diversity of age and abilities, and showcasing people living with dementia who continue to live full, active lives. While challenges are not ignored, the emphasis is also on problem solving and creative skills used by people living with dementia as evidenced by project participants sharing their stories.

Tip Sheet - Practical Strategies for Interviewing and Videotaping People with Lived Experience of Dementia

Preparation before the interview:

- Research topics that you are less familiar with ahead of time.
- Tailor questions to the participants.
- Send interview questions in advance for review.
- Provide opportunities to discuss or clarify questions prior to the interview.
- Where required, provide an opportunity to get acquainted with technology that will be used.
- Plan for technology difficulties (e.g., have a backup recorder).
- Consider the different contexts and backgrounds of participants (e.g., cultural, linguistic, gender) and how best to respect these in an interview.

During the interview

- Remind participants that the recording will be edited.
- Allow ample time for answering questions; avoid finishing sentences.
- If a person living with dementia has difficulty with a question(s) or with being interviewed virtually, ask the care partner the question and have them repeat it in-person to the person living with dementia. This can help overcome some of the challenges that can arise with an online platform.

After the interview/during the editing process

- Ensure personal information that is shared about a family member is not shared publicly without express consent.

Tips for Hosting Virtual Group Events

- When hosting events online (not necessarily interviews), communicate before the session about "housekeeping rules" or "values" to set the tone of the engagement.
- Consider circulating 2-3 discussion questions ahead of time to allow participants to reflect beforehand.
- Find a quiet space or use headphones for privacy, particularly in a support group setting. Persons living with dementia and /or care partners may find it challenging to be honest about their struggles if others are nearby and can hear.
- Keep virtual meetings short (e.g., an hour or less) to avoid screen fatigue, but be flexible if conversation is still flowing well.
    - In-person meetings may be easier to offer longer and more frequent sessions.
- Encourage first time users to log in early to practice using the online platform.
- Assign someone to help participants the first few times, if needed.

*This Tip Sheet was compiled from the Share and Solve Session on Tips and Strategies for Interviewing and Videotaping People Living with Dementia and Care Partners, and shared learnings from those that attended. Input and additional suggestions and strategies are welcomed. Please contact Danielle Krisman at danielle.krisman@the-ria.ca if you would like to contribute.