Research Priority Setting Think Tank

Family Caregiver Communication Issues

November 5 and 6, 2012

Inn at the Forks
75 Forks Market Road
Winnipeg, Manitoba

Final Report

Prepared by Workshop Director:
Dr. Michelle Lobchuk
Associate Professor and
Manitoba Research Chair in Caregiver Communication
Faculty of Nursing, University of Manitoba
Winnipeg, Manitoba
# Table of Contents

Acknowledgments........................................................................................................... 3

Application Form: Canadian Institutes of Health Research (CIHR)  
Institute of Health Services and Systems for an Aging Population under the  
Planning Grants Funding Program................................................................................. 4

Workshop Agenda........................................................................................................ 14

Photo of Workshop Participants................................................................................. 16

List of Workshop Participants.................................................................................... 17

Synopsis of Workshop.................................................................................................. 23

Day 1 – Presentations and Situational Analysis ....................................................... 24

Day 2 – Provisional List of Research Priority Areas ............................................. 29

Day 2 – Initial Research Project ................................................................................ 37

Appendices:

Appendix A: Presentations – Family caregiver communication and the health care system – Genevieve Obarski, Bonnie Schroeder, Julie Donaldson, and Penny MacCourt

Appendix B: Presentations – Family caregiver communication and the health care professional – Sonia Udod, Britt-Inger Saveman, and Michel Bedard

Appendix C: Presentations – Family caregiver communication and the patient – Christine McPherson, Christina Quinn

Appendix D: Think Tank Participant Evaluation Responses
Acknowledgements

We would like to acknowledge funding support for this workshop provided by:

- Canadian Institute of Health Research (CIHR) Institute of Health Services and Systems for an Aging Population under the Planning Grants – PA ($24,421)

We would also like to acknowledge donations of materials (e.g., conference bags, pens, writing pads) from:

- Manitoba Centre for Nursing and Health Research
- University of Manitoba, Faculty of Nursing
- Home Instead Senior Care
Workshop Title:
Research Priority Setting Think Tank
Family Caregiver Communication Issues

Proposal Abstract
On November 5 and 6, 2012 a two day workshop was held in Winnipeg, Manitoba to form a ‘think tank’ comprised of researchers, family caregivers, government representatives, organizational leaders, and practitioners with health and social service agencies who are involved in the area of family caregiving. This workshop involved the development of a Family Caregiver Communication Research Collaboration involving local, national, and international stakeholders to address critical challenges in the area of communication needs by friend and family caregivers as partners with clinicians in promoting safe care for the elderly, chronically or seriously ill, or disabled individuals in the community. Our primary aim was to formulate an effective research agenda and to take the first tangible steps to address the research agenda by identifying an initial research project on meeting the communication needs of family caregivers as they interact with: the health care system, health care professionals, and/or the aged care recipient.

Dr. Michelle Lobchuk, Associate Professor and Manitoba Health Research Council Research Chair in Caregiver Communication at the Faculty of Nursing, University of Manitoba hosted this Think Tank where she posed the following questions: “What is the state-of-the-science in the area of family caregiver communication needs during their interactions with the health care system, health care professionals, and the care recipient?”, “What are the research priorities relating to caregiver communication?”, and What research project is vital to advancing best practices in caregiver communication with the health care system, health care professionals, and/or the care recipient?”

As a result of this workshop, an interdisciplinary and inter-sectorial collaboration was formed as well as the development of an agenda of research priorities in family caregiver communication at the system-, health care provider-, and patient –levels. A key recommendation was made by Think Tank participants for an immediate research project to uncover stakeholders’ perspectives on how to meet communication needs across three levels where known challenges and needs arise for family caregivers. Other Think Tank participants have also committed their support for this key project and have agreed to serve as either Co-investigators or Collaborators. Dr. Michelle Lobchuk and Dr. Christine McPherson
will take the lead on developing a CIHR grant proposal for submission in 2013 that targets this key project.
Canadian Institutes of Health Research (CIHR)
Institute of Health Services and Systems for an Aging Population under
the Planning Grants – PA

Workshop Title:
Research Priority Setting Think Tank
Family Caregiver Communication Issues

Proposal Detail

Significance of the workshop, objectives, and planned activities: World-wide, research efforts in caregiving are growing as our global population ages and individuals live longer with chronic conditions (United Nations International Day of Older Persons 2008: Global Perspectives on Family Caregivers). While efforts are ongoing to develop and test interventions to enhance communication skills in health care professionals, best practice guidelines to support communication competence in family caregivers is largely deficient (Northouse et al., 2010). Competence in communication is recognized as a fundamental aspect in the provision of providing quality, patient focused care (Boscart, 2009). Although technical skills garnered by formal and informal caregivers are important, communication skills are often viewed as mundane or a secondary skill, that is, until crisis strikes. The crucial nature of caregiver communication catches our attention only when the media reports on crisis events due to break-downs between health care professionals and family advocates for the patient that result in sub-optimal patient care and dissatisfied caregivers with costly care and legal outcomes for the health care system. The area of family caregiver communication cross-cuts multiple levels where care occurs: that is, when caregivers transition across the health care system, plan care and set goals with health care professionals, and provide direct care to the patient.

Dr. Michelle Lobchuk, Associate Professor and Manitoba Health Research Council Research Chair in Caregiver Communication at the Faculty of Nursing, University of Manitoba will host this think tank and pose the following questions: “What is the state-of-the-science in the area of family caregiver communication needs during their interactions with the health care system, health care professionals, and the care recipient?”, “What are the research priorities relating to caregiver communication?”, and What research project is a priority in order to meet caregiver communication needs? Based on Lobchuk’s research in family caregiver communication, she has identified the need to bring researcher and clinician stakeholders together to develop a research agenda that drives future studies in this area. As a result of this workshop, a number of interdisciplinary and
inter-sectorial initiatives will emerge for new collaborations that focus on key recommendations for future research focusing on communication needs for family caregivers.

The objectives and planned activities of the workshop are to:

**Day 1 - Foster team building by dialogue and a critical discussion of communication needs**
1. Conduct presentations and a critical discussion of the ‘state of the science’ and experiences of researchers, family caregivers, advocates, and service agency groups with caregiver communication needs at the system-, clinician-, and care recipient- levels of interaction;
2. Identify provisional priority areas for empirical work on family caregiver communication at three levels (the system, the clinician, and the care recipient) in small groups to develop the final research agenda on Day 2.

**Day 2 – Develop the Research Agenda and Foster a New Family Caregiver Communication Research Collaboration for a Priority Research Project**
3. Develop an agenda of priority research topics and questions that target caregiver communication needs with the health care system, health care professionals, and the patient;
4. Reach consensus on one priority topic for an initial project on caregiver communication research;
5. Identify a collaborative group of researchers, clinicians and health/social service groups from the Think Tank and others for an initial research project;
6. Initiate discussion on key research questions, dependent and independent variables, a research design, key outcomes for an initial research project, and a target date to submit a proposal for funding; and,
7. Identify next steps for an initial research project (e.g., lead researchers, collaborators, ongoing grant development) and future projects.

**CIHR Priority Topics:** This workshop on family caregiver communication targets two CIHR priority topics. The first priority topic is ‘primary and community-based healthcare’ under Health Services and Policy Research (PLH). With an aging population living longer with chronic disease in the community, increased attention needs to be paid to the communication needs of family caregivers who are also aging to provide quality care. Policy is moving toward promoting self-management that is heavily dependent on the communication skills of family and friends (Naismith et al., 2010). Caregiving family and friends require
supports to ensure they maintain clear lines of communication to meet their own and patient needs so as to optimize care and avert costly physical and psychological sequelae when needs are not met (Naismith et al., 2010). The second priority topic is funding for applications that will stimulate research and planning activities and research partnership development including, “quality and continuity of care across formal and informal care transitions” that are relevant to **Health Services and Systems for an Aging Population (HLA)**. Lobchuk’s aim is to bring together academic researchers (from Sweden, United States, and Canada), organizational leaders, government representatives, and practitioners from a number of health and social service agencies who play a key role in pursuing quality of care by addressing communication needs of families as they strive to secure safe, optimal care for aged care recipients, and to meet their own needs from the health system and clinicians. This interdisciplinary and intersectorial collaboration will ensure clinical, social and personal relevance of the research agenda, facilitate its transfer to a wider clinical and research audience, and identify an initial project for future research.

**Workshop discussion (see attached agenda).** The two-day workshop will consist of presentations and an opportunity for dialogue and discussion. Participants will be sent a readings package to prepare for discussion including literature and reviews on caregiver communication needs, interventions, gender differences, and frameworks to guide communication studies at the system, clinician, and care recipient levels (see Appendix for references to reading material). The following briefly identifies the literature and work of participants that will be the focus of brainstorming by our ‘think tank’ to advance research in the area.

**Communicating with the health care system.** Caregiving is a career with transition points that requires different things of families and supports from the health care system: pre-, during, and post-caring role (Levine, 2004). Most chronic illnesses are also a journey where aged patients and caregivers must negotiate a maze of services and supports. The role of skilled individuals, known as ‘patient navigators’, has recently emerged to help patients address the increasing fragmentation of a complicated health care system and facilitate needed services along the illness journey (Levine, Reinhard, Feinberg, Albert, & Hart, 2004). While it is assumed that families support patients in their transitioning across the system (i.e., as advocates, providers of practical information ‘about’ and preferences of the patient, and service coordinators), the caregiver’s role and needs are not explicit in service models which are currently being addressed in the PATH project by The Change Foundation (2011). Schroeder (2011) recently identified the need to examine the feasibility of including family caregivers as the patient’s interpersonal resource in a partnership model of patient navigation. The Manitoba
Caregiver Coalition (2010), a group consisting of 40 caregivers and stakeholders representing various organizations and agencies, identified “imparting information to help caregivers navigate the system to identify and harness resources to meet their and patients’ needs’ as a priority for the Coalition.” Dr. Bédard and colleagues’ (Bédard et al., 2005 [attached], Brazil et al., 2009) work also indicated differences in how community services are used by male and female caregivers, however the reasons are unknown. Could gender have an impact on ‘how or ‘to what degree’ caregivers see themselves communicating their needs with the wider system? Our think tank needs to consider, “How can health care service models include and support caregivers, based on gender differences, as vital communication partners in the care of the patient and self?”

**Communicating with health care providers.** ‘Partnerships’ and ‘patient-centered care’ are growing phenomena in the literature and clinical practice that identify family and friends as part of a support network who provide essential perspectives in the management of aging and chronic illness. Boscart (2009) identified that communication is essential for assessment and tailoring care to the unique and complex needs of individuals. Despite research that demonstrates the vital aspect of good communication, communication problems exist and are common in practice (Whitlatch, 2008). Patients and caregivers are becoming more critical of communication with clinicians who are working in highly pressured, time deficient environments that constraint meaningful conversations and translation of evidence-based practices to make informed decisions. Lobchuk et al., (2012), Lobchuk and Udod (2011), and Saveman et al. (2011) [attached] identified that work-life factors and/or nurse and other clinician attitudes toward families (i.e., lack of time required to attend to family questions, limited educational or support sessions on communicating with conflicted families, and privacy issues) posed significant barriers to clinician confidence and ability to develop relations with families. These work-life factors and clinician attitudes can potentially impact the delivery and outcomes of communication interventions for caregivers by nurses and other clinicians. Sustainability of the overall effects of communication training in clinicians and work environments that support meaningful and timely interactions between clinicians and families of aged individuals dealing with chronic illness (Uitterhoeve et al., 2009) also warrants further discussion by our ‘think tank’.

**Communicating with patients.** It is widely documented in reviews of family caregiver interventions that family and friends receive little preparation, information or support to perform the caregiver role (Northouse et al. 2010). When interventions are targeted at family caregivers, the outcomes focus more on improving patient outcomes (e.g., management of symptoms, quality of life) and less on the needs of caregivers. Interventions that focused on partner
communication to improve family relationships in comparison to usual care had positive effects: however, these positive effects were not sustained (i.e., after 3 to 6 months post intervention) (Northouse et al., 2010). Across states of health and illness, researchers have captured various communication challenges that exist between patients and family caregivers. For example, Lobchuk and McPherson found that caregivers’ judgment, blame, and anger impact their’ empathic responses toward afflicted individuals (Lobchuk et al., 2012) [attached]. Of interest, however, Quinn (2011) [attached] recently presented promising results on an empathy-related intervention with caregivers of heart failure patients that warrant further discussion as a technique to help formal and family caregivers who are challenged in their communication with patients. Our think tank needs to critically analyze the communication field involving dynamics between family caregivers and patients, and to identify what is the state of the science in the area of family caregiver communication needs during their interactions with care recipients? What kinds of interventions are required to boost family caregivers’ communication competence with patients?

**Dissemination Plan.** Preparation of a workshop report for submission to CIHR and other local (Manitoba Caregiver Coalition, Manitoba Health, the Minister of Healthy Living Manitoba) and national (VON Canada, Canadian Caregiver Coalition) stakeholders that outlines the research agenda and meeting discussion. Develop a news release about the workshop to relevant university (e.g., University of Manitoba newspaper), and local and national organizations that respond to the needs of caregivers (e.g., Huntington Society, Hospice & Palliative care, Alzheimer Society). Lobchuk will lead a publication that identifies our literature review and research agenda that addresses caregiver communication needs across the system, and with clinicians and care recipients.
References


<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>0730 - 0800</td>
<td>Registration</td>
</tr>
<tr>
<td>0800 - 0815</td>
<td>Welcome and introductions of participants by Dr. Michelle Lobchuk</td>
</tr>
<tr>
<td>0815 - 0830</td>
<td>Review goals for the meeting by Dr. Michelle Lobchuk</td>
</tr>
<tr>
<td>0830 - 0900</td>
<td><strong>FAMILY CAREGIVER COMMUNICATION AND THE HEALTH CARE SYSTEM</strong></td>
</tr>
<tr>
<td>0900 - 0930</td>
<td>Presentation by Bonnie Schroeder, VON Canada on their experiences in supporting communication with the caregiver-care receiver dyad from a program and service perspective</td>
</tr>
<tr>
<td>0930 - 1000</td>
<td>Presentation by Julie Donaldson, President, the Manitoba Caregiver Coalition and Dr. Penny MacCourt, University of Victoria facilitating communication supports for family caregivers at the systems level</td>
</tr>
<tr>
<td>1000 - 1030</td>
<td>Break and informal discussions</td>
</tr>
<tr>
<td>1030 – 1130</td>
<td>Discussion of presentations; gaps in knowledge; and question and answer period</td>
</tr>
<tr>
<td>1130 - 1230</td>
<td>Lunch in meeting room</td>
</tr>
<tr>
<td>1230 - 1300</td>
<td><strong>FAMILY CAREGIVER COMMUNICATION AND THE HEALTH CARE PROFESSIONAL</strong></td>
</tr>
<tr>
<td>1300 - 1330</td>
<td>Health care professional attitudes toward family care by Dr. Britt-Inger Saveman, Professor, Umea University, Sweden</td>
</tr>
<tr>
<td>1330 – 1400</td>
<td>Health care professional-caregiver communication in primary care by Dr. Michel Bedard, CRC Chair, Lakehead University, Ontario</td>
</tr>
<tr>
<td>1400 – 1500</td>
<td>Discussion of presentations; gaps in knowledge; question and answer period</td>
</tr>
<tr>
<td>1500 - 1515</td>
<td>Break and informal discussions</td>
</tr>
<tr>
<td>1515 – 1545</td>
<td>Factors that impact patient-caregiver relations by Dr. Christine McPherson, Associate Professor, School of Nursing, University of Ottawa</td>
</tr>
<tr>
<td>1545 - 1615</td>
<td>Developing an empathic communication intervention by Dr. Christina Quinn, Associate Professor, Gordon College, Atlanta, Georgia, USA</td>
</tr>
<tr>
<td>1615 – 1715</td>
<td>Discussion of presentations; gaps in knowledge; question and answer period</td>
</tr>
<tr>
<td>1715 – 1730</td>
<td>Break and informal discussions</td>
</tr>
<tr>
<td>1730 – 1900</td>
<td>Working Dinner. Small group discussions based on today’s presentations to summarize gaps in knowledge and identify priority topics for a research agenda to be further developed in large group on the second day.</td>
</tr>
<tr>
<td>Time</td>
<td>Activity</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>0830 - 0845</td>
<td>Discussion of the day’s activities; review of discussions held on Day 1; distribution of any materials</td>
</tr>
<tr>
<td>0845 – 0915</td>
<td>Group 1 presentation of gaps in knowledge, priority research topics, and possible future research direction; question and answer period</td>
</tr>
<tr>
<td>0915 - 0945</td>
<td>Group 2 presentation of gaps in knowledge, priority research topics, and possible future research direction; question and answer period</td>
</tr>
<tr>
<td>0945 - 1015</td>
<td>Group 3 presentation of gaps in knowledge, priority research topics, and possible future research direction; question and answer period</td>
</tr>
<tr>
<td>1015 – 1030</td>
<td>Break and informal discussions</td>
</tr>
<tr>
<td>1030 - 1200</td>
<td>Big group discussion – Research agenda – reaching consensus on research priorities and future directions</td>
</tr>
<tr>
<td>1200 - 1300</td>
<td>Bagged Lunch</td>
</tr>
<tr>
<td>1300 - 1400</td>
<td>Brainstorming session and taking the first step in meeting the research agenda by identifying an initial project for submission to CIHR within the next year.</td>
</tr>
<tr>
<td>1400 - 1430</td>
<td>Break</td>
</tr>
<tr>
<td>1430 - 1545</td>
<td>Action Planning and Summary of Next Steps – Discuss who will be involved, the need for additional participants, geographic locations, and the timeline for next steps</td>
</tr>
<tr>
<td>1545 - 1600</td>
<td>Evaluation of workshop by participants</td>
</tr>
</tbody>
</table>
List of Workshop Participants

Family Caregiver Think Tank – November 5 and 6, 2012, The Inn at the Forks, Winnipeg

Back row: Kerenza Ploehman, Madeline Kohut, Maria Mathews, Christina Quinn, Sonia Udod, Penny MacCourt, Michel Bedard, Christine Scoville, Shannon Kohler, Christine McPherson, Mohammad Shaibie.

Front Row (sitting): Britt-Inger Saveman, Michelle Lobchuk, Bonnie Schroeder, Sue Bates

Missing: Kerstin Roger, Bob Thompson, Julie Donaldson, Chen Jin, Suzanne Verstraete, Genevieve Obarski, and Diane Cepanec
An interdisciplinary team including researchers and clinicians in nursing, social work, and family studies from Canada, Sweden, and the United States, participants from consumer groups and health and social service agencies in Manitoba, governmental representatives from Manitoba, a family caregiver, and graduate nursing students from the Faculty of Nursing, University of Manitoba. All these invited participants engage in issues associated with communication needs of caregivers and have respective in-depth understanding of the barriers and needs of caregivers as key partners in providing quality care to patients. It is anticipated that the following new Family Caregiver Communication Research Collaboration will involve new and existing collaborations including:

**Principal Investigator:** Dr. Michelle Lobchuk, Associate Professor and Manitoba Health Research Council Research Chair in Caregiver Communication. Her research program focuses on caregiver communication in health promotion, chronic illness, and stigmatized health conditions.

**Invited Participants:** The following participants have in-depth knowledge on the communication needs of family and friends who provide care along the trajectory of aging and chronic illness. Other participants have experiences with the health care system and/or workplace environments that facilitate or hinder communication by family caregivers (see Appendix for samples of their respective work).

**Speakers:**

*Drs. Christine McPherson,* Associate Professor, School of Nursing, University of Ottawa is a long-time collaborator with Dr. Lobchuk in caregiver studies that focus on empathic interaction and perceptual understanding by caregivers on patients’ illness experiences.

*Dr. Christina Quinn,* Associate Professor, Gordon College, Barnesville, Georgia, U.S.A., is a collaborator with Dr. Lobchuk in developing an intervention to enhance family caregiver empathic communication and symptom management with patients diagnosed with congestive heart failure.

*Dr. Britt-Inger Saveman,* Professor, Umea University, Sweden has expertise in the area of family care and has recently forged a collaborative relationship with Dr. Lobchuk to develop a study that examines nurse attitudes toward the importance of family care in the Canadian context of health care for comparison with nurse attitudes in Sweden.
Dr. Sonia Udod, Assistant Professor, School of Nursing, University of Saskatchewan has collaborated with Dr. Lobchuk when they studied nursing work life issues that impact nurse relations with families of cancer patients. Her expertise is vital in terms of identifying key elements in the work environment of nurses and other health care professionals that impact their ability to intervene with family caregivers.

Ms. Bonnie Schroeder, Director, Caregiving, Practice, Quality, and Risk Team, VON Canada presented on supporting communication with caregiver-care recipient dyads from a program and service perspective.

Ms. Julie Donaldson, Steering Committee of the Manitoba Caregiver Coalition and owner of Home Instead Seniors Care in Winnipeg addressed a survey undertaken by Home Instead about seniors needs.

Dr. Penny MacCourt, Faculty of Social Work, University of Victoria presented on the Caregiver Toolkit and caregiver communication needs.

Dr. Michel Bédard, Canada Research Chair in Aging and Health, and the Director of the Public Health Program at Lakehead University, Ontario addressed physician attitudes toward family caregivers in primary care settings.

Ms. Genevieve Obarski, Executive Lead, Program Implementation with the Change Foundation in Ontario (an independent health policy think tank) presented on the experiences of individuals and family caregivers, and their ideas for innovative solutions for a better path through health care transitions (see Appendix for their funded PATH project).

**Other participants (non-speakers):**

Ms. Maria Mathews, Manager of Client Support, The Alzheimer Society of Manitoba, Winnipeg.

Ms. Suzanne Verstraete, Member Relations Coordinator, Long Term and Continuing Care Association of Manitoba.

Dr. Kerstin Roger, Assistant Professor, Family Studies, Department in Human Ecology, University of Manitoba who is developing a better understanding of
verbal and non-verbal communication during decision-making between caregivers and individuals living with chronic neurological conditions

Ms. Sue Bates, Director of Patient Navigation, CancerCare Manitoba.

Ms. Madeline Kohut, Community Development and Seniors Specialist with the Winnipeg Regional Health Authority.

Mr. Bob Thompson, Caregiver and Appointee to the Ministerial Advisory Committee for Caregivers.

Ms. Shannon Kohler, Consultant, Manitoba Seniors and Healthy Aging Secretariat.

Ms. Christine Scoville, Graduate Nursing Student, Faculty of Nursing, University of Manitoba

Ms. Chen Jin, Graduate Nursing Student, Faculty of Nursing, University of Manitoba

Mr. Mohammad Shaibie, Graduate Nursing Student, Faculty of Nursing, University of Manitoba

Ms. Diane Cepanec, Research Coordinator, Manitoba Centre for Nursing and Health Research, Faculty of Nursing, University of Manitoba.
<table>
<thead>
<tr>
<th>No.</th>
<th>Name of participant</th>
<th>Email address</th>
</tr>
</thead>
</table>
| 1   | Sue Bates  
    Director of Patient Navigation  
    CancerCare Manitoba                      | sue.bates@cancercare.mb.ca     |
| 2   | Michel Bedard  
    Canada Research Chair in Aging and Health  
    Professor, Department of Health Sciences, Lakehead University | mbedard@lakeheadu.ca           |
| 3   | Diane Cepanec  
    Research Coordinator  
    Manitoba Centre for Nursing and Health Research  
    University of Manitoba                      | Diane.Cepanec@ad.umanitoba.ca  |
| 4   | Julie Donaldson, Owner  
    Home Instead Senior Care  
    Winnipeg  
    President of the Manitoba Caregiver Coalition | homecare@mymts.net              |
| 5   | Chen Jin, Graduate Nursing Student,  
    Faculty of Nursing, University of Manitoba | umjinc@cc.umanitoba.ca         |
| 6   | Shannon Kohler, Consultant  
    Manitoba Seniors and Healthy Aging Secretary | Shannon.Kohler@gov.mb.ca        |
| 7   | Madeline Kohut  
    Community Development and Senior Specialist  
    Winnipeg Regional Health Authority           | mkohut@wrha.mb.ca               |
| 8   | Michelle Lobchuk  
    Associate Professor  
    Faculty of Nursing  
    University of Manitoba                          | Michelle.Lobchuk@ad.umanitoba.ca |
<table>
<thead>
<tr>
<th></th>
<th>Name</th>
<th>Title/Position</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td><strong>Penny MacCourt</strong></td>
<td>Adjunct Professor&lt;br&gt;School of Social Work&lt;br&gt;University of Victoria, B.C.</td>
<td><a href="mailto:PennyMacCourt@shaw.ca">PennyMacCourt@shaw.ca</a></td>
</tr>
<tr>
<td>10</td>
<td><strong>Maria Mathews</strong></td>
<td>Manager of Client Support&lt;br&gt;The Alzheimer Society of Manitoba</td>
<td><a href="mailto:MMathews@alzheimer.mb.ca">MMathews@alzheimer.mb.ca</a></td>
</tr>
<tr>
<td>11</td>
<td><strong>Christine McPherson</strong></td>
<td>Associate Professor&lt;br&gt;School of Nursing, University of Ottawa</td>
<td><a href="mailto:cmcphers@uottawa.ca">cmcphers@uottawa.ca</a></td>
</tr>
<tr>
<td>12</td>
<td><strong>Genevieve Obarski</strong></td>
<td>Executive Lead&lt;br&gt;Program Implementation&lt;br&gt;The Change Foundation, Ontario</td>
<td><a href="mailto:gobarski@changefoundation.com">gobarski@changefoundation.com</a></td>
</tr>
<tr>
<td>13</td>
<td><strong>Kerenza Plohman</strong></td>
<td>Project Coordinator to Dr. Michelle Lobchuk&lt;br&gt;Faculty of Nursing, University of Manitoba</td>
<td><a href="mailto:Kerenza.Plohman@ad.umanitoba.ca">Kerenza.Plohman@ad.umanitoba.ca</a></td>
</tr>
<tr>
<td>14</td>
<td><strong>Christina Quinn</strong></td>
<td>Associate Professor, Nursing and Health Sciences&lt;br&gt;Gordon State College&lt;br&gt;Georgia, Atlanta, United States</td>
<td><a href="mailto:cquinn@gdn.edu">cquinn@gdn.edu</a></td>
</tr>
<tr>
<td>15</td>
<td><strong>Kerstin Roger</strong></td>
<td>Assistant Professor&lt;br&gt;Human Ecology, Department of Family Social Sciences, University of Manitoba</td>
<td><a href="mailto:rogerk@cc.umanitoba.ca">rogerk@cc.umanitoba.ca</a></td>
</tr>
<tr>
<td>16</td>
<td><strong>Britt-Inger Saveman</strong></td>
<td>Professor, Nursing&lt;br&gt;Umea University, Sweden</td>
<td><a href="mailto:britt-inger.saveman@nurs.umu.se">britt-inger.saveman@nurs.umu.se</a></td>
</tr>
<tr>
<td>17</td>
<td><strong>Bonnie Schroeder</strong></td>
<td>Executive Director&lt;br&gt;VON Ottawa and Eastern Ontario&lt;br&gt;(former Director, Caregiving)</td>
<td><a href="mailto:Bonnie.Schroeder@von.ca">Bonnie.Schroeder@von.ca</a></td>
</tr>
<tr>
<td>No.</td>
<td>Name</td>
<td>Title/Position</td>
<td>Email</td>
</tr>
<tr>
<td>-----</td>
<td>---------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>18</td>
<td>Christine Scoville</td>
<td>Graduate Nursing Student, Faculty of Nursing, University of Manitoba</td>
<td><a href="mailto:umscovil@cc.umanitoba.ca">umscovil@cc.umanitoba.ca</a></td>
</tr>
<tr>
<td>19</td>
<td>Mohammad Shaibie,</td>
<td>Graduate Nursing Student, Faculty of Nursing, University of Manitoba</td>
<td><a href="mailto:umshaibi@cc.umanitoba.ca">umshaibi@cc.umanitoba.ca</a></td>
</tr>
<tr>
<td></td>
<td>Family Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Member of the</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ministerial Advisory Committee for Caregivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Bob Thompson</td>
<td>Family Caregiver, Member of the Ministerial Advisory Committee for Caregivers</td>
<td><a href="mailto:bobthompson@mts.net">bobthompson@mts.net</a></td>
</tr>
<tr>
<td>21</td>
<td>Sonia Udod</td>
<td>Assistant Professor, College of Nursing, University of Saskatchewan</td>
<td><a href="mailto:sonia.udod@usask.ca">sonia.udod@usask.ca</a></td>
</tr>
<tr>
<td>22</td>
<td>Suzanne Verstraete</td>
<td>Member Relations Coordinator, Long Term and Continuing Care Association of</td>
<td><a href="mailto:suzanne_verstraete@hotmail.com">suzanne_verstraete@hotmail.com</a></td>
</tr>
</tbody>
</table>
Synopsis of Workshop Exercises and Outcomes

Dr. Michelle Lobchuk, Principal Investigator introduced the Think Tank participants to main objectives of the workshop: a. to develop an interdisciplinary collaboration of researchers, clinicians, service agencies, government representatives, family caregivers, and nursing students to engage in a research priority setting exercise, b. to develop a research agenda of priority areas for communication research at the systems-, health care provider-, or patient-level of caregiver interaction issues; and, c. to identify at least one key research project for immediate development and submission for CIHR funding in 2013.

Dr. Lobchuk explained that the research priority setting exercise she will follow is based on a framework for facilitators as developed by the Essential National Research Council (Okello, D., & Chongtrakul, P. [2000]. *A manual for research priority setting using the Essential National Health Research Strategy*. Downloaded on October 15, 2012: http://www.cohred.org/downloads/578.pdf). The research priority setting exercise included 4 levels (see Box 1):

**Box 1. Levels of research priority setting exercises**

| Level 1 exercise | Invited presentations of key communication issues at 3 levels: system-, health care provider-, and patient- levels; to encourage understanding of the broad “landscape” of communication issues perceived as being salient to family caregivers according to a range of speaker and participant perspectives. |
| Level 2 exercise | “Situational analysis” of communication issues – large group dialogue – identification of broad issues based on information from presentations and other participants’ experiences. |
| Level 3 exercise | “Provisional list” of research priorities in family caregiver issues – small group dialogue with follow-up presentation and dialogue in the large group. |
| Level 4 exercise | Identifying a “priority research project” for immediate attention – large group dialogue. |
Day 1

November 5, 2012

Presentations

Situational Analysis
Day 1 – November 5, 2012: Invited Presentations, Situational Analyses of Communication Issues, and Provisional Lists of Research Priority Areas

**Level 1 exercise: Presentations of communication issues x 3 levels**

Involved nine, 30-minute presentations by invited speakers who addressed family caregiver communication issues at either the system-, health-care provider-, or patient- levels of interaction. The speakers provided Think Tank participants with information to engage in an hour-long dialogue and a situational analysis of communication issues after each level (3-levels) of presentations. For Level 1 exercise, see Appendices for power-point slides.

**Level 2 exercise: Situation Analyses of communication issues x 3 levels**

Involved situation analyses and dialogue by participants in the large group who identified a broad ‘landscape’ of communication issues experienced by family caregivers at all 3 levels of communication (see Box 2.1, 2.2, and 2.3).

**Box 2.1. Patient-level Situation Analysis**

<table>
<thead>
<tr>
<th>Main issues:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patient – Caregiver Communication and Perceptual Congruence issues on Understanding Care Needs for Self and Other</td>
</tr>
<tr>
<td>2. How to engage in effective communication as a family caregiver in an intimate relationship</td>
</tr>
<tr>
<td>3. Distance Caregiving and Communication Issues</td>
</tr>
</tbody>
</table>

**Strategies (being done or can be done to address the above issues):**

| 1. Case conferences involving the caregiver and patient to improve communication and understanding of caregiver and patient needs |
| 2. Dyadic focused interventions |
| 3. C.A.R.E. tool (Guberman et al.) for caregiver to make needs known to patient; need for ongoing assessment as caregiver needs change over the illness trajectory |
4. Identify communication issues at the patient-caregiver level from surveys already conducted – e.g., Home Instead survey

5. Timing – identify ‘when’ to address patient-caregiver communication issues (intervention)

**Box 2.2. Health Care Provider-level Situation Analysis**

**Main issues:**

1. Navigating the system – communication needs at transitional points

2. Communication to better identify caregiver exhaustion – appropriate health care provider to identify caregiver exhaustion (i.e., Home Care, Primary Care e.g., general physician practitioners, nurse practitioners)

3. Education – how to communicate with family caregivers – need for empathic communication to identify caregiver needs

4. Worklife / environment impact – need to facilitate a change to practice and/or workplace culture that reflects communication with and care of families

5. How to communicate with caregivers who are not accepting of available services/resources – how to have ‘that’ conversation with families

6. Enhancing health care professional initiative/motivation/drive to communicate with family caregivers about their needs. Some dialogue occurred regarding ‘time’ was a factor for nurses’ lack of communication with families. Evidence was discussed that nurses’ workplaces make demands on their work ability to consistently provide safe, quality care.

**Strategies:**

1. ‘One-stop shops’ to meet family caregivers’ communication needs – e.g., Northern Health Authority, BC

2. Independent Think Tank investments to meet caregivers’ communication needs across different jurisdictions of care (address differences in resources/culture available in jurisdictions)
3. Implementing communication and follow-up by formal care providers (continuity of care) – ensuring safe, optimal transition of care needs of families in caregiver role

4. Health care professionals to engage in Caregiver Policy Lens analysis and pilot studies to capture impact of increased reflection on supports/policies in place to support meeting family caregivers’ communication needs

5. Identify ‘which’ health care professionals are key to supporting family caregivers’ communication needs – hospital versus community care – who recognizes the caregiver role and is able to support needs/ timeliness in recognizing needs.

6. Label of ‘caregiver’ – Is it necessary? It may deter timely communication with health care providers to self-identify needs (e.g., derogatory view of the label; people don’t identify with the label)

7. Caregiver Screening (e.g., Guberman tool) to stimulate dialogue between health care providers and family caregivers

8. Advocacy – participatory action research involving non-governmental agencies, health and social service organizations, caregiver support groups to identify key communication needs in the community

---

**Box 2.3. System-level Situation Analysis**

**Main issues:**

1. Culture – impact on how family caregivers and their communication needs are viewed/addressed (are they seen as resources, clients, co-clients, etc.)?

2. Divergent priorities of ‘communication’ needs between health care professionals and caregivers based on system needs and expectations

3. Top-down directives that ‘mis-match’ how to optimally involve and communicate with family in care settings

4. Transitional points – addressing family caregivers’ communication needs to prevent ‘falling through the cracks’ (e.g., hospital to community care)
5. Primary care practitioners (GPs / NPs) – questioned whether they see a role for themselves in communication with and care of the family unit

6. Structural supports are not ‘there’ for care of and communication with the caregiver – philosophy not present / resources not available

7. Fragmentation (related to #4) – barriers in communication between health and social service organizations / agencies

**Strategies:**

1. Coalitions – advocacy for meeting caregiver communication needs

2. Networking across health care and social service sectors to enhance communication

3. Better marketing of caregiver needs to enhance reflection, dialogue, professional philosophies of care and communication with family caregivers

4. Identify what’s working well for others in mitigating / removing fragmentation of communication between health and social service agencies (e.g., Alzheimer Society of Manitoba)

**Level 3 exercise: Provisional lists of research priority communication areas**

Day 1 also involved a dinner meeting with two working groups who ‘filtered’ and ‘identified’ key research priority areas. The main aim for the working groups was to delineate a provisional list of key communication areas for future research and dialogue in Day 2.
Day 2

November 6, 2012

Provisional List – Research Priority Areas
Day 2 – November 6, 2012: Developing a Provisional List of Research Priority Areas and identifying an Initial Research Project

The Level 3 exercise continued into Day 2 (to develop the provisional list of research priority communication areas). Dr. Michelle Lobchuk first encouraged Think Tank participants to take an appreciative inquiry approach to address what is working well in practice and research to address the communication needs of family caregivers. *Appreciative Inquiry* (AI) was selected as an approach to stimulate reflection and dialogue in the large group to help participants envision positive images of being able to meet communication needs of family caregivers. AI is “an approach to organizational and community development that has been used successfully worldwide to cultivate hope, build capacity unleash collective appreciation and imagination, and bring about positive change” (Browne, B. *What is Appreciative Inquiry*? . Retrieved from: http://www.imaginechicago.org/inquiry.html on August 15, 2012).

Groups 1 and 2 engaged in a respective dialogue with the large group in relation to their identification of communication issues x 3 levels as their Provisional List of research priority areas. See Box 3.1 and 3.2 for two Provisional Lists of Research Priority Areas to meet caregiver communication needs x 3 levels.

**Box 3.1. Group 1 Provisional List of Research Priority Areas**

**System-Level:**

1. Need to understand how caregivers and their communication needs are perceived at the system-level
   - Discussed concerns in relation to transitional care and communication needs across systems
   - Need to understand perceptions of program managers / middle management (i.e., as powerful facilitators in changing culture / philosophy about family care and optimal communication at points of care) but in which care setting – i.e., hospital?; targeting cross-sectors of where caregivers transition in their role and have communication issues across the illness trajectory of the patient
   - Issues of interprofessional collaboration in meeting caregivers’ communication needs e.g., following care needs of caregivers in stroke care – from acute care phase – rehabilitation – community care into the long-term
   - During “hand-off” of care from one sector to another sector, there is a current
lack of comprehending what was communicated to families as they transition care systems

- Discharge teaching/communication – ‘who’ did it, ‘what’ said, and ‘when’ done
- Testing a system of keeping track of caregivers and how their communication needs were addressed across their journey in the system; avert falling through the cracks

2. Caregiver Navigation
- Is navigation truly patient centred inclusive of meeting family caregivers’ communication needs) versus meeting health care professionals’ needs?
- Need to link evaluation of navigation programs and communication processes to fiscal outcomes (at all levels i.e., for the system, health care professional and patient-caregiver dyad); also need to link caregiver and patient outcomes – does navigation make a difference in meeting family caregiver and patient communication needs?
- Caregivers are commonly viewed as a ‘weak’ communication partner in navigation systems but there is a need to take more of a triadic approach, inclusive of family caregivers

3. Need for advocacy – including non-health care coalitions; Given the vulnerability of caregivers, coalition groups developed in the community both at regional and federal levels can act in critical ways as a voice for caregivers. Including coalition groups (Manitoba Caregiver Coalition) in discussions means that caregivers can have a forum set apart from formal health care systems, where their concerns and issues can be raised, compiled, and strategically communicated. For this reason, ensuring that such partnerships are strengthened means that community is well represented in forward thinking discussions on care and health care.

Health care provider–level:

1. Education of health care professionals
- Need for systems-thinking (inclusive of family) in curricula (basic training, continuing education) to promote communication competence with families
- Basic training – clinicians should be taught to think more about how they communicate with family caregivers who must deal with co-morbidities (versus just communicating on how to care for the patient’s single disease condition; seniors often have multiple diseases or conditions)
- Viewing empathic care and communication as VITAL tools in addressing BOTH patient and family caregiver needs ('singular’ needs as well as caregiving ‘dyad’ needs)
- Reflective thinking about how families are viewed as care partners that impacts how clinicians communicate with family caregivers
- Critical Thinking about communication as a tool to assess and meet caregivers’ needs; negotiation skills needed
- Empathic communication to enhance perceptual understanding and optimal family-centred care
- Team communication skill sets for self and others to not only interact meaningfully with family caregivers as partners with the interdisciplinary health care team BUT also ‘within’ the team to ensure that family caregivers’ needs are being met
- Intervention development – key focus should be on protecting the health of caregivers; good communication skills by health care providers to support and coach is needed
- Use of appropriate models on how to foster understanding of caregivers and their hierarchy of needs (in mental health); identification of high risk caregivers and how to interact with and address their needs at various levels of need: 1. Assessment (basic), 2. Education, 3. Psychosocial Interventions – dyadic approach, 4. Consultation with health care professionals (pyramid model mentioned by Dr. MacCourt)
- Offer Continuing Education – e.g., UOM Extended Learning – Bill Koops – How to train the trainer; caregiver forums being offered (1st in December 2012)
- Offer post-graduate courses – e.g., In Sweden this is being done to enhance skills in reflective thinking, empathy, role play with family caregivers to enhance communication and understanding skills
- Offer Elective courses in communication skills for health care and social service students
- It was noted that communication courses are often viewed as an ‘add-on’ with an already dense curricula in medicine/nursing
- How to argue need for more government support and resources to offer communication content for inclusion in basic training?
- Tap into interdisciplinary communication efforts already underway (e.g, UOM Interprofessional Education Initiative [IPE])
- Link to a crisis that identifies gaps in good communication
- Link caregiver communication needs to their health outcomes that in turn impacts resources/dollars in the health care system if not tended to.
2. There is a need to know ‘who’ do families desire receiving information/support from, ‘when’, ‘where’, and ‘what’ information?

Patient – level:

1. Need to market **partnerships** among health care professionals-patients-family caregivers
   - Health care professionals need to acknowledge the role of families as partners in care in need of support (e.g., use of assessment to identify needs – C.A.R.E. tool, offer respite to ensure support for taxing caregiver role, and engaging in health maintenance/self-care coaching to help keep the caregiver healthy)

2. Family caregivers need to learn the **caregiver art of ‘questioning’ and ‘listening’** to optimally meet patient’s needs in intimate relationships
   - Both formal and family caregivers are in need of similar communication skills

3. **Identification of caregivers in the community** who can give ‘voice’ to communication issues/ needs— (service organizations, coalitions).
System – level:

1. **Identify ‘caregiver’**
   - Potential studies on how to identify individuals in the caregiver role (e.g., other than calling individuals in caregiving roles, ‘caregivers’)
   - When do family in the community ‘cross-over’ from caring people to ‘caregiver’?
   - “Need to take a multi-level approach to address this (from the system-, health-care provider, and caregiver/patient- levels)” (Think Tank participant statement).

2. **Review system structure in light of desired or intended caregiver outcomes**

   **Conduct policy analysis** – at the provincial level e.g., RHAs by employing the Caregiver Policy Lens. Ask questions like:

   - “How is policy being implemented that supports and promotes communication with family caregivers across health care jurisdictions or sectors in support of caregivers?”
   - Examine transitional care and caregiver communication patterns across settings including the identification of staff attitudes, ratios, mix
   - Identify barriers to meeting caregivers’ communication needs in the system
   - Identify the organizational drivers and outcomes in relation to meeting caregiver communication needs
   - Need to focus caregiver outcomes (apart from and not just on patient outcomes) in relation to interaction and meeting communication needs in the system
   - Feasibility issues when conducting policy analysis; the group spent some time discussing approaches to develop a template (methodology) on evaluating effects of existing programs (what is working well or existing in support of caregiver needs); generalizable template / methodology to apply across conditions (caregivers tend to have similar needs in communicating with the system and/or care professionals); as in USA where there is a keen interest in addressing ‘revolving door’ conditions e.g., heart failure and punitive measures (decrease funding) against health care settings that don’t work at averting readmissions (optimal or meaningful communication and support of family caregivers to provide optimal care in the home to delay or prevent readmissions/medical attention)
- “System planners need to see the value of caregivers (not only to the health outcomes of the patient), but also to the broader health care system; evaluate the Caregiver Act legislation on the health outcomes of people and financial outcomes for the system.” (Think Tank participant statement)
- “I think policy makers should understand the importance of communication needs for family caregivers.” (Think Tank participant statement)

3. Other ideas for #2 (above point)
- Focus communication studies on magnet ‘settings’ (gold standard) across provincial sites/regions; conduct environmental scan of policies; some of this work is already being done; e.g., use of Caregiver Policy Lens (L. Funk, U of Manitoba, Sociology)
- Develop / identify key outcomes for caregivers as impacted by communication interventions
- Test the impact of one-stop shops for meeting caregiver communication needs
- Engage in projects that examine existing data (e.g., PALS/GSS Cycle 26 data to be released next year) which can inform policy in support of caregiver communication needs; social construction of data
- Need to capture the perceptions of a range of stakeholders (policy-makers, administrators/managers with resources/power) on meeting communication needs of caregivers; one-to-one interviews or focus groups
- Review of communication needs in the community care system (i.e., outside formal care systems like hospitals or residential care); conduct interventions at that level; ongoing synthesis work of what works in the community?

4. Knowledge Translation
- Conduct environmental scans / synthesis work on what’s being done; can lead to new initiatives and implementation projects that evaluate caregiver support programs and whether their communication needs were met in the program
- Better dissemination of evaluation results for effective programs that support caregiver communication needs;
- More studies that capture the ‘voice’ of stakeholders and use of an appreciative enquiry approach to capture perceptions of what’s working well and vision; case study approaches
- Need for a National Centre for Caregiving Clearinghouse – program
evaluation of this type of communication support mechanism is being done; including a synthesis of interventions by the Women’s Secretariat

**Health care professional – level:**

1. **Screening** – when to have this conversation with family caregivers?
   - To identify priorities – health care professional and caregiver
   - To identify the individual in the caregiver role and his/her needs

2. **Dealing with divergence / congruence in understanding caregiver needs**

3. **Pre and post education** – empathic communication skills, team communication focusing on meeting caregiver needs

4. **How to identify high risk caregivers** – poor care, poor health (self/patient)

5. **Analysis of nurse role** – very task oriented with no room for care of families; develop models of care for nurses as potential primary contacts in hospital settings for caregivers

**Patient – caregiver level:**

1. **Identification of the caregiver’s needs in the caregiving dyad and when it needs to be done?**; can use the C.A.R.E tool (Guberman)

2. **How to have conversations with health care providers** – including how to negotiate the caregiver role and meeting patient/caregiver needs, as well as care planning and promoting congruent understanding of needs; inclusive of empathy and meaningful engagement with professional care providers as a partner and negotiation of needs (#2 above).

3. **How to capture interaction data between patients and caregivers** – to help target interventions to enhance their communication
Day 2

November 6, 2012

Initial Research

Project
Day 2 – November 6, 2012 – Identifying the Initial Research Project

Level 4 exercise: First steps in meeting the research agenda

The large group engaged in a brainstorming session to take the first steps in meeting the research agenda by identifying an initial project for submission to CIHR within the next year. The large group focused on action planning (who will be involved, the need for added collaborators, geographic locations for the study, and the timeline for next steps).

One major action item arose from the workshop:

Prepare and submit a research proposal that addresses the following research questions from the perspective of key stakeholders (i.e., from the system-, health-care provider-, and the patient- levels) where communication issues for caregivers occur:

- **Research Questions:**
  
  “What are the in-depth perspectives of key stakeholders across 3 levels about factors that support their vision of meeting the communication needs of families?

  “What caregivers at what time need what kind of support to meet their communication needs?”

  “How can these communication needs be supported in the future?”

- **Lead and Co-Investigators and Collaborators**
  
  Co-PIs: Michelle Lobchuk and Christine McPherson volunteered to lead this project. They plan to discuss the timeline and appropriate grant mechanism, as well as the next steps to begin preparation of a CIHR grant proposal for submission in 2013 (likely Fall due to the short-time line for the March 2013 call, and outstanding need to further develop or identify the research team); a Skype call meeting is planned for November 21, 2012 between the Co-PIs for next steps.
Co-investigators or Collaborators: As recommended by participants, the Co-PIs should consider including and/or inviting the following individuals to serve on the grant proposal (e.g., submit suggestions for revision to the proposal and approve final proposal; submit Registration and Full application CVs before CIHR deadlines)

Janice Keefe (Policy, Nova Scotia)
Wendy Gifford (KT, First Nations, Management; Ottawa)
Sue Bates (Navigation, Cancer Care, practice / management); agreed to serve as a collaborator
Bonnie Schroeder (VON Canada, practice); agreed to serve as a collaborator
Bob Thompson (Lay Caregiver; Ministerial Advisory Committee)
Daniel Lai (Social Work; cultural lens)
Laura Funk (Sociology, responsibility, policy analysis)
Kerstin Roger (Family Studies, decision-making)
Nora Keating (Human Ecology)

Reviewers of grant draft (volunteered): Britt-Inger Saveman, Christina Quinn

To include in the grant, as recommended by Think Tank participants:

- An Advisory Board (e.g., to provide direction in methodology, sample / setting, and development of the interview script for different stakeholders).

- Obtain letters of support for project – (indicating jurisdictional support) – Seniors Secretariat (Shannon Kohler, agreed); Ministerial Advisory Committee (Shannon Kohler, agreed); Canadian Caregiver Coalition, Ontario Caregiver Coalition, Manitoba Caregiver Coalition

- Need to develop a strong rationale for conducting the study in 2 provinces (e.g., is there added value to the grant?). For example, Manitoba has legislation in support of caregivers versus no legislation in Ontario that can impact supports to meet the communication needs of family caregivers.
- Qualitative methodology (e.g., focus groups) as guided by an Appreciative Enquiry approach. Example of four key questions (below) posed in Saveman and Lobchuk’s CIHR grant with RNs in direct patient care in Manitoba:

There are four main stages with Appreciative Inquiry: Discovery (valuing), Dream (envisioning), Design (through dialogue) and Destiny (co-constructing the future) that can guide the development of 4 core focus group questions x 3 sub-groups of stakeholders (system-, health care provider-, and patient- levels):

“What do you believe is good about your communication with families in your health care agency?” (Discovery)
“What do you want to achieve in your communication with families? (Dream)
“What are the areas where you feel you need to focus on that could have the most impact on improving the quality of communication with families?” (Design) and,
“What is needed to make your vision to engage in supportive communication with families more of a reality in your care setting?” (Destiny)

Sample: Target three sub-groups of stakeholders: a. System level management, b. Health Care Providers, and c. Family Caregivers; need to further identify individuals and settings at 3 levels; as indicated above, a key recommendation was to be clear in what we are trying to achieve by targeting two provinces which adds complexity to the project plus need for more funding.

- System level management – still unknown ‘who’ to target; perhaps key policy-makers / decision-makers who have the power to make decisions about communication supports and resources, and can leverage change in promoting family care and communication; include those involved with ensuring optimal transitioning of caregivers across care settings (e.g., hospital to home, home to long-term care, etc.) and being able to meet their communication needs.
Further planning is required to discuss the appropriate sample and settings including ‘what’ health care providers to include, as well as where to recruit family caregivers?

Addendum: In Fall 2012, Saveman and Lobchuk submitted a CIHR grant proposal that addressed similar questions with RNs who are in direct patient care in Manitoba; there is the possibility of drawing on the same methodology as proposed in Saveman and Lobchuk’s grant.
Appendix A

Family Caregiver Communication and the Health Care System

Ms. Genevieve Obarski

Bonnie Schroeder

Julie Donaldson

Penny MacCourt
A minute on The Change Foundation

- Endowed by the Ontario Hospital Association in 1996
- Spent 10 years as a granting agency focused on local system change
- Reorganized in 2007 – Health policy think tank focused on issues of integration, quality improvement and patient experience
- Mandate is to promote, support and improve health and delivery of healthcare in Ontario
"Hearing the stories, changing the story"

- At The Change Foundation
  - Listen & Learn from the experience of individuals and caregivers at key transition points.
  - Incubate and Innovate to find solutions to identified problematic transitions within communities
  - Advise and Advance. We'll engage users, stewards and stakeholders around solutions and support to improve health-care experience and integrated care. We'll promote system-level adoption of innovations to improve individual/caregiver experience through greater health-care integration.

The Change Foundation Strategic Plan

Carrying out our mandate:

- Research- literature review, surveys
- Policy Analysis- synthesis and interaction with government
- Public Engagement
- Care Delivery Re-design
  *Partners Advancing Transitions in Healthcare (PATH)*
Public Engagement: 
Listening to the patient’s experience

Movie Link:

What are patients telling us?

About the system:
- Navigation
- Repetition, redundancy and delay
- Communication and transmitting important information
- Getting lost in the transitions
- Who is connecting the dots?
What are patients telling us?

At the local level:

- They want to be treated with human dignity and respect.
- They want to be regarded as an equal to the care providers.
- They want to be part of their care decisions.
- They want access to their medical information.
- They want safe care.
- They don’t want to wait for care.

The Change Foundation Strategic Plan

Carrying out our mandate:

- Research- literature review, surveys
- Policy Analysis- synthesis and interaction with government
- Public Engagement
- Care Delivery Re-design
  Partners Advancing Transitions in Healthcare (PATH)
What is PATH?

- A provider-patient partnership to identify and address key problem areas in transitions between healthcare settings.

- Understand and improve the experiences of patients and their informal caregivers at key transitions between healthcare settings and services.

- Support a community coalition of providers, patients and informal caregivers to re-design transition problems that they identify together.

- Provide resources to build and support the provider patient coalition, engage patients and their caregivers in co-design, process design and improvement expertise, and project implementation.
Key components/features of the PATH project

- Seniors with chronic health conditions

- One community partnership
  - Patients
  - Informal caregivers
  - Social support providers
  - Acute care providers
  - Home and community care providers
  - Primary care providers
  - Funders and other stakeholders
  - Mental health care providers

- Care transitions

- Patient experiences

- Patient co-design

Goals

- Improve people's experience as they move in, out of, and across Ontario's healthcare system by engaging and supporting a community coalition

- Demonstrate the value of experience based co-design for the broader system
Experience Based Design principles

- It's a **partnership** between patients, caregivers and staff.
- The emphasis is on **experience** rather than opinion or attitude.
- Story telling is used to identify **touch points**.
- The emphasis is on **co-design**.
- Systematic **evaluation** of improvements and benefits is mandatory.
Continuum of patient influence

Evolution of patient experience

<table>
<thead>
<tr>
<th>Doing &quot;to&quot; patients</th>
<th>Doing &quot;for&quot; patients</th>
<th>Doing &quot;with&quot; patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>To</td>
<td>For</td>
<td>With</td>
</tr>
</tbody>
</table>

Provider makes rules and controls all schedules
Information not shared with patients
"I talk-you listen"
Compliance focus
Unilateral

Reproduced from [Sato SF, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Quality and Safety in Health Care. 2006; 15 (5):397-105] with permission from BMJ Publishing Group Ltd.
Evolution of patient experience

<table>
<thead>
<tr>
<th>Doing &quot;to&quot; patients</th>
<th>Doing &quot;for&quot; patients</th>
<th>Doing &quot;with&quot; patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>To</td>
<td>For</td>
<td>With</td>
</tr>
<tr>
<td>Patient/family have some input</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some transparency, public data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;We help you&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improvement focus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benevolent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Evolution of patient experience

<table>
<thead>
<tr>
<th>Doing &quot;to&quot; patients</th>
<th>Doing &quot;for&quot; patients</th>
<th>Doing &quot;with&quot; patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>To</td>
<td>For</td>
<td>With</td>
</tr>
<tr>
<td>Patient/family as source of control</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shared knowledge and decision making</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;We walk together&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-design focus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partnership</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Evolution of patient experience

<table>
<thead>
<tr>
<th>To</th>
<th>For</th>
<th>With</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider makes rules and controls all schedules</td>
<td>Patient/family have some input</td>
<td>Patient/family as source of control</td>
</tr>
<tr>
<td>Information not shared with patients</td>
<td>Some transparency, public data</td>
<td>Shared knowledge and decision making</td>
</tr>
<tr>
<td>“I talk-you listen”</td>
<td>“We help you”</td>
<td>“We walk together”</td>
</tr>
<tr>
<td>Compliance focus</td>
<td>Improvement focus</td>
<td>Co-design focus</td>
</tr>
<tr>
<td>Unilateral</td>
<td>Benevolent</td>
<td>Partnership</td>
</tr>
</tbody>
</table>

## Patient experience and patient influence

![Diagram showing the evolution from doing “to” patients to doing “with” patients]

1. Complying
2. Giving information
3. Listening and responding
4. Consulting and advising
5. Experience-based co-design

*Date & Robert 2006*
Listening to the patient's experience

Doing "to"  Doing "for"  Doing "with"

- Suggestion box, complaint letters, surveys,
- Focus groups, interviews, blogs, patient opinion website
- Patient advisory councils, feedback on patient materials
- Patients on improvement teams, patients on Boards, open access, patients co-design processes and services

Execution of PATH

- Select one community coalition of patients and providers
- Resources to build and support the provider-patient coalition
- Engage patients and caregivers in co-design
- Resources for process design, measurement
- Guide the overall project
PATH Timeline

- **July 2011**: Letter of Intent call was issued; 27 submissions received
- **November 2011**: Letters of Intent reviewed; short list of five submissions determined
- **January 2012**: Five communities invited to submit full project proposal
- **March 2012**: Full proposal submitted to the Foundation
- **April 2012**: Site visits by Foundation staff to all five sites
- **May 2012**: Final determination of PATH community

PATH Proposal Characteristics

**Common Themes in Proposals**
- Community “heart”
- Understand unique community issues
- Quality improvement capability in hospital, CCAC partners
- History of successful collaboration
- Lead organization recognized as strong convener

**Variation Among Proposals**
- LHIN involvement
- Patient/caregiver involvement in proposal, site visit
- Measurement clarity
- Project management capability
- Patient/caregiver recruitment strategies
- Depth of co-design commitment
- Primary care involvement
Attributes of Selected Community

- Patient/family/caregiver co-design central
- Lead organization strong, attracted key partners
- Successful track record of joint projects
- Governance and project management plans
- Leadership commitment and alignment
- Strong partnership array
- Solid evaluation, measurement and data collection
- Excellent focus on community issues
- Shared goals for community level improvement

PATH Partnership

- Patients and Caregivers
- Providers
  - Northumberland Hills Hospital
  - Northumberland Family Health Team
  - NHH Comm. Mental Health Services
  - Central East CCAC
- Community Organizations
  - YMCA Northumberland YMCA
  - Community Care Northumberland
  - Golden Plough Lodge Long Term Care Home
  - Palisade Gardens Retirement Residence
- Others
  - Central East LHIN
  - Health System Performance Research Network
  - Patients' Association of Canada
  - QoC Health
<table>
<thead>
<tr>
<th>Date</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>June 2012</td>
<td>Experience Based Design and Quality Improvement Training for 56 PATH partner clients, caregivers, and clinicians</td>
</tr>
<tr>
<td>July-Sept. 2012</td>
<td>Project infrastructure being set-up, Convened Steering Committee, Project Manager hired, Patient/Caregiver recruitment strategy designed</td>
</tr>
<tr>
<td>October 2012</td>
<td>Attend Patient and Family Centered Care Conference (IPFCC) Recruit patients/caregivers to share experiences, work on teams</td>
</tr>
<tr>
<td>Nov. 2012</td>
<td>Project positions in QI coaching, admin support, etc. Draft Project Charters for improvement teams</td>
</tr>
<tr>
<td>Nov. 2012</td>
<td>Patients/caregivers share stories that inform improvement team work</td>
</tr>
<tr>
<td>Dec. 2012</td>
<td>Patients/caregivers and providers participate as equals on project teams</td>
</tr>
</tbody>
</table>

---

**What a Good Patient Experience Means to People**

- Encourages my questions and gives me answers
- Values my and my family's time as much as the providers
- Listens to me carefully, talks to me clearly, respects my wishes
- Diagnoses me accurately and comprehensively
- Gives me high quality, holistic care when I need it
- Equips me to self-manage if appropriate
- Uses 21st century technology to meet my needs

*S. Lewis, AOHC, 2012*
### How the System Would Communicate

<table>
<thead>
<tr>
<th>NOW</th>
<th>THE FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Short &amp; Frequent Visits</td>
<td>Longer &amp; Fewer Visits</td>
</tr>
<tr>
<td>• In-person Is Default</td>
<td>Multi-Mode</td>
</tr>
<tr>
<td>• See the Doctor</td>
<td>See Anyone Competent</td>
</tr>
<tr>
<td>• Parallel &amp; Unsynchronized</td>
<td>Streamlined &amp; Coord.</td>
</tr>
<tr>
<td>• Talk Much, Listen Little</td>
<td>Listen First, Then Talk</td>
</tr>
</tbody>
</table>

### How Providers Would be Educated

<table>
<thead>
<tr>
<th>MORE EMPHASIS</th>
<th>LESS EMPHASIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Teamwork</td>
<td>Individual Roles</td>
</tr>
<tr>
<td>• Chronic Diseases</td>
<td>Exotic Diseases</td>
</tr>
<tr>
<td>• Emotional Intelligence</td>
<td>IQ</td>
</tr>
<tr>
<td>• Holistic Care</td>
<td>Disease Compartmentalized</td>
</tr>
<tr>
<td>• Aging and Frailty</td>
<td>Medical Miracles</td>
</tr>
</tbody>
</table>
How We Would Define Performance

<table>
<thead>
<tr>
<th>CURRENT</th>
<th>FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of Pop. Screened</td>
<td>% of Needs Addressed</td>
</tr>
<tr>
<td>Low Wait Times</td>
<td>Avoided Interventions</td>
</tr>
<tr>
<td>Access to Specialists</td>
<td>Primary Care Reduces Referrals</td>
</tr>
<tr>
<td>Quality of Technology</td>
<td>Quality of Communication</td>
</tr>
<tr>
<td>System-Defined Outcomes</td>
<td>Patient-Defined Outcomes</td>
</tr>
</tbody>
</table>

How the System Would Value Time

<table>
<thead>
<tr>
<th>CURRENT</th>
<th>FUTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Time Worth Nothing</td>
<td>My Time Worth As Much As Yours</td>
</tr>
<tr>
<td>Travel Time Is Pt’s Problem</td>
<td>Travel Time a Burden to Avoid</td>
</tr>
<tr>
<td>Non-Direct Care Time Is Overhead</td>
<td>Learning Time Is Essential</td>
</tr>
<tr>
<td>Schedules Months in Advance</td>
<td>Schedules Open and Flexible</td>
</tr>
</tbody>
</table>
Thank you
Genevieve Obarski, phone 416-205-1564
Gobarski@changelfoundation.com
Roles, Responsibilities, and Relationships: Exploring the Caregiver – Care Receiver Dyad from a Program and Service Perspective

caregiver-connect.ca | from caring to sharing.

Outline

- Nature of care – role, responsibility and relationship
- Who is the client? and under what conditions?
- Challenges and advantages
- Canadian best practices
- Future directions
The Nature of the Dyad

Care·giver·er:
n. an individual who provides ongoing care to family members and friends with physical, cognitive, or mental health conditions.
The Caregiving Role

- Self-identification – a part of the process
- Struggling to juggle
- In it for the long haul
- Multiple caregiving roles
- A social determinant of health
- Not always a choice
- A role with limited benefits

The Caregiving Responsibilities

- The need for care varies
- More than transactional care
- ‘Constant vigilance’ or ‘always on call’
- Context makes a difference
- It has economic value - $25 billion CDN
The Caregiving Relationship

- ‘Caring for’ and ‘caring about’
- It more than the dyad - 1:1
- More than a family affair
- Quality counts
- Proximity matters

Caregiving is...

...a common human experience.

...a relationship.

...a growing concern for an ailing and aging population.

...a role that requires support.

...a social issue that requires a vision to address the needs.
Who is the Focus? and Under What Conditions?

Who is the client?

- Care receiver as client – caregiver peripheral
- Caregiver as resource
- Caregiver as co-client
- Caregiver as ‘partners in care’
- Community partnerships

~ Twigg 1989; Guberman & Maheu, 2000; Ward-Griffin, 2001

Supporting Caregiving Dyads • Page 10 • www.von.ca • www.caregiver-connect.ca
### Who is the client?

<table>
<thead>
<tr>
<th></th>
<th>Caregivers</th>
<th>Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peripheral</td>
<td>25%</td>
<td>14%</td>
</tr>
<tr>
<td>Resource</td>
<td>25%</td>
<td>14%</td>
</tr>
<tr>
<td>Co-clients</td>
<td>18%</td>
<td>29%</td>
</tr>
<tr>
<td>Partners in Care</td>
<td>17%</td>
<td>48%</td>
</tr>
</tbody>
</table>

(VON Caregiver Support Best Practice, 2004)

---

### Challenges and Advantages
Challenges

- Requires a paradigm shift
- Limited resources
- Unrealistic program expectations
- Increased complexity of need
- Lack of understanding of or conflicting needs
- Geography
- Legal and ethical issues

Challenges continued

- Safety issues
- Quality of the relationship
- Dealing with the emotional side of caregiving
- Fragmented and uncoordinated health, home care and community services
Advantages

- Sustains the dyad as ‘partners in care’
- Strengthens the triad of the caregiver – care receiver – provider
- Integrates caregiver assessment
- Increases flexibility and choice
- Supports transitions in care

Supporting Caregiving Dyads • Page 15 • www.von.ca • www.caregiver-connect.ca
Best Practices

- Found 17 Canadian best practices
- 2 journal article, 1 book, 14 from 7 different organizational websites
- Conditions: dementia, mental health, stroke
- Focus: person/client/family centred care, strengthening families, therapeutic relationship, respite, caregiver support and counseling, organizing health care delivery systems, bereavement care
- Setting: community, long term care, nursing practice
- Type: end of life

CAMH Family Centred Initiative

www.camh.net
Future Directions

- Recognize the increasing complexity of dyads
- Embrace a family centred approach
- Acknowledge as ‘partners in care’
- Bundle a comprehensive package
- Integrate technology
- Create a system of accountability
Future Directions

To what extent do the experiences of caregivers and care receivers inform programs and services?
What programs and services have the best effect?
What influences the outcomes for them individually and as a dyad?
What assessment tools, interventions and resources should be used?
How can policy and research support the further development of programs and services?
Bonnie Schroeder, MSW, RSW
Director, Caregiving
bonnie.schroeder@von.ca

caregiver-connect.ca | from caring to sharing.

Caregiving Resources
VON Canada
www.von.ca
Caregiver Connect/aidants-en-réseau
www.caregiver-connect.ca
Canadian Caregiver Coalition
www.ccc-ccan.ca
La référence pour proches de personnes âgées
http://aidant.ca
Caregiver Think Tank
November 5 & 6, 2012

Partners Include
PRIORITIES

- Policy/Advocacy
  - Caregiver Recognition Act
    - Caregiver Recognition Day
  - Advisory Committee
- System Navigation – Unanimous Top Priority
  - Central Point of Access
    - Telephone (Health Links/Info Sante)
    - Website (Healthy Child)
    - Senior Advocate (Child Advocate/Womens Advocate)
  - Tool/Resource Kit
Study Findings

- Knew Little about the care options that are available
  - 73% Adult Children neither thought or planned
  - 50% Seniors never planned their future
- Were misguided about the costs of these options
- Were poorly informed about what financial resources will be needed to cover the cost of care
As Manitoba moves forward on System Navigation

- Armed with enough accurate information, seniors and their caregivers will be able to make informed choices about the most appropriate and affordable kind of care at each stage of the aging process. Absent of such information, many will make choices that are wrong for the senior’s situation and budget-busting for the family.
- A public information campaign to bridge the Information Gap would pay for itself many times over in lowered costs for senior care and less suffering.
- The campaign should tap every source of modern communications to reach the widest possible audience.
Family Caregiver Communication
Think Tank

Dr. Penny MacCourt

November 5, 2012, Winnipeg

What is the Caregiver Toolkit?

- A 3-year project to bring together diverse knowledge, skills and perspectives related to supporting caregivers.
- A ‘one-stop shop’ for those providing services to, or planning policies and programs for, caregivers
- Three main resources:
  ✓ The Caregiver Policy Lens (CGPL)
  ✓ The Service Provider Resource Guide (SPRG)
  ✓ Web site caregivertoolkit.ca
Project Goals

- Provide evidence-informed support to those working with caregivers (either directly or indirectly)
- Provide a framework to support inclusive policies and programs that affect caregivers
- Increase capacity across and between jurisdictions/organizations

Background

- Interdisciplinary National Advisory Committee
- Consultation with more than 250 caregivers, service providers and organizations, policy analysts, educators, and advocates.
- Review of academic and professional literature
- Review of best and promising practices
- Piloted in diverse settings across Canada
The CGPL is a resource designed for those who are interested in including caregivers in the design, implementation and evaluation of policies, programs and practices that affect them (either directly or indirectly).

11 question categories

Designed to be answered with:
- Yes, No, Not Sure, Not Applicable

Generates a report

Action plan

Can use all questions or focus on those most relevant to you
Caregiver Involvement
How are caregivers, caregiver advocates and caregiver organizations involved in the design/review of the policy, program or practice?

Collaboration
Are relevant organizations, Ministries, interest groups and individuals concerned with caregiving involved?
Respect and Dignity
Does the policy, program or practice reflect respect for caregivers and support their dignity through valuing the importance of their contribution and acknowledging their relationship with the senior?

Diversity and Marginalization
Does the policy, program or practice assess whether diverse caregivers are likely to experience inequities or negative impacts resulting from their membership in marginalized groups?

Self-Determination and Independence
Does the policy, program or practice promote and support caregivers' self-determination and independence?

Accessibility
Does the policy, program or practice facilitate access to the services available to caregivers of seniors and make appropriate adaptations to accommodate diverse needs?
Responsiveness
Is the policy, program or practice designed in such a way that crises and excess use of system supports are minimized?

Communication
Are there clear lines of communication and responsibility between service providers and caregivers, and between agencies?

Resiliency
Does the policy, program, or practice support the caregiver’s capacity to cope with stress and adversity?

Individuality
Are caregivers assessed for their own needs and addressed separately from the care recipient?
Sustaining Caregivers
Does the policy, program, or practice help equip caregivers with knowledge, skills and respite to carry out their role?

Sustaining Systems
Is the policy or program for seniors sensitive to the needs and concerns of caregivers, and delivered by knowledgeable staff with sufficient time and skill to develop caring, trusting relationships?

Fairness and Equity
Does the policy, program, or practice ensure fairness to caregivers while not diminishing benefits to others?

Evidence Informed
Is the policy, program, or practice informed by evidence?
The SPRG is a practical “one stop shop” of evidence-based resources to increase the capacity of those working with caregivers, either directly or indirectly.

- Caregiver Assessments
- Caregiver Interventions
- Issues in ongoing case management
- Federal and provincial resource directory of caregiver supports

**ISSUES IN CASE MANAGEMENT**

- Provides an overview of common issues that may arise between caregivers and care recipients, and caregivers and service providers
- Highlights the possible tensions these issues can create for service providers
- Identifies other resources that can help to address and resolve these issues
CAREGIVER-CARE RECIPIENT ISSUES

• Caregivers and care recipients may not agree on service options or most appropriate plan of care
• Family dynamics
• Role expectations between caregivers and care recipients
• Generational issues

CAREGIVER SERVICE PROVIDER ISSUES

• Time constraints
• Confidentiality
• Caregiver lack of system knowledge
• Service delivery issues
  No and diversity of care providers
  Lack of privacy
  Inability to control timing of service provision
• Access — waitlists, eligibility/criteria
SYSTEMIC ISSUES

- Caregivers’ needs are not addressed in their own right
- Acute care focus
- Poor service integration
- Under-resourced services
- Tensions between services

Transitions, Crises & Difficult Conversations

- Difficult Emotions
- Legal issues
  - Power of attorney
  - Abuse
  - Capacity, competency & decision making
  - Living at Risk
  - Confidentiality
- Diversity
- Stress and self-care
Appendix B

Family Caregiver Communication and the Health Care Provider

Sonia Udod

Britt-Inger Saveman

Michel Bedard
Health Care Professional-Caregiver Communication and Work Life Factors

Think Tank
Winnipeg, Manitoba
November 5, 2012
Sonia Udod, RN, PhD

Outline

- Nurses’ Quality of Work Life (NQWL)
  - NQWL, nurses job satisfaction, and patient outcomes
- Nurses’ Quality of Work Life in Oncology Settings
  - Family caregiver communication
  - Implications for nurse leaders
  - Potential research questions
Introduction

- Restructuring has negatively affected nurses’ work life
- Increased demand for care has not been consistently matched with resources in care delivery
- Canadian documents (2001; 2006)
- Canadian Nurses Association (2006) believes quality environments maximize outcomes for client, nurses, and systems

Quality of Nurses Work Life

- Comprised of several themes: Leadership/mgt style, shift work, benefits and relationships with colleagues, demographics, and workload/job strain
- O’Brien-Pallas & Baumann (1992) developed the first conceptual framework
  - Internal dimensions- individual, social context, operations, and administration
  - External dimensions- client demand, health care policy, and labour market
Work Life Factors, Job Satisfaction and Patient Outcomes

- Larrabee et al. (2003) found dissatisfaction was a predictor of intent to leave.
- Aiken et al. (2002) found workloads were related with lower quality care and increased mortality.
- Laschinger (2001; 2006; 2010) found that structural empowerment is associated with job satisfaction.
- A predictor of job satisfaction is unit relationships.
- Job satisfaction is related to patient outcomes.

Nurses’ Work Life in Oncology Settings

- Predicted nursing shortage in Canada in 2016.
- Studies related to NWL in oncology settings:
  - Grunfeld et al. (2005) found sources of job satisfaction: relationships with families and colleagues.
  - Sources of job stress: conflicting demands, workload and staffing.
  - Sale & Smoke (2007)

www.usask.ca/nursing
Nurses’ Work Life in Oncology Settings

- Studies related to Nurse leaders and NWL:
  - Cummings et al (2008) developed and tested a theoretical model of oncology work environment factors influencing job satisfaction
  - Guruge et al (2004) explored staff-family relationships and the role of NM

Nurses’ Work Life in Oncology Settings

- Lobchuk & Udod (2011) explored nurse-family relations and work environments in promoting satisfactory care
- Nurses perceptions of their care in relationships with patients and their families
- Facilitators and barriers
- Perceptions of work environments
QNWL and Family Caregiver Communication

- Caregiving throughout the lifespan
- Shift in care (Yaffe & Jacobs, 2008)
- Quality of care dependent on RN and/or family but also on staff-family
- What is less clear is how NWL affects interactions with family caregivers

Implications

- Nursing leadership is essential in creating positive workplace environments
- Ward-Griffin et al (2003) indicated mentorship of nurse leaders is important in fostering family centered care
- Nurses well situated to play a more active role in advancing care for family caregivers
Potential Research Questions

Conceptual
- Nature of communication between nurses, patients and family caregivers in the context on which these interactions occur
- The nature of interactions (strengths and weaknesses) of health care team members working with family caregivers, as well as barriers and facilitators in the environment in these encounters

What are the perceptions of NL’s regarding workplace phil and work environments on family centered care that support or hinder nurses’ ability to care and develop relationships with families of patients with cancer?

Methodological
- Longitudinal studies in addressing the complex contextual influences among family caregiving and nurses work life
Conclusion

- Leadership is key in creating conditions for professional nursing practice
- Relationships and caring for the needs of patients and their families are common among studies in providing care to oncology patients and caregivers
Nurses attitudes towards family care

Britt-Inger Saveman, RNT, PhD, Professor, Umeå University, Sweden

The aim is to present:

- A limited review of nurses attitudes about families in care
- an instrument for measuring Families Importance in Nursing Care – Nurses Attitudes (FINC-NA)
- some of the findings from Icelandic and Swedish FINC-NA surveys
- some research gaps
Studies on nurses attitudes towards families in care

- Contextspecific (hospital, primary health care, community care)

- Care specialties (emergency care, geriatric care, psychiatric care, pediatric care)

- Studyspecific questionnaires or interviews

Working with families is important

- to establish a good relationship
- the needs of the patients and the families guide engagement
- a good relationship for establishing a nonhierarchal encounter
- when organizing continued treatment and establishing a holistic view of the care
Difficulties when working with families

- families from foreign cultures
- demanding, troublesome, or suffering families
- family members with feelings difficult to handle
- feel controlled by families
- own shyness about contacting families
- medical and technical tasks considered most important

Constraining beliefs about working with families

- involvement with families take too much time
- care of a patient is a task for nursing staff
- families lack skills and understanding of the patients’ conditions
- family members are primarily a source of information
Factors of importance for the attitude towards families

- Age
- Sex
- Education
- Work experience
- Personal experience with a seriously ill family member in own family
- A general approach to the care of families at the place of work

A long exiting trip...
The background for developing a generic questionnaire

- Previous studies provided an ambiguous picture of nurses' attitudes
- Nurses hold both supportive and less supportive attitudes about families
- Findings were limited to specific health care contexts

The developmental phases of FINC-NA were divided into:

- The inductive item producing process including literature review
- The content validity and the 1st psychometric testing process
- The refinement and the 2nd psychometric re-evaluation process
- The usefulness and the world-wide disperse of the FINC-NA instrument
The inductive item producing process including literature review

- Both a manual and data based literature searching
- Focusing on nurses’ attitudes towards the importance of families in nursing care
- Constructed 117 items and sorted the items in cognitive, affective and behavioral dimensions
- Face-validity tests of the items among RNs and faculties

The content validity and the 1st psychometric testing process

- The instrument consist of 59 items and a 4-point Lickert scale
- Test group: 634/980 randomly selected Swedish RNs
- Response rate 65%
- Results presented by content and psychometric statistics
Development of the original version (n=634)

<table>
<thead>
<tr>
<th>Analyses</th>
<th>Purpose</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data quality</td>
<td>Descriptive statistics</td>
<td>To identify problems with floor and ceiling effects</td>
</tr>
<tr>
<td>Construct validity</td>
<td>Item-total correlations</td>
<td>To identify items that correlated weak with the total score (the construct) and that was considered for deletion.</td>
</tr>
<tr>
<td>Construct validity (dimensionality)</td>
<td>Factor analysis (principal component factoring)</td>
<td>To identify underlying dimensions that could construct subscales</td>
</tr>
<tr>
<td>Construct validity (convergent and discriminant validity)</td>
<td>Spearman's Rho</td>
<td>To test the hypothesis that the correlation between each subscale and the total scale should be stronger than the correlations between the subscales</td>
</tr>
<tr>
<td>Internal consistency reliability</td>
<td>Cronbach's alpha coefficient</td>
<td>To test if the items in the 13.5-NA scales correlated sufficiently with each other.</td>
</tr>
</tbody>
</table>

Family as a resource in nursing care (Fam-RNC)

The presence of family members eases my workload
The presence of family members gives me a feeling of security
The presence of family members is important to me as a nurse
Family members should be invited to actively take part in the patient's nursing care
Family members should be invited to actively take part in planning patient care
A good relationship with family members gives me job satisfaction
Getting involved with families gives me a feeling of being useful
I gain a lot of worthwhile knowledge from families which I can use in my work
The presence of family members is important for the family members themselves
It is important to spend time with families
Family as a conversational partner (Fam-CP)

I invite family members to have a conversation at the end of the care period.

I ask family members to take part in discussions from the very first contact, when a patient comes into my care.

I always find out what family members a patient has.

I invite family members to speak about changes in the patient’s condition.

I invite family members to speak when planning care.

It is important to find out what family members a patient has.

I invite family members to actively take part in the patient’s care.

Discussion with family members during first care contact saves time in my future work.

Family as a burden (Fam-B)

The presence of family members makes me feel that they are checking up on me.

The presence of family members makes me feel stressed.

The presence of family members holds me back in my work.

I don’t have time to take care of families.
Family as own resource (Fam-OR)

I encourage families to use their own resources so that they have the optimal possibilities to cope with situations by themselves.

I see myself as a resource for families so that they can cope as well as possible with their situation.

I consider family members as co-operating partners.

I ask families how I can support them.

The Swedish study (n=634)

Swedish RNs have a supportive attitude about the importance of families in nursing care:

- Being a male RN
- Being a newly graduated RN
- Having no general approach to families at the place of work ...

... predict a less supportive attitude.

The Icelandic FINC-NA study (n=81)

- women, >15 years of work experience, child and adolescent psychiatric nurses had an allover more positive attitude
- women more positive to view family as an own resource in nursing care and not seeing family as a burden
- The more educated nurses and nurses who had experienced illness in their family - the less they see family as a burden
- 1 year after education and training psychiatric nurses (64%) viewed families as less burdensome


Family systems nursing conversation

A brief family conversation in clinical practice including:

- Manners
- Therapeutic conversations
- Family assessment (genograms and ecomaps)
- Using therapeutic questions
- Commend the family

(Wright L and Leahey M. Nurses and Families. 2009)
The refinement and the 2nd psychometric re-evaluation process

- To further improve the validity and reliability of the 26 item instrument
- A 5-point Lickert scale replaced the 4-point
- A web-based distribution
- Test group 246/736 RNs, response rate 33%
- Test-retest n=113/246

The refinement of the FINC-NA (n=246)

<table>
<thead>
<tr>
<th>Analyses</th>
<th>Purpose</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data quality</td>
<td>Descriptive statistics</td>
<td>Most items still skewed but with a greater variation</td>
</tr>
<tr>
<td></td>
<td>D'Agostino test of skewness</td>
<td>Some scale scores were still skewed but with a good variation</td>
</tr>
<tr>
<td>Construct validity</td>
<td>Item-total correlations</td>
<td>All items correlated</td>
</tr>
<tr>
<td>Construct validity</td>
<td>Factor analysis (principal component factoring)</td>
<td>All items correlated</td>
</tr>
<tr>
<td>Construct validity</td>
<td>Ordinal regression modeling</td>
<td>All items correlated</td>
</tr>
<tr>
<td>Internal consistency</td>
<td>Cronbach’s alpha coefficient</td>
<td>All items correlated</td>
</tr>
<tr>
<td>Test-retest reliability</td>
<td>Intraclass correlations</td>
<td>All items correlated</td>
</tr>
</tbody>
</table>
Instrument development articles


The usefulness and the world-wide disperse of the FINC-NA instrument
Content from the revised FINC-NA study (n=206)

- RNs have a supportive attitude towards the importance of families in nursing care
- Younger RNs had an overall less supportive attitude
- Younger RNs and male RNs had a less supportive attitude towards families as a conversational partner
- Younger RNs were more prone to see families as a burden and less positive towards families as its own resource

Gille M. Registered nurses' attitudes towards family's importance in nursing care – a descriptive study. Master thesis, Umeå University, 2009

Education and interventions

- The Icelandic family systems nursing program
- The Swedish Health promoting conversations with families – an intervention model
- To teach family systems nursing using on-line
- Literature (books and research articles)
To teach family systems nursing using on-line

15 RNs attended a 10-week master course in nursing using a technology enhanced learning. The students were satisfied:
- learned to “think family”
- acknowledged the content of the course
- gained a useful tool for their future family nursing practice
- even stronger supported FINC-NA attitudes post-course: Seeing family as a resource in nursing care, family as own resource and seeing family as less burdensome.

Conclusions

- The findings from the revised FINC-NA allow the use of the instrument in order to examine nurses' attitudes towards the family's importance in nursing care.
- Nurses hold a positive attitude towards families.
- Education and experiences (personal and work) seems important for a positive view of families.

Gaps

- More comparable studies on nurses attitudes using e.g. FINC-NA
- Between attitudes and nurses actual actions
- Family systems nursing in interventions and research
- Education, e.g specific courses in family systems nursing
Thank you for your attention!
Background

- Seniors with dementia should be supported to “age in place”
  - Role of informal caregivers (e.g., spouses)
  - Increasing demands/at-risk (see Lilly et al., 2012)
- Caregivers are at risk for:
  - depression
  - anxiety
  - chronic illnesses
  - stress-related conditions
- Caregivers may also have health issues of their own
Basic premises

- View caregiver and care recipient health as one entity
- A healthy caregiver is the best resource for someone in need

Family physicians are positioned to assess caregiver health...
- identify caregivers at risk
- provide medical support

They could also
- give instrumental advice,
- help caregivers access resources
- normalize feeling of resentment, anger, frustration,
- encourage caregivers to take care of themselves
BUT!
- Dealing with caregivers goes much beyond diagnosis issues
- Physicians find caregiving issues stressful (see Yaffe, 2002)
- Caregivers’ support may differ across physicians
- Requires guidelines (see Schoenmakers et al., 2009)
- We have little knowledge of Canadian family physician perspectives on caregiver issues

Study Objectives

Develop a questionnaire to:

1. Understand family physicians’ knowledge of and attitudes about caregiver issues
2. Assist health planners/decision makers in optimizing the role of family physicians in supporting caregiver health and well-being
3. Indirectly maximize the health status and quality of life of seniors
## Methods

### StAGE 1: Literature review & item development

<table>
<thead>
<tr>
<th>Main Domains</th>
<th>Sub Domains</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Health Outcomes &amp; Accountability</strong></td>
<td>a. caregivers' health (including psychological health)</td>
</tr>
<tr>
<td></td>
<td>b. identification of caregiving strain</td>
</tr>
<tr>
<td></td>
<td>c. validation of caregiving role</td>
</tr>
<tr>
<td></td>
<td>d. emotional/psychological support</td>
</tr>
<tr>
<td></td>
<td>e. education of caregivers</td>
</tr>
<tr>
<td></td>
<td>f. practical assistance regarding available services</td>
</tr>
<tr>
<td></td>
<td>g. advocating for caregiver access to services</td>
</tr>
<tr>
<td></td>
<td>h. case managing</td>
</tr>
<tr>
<td><strong>2. Preparation</strong></td>
<td>a. training to identify caregivers and their needs</td>
</tr>
<tr>
<td></td>
<td>b. training to respond to health challenges</td>
</tr>
<tr>
<td></td>
<td>c. training to respond to emotional/psychological needs of CGs</td>
</tr>
<tr>
<td></td>
<td>d. training to educate caregivers</td>
</tr>
<tr>
<td></td>
<td>e. knowledge of available resources</td>
</tr>
<tr>
<td><strong>3. Barriers</strong></td>
<td>a. time</td>
</tr>
<tr>
<td></td>
<td>b. reimbursement</td>
</tr>
<tr>
<td></td>
<td>c. team/local resources</td>
</tr>
<tr>
<td></td>
<td>d. confidentiality with caregivers/care recipient present</td>
</tr>
<tr>
<td></td>
<td>e. understands role of caregivers</td>
</tr>
<tr>
<td></td>
<td>f. understands link between caregiver health and patient outcome</td>
</tr>
</tbody>
</table>

- Created Version I of the survey
  - 38 questions
  - 5-point scale – Strongly Disagree to Strongly Agree
  - Focus on caregivers of people with dementia
  - 4 sections:
    1. general
    2. caregivers who are patients
    3. caregivers who are not patients
    4. demographics
STAGE 2: Feedback

1. Pre-tested survey with experts (n=2)
2. Created Version II
3. Interviewed health planners/decision makers (n=7)
4. Interviewed family physicians (n=9)
   - 6 urban, 3 rural
   - completed survey using “think-aloud” approach and probing

STAGE 3: Final Revisions

- Results compiled and reviewed
- Final version created
Results

EXPERT FEEDBACK

- Reformatting suggestions (e.g., reduce font size)
- Reduce survey length
- Booklet format

PARTICIPANT INTERVIEWS

<table>
<thead>
<tr>
<th>Family Physicians said:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remove</td>
</tr>
<tr>
<td>• Questions about medical concerns and responding to practical concerns</td>
</tr>
<tr>
<td>Add</td>
</tr>
<tr>
<td>• Question about training on caregiver issues</td>
</tr>
<tr>
<td>• Question about tools to assess caregiver strain</td>
</tr>
<tr>
<td>In General</td>
</tr>
<tr>
<td>• Reflects experiences with caregivers</td>
</tr>
<tr>
<td>• Make applicable to all caregivers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health Planners/Decision Makers said:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Questions about medical abilities</td>
</tr>
<tr>
<td>• Similar/repetitive questions</td>
</tr>
<tr>
<td>• Question about training on caregiver issues</td>
</tr>
<tr>
<td>• Useful for health planning</td>
</tr>
<tr>
<td>• Make applicable to all caregivers</td>
</tr>
</tbody>
</table>
**FAMILY PHYSICIANS (n=9)**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Sex (Female)</strong></td>
<td>5 (55.6%)</td>
</tr>
<tr>
<td><strong>2. Years in profession</strong></td>
<td>M = 15.7, SD = 13.4</td>
</tr>
<tr>
<td><strong>3. Work setting (more than one response possible)</strong></td>
<td></td>
</tr>
<tr>
<td>Private office/clinic</td>
<td>7 (77.8%)</td>
</tr>
<tr>
<td>Nursing home/Home for the aged</td>
<td>2 (22.2%)</td>
</tr>
<tr>
<td>Community clinic/health centre</td>
<td>2 (22.2%)</td>
</tr>
<tr>
<td>Community hospital</td>
<td>5 (55.6%)</td>
</tr>
<tr>
<td>University/Faculty of medicine</td>
<td>3 (33.3%)</td>
</tr>
<tr>
<td>Free-standing walk-in clinic</td>
<td>1 (11.1%)</td>
</tr>
<tr>
<td>Emergency Department</td>
<td>2 (22.2%)</td>
</tr>
<tr>
<td><strong>4. Number of patients rostered in practice</strong></td>
<td></td>
</tr>
<tr>
<td>Less than 750</td>
<td>1 (11.1%)</td>
</tr>
<tr>
<td>751 to 1500</td>
<td>2 (22.2%)</td>
</tr>
<tr>
<td>1501 to 2250</td>
<td>1 (11.1%)</td>
</tr>
<tr>
<td>2251 and over</td>
<td>3 (33.3%)</td>
</tr>
<tr>
<td>Does not apply</td>
<td>3 (22.2%)</td>
</tr>
</tbody>
</table>

**GENERAL QUESTIONS (MEAN, SD)**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients and CGs have different agendas</td>
<td>4.1, 0.8</td>
</tr>
<tr>
<td>Have knowledge to assess the specific needs of CGs</td>
<td>3.6, 0.9</td>
</tr>
<tr>
<td>Patient health outcomes linked to CG health</td>
<td>3.9, 1.1</td>
</tr>
<tr>
<td>Have knowledge to respond to medical needs of CGs</td>
<td>4.4, 0.7</td>
</tr>
<tr>
<td>Have knowledge to educate CGs about resources</td>
<td>3.4, 0.7</td>
</tr>
<tr>
<td>Have knowledge to educate CGs health impacts</td>
<td>3.6, 0.9</td>
</tr>
<tr>
<td>Have knowledge to educate CGs about specialized services for patient</td>
<td>4.4, 0.8</td>
</tr>
<tr>
<td>Have knowledge to educate CGs about patient's health</td>
<td>4.4, 0.5</td>
</tr>
<tr>
<td>Comfortable talking to patients in presence of CGs</td>
<td>4.2, 0.4</td>
</tr>
<tr>
<td>Comfortable talking to CGs in presence of patient</td>
<td>3.9, 0.3</td>
</tr>
<tr>
<td>Am part of solution to CG issues</td>
<td>3.6, 0.5</td>
</tr>
<tr>
<td>Adequate services for CGs</td>
<td>2.2, 0.8</td>
</tr>
<tr>
<td>Have knowledge to assess caregiver strain/burden</td>
<td>3.1, 1.3</td>
</tr>
<tr>
<td>Healthy CG best source of support for patient</td>
<td>4.4, 0.7</td>
</tr>
<tr>
<td>Have knowledge to identify CGs who need assistance</td>
<td>3.3, 1.0</td>
</tr>
<tr>
<td>Role of CGs is difficult</td>
<td>4.7, 0.5</td>
</tr>
<tr>
<td>Have knowledge re: emotional/psychological needs of CGs</td>
<td>3.6, 0.5</td>
</tr>
</tbody>
</table>
## Comparison of When the Caregiver Is a Patient and When the Caregiver Is Not a Patient

<table>
<thead>
<tr>
<th>Responsibility to Identify Caregivers Who Are Strained</th>
<th>M</th>
<th>SD</th>
<th>t</th>
<th>p</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>4.22</td>
<td>0.44</td>
<td>1.84</td>
<td>0.10</td>
<td>0.78</td>
</tr>
<tr>
<td>Not Patient</td>
<td>3.78</td>
<td>0.67</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educate About Patient's Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.56</td>
<td>0.53</td>
<td>1.00</td>
<td>0.35</td>
<td>0.23</td>
</tr>
<tr>
<td>Not Patient</td>
<td>4.44</td>
<td>0.53</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educate About Specialized Services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.33</td>
<td>0.50</td>
<td>0.00</td>
<td>1.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Not Patient</td>
<td>4.33</td>
<td>0.50</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educate About Impact on Caregiver's Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.11</td>
<td>0.60</td>
<td>0.00</td>
<td>1.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Not Patient</td>
<td>4.11</td>
<td>0.60</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educate About Community Resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.33</td>
<td>0.50</td>
<td>1.51</td>
<td>0.17</td>
<td>0.40</td>
</tr>
<tr>
<td>Not Patient</td>
<td>4.11</td>
<td>0.60</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate Time for Caregiver Issues</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>2.44</td>
<td>1.24</td>
<td>1.00</td>
<td>0.35</td>
<td>0.39</td>
</tr>
<tr>
<td>Not Patient</td>
<td>2.00</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reimbursed Adequately for Supporting Caregivers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>3.00</td>
<td>1.23</td>
<td>1.79</td>
<td>0.11</td>
<td>0.57</td>
</tr>
<tr>
<td>Not Patient</td>
<td>2.33</td>
<td>1.12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wait for Caregivers to Express Strain Before Discussing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>1.89</td>
<td>0.53</td>
<td>1.89</td>
<td>0.10</td>
<td>-0.73</td>
</tr>
<tr>
<td>Not Patient</td>
<td>2.44</td>
<td>0.53</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Comparison of When the Caregiver Is a Patient and When the Caregiver Is Not a Patient

<table>
<thead>
<tr>
<th>Responsibility to Recommend and Coordinate Social Services</th>
<th>M</th>
<th>SD</th>
<th>t</th>
<th>p</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>4.00</td>
<td>0.50</td>
<td>5.55</td>
<td>&lt;.001</td>
<td>2.01</td>
</tr>
<tr>
<td>Not Patient</td>
<td>2.89</td>
<td>0.60</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responsibility to Advocate on Behalf of Caregivers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.11</td>
<td>0.93</td>
<td>5.50</td>
<td>&lt;.001</td>
<td>1.15</td>
</tr>
<tr>
<td>Not Patient</td>
<td>2.89</td>
<td>1.17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responsibility to Provide Emotional Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.56</td>
<td>0.53</td>
<td>3.04</td>
<td>.02</td>
<td>1.60</td>
</tr>
<tr>
<td>Not Patient</td>
<td>3.11</td>
<td>1.17</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responsibly to Support Caregivers Experiencing Stress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.44</td>
<td>0.53</td>
<td>6.83</td>
<td>&lt;.001</td>
<td>3.37</td>
</tr>
<tr>
<td>Not Patient</td>
<td>2.33</td>
<td>0.71</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responsibility to Respond to Medical Concerns of Caregivers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>4.50</td>
<td>0.54</td>
<td>6.25</td>
<td>&lt;.001</td>
<td>3.29</td>
</tr>
<tr>
<td>Not Patient</td>
<td>1.88</td>
<td>0.99</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Discussion

• Suggestions from participants used to create final version of survey tool
  – 31 questions
  – Booklet format
  – Applicable for all caregivers
• Informal caregivers, regardless of their situation, face common challenges and may experience strain

• Real differences in the interactions that physicians have with caregivers who are patients and those who are not
  – Mostly related to medical care
  – Effect sizes are robust
  – Suggest the questionnaire is valid
• Data from larger scale administration of the survey could inform health planners and decision makers
Next Steps

• Administer the survey to Canadian family physicians using appropriate survey methodology to:
  1. Document psychometric properties (e.g., validity, reliability, factor structure)
  1. Document the situation of family physicians
  2. Gauge the usefulness of the data for health planners/decision-makers

• Long-term potential use of the survey
  • Develop targeted interventions and training for family physicians
  • Policy changes
  • Improve health of caregivers and care recipients
Thank You!

Special thanks to:

• Sandra MacLeod
• Dr. Peteris Darzins
• Dr. Jon Johnsen
• Jerry Chek-Hung Koh
• Health planners/decision makers
• Family physicians
Appendix C

Family Caregiver Communication and the Patient

Christine McPherson

Christina Quinn
FACTORS THAT IMPACT PATIENT-CAREGIVER RELATIONS

Christine McPherson, RN, PhD
Associate Professor
University of Ottawa

OVERVIEW

PATIENT-CAREGIVER RELATIONS

- Open communication
- Factors that effect open communication
  - Individual
  - Dyadic relationship
  - Situational
COMMUNICATION

- Decision making
- Supporting
- Advocacy
- Care provision
- Symptom assessment and management

COMPARISONS

OPEN COMMUNICATION

- Quality of life
- Coping
- Empathy
- Family support
- Psychosocial adjustment
- Caregiver burden

CLOSED COMMUNICATE

- Sense of control
- Self-esteem
- Psychological
- Physical
- Uncertainty
OVERVIEW

Situational

Patient  Caregiver

Dyadic relationship

Patient Level
INDIVIDUAL LEVEL

Patient
- Physical and psychosocial functioning and concerns
  - Cognitive functioning
  - Sensory impairments
  - Coping (i.e. denial, positive outlook)
  - Psychological distress
  - Fear of death
  - Maintaining autonomy, independence and sense of self

SENSE OF SELF

“For my children, their first question is “how do you feel today?” ...and you know it’s... It has changed the whole relationship in the sense that they are concerned about my pain” (P15).
Family Caregiver Level

Open Communication: Caregiver Factors

- Interviewed 236 FCGs
- Patient ≥60 years; cancer
- Interviewed 283 days after patient death
- 77.5% FCG female
- 44.9% partner; 47.9 son/daughter
- Duration of caregiving approx. 19 months

(Bachner & Carmel, 2009)
Quantitative descriptive research design

Measures-
- Caregiver characteristics
- Sense of coherence
  - (Comprehensible, meaningful and manageable)
  - “Do you feel there isn’t much meaning in the things you are involved, in your daily life?”
- Optimism
  - “In uncertain times I expect the best”.

- Mastery
  - (control over life)
  - “I can do almost anything I decide to do”
- Self-Efficacy
  - “I am sure I will be able to cope with unpredictable situations”.
- Fear of death and dying
- Emotional Exhaustion
  - (burnout)
- Depression
Main findings:

Positive correlations with open communication:
  - Optimism
  - Self-efficacy

Negative correlations with open communication:
  - Fear of death and dying
  - Emotional exhaustion
  - Depression

Family caregiver
  - Coping (i.e. denial positive outlook)
  - Caregiver burden
  - Fear of death and dying
  - Emotional exhaustion
  - Depression
  - Optimism
  - Self-efficacy
  - Psychological distress (i.e. self-protection)
“Everything was pretty much surface, 'cause you couldn’t crack my shell so easy and, of course, she didn’t want to see me cry, so. That’s why I’m mad that I couldn’t get through that enough to help her. And I wasn’t being selfish on purpose, but I was being selfish, you know? I was so trying to keep myself together, which I didn’t, and I couldn’t. That I couldn’t go that next step to offer her help.”

(Participant direct quote from Stone, et al., 2012, p. 96)
DYADIC LEVEL

- Relationship (type and quality)
- Communication style (tone and expression)
- Congruence in views and goals
- Attributions of blame and responsibility
- FCG feelings of anger and frustration toward the patient
- Mutual "Protective Buffering"
  - Self-perceived burden
  - FCG- Reluctance to discuss feelings and experiences

"Well our whole life is just around him now you know it's just pretty much every day it's all about him. I guess he's a victim" (FCG2)


**DYADIC LEVEL**

- Relationship (type and quality)
- Communication style (tone and expression)
- Congruence in views and goals
- Attributions of blame and responsibility
- FCG feelings of anger and frustration toward the patient
- Mutual “Protective Buffering”
  - Self-perceived burden
  - FCG- Reluctance to discuss feelings and experiences

---

**SELF-PERCEIVED BURDEN**

“*Yes I tell her but I don’t want to stress her out anymore about it .... I wait until she asks you know. She is busy with her own life and her own things. I don’t want her to have to worry about me you know*” (P 7).
Social support
- Health care services
- Family
- Competing demands
- Distance
- Duration and intensity of caregiving
- Content of the interactions (cause, symptom, challenging situations)
- Over time (disease trajectory)

Examined patterns of change in dyadic communication between patients with prostate cancer and partners
- 134 dyads
- Demographic
- Measures
  - Social support
  - Uncertainty
  - Symptom distress
  - Dyadic communication
- Longitudinal - baseline, 4, 8 and 12 months

(Song et al., 2012)
Findings:
- Communication decreased over time
- Phase of illness affected communication at baseline (diagnosis) but not patterns of change over time
- Less communication for those with localized illness compared to recurrent or advanced illness.
- Communication increased with more social support, less uncertainty, and fewer hormonal symptoms in patients.

"its [pain] just...an accepted part of our relationship. .. We got to the point where we communicate only about our pain, only when it is so overwhelming" (P 15).
**MAIN POINTS**

- Communication
- Potential impact on caregiver and patient
- Practical implications

**FUTURE RESEARCH AREAS**

- Lack of research
- Research cancer
- Cross-sectional
- Underlying mechanisms
- Identify those needing support
- Strategies and interventions to enhance communication
References


References


Developing an Empathetic Communication Intervention

Christina Quinn RN,DNS
Associate Professor
Gordon College; Barnesville, Georgia
cquinn@gdn.edu

Objectives:

- Summary of perspective-taking prompt
- Importance of perceptual congruence at the patient-caregiver dyad level.
- Examples of empathic communication issues between the patient and caregiver
Improving Heart Failure Symptom congruence: a perspective taking intervention

- A pilot longitudinal study
- Tested a perspective-taking intervention between family CG’s and Heart Failure patients
  - Examined the degree of symptom assessment congruence pre and post intervention

Subjects

- Home health HF patients and their designated FCG (family caregiver)
- 11 dyads
Demographics

<table>
<thead>
<tr>
<th>Heart Failure Patient</th>
<th>Family Member</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>76 ± 8 years</td>
<td>54.8 ± 15 years</td>
</tr>
<tr>
<td>NYHA Class</td>
<td></td>
</tr>
<tr>
<td>II = 18%</td>
<td></td>
</tr>
<tr>
<td>III = 64%</td>
<td></td>
</tr>
<tr>
<td>IV = 18%</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>18% Male</td>
<td>18% Male</td>
</tr>
<tr>
<td>82% Female</td>
<td>82% Female</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>45% African-American</td>
<td>Same as HF Patient</td>
</tr>
<tr>
<td>55% Caucasian</td>
<td></td>
</tr>
<tr>
<td>Relationship of FM to HF Patient</td>
<td>37% Adult Children</td>
</tr>
<tr>
<td></td>
<td>27% Adult Sibling</td>
</tr>
<tr>
<td></td>
<td>9% Spouse</td>
</tr>
<tr>
<td></td>
<td>27% Other</td>
</tr>
<tr>
<td></td>
<td>(niece/nephew)</td>
</tr>
</tbody>
</table>

Heart Failure Symptom Survey (HFSS)

- Patient and FCG completed this measure pre and post intervention.
- Frequency and severity of 14 common HF symptoms (over the past week)
- Scale of 0–10
- Higher scores indicate higher intensity of symptoms
**Intervention**

- The imagine-patient perspective-taking intervention was explained to the CG in private.
- The CG was asked to notice their loved ones’ symptoms over the following two weeks.
- When recognizing a symptom, they should try to imagine how the symptom was felt by the HF patient.
- The CG was asked to put themselves “in the patient’s shoes” when evaluating each symptom.

**Intervention (cont’d)**

- The FCG was instructed to validate what they observed as the HF patient was having the symptom.
- A summary of what the intervention involved was given to the FCG.
- The researcher encouraged the FCG to write down notes as the 2 weeks progressed.
- These notes were referred to with the researcher after two weeks.
**Intervention (cont’d)**

- Two weeks after the intervention, the HF patient and FCG were be asked to complete the HFSS.
- The FCG was then asked if they noticed anything different in how they perceived symptoms differently with this new perspective-taking technique.
- Comments were recorded by researcher as the FCG spoke

**Intervention Script**

- Step 1: FCG and researcher in a private area
  - “the purpose of my visit is to teach you a different way to look at how HF symptoms are interpreted in order to improve your ability to recognize what your loved one is going through”
- Step 2: realize different ways of looking at things
  - “there are several ways of looking at the same thing; think of a situation when you were anxious—did you wish others could understand how you were feeling”
Intervention Script (cont')

- Step 2 cont'd:
  - "now, can you think of a symptom you have had trouble recognizing related to your loved one's HF?
  - FCG then tells researcher which symptom they have trouble recognizing
  - Researcher teaches Perspective Taking and leaves a "practice" sheet with the FCG

FCG Practice

- 1. Whenever you notice a change in your loved one, think how you noticed the change (verbal, nonverbal)
- 2. Put yourself in their shoes and think about how your loved one might respond in terms of a change in their symptoms
- 3. Ask and validate your interpretation with your loved one and see if your assessment was accurate or not
Assessment of use of Perspective Taking

Post Intervention questions:
- What cues did you use to answer the symptom questions (verbal, non-verbal, both)
  - 9 responded – both; 1 responded verbal
- Were any cues self-oriented?
  - 6 responded "my history with the patient"
  - 3 responded "thinking about what I would do if I had this disease"
- Did you rely on any other cues?
  - Comment: "even though mother did not complain, I knew something was wrong"

Results: symptom assessment congruence increased in 6/14 symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Spearman’s Rho (p value) – pre intervention</th>
<th>Spearman’s Rho (p value) – post intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>SOB at rest</td>
<td>.280 [.405]</td>
<td>.306 [.38]</td>
</tr>
<tr>
<td>SOB w/ activity</td>
<td>.547 [.082]</td>
<td>.689 [.62]</td>
</tr>
<tr>
<td>SOB lying down</td>
<td>.527 [.144]</td>
<td>.795 [.01]</td>
</tr>
<tr>
<td>SOB wake up at night</td>
<td>-.240 [.505]</td>
<td>.669 [.000]</td>
</tr>
<tr>
<td>Edema in feet/ankles</td>
<td>.158 [.643]</td>
<td>.520 [.12]</td>
</tr>
<tr>
<td>Bloating abdomen</td>
<td>.061 [.877]</td>
<td>.302 [.43]</td>
</tr>
<tr>
<td>Fatigue</td>
<td>-.100 [.784]</td>
<td>.545 [.10]</td>
</tr>
</tbody>
</table>
Results (cont’d)

Heart Failure Symptom Survey

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>Spearman’s Rho (p value) – pre intervention</th>
<th>Spearman’s Rho (p value) – post intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest pressure</td>
<td>.750 (.020)*</td>
<td>.862 (.001)*</td>
</tr>
<tr>
<td>Irregular heart beat</td>
<td>.106 (.786)</td>
<td>.750 (.02)</td>
</tr>
<tr>
<td>Worsening cough</td>
<td>.504 (.167)</td>
<td>-.632 (.93)</td>
</tr>
<tr>
<td>Dizziness/ lightheaded</td>
<td>.699 (.023)*</td>
<td>.529 (.11)</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>.203 (.574)</td>
<td>.784 (.007)*</td>
</tr>
<tr>
<td>Forgetfulness</td>
<td>.465 (.149)</td>
<td>.731 (.011)</td>
</tr>
<tr>
<td>Depressed</td>
<td>.133 (.713)</td>
<td>.494 (.14)</td>
</tr>
</tbody>
</table>

Did you notice anything different in yourself or the HF patient in the last two weeks since learning this perspective taking intervention?

FCG responses to question:
 “it changed the way I look at my mother”
 “I was much more aware of changes in my brother and how drastic a change in his condition can be”
 “I understand her a little better...how someone with a chronic illness feels”
 “It changed the way I look at her. I noticed when she could not sleep and other changes like the ankle swelling today. I watched her more closely in the last two weeks”
 “Because of what you taught me, I noticed my sister’s leg was hurting. I had never noticed that before, so after I saw that, I asked her about it”
 “This was different from the past. I used to wait until she told me and then it was usually really bad by then. This time with the teaching you gave me, I was more alert to her problems”
 “This teaching you gave me changed the way I look at my Aunt’s symptoms. Her facial expressions of her mood were the cues I noticed before she even said anything was wrong”
 “This teaching will help me in the future to make sure I ask more questions when I notice a change even before she says anything”
 “I don’t think I had noticed her facial expressions when she was short of breath before, so that was something new for me”
Summary:

- At baseline, there was high symptom assessment congruence on one symptom (chest pressure)

- Post intervention: symptom assessment congruence increased in 6/14 symptoms (SOB lying down, SOB waking up at night, chest pressure, irregular heart beat, difficulty sleeping, and difficulty concentrating)

Summary (cont’d)

- Though a limited sample size, perspective-taking as an intervention, improved symptom assessment congruence in HF patients and their FCG

- This intervention stimulated the FCG to use a patient-oriented empathetic process to understand HF symptoms from the patient’s point of view
Future Research

- Perspective-taking warrants further development and testing in a larger sample for its ability to improve HF dyad symptom assessment congruence, and ultimately health care use and health related quality of life.
Appendix D

Think Tank Participant Evaluation Responses
Family Caregiver Think Tank
November 5 and 6, 2012

**Participants:** We very much appreciate the precious time you have taken to participate in this Think Tank. To help us evaluate aspects of the meeting, we are requesting your feedback on the following items that may apply to you.

Please return your evaluation (2-sided page) to Ms. Kerenza Plohman, Project Coordinator at the end of the 2-day meeting. Thank you.

---

Please indicate how much you agree with the following statements by circling your response using the scale provided, where 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, and 5 = strongly agree.

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Average Participant Response (n= 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1. The meeting purpose and objectives were clearly stated.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>4.3 (range: 3-5)</td>
</tr>
<tr>
<td>Comments: “Language barrier”</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#2. Our meeting time was convenient for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>4.3 (range 4-5)</td>
</tr>
<tr>
<td>Our meeting place was convenient for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>4.58 (range 4-5)</td>
</tr>
<tr>
<td>Comments: “Thanks for bringing me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
We shared decision-making at this meeting. | 1 | 2 | 3 | 4 | 5 | 4.5 (range 3-5)
Comments: “Yes!!”

All meeting participants were actively involved. | 1 | 2 | 3 | 4 | 5 | 4.08 (range 2-5)
Comments: “A few grandstanders”

We used our meeting time effectively. | 1 | 2 | 3 | 4 | 5 | 4.42 (range 3-5)

I am satisfied with this meeting. | 1 | 2 | 3 | 4 | 5 | 4.42 (range 3-5)
Comments: “Hopeful”

I enjoyed this meeting. | 1 | 2 | 3 | 4 | 5 | 4.75 (range 4-5)

*PLEASE RESPOND TO QUESTIONS ON THE BACK OF THIS PAGE*

What aspects of this meeting were particularly good for you? For your organization? (e.g., what are you ‘taking away’ with you from this meeting?)

Participant: 1. More appreciation of perspectives from different disciplines of challenges facing health care providers to address and identify caregiver needs; 2. Caregiver role significance; and, 3. Need for increased awareness at systems- and health care provider-levels re: needs of caregivers

Participant: Communication issues and how it influences system-level, caregivers, and health care providers. I am talking about the importance of understanding the communication concept in terms of the family caregiver.

Participant: Networking opportunities; learning about new work across the country and world.

Participant: Awareness of caregiver problems at 3 levels – system, health care provider, and patient.

Participant: Hearing the various researchers and what is being found in the research.

Participant: Different levels – systems, organization, health care provider-family caregiver, patient-family caregiver.

Participant: Information sharing and learning from work/research being done.

Participant: Networking. Sharing aspects. Identifying what needs to be addressed. Sharing what’s going on and where.

Participant: The focus at the practice level – the intersection of the caregiver and care receiver; the rich dialogue and respect for others’ viewpoints.

Participant: Learning to work this way; Impressed – Michelle.

**What would have made the meeting better for you? For your organization? (e.g., how could the meeting have been made more meaningful to you / your colleagues?)**

Participant: More collaboration prior to gathering from ‘like’ areas/specialties i.e., community, researchers and health care providers to identify challenges/gaps in systems and objectives.

Participant: Shorter Day 1!

Participant: Have more policy makers, clinicians engage.
Participant: Remote slide advancer

Participant: An excellent meeting.

Participant: Not applicable.

Participant: Nothing so far.

Participant: Not sure.

**Did you enjoy the venue (The Inn at the Forks, Winnipeg)? Positives? Negatives? Suggestions for improvement?**

Participant: Meeting room temperature was never consistent –either too hard or too cold; food was excellent.

Participant: Nice venue. Good food.

Participant: Yes.

Participant: Very much.

Participant: Yes, great location, meeting room, site, food, and courteous staff.

Participant: Nice venue.

Participant: Yes.

Participant: Great venue.

Participant: Nice setting. However, room temperature fluctuated +++ (cold more so)

Participant: Loved the Forms – relaxing and friending staff.

Participant: Very much.

Participant: Yes, hotel was excellent; great accommodations and great food; a smaller hotel which was excellent.
What advice can you offer the research team as they move forward in addressing the communication needs of family caregivers (e.g., priority area to address, future meetings, key people ‘who’ should receive a final report of this meeting)?

Participant: Curious? When does family, community members cross over from caring people to ‘caregiver’. Many ‘caregivers’ do not perceive themselves as ‘caregivers’ until a crisis occurs (not diagnosis but increased care needs for patient or caregiver); would be interesting to know ‘when’ caregivers see themselves as transitioning to a caregiver.

Participant: Done!

Participant: I think policy-makers should understand the importance of communication needs for family caregivers.

Participant: System planners need to see the value of caregivers to not only the health outcomes of the patient, but also to the broader health care system; evaluate the impact of the Caregiver Act Legislation on the health outcomes of people and financial outcomes for the system.

Participant: What works! Identifying supports for family caregivers!

Participant: Would be great to continue to collaborate and have a mechanism for sharing information.

Participant: Must be multi-dimensional – system / health care provider / caregiver-patient level.

Participant: Good luck! Hear from you!

Participant: Thank you for involving me – excellent!!!