Knowledge Café Final Report

Case Manager Work and Workload and the Relation to Quality of Home Care for Clients and Families

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Table of Contents

World Cafe Goals & Objectives

Goal: The purpose of the event was to engage Alberta Health Services (AHS) home care case managers and home care leaders with the researchers and teams that are a part of the PRIDE in Home Care Research Unit at the University of Alberta. The research studies that form the basis of the knowledge shared at the World Café, were conducted predominantly in Alberta; additional studies occurred in several other Canadian provinces, including Ontario, Nova Scotia, and Quebec as part of larger team grants.

Objectives:

This event was designed to engage attendees:

- To explore more deeply the relevance and resonance of the research findings and recommendations,
- To identify the practice and policy implications of the findings,
- To identify potential strategies to promote the uptake of relevant research findings, and
- To contribute to discussion and interaction for continued knowledge needs and knowledge translation work between home care stakeholders, researchers, and trainees.

Acknowledgements:

For the studies: This multi-faceted, multi-study program of research (PRIDE in Home Care) is supported by several funders including; the Canadian Institutes of Health Research, several health ministries, the Canadian Institute of Healthcare Improvement, and the Faculty of Nursing at the University of Alberta. We would also like to acknowledge the many study participants, stakeholders and collaborators involved in this research program.

For the World Café held January 28, 2016: Thank you to my research staff and trainees, Kelly Shaw and John Miklavcic, Susan Labonté and Janelle Otsby, MN students, and Lisa Garland Baird and Ashley Cornish, PhD students. Your individual and collective contributions made the event what it was—a fun, productive and highly engaging day!

A huge thank you to AHS (spell out) Home Care for supporting, attending, and being so highly engaged. It was a rich day and the enthusiasm of the researchers, students, case managers and home care leaders was powerful. The opportunity to participate in dialogue with the time to think deeply about home care programs and services, the effects on clients and family members, and the opportunity for moving evidence into practice for improved home care was powerful. I would like to thank the table hosts from both the research team and home care for being engaged, focused and process oriented in order to keep the balance that the world café intends-promote engagement and discussion yet stay on task and be cognizant of time and note-taking. The table host task is not always easy and the attention and skills all of you brought to the café is evident in our findings!

Thank you to Sam Hester of the 23rd Story for graphically recording our day. The data and conversations you were able to capture truly reflects the passion for evidence-based home care!

Thank you again to each and every one of you for the time and effort you dedicated to this day. It would not have been the same without you!

With deepest appreciation,

Kim

World Café Report

We had 35 people in attendance with only three who could be with us for part of the day only. In total we held an opening and closing full-group discussion, four distinct café discussion sessions with eight tables of 5-6 participants, each synchronously followed by a large group harvest, two Delphi sessions to vote on priority research findings and recommendations, time to observe art-work based on the studies, and a wonderful lunch buffet.

During the day we remained focused on the research and the questions guiding the café. It was our mutual intent that we would not simply agree with or restate the findings and recommendations, but rather that we would think more deeply around what findings resonated, or seemed to have the highest stakes, and what recommendations could possibly be moved forward. So there were essentially two goals. First, to do some sense making of the various studies' findings and recommendations. Second, to determine what and how to move forward.

The following synopses were derived from the copious note-taking by the table hosts. While we did not do a formal thematic analysis, we captured the salient broad areas that were represented in the data.

In addition to this report, highlights of the conversations and key points were graphically recorded and are available to see through PRIDE in Home Care or AHS Home Care.

The **Graphic Recording** is on the next page.

World Café Questions and Highlights of Discussions:

Café 1 and Café 2 combined

We felt that it was important to hold two cafés with the first question to facilitate the opportunity to mix and have conversations with different people.

Café 1: *What are your reflections on the research findings?*
Café 2: *What story jumps into your head that says* ***'I know for sure this is true*** *(or false) because….' It may have been fleeting or deep or enduring.*

Highlights:

The consistent messages from the first two cafés were: (a) home care clients and the general public have unmet information needs; (b) case managers and their work are variable and keeping balance among competing forces is a necessary strategy; (c) the moral distress that case managers experience is perpetuated by insufficient home care resources, client complexity and a fast and furious home care environment; d) respite is often an unmet need; and e) there was consistent agreement on the content of the research findings presented, as well as a noticeable service gap that was identified for specific client groups who have unique needs for care and support, namely people experiencing addictions, homelessness, and single parent families. Each of these key highlights will be addressed below.

Home care clients and the general public have unmet information needs. Case managers find this to be true on a regular basis. There are misconceptions about the kind of care that is provided in the home. This is true among the general population and health care professionals who work in different sectors of the health care system. Client and family expectations for care are may not in line with available resources or program goals. Case managers are often responsible for explaining what home care is and is not, and what services the program can offer. This puts case managers in a difficult quandary with the clients for whom they are trying to provide support.

Case managers and their work are variable. There is variation across case managers that affect client care experiences and the services that can be offered to clients. Notably, case managers do not always have the education needed when they come into their role. On-the-job learning as well as mentorship is needed to address gaps in required skills. The on-site case manager in-service education program is helpful. Case managers often have to balance competing needs and negotiate with clients in order to carry out their work and make the best possible decisions for and with clients. Case managers vary in their ability to manage caseloads and complex clients. Mentorship is necessary and is required to build capacity, strengths, and skills among case managers, along with other system improvements, such as information technology (IT) and administrative demands. As clients increase in number and acuity, mentorship is viewed as an additional way to build capacity and to help case managers effectively manage caseloads. Participants report that if systems and processes were more efficient, that could help increase the capacity to meet the growing demand for home care services.

The moral distress of case managers is perpetuated by insufficient home care resources, client complexity and a fast and furious home care environment. Balance among competing forces is a necessary strategy to meet client, system, and program needs. Case managers desire to make a positive difference for clients and families and want to focus on client strengths in order to provide individualized care. Case managers recognize the unique strengths of clients, but believe systems are not strengths-based, which causes a need to juggle priorities, workload, tasks, and demands. They balance competing needs and negotiate with clients to try to meet client needs, while at the same time working with limited and insufficient resources. This juggling act often causes moral distress for case managers, as they cannot always meet client needs.

Case managers believe that client goals are highly significant to care and the client's ability and willingness to follow through with assigned tasks. They balance and negotiate around client expectations for care and case manager expectations of client ability and self-management, between system goals and client goals, between increased demands for service and insufficient resources, and between wanting to do more and needing to do less for clients. There needs to be a better way to measure workload and to distribute workload more equitably, which requires an evidence base for improvement. There are challenges around navigating the system, which continues to be siloed and acts as a barrier to integrated, client-centered care. Reactivity rather than proactivity is a common coping strategy for workload management.

Respite is often an unmet need. Case managers know that respite needs are as unique as the clients for whom they provide care. For out-of-home respite there is typically a six month waiting list which many believe is unacceptable. There is not a one-size fits all approach. Case managers believe that a service gap exists because health care aides are generally not adequately trained to provide respite to clients or to meet the psychosocial or emotional needs of clients in a holistic manner. This situation is likely perpetuated by the task-oriented approach that has become an integral part of home care practice. Case managers believe that respite is ill defined in home care. There is no specified or defined approach to meet clients' psychosocial or emotional needs. In many home care offices, respite is often considered the least important service, while personal care needs are considered the most important service provided to clients.

Service gaps for unique populations. There was consistent agreement on the content of the research findings presented as well as a noticeable service gap that was identified for specific client groups who have unique needs for care and support, namely people with addictions, homelessness, and single parent families. While the findings resonated for the majority of case managers, there are client groups with special needs that are more challenging for case managers. The needs of these groups should be better understood as well as what the best practices are that would best meet their needs. Specifically, people with addictions, mental health needs, homeless clients, and single parent families have unique needs that are not easily addressed by home care and more research is needed to shed light on these client populations.

Large Group Harvests were used to facilitate a short recap of the topics that seemed to be the most important at the various café tables, rather than simply reporting back on what was said at each table. We took a 'popcorn' approach where key ideas were shared spontaneously.

Large Group Harvest 1

Key points:

Gaps

- Not enough respite, clients have to book six months in advance and still cannot get it in many cases, not enough capacity.
- Funding for the family caregiver – by the time the application for compassionate care is processed, it is not needed.
- Clients are not always able to build relationships (which is a key aspect for effective case management) with case managers where there are vacancies, casuals, or leaves.
- Too much administrative red tape and protection of privacy legislation, although important, can be a barrier to optimal care as people need more access to client records.
- Difficulty of standardizing services, service provision depends on case manager experience, values, and education.
- Case managers feel that there is no accountability of contracted service providers and there is inconsistency in practices and service provision by the agencies.
- Acuity/complexity for clients has increased quite dramatically, as well as frailty, given that more people are living longer and staying in their homes.
- Home care has become crisis-oriented, and reactionary, not preventive or health promoting.
- Nursing and allied health professional student practicums are mostly done in a facility or hospital, not in the community where different knowledge is required.
- Assessments are deficit-based rather than strengths-based.
- Lack of funding to allow for better information systems and information technology (IT); ineffective IT decreases case manager efficiency and effectiveness.

Recommended Strategies

- Create an integrated approach between all sectors such as home care, acute care and primary care.
- Transition coordinators for client movement from sector to sector would help, i.e. from acute care to home care.
- Define goals for respite care, in general there needs to be a family/client-centered approach to care.
- Develop respite care to be a lucrative option for students – there could be leadership or other awards used to promote the desire to provide respite care.
- Develop better linkages with educational institutions for improved practicums.
- Incorporate volunteerism and community engagement in coursework for health care professional education as this seems to be a gap.
- Educate clients and families about the goals of home care so they have reasonable expectations.

- Educate staff to provide respite care that meets emotional and physical needs; may need to provide more than social supports depending on client need.
- System navigation should be done together by home care and client.

Café 3: *What stories can you share that speak to* ***what matters the most about case management work and workload****?*

Highlights:

While similar words and messages were shared at the event, the context within which they were shared was influenced by the question posed at each café. In this session, case managers reflected on exemplar stories or situations that illustrated real life instances of what matters the most about case management work and workload.

Six topics consistently came up across the cafés during this session: (a) relationships, (b) information sharing, (c) systems and processes, (d) skills of case managers, (e) workload, and (f) contributors to stress in the case manager's daily work.

Relationships. There are multiple relationships to manage as a case manager. These include relationships with the client and family; the client's care team, such as the physician, pharmacist and specialists; the home care team and managers; the service provider organizations; and hospital transition and discharge planners. It takes time to build relationships. Where there are good relationships and people are more familiar with each other, work is managed more efficiently. Too often there is a lack of communication among the physician, the client, the case manager, and the pharmacist. Cohesiveness with a full team working on the same goals for the client is difficult to achieve. It is possible, but it takes time to build relationships and ensure everyone is working on the same page and that all team members are responsive to each other for the benefit of the client. There is a necessary time commitment that is required to develop and maintain effective relationships, which are important to quality client care. Clients tell their story repeatedly and case managers spend an inordinate amount of time on the phone problem solving and getting things in place for clients.

Information sharing has some overlap with relationships, but differs in important ways. Many parties say the other is not available or responsive enough. Case managers report that service provider staff are not always available when they need them. It can be difficult to consult with physicians and other members of a client's health care team who may be outside of the home care program. Additionally, clients are not sure who to talk to about what. Clients and care provider agencies find that case managers are not easily available and multiple messages are often left on voice mails. It is also unknown whether the client's own case manager or a covering or temporary case manager will return the call or when. Clients report that the volume of casual and covering case managers they have to deal with is frustrating. They want access to a consistent case manager to ensure continuity of care. If their case manager gets moved off their case, there can be challenges to obtaining action in relation to any outstanding client requests.

Case managers themselves feel that vacancies in case manager positions, leaves of absence, and sick time affect information sharing and the availability of comprehensive information in client files. Case managers report that few Resident Assessment Instruments (RAIs) are fully completed. There are time and information technology challenges which include air cards that are not always reliable, hardware and software glitches that create inefficiencies, and case managers that do the RAI by hand and then return to the office to enter the information into the computer. RAIs completed on paper tend to build up on desks and are not entered electronically in a timely manner. Case managers can fall behind as client concerns and needs impact the "office time" that is available to perform administrative duties.

Client and families do not have accurate information about what home care services are available as case managers are not consistent in what they share or offer clients. Comprehensive information about home care is not well documented, easy to find, or available in plain language, which causes frustration for clients and family members. The lack of basic information on home care leaves it up to the individual case manager to package the information and share it repeatedly with clients. As not all case managers do this the same way, there is inconsistency in the services offered, which leads to exasperated clients. Clients are not sure what they can access through home care and do not feel engaged in decisions or possible solutions that could work for them. Services are offered that may or may not address what works best for the client. Many clients want more information and to be fully engaged in the decision-making process. However, they feel that they first must understand what services are available.

System and process issues impact case managers' work. There is a task-oriented approach to case management. The café conversation was about how the tasks that need to be done in a day sometimes inhibit a comprehensive case management approach that case managers feel they should be providing to clients. Repetition and duplication limits the time available in a day's work to complete tasks. Administrative duties and requirements sometimes make it necessary to hand off some client needs so that case managers can complete their administrative tasks. This causes job dissatisfaction and moral distress as case managers say they receive the most job satisfaction from case managing, not from performing administrative tasks. Yet, because they have the details in their notes or in their heads, the administrative tasks cannot be transferred, and clients get handed off to other case managers for support. Case managers want time to spend on the tasks and care that benefit clients the most. For instance, some conversations case managers need to have with clients and families may be difficult or challenging and require planning and thoughtful intervention, yet adequate time is not available due to system and process barriers. In short, case managers do not feel they are always spending time on the right things.

Skill sets of case managers vary. Clients are complex, crisis management is complex; home care has become a fast and furious environment. These things coupled with the fact that case managers have little to no formal education in case management (it is not offered through their university degree other than perhaps a chapter in one course), contribute to significant variation among case manager competencies and skill sets. New case managers need mentorship, which is not formally organized or available. New case managers have specific needs around navigating and accessing resources for clients. Critical thinking is constantly necessary as case managers

often “do not know what they are walking into” when they take on new clients. Basic knowledge on home care is necessary for those new to home care. A strong message that was conveyed throughout the day was that a formal mentorship approach is needed for case managers.

Workload matters. The fundamental principal that came up repeatedly is that workload matters. In general, workload is very high for most case managers. How well a team functions and the number of clients on a given caseload do matter and impact both client and case manager outcomes. There is variation in case manager skill sets, in team functioning, and among home care offices, all of which affect overall workload and workload management. The upper limit of what is reasonable and feasible for a single case managers’ caseload is unknown. There is no known benchmark and caseloads vary in size and complexity. There is variation among case managers in terms of experience and number of hours worked. There is unequal distribution of work and caseloads. Case managers report that workload management is “always a struggle” for them. Some case managers note that when there were large caseloads the quality of work decreases, as does the ability to provide holistic care and see the big picture. The various disciplines approach case management differently (i.e., RNs, PTs, OTs, SWs, although it was noted that most case managers are RNs). The fact that casual staff cannot do assessments means that casual replacements will not be able to perform all of the required tasks, which impacts case manager workloads. Strategies in some offices, while seemingly affecting time, such as weekly client reviews, are effective in managing workload as they ultimately promote teamwork, group functioning and problem solving. However, approaches to workload management are not consistent across offices.

Workload-related stress among case managers and the contributors to work-related stress need to be better understood and managed. Work*load* related stress is a little different than work-related stress. Case managers do not talk about their work in general creating stress, but rather that the excessiveness of their workload can create stress. There are many unknowns when case managers begin their day; new assessments in particular bring about unknown factors that can impact their workload in the moment that the assessment occurs. Case managers talk about too many clients and that it is impossible to manage their time effectively. They feel responsible for clients and share that they want to do a great job.

There are instances where case managers are not well matched with clients who require their disciplinary knowledge. For example, a physical (PT) or occupational therapist (OT) may have medically complex clients who are better served by a registered nurse (RN); whereas an RN may be assigned a client with more rehabilitation needs who would be better managed by a PT or OT. The overall complexity of clients is increasing requiring more timely assessments, planning and interventions. A case manager from an appropriate discipline could improve workload in these instances, as would a more experienced case manager.

Case managers report they cannot practice the way they want to due to time constraints and system issues. The administrative and documentation processes are not efficient and are direct contributors to workload stress; they do not facilitate effective workload management. Many case managers talk about documentation being deficit-based rather than strengths-based. Due to the deficit-based approach of home care, more documentation is often required. The unpredictable factors that affect case managers’ workloads, such as communicable disease

outbreaks, family dynamics, and the increasing complexity of newer clients, increase workload stress levels. Case managers feel they do not have enough support in their daily work and report noticing stress in other health care providers due to workload pressures. As one case manager reported, “a lot of my colleagues are stressed out and not getting supported.” There is a lot of concern about the unknown work to come and the approach to case management. As another case manager reported, “it often feels like we are in a heightened sense of panic; we’re just putting out fires.”

Café 4*: What can you say about the affect of these stories on your clients and families?*

Highlights:

Case managers shared their stories about workload as they related to client care. Case managers and home care leaders are aware of the impact of their work and what they experience day-to-day as having an effect on clients and families.

The conversations highlighted system and process issues that affected case manager work and workload and that extended to the client’s home care experience. System and process issues directly affected clients, case managers’ ability to build effective relationships with their clients, information needs of clients, and client access to reliable respite. Case managers are keenly aware of the effect of their own workload stressors on clients and families and these stressors perpetuate moral distress in case managers, as previously discussed. While case managers are aware of their workload issues and the impact they can have on clients and families, case managers often feel powerless to change anything.

Case managers acknowledge that clients want to know that their case manager is available to them. Case managers also have a strong desire to be available and accessible to their clients. They believe that that part-time work does not effectively support clients and families. For example, one story was shared where it was the presence of a consistent case manager that was ‘the glue’ that held everything together for four years for a client with dementia and their family caregiver.

They system is organized around specific needs and tasks, not around a health promotion or preventative model that might be more fitting for the populations that are served by home care. The system inequities across the province affect what clients can access and these inequities should be explored and better understood. In Edmonton for example, we have resources such as Nurse Practitioners and the Geriatric Consult Team, which are especially important to assist in the care of clients who cannot access their family physician. However, there are discrepancies in who can access such resources in other parts of Alberta, particularly in rural areas.

Processes such as the requirement to enter the RAI data into the computer, affect the relationships that case managers can have with clients. One case manager stated, “I do not want to take the computer out, when I read, it draws me away from the client.” Case managers report that although the RAI questions are the questions that need to be addressed according to the standardized format, it prohibits them from obtaining a more holistic view of their clients. Clients’ stories are not obtained from the RAI and case managers report that the RAI reduces the assessment to a narrow entity rather than the whole person. Rather case managers end up focusing on the time required for a bath or what kind of equipment would help a client rather

than considering the client's health and social situation in a holistic manner, which many believe is a key factor in effective case management. Case managers wonder whether or not we are moving away from asking clients and families the right questions and if we have become so system-centered that we simply cannot get at what matters. Case managers indicated that we should consistently ask each client and family, "What are your goals?" and "What do you need from homecare?" Interestingly some case managers perceive that using the RAI removes clinical judgment and decision-making and that decision-making can be more prescriptive depending on the outputs of the RAI.

Case managers observe that clients learn how to make the system work for them, which can affect overall resource allocation. When clients receive many blocks of care in a day or a week, they learn which care providers they like and whom they do not like. Although they may say, "I don't need help to dress on weekends," that can mean, "I don't want the weekend worker here." This approach to managing care can waste resources and these subtleties can be difficult to manage.

Many case managers believe that "the system" is rigid and inflexible and that they can only do so much within the system. Case managers feel that if home care and case management were more valued (by senior health care system decision-makers, by society, and by providers and administrators in other sectors), then better client outcomes could be achieved and care might have a chance at becoming more integrated for clients.

The lack of system integration impedes good case management and affects client outcomes. For example, the lack of understanding about best practices and approaches to mental health support services in the community were a recurrent conversation during this café. The lack of integration makes it difficult for client navigation and generates mistrust of the system. While the system purports to have an integrated system, that is not what clients experience. Many issues occur for clients who transition between acute and home care. Many case managers believe that the health care system does not support home as the best place of care.

Relationships with clients are affected by case manager work and workload. Case managers know that for clients to be well supported at home, they often need to rely on family caregivers. Case managers need good/trusting relationships with both the client and the family caregiver. If there is not enough time to build a relationship with a consistent case manager, who gets to know the client situation and how he or she is coping, care experience can be negatively impacted. Sometimes families feel they need to advocate in a rather strong manner as there is no one who truly understands them and their situation.

At times when families are advocating for more care or respite care, case managers believe that some clients feel a sense of entitlement, whether the care or service requested is a part of home care or not. This may be related to the lack of understanding of what home care is and does for clients and family caregivers. Misinformation about home care is often shared, sometimes unintentionally or due to a lack of knowledge about home care from health care professionals in other sectors.

When clients and families do not obtain adequate support from case managers, they share their experiences with other caregivers when those opportunities arise. Sometimes this strengthens the resilience and resourcefulness of clients and families. Case managers know that caregiving is exhausting for family caregivers and that more respite care is needed. They believe that respite care is not getting the attention it needs. They believe that respite is not as valued as is hands-on physical care. When appropriate respite cannot be accessed, regardless of the reason, families are not happy, family caregivers become exhausted, and resentment can build which can also affect relationships with case managers.

Case Manager skills and competencies affect clients. The presence of full-time case managers who are matched to client-related factors, such as needs, complexity, and goals would likely improve outcomes. Clients want consistent case managers who know them and understand their situations. Most case managers think that case managers who know their clients are able to provide better care/solutions.

Skilled case managers can get at the client *story*. They are able to discern needs and identify resources. These skilled case managers are able to respond to clients quickly and can think on their feet. They can build an effective relationship between the client and family. Case managers know that, whereas some clients feel that the case manager is a road block and that they need to push the case manager to obtain what they want, others see the case manager as hard working and caring.

Case managers feel that more time needs to be invested into building relationships by conducting more follow-ups and intentionally building proactive connections with clients. However, time usually prevents this and causes case managers to be doing reactive case management in most cases. Greater time dedicated to the beginning of relationships will lead to more effective home care experiences for clients. In these situations, case managers will know their families well and be able to respond effectively to their needs and in a timely manner. In essence, better time invested up front could actually create more efficiencies in case management as time goes on with clients and families.

Newer case managers sometimes struggle to make sense of both the complexity of care required by clients and also the complexity of case manager work. A new case manager can find it difficult to navigate through all the complex needs while at the same time sourcing out resources and determining how to set priorities. Many home care leaders and case managers believe that a mentorship program would support case managers. The variation in case managers and case management practices can cause variation in client services and outcomes.

Information Sharing. The lack of access to information is a frustration for clients. Rarely do they get a solid understanding of home care and what services are available. They feel they are working with bits of information and the lack of information makes it difficult to navigate home care. This prevents clients from being fully engaged in the decision-making process. Case managers report that clients do not feel as though they are being heard and consequently do not feel valued. Adults have the right to self-determination and so clients need to be involved in the decision-making process and in discussions regarding their care.

Sometimes client expectations are not in line with the mission, policies and practices of home care. The lack of information causes some clients to expect the home care situation to be the same or similar as what they experienced in the hospital. If there is incorrect or no information provided about home care client expectations may not be met. This often affects relationships and takes time for case managers to work through these issues with clients and family caregivers.

This holds true for both pediatric and older adult clients. Some families may feel a sense of entitlement and have a higher expectation of care than what can be provided. If the level of desired care and support can be provided, it still takes time for the case manager/client relationship to evolve to the point where effective and consistent support is routine. Clients are often confused about home care and its services. A clear mandate in home care may be lacking and thus the boundaries of care provision are blurred so if case managers are not consistent with their information and messages to client then they will continue to have a lack of understanding about the role of home care.

Stress and workload. Case managers are often caregivers on-the-job and at home (double-duty caregiving). It takes an emotional investment to care for all of your clients and case managers report there is increased stress when they are juggling very large caseloads. When workload stress is high providing quality holistic care is hindered. The pressure to conduct thorough assessments under time restraints adds to workload burden in multiple ways; more clients, more details, more phone calls. Workload stress is compounded by the pressure to coordinate care and services for new referrals. When case managers believe they do not have the time to invest in setting up their clients care as well as they would like, this increases their overall workload stress. As a result, clients are rushed and the focus of visits may only be on identifying the top needs of the client, not on providing holistic support for clients.

There is no one to take over case management at the end of the day, as support systems are not in place. For this reason, case managers feel it is only up to them to ensure the best care for their clients, but things can go awry when they are off shift even though they are trying to provide comprehensive case management. Client needs are 24/7 yet the lower number of staff on duty after hours is not conducive to quality care. This causes case managers to feel isolated in managing their workload. There is very little focus on recognition and reward. Ideally, positive feedback would come from both the clients and from upper management. Instead, communication is usually centered on an issue that requires more attention or improvement. So many case managers stress the crucial element of self-care and they believe that it is up to them to “fill their own bucket.”

Large Group Harvest 2

Key points:

Gaps

- Case managers experience burnout and emotional drain and believe there is little to no support available to them; they must rely on self-care.
- Although case managers believe they work hard on behalf of their clients, they also feel that family caregivers often do not understand case manager work and intentions.
- There are fewer resources available for those under pediatric care when they transition to the adult world, yet age is not an indicator of anyone's ability to self-care.
- Volunteer resources are not available at some sites.
- The connection of home care is sometimes lost as part of the overall health care system

Recommended Strategies

- Capitalize on the positive aspects of caregiving; many caregivers report rewarding components.
- Listen to clients with intent to understand, ask more open-ended questions of clients.
- Liaise between case managers and researchers to close some of the research and research-to-practice gaps.
- Engage clients in discussions on home care policy development, explore societal expectations of home care.
- Evaluate current policies: do they truly address client, family caregiver needs? As home care is growing and changing do we have the right policies in place?
- Identify learning events such as the World Café, as they will bring stakeholders together in dialogue and for solution seeking (e.g., client, family caregiver, care providers, health economists and policy-makers).
- Build on the client's strong desire to get home, the power of being at home and build on the client's strengths.
- Establish community relationships with other resources that support home care clients, build capacity to more fully care for and support clients on home care through community development.

Café 5: *What are the core values and practices that would facilitate more effective case management work?*

Café 6: *How would these things support better client/family care and outcomes?*

Highlights

Six topics came up consistently in the café discussion on the core values and practices that could facilitate more effective case management work designed to support client and family care and outcomes. Case managers identified (a) interprofessional teamwork, (b) equity, (c) mentorship, (d) relationships and communication, (e) effective management of workload, and (f) consistency

of home care. Discussion evolved into how these core values and practices would specifically support client and family care, as well as outcomes.

***Interprofessional teamwork*.** There needs to be a better understanding of how to build and work within interdisciplinary teams. Staff that are new to home care are not used to working with interdisciplinary teams. It was evident in their discussions that interprofessional education from most university programs is lacking. If educational programs incorporated better approaches to interprofessional education, then the role and value of case managers on an interprofessional team might be better understood, particularly the benefit of the case manager as a care coordinator. Furthermore, using an interdisciplinary team effectively would draw on the strengths of what each member brings to the client care team and the right person for the various care requirements could be used more effectively.

Engaging in better interprofessional teamwork would help to mitigate the 'siloed' effects and promote integrated care. A comprehensive team approach would better support client-centered care. AHS is a large organization with many appropriate resources already in place and available, yet they are not always offered in an integrated manner. Better linkages among the various professions could support home care case managers to function more efficiently and provide a more streamlined, integrated approach to care for clients and families.

***Equity of service provided*.** Case managers express that equitable service delivery and consistency of care are core values that should be given greater priority. It is a challenge to provide universal access and equitable care to the diverse client population seen in home care. Case managers stressed that equity was not the same as striving for equal services to all as there needs to be appropriate care available to meet unique needs of home care clients. The differences between rural, urban, suburban, and remote clients need to be explored. Principles around what is reasonable would help. These principles need to be developed and shared with clients. Case mangers recognize that there is unequal access to and between various geographic environments. Case managers felt that a firm position on what services home care should and should not fund could support the principles of equity and consistency.

Fairness and equity are principles that should also be used to determine appropriate caseloads. Equitable distribution of work will promote job satisfaction, which ultimately affects case manager attrition and how case manages are able to work with their clients and families. Staffing numbers, the mix of professional designations and availability, affect how case managers are deployed and this sometimes results in inconsistent or inequitable workloads. Clients with case managers carrying very large caseloads have different access and consistency in care than those who have case managers with more reasonable caseloads. However, all agree that caseload numbers are not the only important issue, and that work needs to be carried out to identify the best evidence on which to make decisions about case manager workload. Once this is known, then the number of case managers needed to support the clients and families in a given jurisdiction or within a given home care program could be better predicted. Appropriate numbers of case managers with reasonable caseloads would support the mandate of equitable and fair home care service provision.

***Mentorship program*.** Better mentorship practices will support the development of great case managers. Professional and discipline specific education and experience, while important, does not necessary equate to being a good case manager. Supporting new case managers and enculturing them into the home care environment is needed to support provision of client-centered and integrated care. A structured mentorship program delivered by those who are knowledgeable about the case manager role, how home care works, and what it means to be client-centered in home care could enhance the competency, workflow management, and organizational skills needed to be successful in this role. Such a program could help to build case managers' confidence in their role and trust among home care teams so that issues can be openly discussed when they arise. This could help case managers to be more confident and competent and facilitate better client- and family-centered care.

***Prioritizing relationships and communication*.** An effective rapport with clients, family members, and members of the client's health care team is necessary for integrated care. If it is not established and relationships are not developed at the beginning of the care trajectory, then it is difficult to work effectively with clients and families. The client and the family caregiver need to be included in goal-setting and the plan of care, which then supports the desired outcomes that can be shared across the client's healthcare team. Including family caregivers in planning and action helps engagement and builds relationships with the family unit. This level of desired engagement is meaningful for the client and family and supports a partnership through which their wishes and expectations can be valued and future care transitions can proceed more smoothly. The time spent up front establishing rapport and building relationships is a necessary investment. The result is more effective use of time and enhanced care throughout the client's care trajectory.

Relationships with clients are greater in scope than the simple need to address medical problems. The case manager needs to know where the client's "world starts and ends." Case managers know that their role is about more than tasks and hands-on activity, it is about supporting clients and families to have a better quality of life, as many will be engaged with the health care system and home care until they die. Case managers often need to have difficult conversations with clients and families and a good relationship will support this work. Client outcomes can be less than ideal if case managers do not have the relationships to support these sometimes necessary conversations.

***Effective management of workload*.** Though technology has been implemented in an attempt to streamline assessment, documentation, and client care management and coordination, there are too many inefficiencies in the technology that hinder effective case management. Although a case manager can lessen their workload by delegating certain clerical tasks to appropriate staff, there are still several areas in the electronic systems that need to be improved. Workload and caseload management is negatively impacted because the current documentation requirements are disjointed and cumbersome. Finding and using information is burdensome due to the nature of the current system and approaches that are employed. It is even a challenge to monitor and track client and family goals effectively. Measures to improve the technology, ensure adequate staff training on the system, and implementation of the technology across the continuum of care

providers is needed. More systems need to be created to allow for better sharing of information across care providers with the goal of minimizing duplication and making information accessible to all on the care team. Employing better approaches to information management, technology, and sharing of information will support better communication, reduce the time needed to obtain feedback and input from team members, and potentially decrease unnecessary work and referrals. In essence, improved information processes and technology will lead to more efficient work and promote better care for clients.

Consistency of home care. Core services available in the basket of home care services need to be identified, valued, and shared with all stakeholders including clients and families. Once this is determined, then funding needs to be appropriate to support the basket of services in a consistent manner. Many case managers believe that home care funding ought to be protected and be free from political changes and influences, to better support and promote continuity of care for clients and families that rely on it. They believe that a clear philosophy and framework for home care in Alberta will support a more equitable and consistent approach to care, will lead to improved continuity of care, and will enhance home care client and family outcomes. This will mitigate some of the inconsistencies across zones within Alberta and support client expectations to be in line with the available basket of services and within the philosophy of home care service provision.

Other thoughts that were highlighted was the need to talk about successful stories and positive outcomes of home care service provision. Case managers believe it is timely that the core business of home care be established, as well as the services and expectations around home care clinics. Finally, they stressed the importance of reflection on case management practice to balance the incessant need to always be “doing.” Case managers are aware of the role they play in achieving good client outcomes and the effect of their work and workload management on clients and families.

Large Group Harvest 3

Key points:

Gaps

- Sometimes clients and families have unrealistic expectations that are difficult to manage without an identified basket of services or solid home care framework.
- The physician-centeredness of the current healthcare system can be problematic and impede integrated care.
- Health care education for all disciplines ought to have some clinical practice component both in learning about home care and in working in interprofessional teams.
- The focus of those in senior leadership managerial roles is usually on the client with little attention to the work and workload of case managers, which also affect clients and families.
- There is no current consistent home care philosophy or mandate or defined basket of services.
- While there is language around client-centered care there is no consensus on the definition of client-centered care, person-centered care, family-centered care and which of these approaches should be driving home care.
- It is still a system-centered approach to health care.

Recommended Strategies

- Develop a home care philosophy and mandate to define and articulate the basket of services that are provided under home care and the pivotal role of case managers.
- Determine and implement best approaches to move knowledge and information about of home care forward.
- Develop concrete expectations/benchmarks for case managers at various points in their career.
- Clarify expectations for care in any setting (acute, LTC, home care).
- Move to a province-wide electronic health record that is interdisciplinary.
- Develop and implement mentorship to education programs so students learn about mentorship and are also prepared to evolve into mentors as their own professional practice develops.
- Support both client-centered care, but also case managers and the work they do to support better client outcomes, there needs to be a balanced approach from senior administrators and home care leaders.
- Recognize opportunities for small changes that can lead to either client or system improvements, not all change requires major realignment.
- Establish an understanding of the difference between case management and administrative work and realign roles and functions to support case management, which will improve capacity.

- Develop a marketing and communication program for home care and communicate with stakeholders about the role, benefit, and limits of home care.
- Develop geographically-based interprofessional teams for urban and rural clients with the intent to decrease inconsistencies and variation in care.

Café 7: *What strategies will move this work forward and make a difference for case managers and ultimately clients?*

Highlights

The following strategies were identified to move this work forward and make a difference for case managers and ultimately clients. This event was a brainstorming session and there were lots of great ideas shared with potential to be further developed and implemented.

Model and approach to home care. Revisit the models of care offered throughout continuing care and particularly home care. We need to be less medically-focused and more holistically-focused in terms of care. We also need to move from a reactive, task-focused approach to one that also incorporates prevention and health promotion. We need to determine if there are more effective approaches to care and the most appropriate provider for various client situations. We need to enhance and support the case manager role and determine whether and how case managers are effective.

Client and family care giver engagement. We need to engage the client and family caregivers in shared decision-making.

Communication. Greater collaboration and communication across health sectors and within home care programs is needed. Effective partnerships and relationship building will facilitate the movement of research into policy and practice. There needs to be more support and involvement from AHS leadership for more opportunities for knowledge translation and communication among Albertans who are or will be our clients and/or family caregivers; policy-makers; researchers; and home care leaders and case managers. We need a large-scale strategy for communication and engagement.

Integrated care. Home care philosophy, mission, and policies need to be revisited and modified to align with the current services and approaches to care. We need improved integration of care and the role of case management within integrated care needs to be identified and supported. Definitions and models of care need to be better articulated especially between home care and supportive living. We need to designate transition coordinators in hospitals who work for home care rather than acute care as this would be more effective. Policies and legislation needs to support integrated care rather than to be an unintended barrier to care (i.e., HIA and FOIPP).

Administrative burden of case manager work. We need to decrease the heavy administrative burden required by home care case managers by simplifying the processes and paperwork required. The assessment tools (e.g., RAI) or approaches to information management need to be revised as case managers are spending too much time on the documentation part of assessment and less time engaged with clients to determine goals and build effective care plans. Administrative and non-professional tasks need to be off-loaded to clerical staff.

Workload and caseload management. Ways to measure and distribute case manager workloads and caseloads need to be identified. The approaches to workload management are not consistent, which leads to inequities, inefficiencies, and overwork.

Data collection and quality improvement. The collection and management of evaluation data, particularly from the client perspective are important. Employing tools such as participatory action research and inviting students to conduct small-scope research projects could both support their engagement in home care and develop valuable information that could lead to system and client care improvements.

Information technology. Technology needs to be upgraded so that data tracking is more effective and efficient. Case managers are challenged by "point of care" charting given the current technology and systems. A better platform across all care sectors is needed to support communication and integrated care.

Staff mix. We need to look at whether we have the right mix of home care professionals and support staff. We need to ensure that we choose the right people for the right job. Adding more case manager practice leads, nurse practitioners, and clinical nurse educators could enhance home care programs and ultimately improve the client experiences and outcomes.

Continuing education, mentorship, and support. Education, growth, and opportunities for advancement for case managers need to be identified and implemented. We need to ensure that case managers are well equipped to take on their roles and responsibilities. Enhanced orientation and in-service education should include core knowledge about the home environment, a community focus, communication and conflict resolution skills. The McMaster Case Management Program is a good model upon which further educational programs could be based. We need to provide better supports to home care staff. A formal mentorship program for case managers needs to be a priority.

Formal education programs. Pre-service education for all health care providers and health professionals should include basic knowledge about care across health services (acute care, home care), as well as knowledge about client populations and the social determinants of health. All health care providers need to have knowledge that spans across relevant service sectors so that they can facilitate transitions (e.g., from acute to home care). We need to examine scopes of service practice overlap. Education that is provided to nursing students should include community work and leadership training.

Case manager job satisfaction and retention. We need to address the issues of case manager job satisfaction and retention. This will likely involve reducing workloads, caseloads, instituting regular follow-ups and managing expectations so that staff can provide effective care to clients and families.

Public education. Public education and awareness about home care needs to be improved. We need to strengthen marketing strategies and share good news stories. Educating the public about home care will help manage expectations.

Delphi Exercise #1

Priority **Findings** from Research Studies Presented at the World Café:

Participants at the World Café were given five dots to rank their top five findings according to (a) case manager-focused studies and (b) client-focused studies. The results are below in order of priority.

From the studies **from the perspectives of case managers and home care leaders about case manager work and workload**, case managers and home care leaders attending the World Café ranked the most important findings for action as:

1. The nature of the home care program (i.e., policy, eligibility) is unknown to most other health care sectors;
2. Computer technology and software programs function poorly;
3. There is greater client complexity now than when home care programs were first established;
4. There is a lack of integration of home care with other sectors;
5. Case managers need strong skills such as organizational, communication and coping skills;
6. There is a lack of human resources in home care; and
7. Transitions and discharges are poorly planned and implemented.

From the studies centered on **the perspective of clients and family caregivers about living with home care and caregiving**, case managers and home care leaders attending the World Cafe ranked the most important findings for action as:

1. There is a need for more public awareness about home care and its current state;
2. There is a lack of sufficient resources in home care;
3. The complexity of each household, not only clients but families, affects the home care experience;
4. The impact on the daily lives of family caregivers, physically, emotionally, socially, and financially is significant;
5. There is a lack of continuity of care;
6. Disruptions and transitions in care are an issue;
7. Many believe that home is the best place for care to be provided; and
8. The goals of clients, caregivers, and home care providers may or may not overlap and can cause challenges in care planning and goal attainment.

Delphi Exercise #2

Priority **Recommendations** from Research Studies Presented at the World Café:

Participants were given five dots to use to rank their top five recommendations for action based on the research findings. Participants reported that the top recommendations were:

1. Reduce workload pressures by streamlining and integrating IT systems;
2. Implement mentorship program for case managers;
3. Strengthen community resources and networks for client and family supports so that they can remain in their homes;
4. Decrease the administrative burden for case managers to support better case management;
5. Implement policy changes for home care improvements;
6. Diagnose and address critical gaps between sectors and among team members to increase the rate of appropriate referrals (e.g., addressing lags with netCare documentation of new mediations, improving home care notifications regarding emergency visits and new medications, ensuring discharge education, and having essential home care services in place before discharging);
7. Improve tools and technology designed to communicate and share information across settings, disciplines, clients, and caregivers;
8. Consider the family as the client unit; and
9. Implement a philosophy of family-centered care.

Concluding Remarks and Next Steps

Participants were asked to consider "*what question, if answered, would make the greatest difference to moving work in this area forward?"*

The responses to this question were turned into strategies that the participants identified as the most important ones to implement. Then participants added their names to sign up sheets created to track interest in pursuing the following recommended strategies.

Develop and implement programs for mentorship, clinical competence development, and case management practice support,

- Have clear expectations for new CMs at 3-6-9+ months, commit to targets for a mentorship model,
- Address the administrative burden of case managers,
- Revise the current home care model, which provides little support for case managers and enhances burnout for many new hires in first year as they do not feel supported or competent,
- Incorporate the sophisticated clinical aspects of home care client requirements in current McMaster education, and
- Modify the professional development of practitioners to meet the clinical diversity clients.

Create public awareness about home care,

- For awareness: community conversations are important- just get out and answer questions, and
- Get the knowledge in the right format to the right people who can hear and receive it and make the right informed decisions.

Integrated care across sectors would improve care transitions

- Develop integrated systems as they are currently not integrated
- Develop better linkages between acute care, primary care, and home care particularly

Collaborate with researchers on research, quality improvement initiatives and practice development,

- Conduct more research on home care to provide the best care to clients and families,
- Increase knowledge for and about case management and work,
- Conduct more systems research on cost outcomes across sectors--cannot look at sectors in silos, and
- Determine what is "good" respite?

Influence policy on home care,

- Teach students how to advocate in their basic education programs, and
- Make advocacy an integral part of educational programs.

Appendix 1 – Workshop Agenda

AGENDA 8:30-4:15

Knowledge Café on Case Manager Work and Workload and the Relation to Quality Home Care for Clients and Families

08:30-9:00	Registration and light breakfast Posters and art-based displays
09:00-9:15	Welcome Kim Fraser & Adina Belland
09:15-9:35	Brief introductions Overview of demographics of study participants Broad overview of research questions and findings Introduction to World Café
09:40- 11:00	**Café 1** **Café 2** Last session is whole group **Harvesting** #1 followed by a moment for Personal Reflection & Delphi activity on Findings
11:00-11:15	Break with posters and art-based displays
11:15-12:15	**Café 3** **Café 4** Last session is whole group **Harvesting** #2
12:15-1:00	Lunch with posters and art-based displays
1:00-1:20	20 minutes recap and brief sharing of recommendations
1:20-2:40	**Café 5** **Café 6** Last session is whole group **Harvesting** #3 followed by a moment for personal reflection & Delphi activity on recommendations
2:40-2:55	Break
2:55-4:00	**Café 7** Whole group discussion moving into next steps
4:00-4:15	Wrap up & thank you Beth Whalley & Kim Fraser

Appendix 2 – Study Teams and Funders

Study Title	Team Members	Funders
Study 1: The Meaning of Home Care: Behind Closed Doors: An Arts-Based Approach	Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta	• 2009 Faculty of Nursing, University of Alberta
Study 2: Testing Collage as a Means of Elicitation: Advancing Arts-Based Inquiry in Research with Family Caregivers	Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta	• 2015 Endowment Fund for the Future Support for the Advancement of Scholarship Research Fund, Faculty of Nursing, University of Alberta
Study 3: Factors that Influence Home Care Case Managers' Resource Allocation Decisions for High-Need Pediatric Clients	Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta	• Faculty of Nursing Establishment Grant
Study 4: Factors that Influence Home Care Case Managers' Workload DICE Substudy 2	Researchers: Fraser, K. D., and Sales, A. E., Faculty of Nursing, University of Alberta Partners: Alberta Health, Alberta Health Services, and Industry Providers Trainees: Lisa Garland Baird	• 2008 Canadian Health Services Research Foundation • 2008 Alberta Heritage Foundation for Medical Research
Study 5: Factors that Influence Home Care Case Managers' Resource Allocation Decisions for Long-Term Care Clients DICE Substudy 3	Researchers: Fraser, K. D., and Sales, A. E., Faculty of Nursing, University of Alberta Partners: Alberta Health, Alberta Health Services, and Industry Providers Trainees: Lisa Garland Baird	• 2008 Canadian Health Services Research Foundation • 2008 Alberta Heritage Foundation for Medical Research
Study 6: Factors that Influence Home Care Case Manager Work, Workload, and Caseload Intensity	Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta Researchers: Cummings, G., Marck, P., Liu, L., O'Rourke, H., and Swanson, S. Trainees: Lisa Garland Baird and Susan Labonté	• 2013 Canadian Institute of Health Research, Knowledge Translation Branch

Study 7: Safety in Home Care: A Four Province Study on Medication Management	Researchers: Ariella Lang, A., Macdonald, M., Marck, P., Fraser, K. D., Hoffman, C., et al.	• 2008 Canadian Health Services Research Foundation • 2008 Canadian Institute of Health Research • 2008 Nova Scotia Health Services Research Foundation • 2008 Ministère de da Santè et des Services Sociaux (Quèbec). • 2008 Ontario Ministry of Health and Long Term Care
Study 8: Managing Multiple Chronic Conditions: A Qualitative Study of the Perceptions of Older Adults, Family Caregivers, and Health Care Providers	Researchers: Ploeg, J., Emili, A., Fraser, K. D., Matthew-Maich, N., Dufour, S., Markle-Reid, M., McAiney, C., Kaasalainen, S., Keefe, J., and Upshur, R. Trainees: Lisa Garland Baird, Ashley Hyde	• 2013 Canadian Institutes of Health Research Team Grant • 2013 Ministry of Health and Long Term Care Ontario. Health System Research Fund Program Award.

Appendix 3–Participants and Evaluation Summary

Participants

In total we had 41 engaged participants:

13 Case Managers

13 Managers, Clinical Operations Managers, or Project Managers

7 Clinical Leads such as professional practice leaders, nurse practitioners and nurse practitioner leaders, members of the geriatric consult team, clinical specials or educators

8 Researchers, Trainees, or Research Coordinators 3 of whom are or were case managers

There were several disciplines represented including Registered Nurses, including Nurse Practitioners, Social Workers, Physical Therapists, and Occupational Therapists.

Evaluation Summary

Fifteen of forty-one participants completed an evaluation form of the World Café. There was overwhelming positive response to the Knowledge Translation Event. Case managers indicated that there was an array of information discussed applicable to their work including the system challenges in home care, workload and work intensity, the case manager mentorship model, and the perception of the roles and duties of case managers in home care as understood by case managers, clients and the public. Feedback from case managers highlighted the importance of having "dedicated researchers investigating issues … critical to [the] frontline case management job;" and the discussion with peers and colleagues "removes isolation" and confirms that "case management in important."

There was strong consensus that a firm mandate and philosophy for home care needs to be developed. Furthermore, it is important to have champions of case management and visionary leaders for continued advocacy of home care. Future Knowledge Translation events should focus on strategies to execute, implement and utilize the appropriate people in and for these roles. Case managers also indicated the importance of hearing client feedback in future events to further the "client and family-oriented … model [in home care]." There was an appreciation for the breadth of disciplines in attendance and there was a strong notion for advancing the scope of home care and in the value of including nurse practitioners, health care aides and other disciplines in Knowledge Translation activities. Ultimately, these future activities would enhance "collaboration with home care and within the greater healthcare system."

Appendix 4 – Research Briefs including References

STUDY 1 RESEARCH BRIEF

The Meaning of Home Care: Behind Closed Coors: An Arts-Based Approach

Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta

What is the research topic?

The need for home care is increasing across Canada, as many clients choose to remain at home with support from family caregivers and home care (Canadian Home Care Association, 2013). Home care is a key strategy to reduce overall health system costs and meet client needs (Canadian Institute for Health Information, 2010; Fraser & Strang, 2004; Williams et al., 2009). To identify gaps in home care service, there is a need for research into what the home care experience is like for families and clients. Although there is a growing body of research about home care in general, little is known about the experience of home care from the client's and family caregiver's perspectives (Fraser, Archibald, & Nissen, 2014). Empirical evidence will help inform practice and policy and enhance client and family outcomes.

What do we know?

- Canada has experienced a large growth in its elderly population in recent decades and home care is becoming an essential health care service (Special Senate Committee on Aging, 2009; World Health Organization, 2002).
- Investment in home care is necessary to improve efficiencies in both home care and other areas of the health care system, yet adequate funding continues to be unavailable.
- The result is that the increased demand for services often exceeds the resources available for home care provision (Fraser, Archibald, & Nissen, 2014).

Research Question

What are the experiences of family caregivers and clients (adults 65 years of age and older with chronic conditions) with home care and caregiving?

How was the study done?

Ten family caregivers and a client were invited to create a work of art and participate in an interview as a means of eliciting their experiences with home care and caregiving. Eleven interviews were conducted and seven pieces of art were generated. An interpretive description design was employed and the data were coded using NVivo. The study was conducted in Edmonton, Alberta.

What are the key findings?

Six themes emerged:

- Caregiving had an enormous impact on the daily lives of family caregivers physically, emotionally, socially, and financially.
- Family caregivers coped with caregiving and the disruption that home care brought into their lives in various ways. This included strategies to mitigate caregiving and maintain a balance in their lives, striving to have a good attitude, coming to acceptance of the situation, taking physical breaks, and keeping up personal interests and activities.
- Family caregivers found it difficult to access information about home care. Case managers were not forthcoming with information about home care and caregivers often learned about services by chance or accident. In addition, home care staff sometimes acted as roadblocks to the acquisition of services.
- General experience with the health care system indicated that there was a lack of sufficient resources, equipment, continuity of care, and health information. Caregivers expressed the need to advocate for their family member and concern for those in the health care system who did not have advocates.
- Family caregivers discussed the experiences that they had with formal caregivers and the qualities that they deemed important for them to have such as, capability, consistency, reliability, compassion, and personality fit.
- Family caregivers agreed that home was the best place for their family member to live. They expressed the need for more funding and support so services could be expanded and home care staff better compensated. They also indicated that there was not enough public awareness about home care and its current state.

  "I don't think it's reasonable to expect somebody to be on call, giving full-time care 24 hours a day for six days a week, and 20 hours [laughs] a day for the rest of it. And that's what it was. " (caregiver)

  "The impact is far more so than just the preparation of meals, looking after laundry and that kind of thing. It affects absolutely everything about your day-to-day procedures." (caregiver)

  "I love you enough to research your condition and your medications and to pester the doctors and pharmacists for answers. Because I love you, I continue to seek answers that will improve your quality of life." (caregiver)

What are the recommendations?

- Funding should be realigned to ensure home care programs are able to effectively meet client need.
- Home care services are for clients and their families and should be client- and family-centered.

- Family caregivers require support through all stages of the caregiving experience. Health care providers should proactively give families relevant service information. Caregivers are over-burdened and should be able to easily access the health care system and obtain necessary services.
- Caregivers often experience financial hardship and currently receive little or no financial benefit from caregiving. Consideration should be given to policy changes that could provide financial and other types of support to caregivers and their families.
- More respite care for caregivers is necessary to help them achieve a healthy balance in their lives and decrease health care utilization costs. It is not sustainable to require a family caregiver to provide care 24 hours a day, seven days a week.
- Establishing good relationships between home care staff and family caregivers is critical. Trust is more easily accomplished when home care staff are consistent, reliable, compassionate, and of similar personalities to those of the client and family caregiver. Home care staff should be purposely matched with clients and family members to build compassionate, respectful relationships.

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Funder

- 2009 Faculty of Nursing, University of Alberta

Related Publications/Presentations

Fraser, K. D., Archibald, M., & Nissen, C. (2014). Uncovering the experience of home care from the perspective of clients and family caregivers: An arts-based and qualitative approach. *Canadian Journal on Aging*. 33(3), 246-258.

Fraser, K. D., (Fall, 2012). *An Art Exhibition: The Use of the Arts to Share the Experience of Home Care*: IQ2012: Inspiring Quality in Continuing Car, November 7 – 8, 2012, Calgary, Alberta.

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Fraser, K. D. (Spring, 2012). Invited Public Lecture: *The Use of the Arts to Share the Experience of Home Care.* Gallery@501 Sherwood Park Community Building. Sherwood Park, Alberta.

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STUDY 2 RESEARCH BRIEF

Testing Collage as a Means of Elicitation: Advancing Arts-Based Inquiry in Research with Family Caregivers

Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta

What is the research topic?

As the population ages, there is greater need for home care programs and family caregivers to support people to live at home as long as possible and to delay the need for more costly services (hospitals, facilities). However, there is very little knowledge about what it means to be a family caregiver while receiving home care for a family member. Empirical evidence about family caregiving is needed to inform practice and policy and enhance client and caregiver outcomes.

What do we know?

- Funding has not kept pace with the need for home care, creating a climate where limited resources must be shared amongst competing clients and families.
- The majority of care (80%) for older adults with chronic conditions living in the community is provided by family caregivers, particularly women, and they assume most of the costs and burdens associated with caregiving (Canadian Institute of Health Information, 2010).
- Research suggests that the level of caregiver strain increases as does the number of chronic conditions, resulting in negative health outcomes and health service use in caregivers (Schultz & Beach, 1999).

Research Question

What are the family caregivers' experiences with home care and caregiving?

How was the study done?

Fourteen family caregivers participated in a three-hour collage-making workshop and a follow-up face-to-face interview as a means of eliciting their experiences with home care and caregiving. The study is on-going in Edmonton, Alberta.

What are the preliminary findings?

- Being a family caregiver impacts their lives.
- Managing relationships takes a lot of time and energy.
- Understanding and being responsive to the client's health status and ability is key to being an effective family caregiver.
- Interactions with formal health care systems (a) are challenging, (b) not sufficient, and (c) influence their caregiving role.
- Time is a constant reminder that they are family caregivers.

What are the preliminary key messages?

1. Provide more respite care and make it more accessible to family members and caregivers.

   "…respite care, I am so strong on that. Raise money, open those facilities. We don't have enough and with that you're getting caregiver burnout and it cannot only devastate the person you're caring for, it devastates the caregiver and our whole family then, you know? "

2. Provide better service delivery to rural areas and suburban areas such as day programs, respite care, and home care.

   "No, as far as respite there's nobody to come in during the day to give you any freedom. There's nothing, absolutely nothing."

3. When providing service delivery people want to be treated individually. Each situation is different.

   "…that each situation is different. There is no one size fits all. Everybody has a different thing and they try to put you … in a box where everybody fits in together and you just can't do that. It's so varied. Everybody needs different things at different times in different ways…"

   "Home care isn't a one size fits all either. People need different things and saying they can only provide, you know, one hour, it was just ridiculous in our situation. "

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Funder

- 2015 Endowment Fund for the Future Support for the Advancement of Scholarship Research Fund, Faculty of Nursing, University of Alberta

STUDY 3 RESEARCH BRIEF

Factors that Influence Home Care Case Managers' Resource Allocation Decisions for High-Need Pediatric Clients

Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta

What is the research topic?

Due to both increased numbers of clients and increased acuity levels there is significant pressure on home care programs (Fraser, Estabrooks, Allen, & Strang, 2009). Case managers are pivotal to home care service delivery, as their resource allocation decisions affect client/family outcomes and overall system resources. Yet how they make decisions about allocating resources to clients/families is poorly understood. Empirical evidence on case manager resource allocation decisions is needed to improve theoretical understanding, inform practice and policy, and enhance client and family outcomes.

What do we know?

- Home care programs in many developed countries have been shaped in the past decade by steady growth in the number and acuity of clients (Peter et al., 2007; Shapiro, 2002).
- Unfortunately funding has not kept pace with the need for home care, creating increased pressure to ration and prioritize services (Fraser & Strange, 2004; Woodward et al., 2004).
- In 2012, 792,000 Canadians reported that their need for help at home due to illness, aging or disability, were only partly met or not met at all (Turcotte, 2014).
- High-need pediatric clients in particular have complex care requirements that often exceed the maximum allowable allocation of home care funds in Alberta (Fraser, Estabrooks, & Strang, 2009).
- Children and families with unmet needs for help at home have lower health status and more trips to emergency and/or the hospital (Turcotte, 2014).

Research Question

What factors influence home care case managers' resource allocation decisions for high-need pediatric clients receiving home care?

How was the study done?

Eleven home care nurse managers and leaders who made resource allocation decisions for high-need pediatric clients participated in interviews and focus groups. The study was conducted in Capital Health's Home Care Program in Edmonton, Alberta.

What are the key findings?

- A taxonomy of factors that influence case manager resource allocation decisions was developed. The four categories of factors are described below:
- Case managers considered **client-related factors** when making resource allocation decisions. Home care staff provided more resources when clients had lower health status, were at higher risk, and had greater complexity, and needs.
- **Family-related factors** were considered the most important factors that influenced decisions. Characteristics of the family that were considered included the number of children, family beliefs, family supports, marital status, coping, risk to the family unit, and socioeconomic status.
- **Factors related to the Children's Home care program** included characteristics of the case manager (experience, beliefs), available resources (funding, human), guidelines, criteria, and the home care team. Team decision making was viewed as better than individual decision making and was used to incorporate more experience into the decision-making process. Specific factors influencing team decisions were experience, the nature of the team, and team processes.
- Finally, **system factors** such as characteristics of the home care program (policy, eligibility), the hospital (wait times for beds and equipment, unidentifiable discharge times), and the client's health care team (experience, beliefs) influenced resource allocation decisions.

  "*The complexity of the situation is about interventions, what you are doing for the child, what are the skills that are needs specifically so that you can look at the level of care that's needed.*" (case manager)

  "*Rationing is probably not a popular word in home care…some families may not consistently get as many of their nights filled…*" (case manager)

What are the recommendations?

- Consider the following practice and policy reforms to home care:
  - ✓ Realign funding to effectively meet service delivery need.
  - ✓ Adequate funding will permit guideline and program criteria restrictions to be lifted so that client need can be better met.
  - ✓ Consider how to better support home care staff who work with high-need clients, especially pediatric clients and their families.
  - ✓ Consider the family as the client unit and implement a philosophy of family-centered care, especially when working with pediatric clients.
  - ✓ Give greater priority to providing informal support for home care staff and supporting team work to facilitate their ability to make effective team decisions.
  - ✓ Improve effectiveness of staff education and training so that they have appropriate first-hand experience and skills development required to work with high-need clients and families.
  - ✓ Strengthen community resources and networks to ensure high-need pediatric clients and their families are better supported and able to remain in their homes.

- ✓ Enhance collaboration between health care agencies and within health care teams to ensure care is effectively coordinated for clients.
- ✓ Coordinate hospital and home care resources more effectively; ensure appropriate discharge planning from hospitals.

- Conduct further research to inform the development of a framework that can capture, recognize and legitimize case manager resource allocation decisions.

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STUDY4 RESEARCH BRIEF

Factors that Influence Home Care Case Managers' Workload DICE Substudy 2

Researchers: Fraser, K. D., and Sales, A. E., Faculty of Nursing, University of Alberta
Partners: Alberta Health, Alberta Health Services, and Industry Providers
Trainees: Lisa Garland Baird

What is the research topic?

Home care programs are growing at unprecedented rates to support people to live at home as long as possible and to delay the need for more costly services. Case managers are pivotal to home care service delivery, yet little is known about the work that they do. The generation of empirical evidence on case manager workload is needed to improve theoretical understanding, inform practice and policy, and enhance client and family outcomes.

What do we know?

- Currently there is no standard approach to determine fair, equitable, or reasonable workloads.
- Measuring workload based simply on caseload numbers or client acuity are only proxy measures of workload and are not accurate measures of workload, but rather only a single approximation.
- Case manager workload is a complex phenomenon with both explicit and implicit factors, which are not captured easily.
- Case manager perceptions of stress and pressure, triggers that put them in situations where they feel overworked or burdened, and factors that contribute to burnout if they are not rectified have only begun to be explored.

Research Question

What are the perspectives of home care managers on workload and its influencing factors?

How was the study done?

Twenty-eight home care managers, three supervisors, and one project lead participated in semi-structured interviews, observations of team meetings, participant journaling, and focus groups. The study was conducted in three Alberta Services Home Care sites in Edmonton, Alberta.

What are the key findings?

- Case managers described workload as the relation between the number of tasks, and the time and energy it takes to complete those tasks.
- A taxonomy of factors that influence workload was developed and the three categories of factors are described below:
  - **Structural factors,** such as inadequate staffing, the shift toward part-time and casual staff, excessive caseloads, and lack of formal support (education, training) increased case manager workload.
  - **Operational factors** increased case manager workload. Home care staff were often not consulted during the development and implementation of operational processes. In addition, the administrative burden for case managers was excessive and computer technology and software programs functioned poorly.
  - **Individual factors** related to the case manager, the client, and the home care team members influenced workload. For instance, case managers were emotionally impacted (stressed, frustrated) by insufficient resources (funding, capacity) and this hampered work effectiveness. Greater experience and strong organizational and coping skills mitigated this situation to some extent. Informal supports, often from home care team members, mitigated pressures and helped staff manage by alleviating stress, through providing advice, learning opportunities, and instrumental or emotional aid.

"I am annoyed that I had to stay late once again to complete my work. I don't feel we have sufficient staff at our location to get the work done…." (case manager)

"When you have casuals, the casuals can't do the [client assessments] and the casuals can't do the new admissions. So it just keeps making the case manager, the workload heavier for them…" (case manager)

"I've always had caseloads that were around 75…but when I was then up to closer to 82, 83…that was too many people to try to phone on a regular basis…" (practice lead)

What are the recommendations?

- Based on study findings, consider the following practice and policy reforms to home care programs:
  - ✓ Realign funding to meet service delivery need. Increased capacity will reduce workloads and the negative emotional impacts that staff experience and facilitate staff sustainability.
  - ✓ Provide appropriate training for part-time and casual positions or eliminate these positions entirely.
  - ✓ Use collaborative models to involve staff in the development and implementation of operational processes.

- ✓ Decrease the administrative burden for staff and upgrade computer technologies and software programs.
- ✓ Give priority to training, education, and informal support for staff.

- Conduct further research to inform the development of a framework that can capture, recognize and legitimize case manager workload and its influencing factors.

Reference

Fraser, K.D., Garland Baird, L. (to be submitted March, 2016). Factors that Influence Home Care Case Managers' Workload: An Ethnographic Study.

Funders

- 2008 Canadian Health Services Research Foundation
- 2008 Alberta Heritage Foundation for Medical Research

Related Publications/Presentations

Fraser, K.D., Sales, A.E., O'Rourke, H.M., & Schalm, C. (2012). Data for Improvement and Clinical Excellence: Protocol for an Audit with Feedback Intervention in Home Care and Supportive Living. *Implementation Science.* 7(4). http://www.implementationscience.com/content/7/1/4

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STUDY 5 RESEARCH BRIEF

Factors that Influence Home Care Case Managers' Resource Allocation Decisions for Long-Term Care Clients DICE Substudy 3

Researchers: Fraser, K. D., and Sales, A. E., Faculty of Nursing, University of Alberta
Partners: Alberta Health, Alberta Health Services, and Industry Providers
Trainees: Lisa Garland Baird

What is the research topic?

Case manager decision making is a complex task that includes client assessment as part of the decision-making process (Fraser, Laing, Lai, & Baird, to be submitted March, 2016). Case managers use various sources of information and data in decision making, yet what they consider and the processes that they use are only partially understood. Empirical evidence on case manager resource allocation decisions is needed to improve theoretical understanding, inform practice and policy, and enhance client and family outcomes.

What do we know?

- A case manager's resource allocation decisions directly affect the level of service a client receives and, in the aggregate, affect overall care program resources, including the ability of a home program to deliver equitable services to all clients receiving services.
- Case managers allocate care and services (home care resources) to home care clients and are essentially the people held accountable for spending these publically funded resources in Canada.
- Case manager resource allocation decision-making in home care is a complex task.

Research Question

What factors influence home care case managers' resource allocation decisions for long-term care clients?

How was the study done?

A sample of 17 home care managers, practice leads, and their managers participated in semi-structured interviews with one-on-one interviews including card sorting activities, and focus groups. The study was conducted within the Alberta Services Home Care Program with a focus on case managers working with clients designated as long-term care clients according to the Inter-RAI classification.

What are the key findings?

- A taxonomy of factors that influence case manager resource allocation decisions was developed. The five categories of factors are described below:
- Case managers gave the most weight to **client-related factors** when making resource allocation decisions. Clients with greater environmental risks, lower health status, higher complexity of health issues, lower stability of health, poorer mental health, fewer coping skills and lower socio-economic status were allocated greater home care resources.
- **Case manager-related factors** also influenced resource allocation decisions. Case managers with less workload, greater experience, a supportive home care team, and strong organizational, communication, and coping skills were more effective at resource allocation decisions.
- **Home care program factors** also influenced decisions. Programs with less restrictive guidelines and criteria, more collaborative agencies, greater staff resources, and in an urban context facilitated resource allocation decisions.
- The **availability of community resources** was also considered in decisions. Fewer home care resources were allocated to clients with greater family support, community/social support or access to community programs.
- Finally, **system factors** influenced resource allocation decisions. There was often not enough planning when clients were discharged from the hospital and home care supports could not be put in place in time to meet client need. There was also very little collaboration amongst health care team members, resulting in poorly coordinated services and ineffective care for clients. Budgetary restraints also influenced the home care resources that could be allocated.

  "And then complexity, that's something that you take into account… The complexity kinda reflects how much time, how much energy, how much other resources, that kind of stuff, the client's gonna need and possibly finding more programs, more support for them." (case manager)

  "The guidelines aren't clear and whatever the guidelines are isn't communicated to all of the case managers…" (case manager)

  "…there are so many factors that affect how things run and what people can receive and the care they can receive because of where they live..." (case manager)

What are the recommendations?

- Consider the following practice and policy reforms to home care:
  - ✓ Realign funding to meet service delivery need, particularly in rural locations.
  - ✓ Adequate funding will permit guideline and program criteria restrictions to be lifted so that client need can be met.
  - ✓ Investigate how to better support and provide services to rural clients and their families.
  - ✓ Improve effectiveness of staff education and training so that they have appropriate first-hand experience and skills development.

- ✓ Give greater priority to informal support for staff to facilitate their ability to make effective resource allocation decisions.
- ✓ Strengthen community resources and networks to ensure clients are better supported and able to remain longer in their homes.
- ✓ Enhance collaboration between health care agencies and within health care teams to ensure care is effectively coordinated for clients.
- ✓ Coordinate hospital and home care resources more effectively; ensure appropriate discharge planning from hospitals.

- Conduct further research to inform the development of a framework that can capture, recognize and legitimize case manager resource allocation decisions.

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Fraser, K. D., Laing, D., Lai, J., & Garland Baird, L. (to be submitted March, 2016). Case manager resource allocation decision-making in long term maintenance clients in integrated home care teams: An ethnographic study.

Funders

- 2008 Canadian Health Services Research Foundation
- 2008 Alberta Heritage Foundation for Medical Research

Related Publications/Presentations

Fraser, K.D., Sales, A.E., O'Rourke, H.M., & Schalm, C. (2012). Data for Improvement and Clinical Excellence: Protocol for an Audit with Feedback Intervention in Home Care and Supportive Living. *Implementation Science.* 7(4). http://www.implementationscience.com/content/7/1/4

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STUDY 6 RESEARCH BRIEF

Factors that Influence Home Care Case Manager Work, Workload, and Caseload Intensity

Principle Investigator: Kimberly Fraser, RN, PhD, Faculty of Nursing, University of Alberta
Researchers: Cummings, G., Marck, P., Liu, L., O'Rourke, H., and Swanson, S.
Trainees: Lisa Garland Baird and Susan Labonté

What is the research topic?

Home care services are expanding to meet the needs of the growing number of older Canadians, to support them to live at home for as long as possible, to delay the need for institutional care and to maintain quality of life. Case managers are pivotal to home care service delivery, yet little is known about the work that they do. The generation of empirical evidence on case manager work, workload, and caseload intensity is needed to improve theoretical understanding, inform practice and policy, and enhance client and family outcomes.

What do we know?

- In 2003, 407,000 Canadians over the age of 65, or 15% of the over 65 household population, reported that they had used home care services. In 2012 that has more than doubled with approximately one million Canadians age 65 and older using formal home care services annually and these numbers are expected to continue to rise due to population aging, attempts to decrease hospital care, and the promotion of and desire for aging in place.
- While home care supports the needs of people of all ages who live in the community, individuals over 65 years of age represent the majority of home care service users.
- Home care is a key strategy used in many provincial health systems to reduce health care costs and demand in other health care sectors.

Research Question

What factors do case managers consistently associate with their work, workload, and caseload intensity within different home care contexts (i.e., different client populations and geographic regions) and what is the relation to quality of care and client and family health outcomes?

How was the study done?

An interpretive descriptive approach was employed to complete a secondary analysis of five textual data sets, one photo data set, and one date set of images. Participants included 57 home care case managers and 4 leaders of case managers including supervisors, managers, and professional practice leaders. Diverse client data were collected from home care agencies in four provinces across Canada: Alberta, Ontario, Quebec, and Nova Scotia.

What are the key findings?

Five themes emerged from the data:

- There is a growing and distinct culture of home care.
- Case managers desire to make a difference and help clients and families.
- Home care is a fast and furious environment.
- There are system failures.
- There is a lack of integration.

What are the recommendations?

Understanding the problem from a 'wicked problem' perspective can shed light on the complexity of the problem. Donebedian's Structure-Process-Outcomes model is one way to unpack and prioritize potential solutions to the wicked problem. Some recommendations include:

- An integrated approach (we talk about it but don't practice it)
- Specialist case managers for the most complex of clients
- Alternate care models (specialists and remote monitoring and intervention)
- Competency enhancements
- Human resources
- Technology improvements and implementation
- Case management education and mentorship
- Improve knowledge utilization (EBP, Knowledge Translation & Exchange activities)
- Explore and use workload measurement tools to achieve more equitable workloads
- Alternative approaches to exploring work processes

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Funders

- 2013 Canadian Institute of Health Research, Knowledge Translation Branch

Related Publications/Presentations

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Fraser, K.D., Garland Baird, L., & Labonté, S. (Fall, 2014). *Case Manager Work, Workload, and Caseload Intensity*. Canadian Home Care Association, November 3-5, 2014. Banff, Alberta.

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STUDY 7 RESEARCH BRIEF

Safety in Home Care: A Four Province Study on Medication Management

Researchers: Ariella Lang, A., Macdonald, M., Marck, P., Fraser, K. D., Hoffman, C., et al.

What is the research topic?

Patient safety is currently a national and international priority, with medication safety earmarked as both a prevalent and high-risk area of concern (Lang et al., 2015). Home care is the fastest growing health care sector in Canada. Medication safety research has focused overwhelmingly on institutionally-based care provided by paid healthcare professionals, which may have little applicability to the home care setting. Understanding what factors reduce the risk of adverse drug events in the home care setting will enable the identification and promotion of safe medication administration practices and set the stage for improved home care standards.

What do we know?

- Medication safety requires the integrity of a complex series of interrelated steps, such that failure to adequately assess, prescribe, dispense, and monitor these steps can potentially lead to adverse events and harm (Lang et al., 2015).
- Compromised safety in medication management can be extremely costly to patients, health care professionals, and the health care system (Ackroyd-Stolar et al., 2005; Jeff et al., 2005; Kidney & MacKinnon, 2001; McGillis et al., 2004; Nickerson et al., 2005; Serembus et al., 2001).
- A recent report on medication safety concluded that approximately 1.5 million preventable adverse drug events occurred per year in the US (ISMP Canada Safety Bulletin, 2014).
- Canadian studies indicate that as many as one in five Canadians suffer adverse events following their discharge home from hospital, and two thirds of those events are related to compromised medication safety (Serembus et al., 2001; Forster et al., 2003; Forster et al., 2004).

Research Question

What medication safety issues do elderly clients with chronic illness, their family caregivers, and health care providers identify as important within publicly funded home care programs in Alberta, Ontario, Quebec, and Nova Scotia?

How was the study done?

A qualitative interpretive description design was used and 32 home care clients, 33 family caregivers, and 29 home care providers participated in interviews, walkabouts with photo narration, and kitchen-table talks. In addition, two focus groups were held in each province, one with home care professionals and one with health care aides. The study was conducted in eight households in each of the following provinces: Alberta (8 households), Ontario (8 households), Quebec (8 households), and Nova Scotia (8 households).

What are the key findings?

Six themes emerged:

- The complexity of each household is significant. Clients and caregivers revealed multiple sources of vulnerabilities such as, cognitive impairment, dexterity, and illness.
- Creating and sustaining networks of support must be done on a continual basis.
- The goals of clients, caregivers, and home care providers may or may not overlap.
- Households employ multiple strategies to manage their medications and other care.
- Medication and health literacy cannot be presumed.
- Each household requires tailored management to optimize safety and mitigate risk.
- Disruptions in care are an issue.
- Barriers and supports to communication are key factors in optimizing roles and engaging team members in decision making and problem solving.

> *"I usually do receive sheets from the pharmacy but I get kind of disgusted because from a layman/s point of view, when you read this you'd be scared to take a drink of water. You know, it's so many things that they list there that you don't know whether to be scared or not."* (client)

> *"I had a client this week…so she's taking these things and I can't help her because these are in a pill box, I'm not allowed but I'm there to watch her. I said, "You took that one already." And she just kept taking and I finally moved them out of her reach…'* (home care health care aid)

> *"…I'm getting people who are not necessarily early discharged but very unstable. I get people home with no caregivers, delirious, like right out of emergency…so medication safety becomes a competing need with all the other needs."* (home care case manager)

What are the recommendations?

- Tools and technology to communicate and education shared across settings, disciplines, clients and caregivers; consider an AHS website information for clients and family caregivers, shared reporting and learning systems across settings that include feedback loops to HCAs, clients and caregivers.
- Engage clients and caregivers as full members of the home care and health care teams, ask how they want to be engaged, provide more on-line resources for medication safety that are client and family caregiver friendly, provide medication risk assessment checklists to clients and caregivers prior to ER and hospital D/C; try using KTTS to conduct home med safety assessments and education.
- Address disruptions in care, diagnose and address critical gaps between sectors and team members to increase the rate of appropriate referrals and decrease inappropriate referrals (e.g., addressing lags with netCare documentation of new medications, improving HC notifications re: ER visits, new meds, ensuring D/C education, ensuring essential HC services in place before D/C.)
- Strengthening networks of support, enhance roles for several team members (e.g., client/caregiver, community pharmacies, HCAs) and facilitate relationships between team members to improve medication literacy, align goals of care and mitigate risks.
- Decrease caregiver burnout, reduce workload pressures by streamlining and integrating IT systems, decreasing unshared documentation, simplifying tools, improving supports for respite, enabling timely communication across clients, caregivers, and the rest of the team.

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- 2008 Canadian Health Services Research Foundation
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- 2008 Nova Scotia Health Services Research Foundation
- 2008 Ministère de da Santè et des Services Sociaux (Quèbec).
- 2008 Ontario Ministry of Health and Long Term Care

Related Publications/Presentations

Lang, A., Macdonald, M., Marck, P., Toon, L., Griffin, M., Easty, T., Fraser, K., MacKinnon, N., Mitchell, J., Lang, E., & Goodwin, S. (2015). Seniors managing multiple medications: using mixed methods to view the home care safety lens. *Health Services Research.* 15(548), 1-15. doi: 10.1186/s12913-015-1193-5

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STUDY 8 RESEARCH BRIEF

Managing Multiple Chronic Conditions: A Qualitative Study of the Perceptions of Older Adults, Family Caregivers, and Health Care Providers

Researchers: Ploeg, J., Emili, A., Fraser, K. D., Matthew-Maich, N., Dufour, S., Markle-Reid, M., McAiney, C., Kaasalainen, S., Keefe, J., and Upshur, R.

What is the research topic?

Recent evidence identifies significant gaps in the delivery of chronic disease prevention and management in vulnerable, older adults in Canada (Canadian Institute of Health Information, 2011; Gilmour & Park, 2006; Morgan et al., 2007; Schoen et al., 2009). Most older adults with multiple chronic conditions (MCC) have access to primary health care but many are not getting the care that is needed to reduce the burden of MCC. The result is care that is fragmented, incomplete, inefficient and ineffective (Canadian Institute of Health Information, 2011). Studies that investigate how older adults, family caregivers, and health care providers manage MCC will result in improved care and better health outcomes for clients and their families.

What do we know?

- As many as 33% of older adults living in the community are diagnosed with MCC and they report poor health status, take five or more prescription medications, have high rates of healthcare utilization and costs, and are at high risk for adverse events (hospitalization, falls) (Canadian Institute of Health Information, 2011; 2012; Broemeling et al., 2008; Vogeli et al., 2007). .
- Seniors with MCCs account for 40% of reported health care use among seniors in Canada, and the intensity of health care use increases as the number of chronic conditions increases (Canadian Institute of Health Information, 2011; US Department of Health and Human Services, 2010; Lehnert et al., 2011).
- Comorbid chronic conditions can impair the client's ability to self-manage his/her care and to adhere to treatment, which increase the probabilities of adverse health outcomes (US Department of Health and Human Services, 2011).

Research Question

What are the perspectives of older adults, family caregivers, and health care providers on managing multiple chronic conditions and provision of care?

How was the study done?

A qualitative interpretive description design was used that involved interviews of (a) 20 adults aged 65 and older who had three or more multiple chronic conditions (at least one of diabetes, dementia, or stroke), (b) 23 family caregivers, and (c) 20 health care providers (physicians,

registered nurses, licenced practical nurses, health care aides, social workers, physiotherapists). The study was conducted in Alberta and Ontario.

What are the key findings?

Clients

- Ability to maintain daily routines and healthy behaviours
- Follow physician advice
- Dependency on family caregivers
- Effects of cognitive decline on management of MCC
- Socialization
- Connection to formal and community-based resources

Family Caregivers

- Normalizing everyday caregiving
- Awareness of the positive aspects of caregiving
- The tremendous responsibility of caregiving
- Need for increased caregiver support

Health Care Providers:

- Use various strategies to support clients and family caregivers
    - Client – and family-centred care
    - Building trusting relationships
    - Client and family education
    - Inter-professional collaboration
- Complexity of home care
    - Complex care needs of clients and family caregivers
    - Complex decision making and prioritization of care
- Lack of client input into care decision making and goal setting
- Health care provider level of education
- Impact of health care delivery setting on interdisciplinary collaboration
- Health care provider satisfaction and rewards

> *"I don't know what to do to help it and especially when you live along, you've got nobody to talk it out to."* (older adult)

> *"At this point, I feel like I'm floundering because I feel overwhelmed. I feel like there's no end in sight."* (family caregiver)

> *"…sometimes the doctor will change it with the client and then not let us [home care case managers] know and then the [home care] agency still think they need to give this dose…so sorting out that kind of communication takes a bit…"* (case manager)

What are the recommendations?

- Realign funding and incentives from a focus on specific diagnoses to MCC.
- Work to expand support for community resource navigators in primary and home care settings.
- Review health care systems that are effective at integrating care across agencies and identify strategies that can be employed locally.
- Explore ways to improve understanding of the collective and collaborative roles that clients, family caregivers, and health care providers play in managing health.
- Modify system structures to include and support family caregivers. Consider financial compensation, employment policies, adequate respite care, and training for family caregivers.
- Explore ways to improve understanding of the collective roles that older adults, family caregivers and healthcare providers (RNs, LPNs, HCAs) play in managing the health of older adults. Revisit the training and educational requirements for HCPs to facilitate their collective efforts.
- Identify opportunities for greater psychosocial support for this population (e.g., telephone support, home visits, on-line support).
- Explore volunteer capacity to support clients and their families.

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- 2013 Canadian Institutes of Health Research Team Grant
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Related Publications/Presentations

Fraser, K.D., Garland Baird, L. & Hyde, A. (2015). *Health Care Professionals Perspectives of Caring for Older Adults with Multiple Chronic Conditions*. Abstract accepted for oral presentation at the Canadian Home Care Association (International) Summit 2015, Ottawa, Ontario, November 8-10, 2015.

Fraser, K.D., Hyde, A., & Garland Baird, L. (2015). *Caring for Older Adults with Multiple Chronic Conditions: The Family Caregiver's Perspective.* Oral presentation at the Canadian Home Care Association (International) Summit 2015, Ottawa, Ontario, November 8-10, 2015.

Fraser, K.D., Hyde, A. & Garland Baird, L. (2015). *Managing Multiple Chronic Conditions: A Qualitative Study of the Perceptions of Older Adults, Family Caregivers and Healthcare Providers in Alberta*. Oral presentation at the Canadian Association on Gerontology. Calgary, Alberta, October 23-25, 2015.

Fraser, K.D., & Hyde, A. (2014). *Caring for Older Adults with Multiple Chronic Conditions: The Family Caregiver's Perspective.* Oral presentation at the University of Alberta Faculty of Nursing Margaret Scott Wright Research Day, Edmonton, Alberta, November, 2014.