Overview

This guide is intended to help facilitate discussion of the film: Care Collectives Re-considering Dementia Care in The Community. We hope it will be useful for a range of audiences including students in health disciplines, practitioners who work with families, caregivers, and policy makers interested in practices of dementia care at home.

Developed By:

Dr. Christine Ceci

Holly Symonds – Brown

Harkeert Judge
**Description of the Film:** Care Collectives: Reconsidering Dementia Care in the Community is a short film (26 min) about care at home for people with dementia and their families. The story shown in the film is based on the real-life experiences of families who participated in a research study about what makes life easier or more difficult when one member of the family has a diagnosis of dementia (for more information on the study see Ceci et al., 2018b). The film does not tell the story of any one family involved in the primary research but rather is a composite case study that dramatizes ‘typical’ or common family experiences. In the film we see the family going on outings, accessing and interacting with formal care services and caregiver supports.

**Use of the Film and Guide:** This film was created to generate discussion about what life is like for families where one member has dementia and they are living at home. The film is intended for a range of different audiences from health care students, practitioners, families, caregiver advocacy groups, and policy makers interested in practices of dementia care.

Below we have provided several topics and questions that might guide your discussion.

**Goals for Discussion**

- Discuss some of the ways families make arrangements for care of a person with dementia at home.
- Identify ways that formal systems of health and social care influence— for good and for bad – everyday life and care for families.
- Discuss the ways that family care at home is a collective endeavor and how this might change how we design and evaluate care for people at home with dementia.

**Recommendations for Group Discussion Format**

Suggested Time Frame: 60-90 min

Materials for film facilitation: audio and visual tools (ex. Laptop/ projector/ speakers), Wi-Fi access, markers, flip chart

Care Collectives: Re-considering Dementia Care in the Community film link: https://www.youtube.com/watch?v=v9X2ymS0SzA&feature=youtu.be

Depending on time and size of the group you can either use large or smaller group discussion. For large group discussions it can be helpful for participation to give group members short periods of time for individual reflection and sharing (Think-Pair-Share) before calling back the group for larger discussion. Provide pens and paper for people to take notes.

Small groups can be arranged informally or by the specific film’s scenes included below. Small groups can be asked to summarize their particular discussions for the larger group.

For either size groups you can discuss the film in its whole or focus the discussion on specific scenes.
Film Scenarios

❖ The Support Group
❖ A Family Outing
❖ A Visit to the Geriatric Clinic
❖ The Commode
❖ Discharge from the Day Program

Background Information on the Film:
This film portrays a 78-year-old man with dementia, named John, who has difficulty walking due to foot drop and balance issues, and attends a day program. His wife, Karen, a retired teacher with no health or mobility issues is his primary caregiver. Together, they live in their home of 25 years and their son, Erik, lives nearby. A researcher observes and interviews this family throughout their daily activities and interactions with the formal health care system and caregiver support groups.

Suggested Discussion Topics

Introduction to Film
Facilitator Talking Points:
As you watch this film, consider the following note from the researcher:
“Part of my work in studying care for people with dementia is to try and think in a different way about how care happens and what might help it be good. This is not a film about individuals who need to change behavior, it is film about how many practices interact between the family, home and formal systems to create care in the community for the person with dementia. I would like to note that all the healthcare professionals that I observed in the field appeared engaged and caring with the families and would like the audience to consider this in their discussions.” (Dr. Ceci)

Because this is a film about real life it can trigger memories or feelings from some people about their own real-life experiences of family caregiving or dementia. If you find yourself experiencing too much discomfort with your feelings, please feel free to take a break from the session and you are welcome to return for the discussion when you are able. If you need assistance, please let me know.

Initial Reflection on Film
Before starting group discussion, it can be helpful to have everyone to take a moment to reflect and take notes on their thoughts and feelings related to the scenarios in the film and to the commentary made by Dr. Ceci.
Activity:
Have discussion group members write down 2-3 ideas about what stood out for them; ask participants to think about what they saw in the film that was making life easier or more difficult for this family.
**Care Collectives: Re-considering Dementia Care in the Community**

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**Thinking about Arrangements**

*Facilitator Talking Points:*

Dr. Ceci talks about arrangements in the film that include people and things - what arrangements or arranging work did you notice of the families and the professionals?

How do people with dementia and their families:
- Make arrangements
- Mobilize resources, and
- Access formal assistance

How does the formal system connect with the families arranging work?
What does it do well and what does it miss?

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**What Matters for Care at Home?**

*Facilitator Talking Points*

Reflecting back on the scenarios, what were some of the overriding concerns of the different people involved? Where would these concerns come from?

What did you see (actions or statements) that made these concerns obvious to you?

What seems to matter most to the family? To the physiotherapy aide (PTA)? To the physician?
To the people at the support group?

What happened when there were differences between these?

How do ideas about safety and/or risk travel through some of these scenarios?

What are the effects of differing values on the relationships between family members and between the family and professionals?

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**Thinking About How it Could be Otherwise**

*Facilitator Talking Points*

What do you think Dr. Ceci means by care collectives?

What is the Knudsen family’s care collective made up of at the beginning of the film and how does it shift over time?

What might be differences between care collectives and the ways we usually think about care?

What would need to change if “supporting enabling arrangements” guided how we designed care at home for people with dementia?

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**Things/Objects in Care**

*Facilitator Talking Points*

This type of research includes paying attention to objects and materials and how they make relations with other things and people. In your groups, take a piece of paper and list the objects or things you noticed in the scenarios? (give few minutes for brainstorming). Examples from the film include: iPad, seat for hockey rink, car, soaker pad for car seat, commode, walker, cane, seat belt, book for tracking falls, the space of the home, stairs, resource lists (binders in final scene).

Now discuss how some things were active in allowing people to do certain things or relate to each other in a certain way.
**Care Collectives: Re-considering Dementia Care in the Community**

### Specific Scene Discussion Points

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<tr>
<th>Scene</th>
<th>Questions</th>
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<tbody>
<tr>
<td><strong>The Support Group</strong></td>
<td>What is going on in this scene? What seems to matter to the facilitator? To the members? How are support groups positioned as part of care in the community? What does the support group offer to Karen and the family? What are its limits?</td>
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<tr>
<td><strong>A Family Outing</strong></td>
<td>How do Karen and John get out of the house to the hockey game? What people and objects are helping them?</td>
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<tr>
<td><strong>A Visit to the Geriatric Clinic</strong></td>
<td>How is the geriatric clinic situated in the arrangements of formal health services? What does the geriatric clinic have to offer to the family arrangements? What things are present in the appointment? For example, how does the fall tracking book work in that appointment?</td>
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<tr>
<td><strong>The Commode</strong></td>
<td>How do the new services from homecare fit within the family's care collective? What is the commode for the physio? What will it do according to the PTA and Karen? What relations are created between Karen and the PTA by the commode? What happens when the formal system arrangements (timing of homecare assistance, adding a commode or ensuring 24/7 supervision) don't fit with family arrangements?</td>
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<tr>
<td><strong>Discharge from the Day Program</strong></td>
<td>How does the day program play into the family arrangements? Why might this discharge happen this way?</td>
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### Tips for facilitators:

It is common to focus on individual behavioral change as solutions to problems in healthcare but this is not an objective of this film. Listening to the discussion and helping participants focus on the organizational and societal views on dementia, care, family, and home will help the group to see the arrangements at work in these scenarios.

Common themes present in discussions about caregiving and dementia often include ‘person centered care’ and ‘system navigation’. While possibly helpful these terms are often taken for granted and used without much specific description. We encourage facilitators to ask people to specifically describe how or what would change for the family in the film through any approaches offered. (For example: Asking what would ‘system navigation’ do for Karen specifically? She is currently connected to a geriatric clinic, a support group, a day program, home care and respite.)
Additional resources

Visit: https://www.ualberta.ca/nursing/research/research-units/care-practice-research-network
