

Listening to the Voices of Family Caregivers

St. Joseph's Health Care London, Ontario, Canada

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Background

- An estimated 8 million people in Canada are family caregivers and save the healthcare system over \$31 billion annually, yet family caregivers are often referred to as the “silent partners” in care¹. In Canada, many health care organizations are moving towards a patient and family-centered care approach
- The Change Foundation, a provincial policy think-tank, partnered with and funded four health care organizations and family caregivers to improve experiences
- St. Joseph's Health Care London is a multi-site health care organization aimed at ensuring patients and families are full partners in their care

Project Purpose: This project aimed to improve family caregiver experiences and level of engagement across the organization.



DISCOVERY



IMPLEMENT

ACTIONS TAKEN

This project followed best practices for experience – based co-design² which includes the following stages:

1. Discovery Phase: Understanding Current Experiences

- Health Care Providers/Staff: 140 individuals participated in 27 focus group sessions and 28 individual interviews
- Family Caregivers & Patients: in-depth individual (or dyad) interviews were conducted with 90 family caregivers/patients
 - Data were analyzed using line-by-line emergent coding techniques

2. Co-Design Events/Working Groups: Co-Designing Solutions

- Experiences, represented in 8 broad themes, were shared in a co-design workshop with 70 family caregivers, patients and health care providers
- In smaller groups, 30 providers and family caregivers brainstormed and co-designed ‘change ideas’ to address the issues identified in the Discovery Phase

3. Implementing the ‘Change Ideas’

- Together, with family caregivers and health care providers, 4 ‘Change Ideas’ are being implemented into practice



Figure 1. Co-Design Event

MEASURE SUCCESS



EVALUATE

- Process data is being collected, in the PDSA Cycle, 18 binders have been implemented with resources
- Baseline information was collected using a family caregiver experience survey (n=25) and a health care provider experience survey (n=45)



Family Caregiver Involvement

What we heard: Caregivers identified the number of providers involved in care is overwhelming

- Co-designed innovation:** A Team Roles List, with names, simplified role descriptions and contact information



Family Caregiver Education

What we heard: Staff said family caregiver training was inconsistent : wanted a standardized process for receiving education

- Co-design innovation:** A template was developed to ensure family caregiver training is transparent and consistent.

What we heard: Family caregivers wanted an online education library with information from trusted websites.

- Co-designed innovation:** Family caregivers and staff are working together to develop resources on St. Joseph's public website.



Transitions of Care

What we heard: There was not enough information shared throughout the care journey, too much information was given on day of discharge.

- Co-designed innovation:** A comprehensive individualized resource binder given out at admission and updated throughout the stay

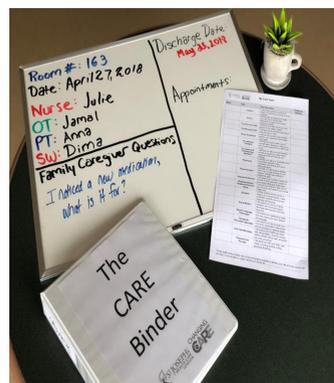


Figure 3. Mock-up of the Change Ideas

1. How often do you communicate with your family/friend's healthcare provider when you need it?	Never	Sometimes	Usually	Always
2. How often do you receive information about your family/friend's health care issues (e.g., doctor visits, personal responsibilities, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. How often do you receive information about what to do if you were worried about your family/friend's situation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. If you did receive information, how well did you understand the information provided to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. If you did receive information, how well did you understand what to expect?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. If you did receive information, were you clear on who to contact with any follow-up questions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. How well do you feel supported in your caregiving role by the health care team?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 2. Example of Family Caregiver Experience Survey

8. How often were you treated with courtesy and respect by healthcare providers?	Never	<input type="checkbox"/>
9. How often did healthcare providers recognize that you are a family caregiver?	<input type="checkbox"/>	
10. How often did you feel responsibilities involved in your family/friend's care plan from healthcare providers (e.g., discharge planning, goal setting, etc.)?	<input type="checkbox"/>	
11. If you didn't feel involved in your family/friend's care planning, what were the reasons? <input type="checkbox"/> I did not want to be involved in the care plan <input type="checkbox"/> My family/friend does not want me involved <input type="checkbox"/> Staff did not welcome me as part of the process <input type="checkbox"/> Staff were busy and prevented them from including me <input type="checkbox"/> Other: (specify) <input type="checkbox"/> Not Applicable (felt meaningfully involved)		
12. How often did your family/friend's healthcare providers treat you as a source of knowledge about your family/friend?	Never	<input type="checkbox"/>
13. How often did your family/friend's healthcare provider ask how you are doing in your caregiving role?	<input type="checkbox"/>	
14. How often did you get the support you needed to care for yourself?	<input type="checkbox"/>	
15. How often did you get the support you needed for concerns you had about your family/friend's condition?	<input type="checkbox"/>	
16. How often did you receive education/training about how to care for your family/friend in preparation for leaving the hospital (e.g., transfers, bathing, dressing, catheterization, medication management, medical health condition, etc.)?	<input type="checkbox"/>	

IMPACT

- Throughout the process staff and family caregivers have shared their feedback about the resources
- 100% of Care Binders distributed were used** by a family caregiver, patient and staff member. Content in binder varied.
- Staff have said:
 - "I never connected with family caregivers before, just the patient. This has caused me to be more intentional about checking in with families to see what they need."
 - "We have come together as a team and really embraced the implementation of these resources."
- Family Caregivers have said:
 - "My mom is very forgetful, she will agree and nod and then does not remember and does not follow up on what she says...the binder does give us a sense of what she is doing [in rehab therapy]."
 - "You know what I like the best; that everything is in one spot."

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RESULTS

Next Steps

- This work started in St. Joseph's specialized geriatric programs and will be spread to other care areas of the organization including long-term care, mental health care, surgery, rehabilitation and chronic disease management.
- 12 community organizations have been involved through a Community Advisory Group – to provide guidance and partnership to support family caregivers throughout their care journey.
- The Change Foundation will be spreading the findings provincially through their network.

"... [we need] layman's terms... medical terms can be complicated and sometimes as an outsider...it's crazy, it is terrifying."

"...[Staff] had a discharge meeting, but not with us..."