

“Living in Care: Balancing Risk and Safety in Long Term Care”
Public Forum - November 12, 2009
Summary Report

Introduction

The Manitoba Institute for Patient Safety (MIPS) is an independent non-profit organization created in 2004 to stimulate and coordinate activities that have a positive impact on patient safety throughout Manitoba. MIPS works with many organizations and partners to raise awareness about patient safety issues and to promote best practices.

Consistent with its mandate, MIPS created a series entitled “*We Listen, We Learn, We Evolve*”. The purpose of the series is to give Manitobans a greater voice on subjects that Institute members feel are of interest and importance to the public regarding patient safety in Manitoba’s healthcare system.

The first forum of this series, held in November 2007, focused on the importance of disclosure and apologies to patients and their families when adverse healthcare events take place. The positive feedback from the public on the first forum led the Institute to continue the series as an ongoing means of raising awareness of patient safety subjects and giving the public an opportunity to voice their concerns, opinions and suggestions.

On Thursday November 12, 2009, the Institute, in conjunction with the Winnipeg Regional Health Authority (WRHA), and with the support of the Long Term and Continuing Care Association of Manitoba Inc. (LTCAM), held the second event of this series, a forum called: “*Living in Care: Balancing Risk and Safety in Long Term Care.*”

The event was free of charge, with no pre-registration required, and was advertised via an extensive distribution list which included: the Long Term and Continuing Care Association of Manitoba Inc. (LTCAM); a number of seniors’ organizations and programs; health care facilities and clinics (including Personal Care Homes throughout Manitoba); health care regulatory bodies; Regional Health Authority networks; Patient Advisory Committees; and community centres, libraries, churches, and bookstores.

The forum was held in an accessible location on the second floor of Deer Lodge Centre in Winnipeg. It was simultaneously webcast to healthcare locations throughout the province allowing people at satellite sites to join with the participants at Deer Lodge in making comments and asking questions. The approximately 100 attendees were healthcare providers, elderly persons (including residents of Deer Lodge Centre), family members of elderly persons, media representatives and other interested members of the public. The session was videotaped for future educational presentations and is accessible through the Institute website at www.mbips.ca.

Balancing the need for autonomy and safety is a significant challenge when providing long term care services to older persons. Policies and regulations intended to ensure

patient safety can conflict with an individual's or their family's ability to make the choices they prefer. This sometimes leads to a complicated, emotional and volatile tug of war between healthcare providers, residents and their family and loved ones. Health care providers and the public were invited to attend this forum to share experiences and perspectives on how to achieve the fullest quality of life for seniors in long term care without compromising patient safety.

The goals of this second forum were to:

- again raise awareness about a patient safety related topic, in this case, balancing risk and safety in long term care, and have the public and providers/managers share perspectives and hear each other's views;
- raise awareness about patient safety and the Institute in general, and specifically matters related to long term and continuing care;
- continue to provide a forum for Manitobans to have their voices heard on patient safety matters;
- encourage people to think about planning for their aging while they are able to self determine the care they want as seniors; and
- create an opportunity to provide input on the future of long term care in MB based on what people feel is important to them.

Synopsis: Living in Care: Balancing Risk and Safety in Long Term Care – A Public Forum

Presentations

Laurie Thompson, Executive Director, Manitoba Institute for Patient Safety (MIPS) provided opening comments and introduced the ***Honorable Jim Rondeau, Minister Responsible for Seniors***. Mr. Rondeau brought greetings on behalf of the provincial government and reinforced the need for the healthcare system to be patient-centered through listening to the needs and wishes of the public.

Réal Cloutier, Vice-President of Long Term Care, and Chief Allied Health Officer, Winnipeg Regional Health Authority (WRHA), provided an informative recap of the evolution of long term care in Manitoba and where care for seniors is at today. He noted that: “Thirty years ago personal care homes (PCH’s) used to be built with parking lots...But the situation is much different today” as personal care home residents now typically have much heavier care needs - related in part to changing societal values around caring for elders at home, and advances in science and other societal improvements leading to longer life expectancies.

Personal care homes, once only loosely connected to the formalized healthcare system are now an integral component of a system of care options for elderly individuals where emphasis is being placed on developing community supports to allow people to stay in their own homes as long as possible.

Mr. Cloutier provided an overview of changes that have been made over the past several years (in response to a tragic death at a Winnipeg PCH in 1997) in order to provide safe,

high quality care for individuals residing in personal care homes (once called nursing homes). These changes have included: the development of legislated personal care home standards linked to licensing; announced and unannounced standards reviews; a complaints management system; staff disclosure legislation; and development of regionalized PCH programs.

The WRHA regionalized personal care home (PCH) program includes:

- service purchase agreements with providers;
- drug program monitoring and quarterly medication reviews;
- regionalized policies and oversight of issues such as restraint use and infection control;
- availability of specialized supports (eg palliative care);
- transparency; monitoring of resident satisfaction;
- use of electronic assessment and care planning tools;
- evaluating the role nurse practitioners can play in the system; and
- education for non-professional staff around dementia, and monitoring of quality and financial indicators.

The RHA also holds monthly meetings with providers and leadership teams to discuss strategic and operational issues. Advanced care plans are discussed with residents and families. Protection for persons in care legislation and critical incident disclosures, investigations and reporting also play a role in striving to provide the highest quality, safest environment possible.

Mr. Cloutier indicated how statistics can be used to monitor both population trends and quality and safety of PCH care. For example:

- ❖ Population trends
 - in the year 2021, baby boomers will be reaching 75 yrs of age
- ❖ Program stats
 - 5600 PCH beds in Wpg.
 - Average age of residents is 84 yrs, 55% over 85
 - Average length of stay – 3 yrs
 - 30.6% have severe cognitive impairment (1st quarter, 2009)
 - 14.3% have fallen (1st quarter, 2009)
 - 31.7% of residents on antipsychotic meds (1st quarter, 2009)

Mr. Cloutier highlighted that the WRHA promotes the philosophy that: “we work in people’s homes rather than residents living in our workplace” which he feels is a respectful approach to caring for the elderly in long term care settings. He noted however that the concept of a PCH as a resident’s home does become more challenging as higher levels of care are required. Mr. Cloutier noted that resource adjustments have taken place to address this increasing complexity of care in PCHs, but suggested challenges for the future will include: the increasing number of individuals potentially requiring long term care; how to provide more care for the elderly in the community, and how to balance what we *can* do with what we *should* do, such as balancing medical interventions with end of life care while maintaining quality of life. He noted that questions about balancing risk and safety (for example measures to prevent falls with injuries) with resident quality

of life, will continue to need to be addressed. He asked the audience to consider how much risk we are willing to tolerate and at what expense to autonomy and overall quality of life? He stressed that these are important questions that care providers and families must consider and there is often no right answer. Mr. Cloutier noted also that: “the relationship between care providers/residents/families is critically important – in the end, most of what we do in healthcare is about people and how we communicate and collaborate with one another.”

Next, *featured presenter, Dr. Rosalie Kane, professor of Public Health at the University of Minnesota and faculty member of the Center for Biomedical Ethics, School of Social Work, and the Center on Aging*, spoke to the forum participants about the perspectives she has developed over many years of study and work with the elderly. Dr. Kane has published numerous articles and a book entitled “The Heart of Long Term Care” and has received many honors for her work.

Dr. Kane began by challenging the group to keep in mind some bottom line messages from her presentation:

- Don’t justify long term care (LTC) status quo as “safety”
- Don’t confuse safety with administrative convenience or entrenched ways of doing things
- Individuals have personal preferences (which vary) for safety vs freedom balance
- Risk is part of adult life
- We don’t know as much about risks as we think – know the limits of our data

Dr. Kane immediately made the point that perhaps what we should be talking about is *long term support services* instead of long term care (LTC), reflecting the notion that we need to move toward finding the range of options that facilitate people’s own needs and choices. She further illustrated this point through presenting 3 case scenarios, all elderly persons who have been able to live meaningfully and participate in society to the extent they could despite significant health challenges. One is her own 101 year old father who is blind, has kidney disease and a faulty gag reflex, but lives in his own home with a companion. He is able to enjoy karaoke evenings and volunteers at a nursing home once a week.

Dr. Kane defined long term care (LTC) as “personal care and related services given over a sustained period for people who have a measurable loss in function and self-care abilities and who need assistance with daily living”. She described what long term care recipients (consumers) *require* (housing, personal care and routine services, health care) and what they *want* for themselves (own home, participation with family and community, meaningful activity, dignity and respect, accurate diagnosis and treatment, pain control, financial well-being, and integration of their life stories). She noted that there are no sharp distinctions between medical and social care needs for this population. While the elderly have a high need for acute care, *the challenge is to provide high quality care without running older people’s lives.*

Trends in LTC include a move to more care in the community. Dr Kane described newer models of LTC which provide more individualization and normalization (particularly for people with cognitive difficulties) with empowerment of certified nursing assistants and residents...these models are part of a continuum of care including assisted living and adult family homes where individuals are cared for in small group settings.

Ethical dilemmas are situations where professionals are unsure what is right to do from a moral or ethical perspective. Dr. Kane suggested that ethical professionals cannot avoid ethical uncertainty and that the greatest ethical angst in long term care concerns safety vs other values. She described many reasons why LTC is an ethics challenge (for example, it involves families, may involve end-of-life issues, involves competing claims of young and old, paradox of dependency etc) and gave examples of some typical ethical dilemmas, noting that these dilemmas are sometimes unrecognized. The tension between safety and senior preferences was a frequently cited ethical issue in a case management ethics study done by Dr. Kane. In studying the values and preferences of elderly consumers' themselves, Dr. Kane found that, in terms of the balance between freedom and safety, 1/3 chose freedom, 1/3 safety, and 1/3 both.

In terms of safety, Dr. Kane noted that negligence or substandard care is never acceptable, and systems to avoid error and acknowledge it when it does occur are important. She challenged participants to think about what is termed an error in long term care. For example, is a fall always an error? Does a bad outcome mean poor attention to safety, or is it more about living a life? She suggested perfect safety is an absurdity and asked: is the goal - maximum quality of life and autonomy as consistent with health and safety; or maximum health and safety as consistent with personal autonomy and choice? She suggested that we can't maximize everything at once and we need to decide which we believe to be the primary goal. She also challenged some of the things that have been done in the name of safety – for example, physical restraints, and chair alarms, pureed diets, thickened liquids, and strict surveillance.

A discussion of safety in home care settings again raised questions for the audience's consideration. For example, who decides if a home is adequate? Can a helpless person ever be left alone? What if a family seems incapable, etc. Dr. Kane described an Australian study of a dementia home care program which allowed people to stay in their own homes with "SWAT teams" of nurses and paraprofessionals coming in "to just try and do what was practical". This study found that people with Alzheimer's seemed to have fewer problems when no one was there "to be disturbed by their behavior".

Assisted Living was described as any group residential setting not licensed as a nursing home providing activities of daily living (ADL) services and routine nursing services to people with functional needs. The question raised was: is staying in assisted living situation housing or a medical decision?

A discussion of nursing homes (which in Manitoba would be called personal care homes), began with a review of some of the historical drawbacks of these settings such as: lack of privacy, impoverished personal and shared spaces, showers down the hall,

rigid routines, lack of choice, learned helplessness, *everything for therapy, nothing for living* (for example, people want to garden, not have horticultural therapy), and money going where older people do not want to go. The emphasis is now on more normalized environments including private rooms, individualized resident routines, emphasis on resident control and quality of life. Again, forum participants were challenged to think about issues typically described as safety concerns from a different perspective - based on residents' individual needs and circumstances. This included reexamining some of the clinical decisions made such as special diets, catheters, alcohol in the home, and who can drive a resident somewhere.

Dr. Kane described the relatively new Greenhouse or small house model, in which care is provided in a small house (10 or fewer residents), meals are cooked in a residential kitchen where folks eat together at a large kitchen table, elder assistant roles are broadened, and professionals provide itinerant clinical support. This model is can work with people with dementia and is contributing to better quality of life for those involved.

Negotiated risk contracting was described as an agreement of a consumer or consumer's agent to accept risks so as to achieve other goals of the consumer after risks have been explained. Dr. Kane noted that this is both a process as well as a product and can be a vehicle for generating alternative ideas. It requires thinking about safety less narrowly. It also requires considering the likeliness of the event as well as the seriousness if it occurs.

Dr. Kane reiterated her bottom line messages and encouraged people to visit her website to explore further information on this topic - www.hpm.umn.edu/lcresourcescenter/. She also invited people to email her if they wish at kanex002@umn.edu.

Discussion

Réal Cloutier took on the role of moderator as the forum audience was invited to engage in an open discussion with the speakers. Comments and questions were raised from both on-site and remote locations. Discussion topics included:

- *Medication safety*
An audience member expressed concern about the potential for over-medication of personal care home residents and asked about the WRHA's monitoring of this issue.

Mr. Cloutier commented that this is a big issue in the personal care home environment as elderly individuals are high users of medications. He noted that the Canadian Institute for Health Information monitors the use of a series of drugs that can be particularly detrimental to elderly individuals. He also commented that this issue is monitored through the WRHA's process of quarterly drug review which looks at not only individual drugs, but the combination of drugs used, as it is often the accumulated effect of a number of drugs that is the issue. He noted that this process is improving with newer developments such as remuneration for physician participation in the quarterly drug reviews.

Dr. Kane also spoke to this issue, saying “many older people are kind of like walking chemistry sets - there are issues of not only over medication but also under medication or giving the wrong medication”, but there are ways of addressing medication safety issues such as simplifying medication regimes and looking at when medications are administered.

- *Falls*

Mr. Cloutier was asked if the same type of monitoring that is used for medication would also apply to the monitoring of falls.

In response, Mr. Cloutier referred to some of the statistics available through the personal care home monitoring system. For example, quarterly results indicated that 14% of 5600 Winnipeg personal care home residents fall. He noted however that last year's statistics indicated that 228 of those falls resulted in injury leading to hospitalization, ie most falls do not result in injury. This is because many measures have been put in place to reduce the incidence of falls, including assessment of individual's propensity to falling, the purchase of low-rise beds, policies avoiding the use of bed rails which have been shown to contribute to injuries from falls, and working with seniors to teach them how to fall. He also noted that we need to consider the extent to which we want to go to reduce the incidence of falls. Do we want to minimize the risk of falling to the extent that we absolutely remove people's autonomy?

- *Ageism*

A representative of a senior's organization raised the question of how much some of the issues seen in long term care are related to ageism. She also asked what we are doing as a province to educate young professionals about gerontology, aging and maintaining autonomy as we age.

Dr. Kane noted that while education for young professionals is a good idea it will take a long time to come to fruition and we may need to ensure a focus now on continuing education and public dialogue.

Mr. Cloutier noted also that change needs to come from public dialogue about what people want in terms of personal care as they age. He noted that the discipline of geriatrics is not attracting people - last year only 3 geriatric residents graduated in Canada. He suggested that we need to focus on developing community options and further noted that the baby boomers who will be turning 75 in 2021 will certainly have an impact on long term care options.

- *Organizational Culture*

A physician who has practiced in Europe commented that organizational behavior is as important as clinical care and suggested we need a less paternalistic model of care in Canada and an emphasis on maximizing the use of the skills of a variety of health care professionals.

- *Personal Care Home Ratings*

An audience member inquired about whether or not there are ratings for Personal Care Homes in Manitoba and the availability of this information to the public.

Mr. Cloutier noted that the current standards assessment process results in a pass/fail determination. This information is not currently publicly available, but it probably will be in the future. He cautioned that although this information should be available so that people can make their own decisions, it also needs to be carefully interpreted. For example, an increase in falls or critical incidents may not be negative results if, for example, they reflect greater autonomy in a home or better reporting of critical incidents.

Dr. Kane suggested that public reporting is a good idea and is available in the US through “Nursing Home Compare” which provides comparative data on a number of parameters. She also expressed caution about interpretation of data noting that sometimes people are concerned about irrelevant things. She suggested it might be most helpful to have some sort of consumer based rating system for nursing homes, along the lines of a Michelin guide or a system similar to hotel or college ratings.

- *Consequences of a shift toward greater autonomy*

Dr. Kane asked the audience how they felt about the issue of someone with a poor gag reflex and whether or not it is negligent to offer a person a choice of food in this type of situation (i.e. regular, rather than pureed food if they have a strong preference).

One audience member described her personal experience with her grandmother who has been given this choice and her support for the way in which this has contributed to a greater quality of life for her grandmother.

Another asked how to deal with the fear engendered by offering someone such a choice (particularly among health care providers). Dr. Kane recognized that the fear of someone choking, falling or being injured relates not just to a fear of litigation, but to a fear of how one might feel. She noted that part of the answer may be to not feel that you are totally responsible. She noted also that we don’t want to minimize safety issues, but we do want to look at ways to minimize potential problems, yet maintain individual autonomy as much as possible.

Mr. Cloutier noted that health care professionals tend to be risk averse, but that leadership is important in giving them the ability to have conversations with individuals and families about such choices. He also noted that as long as decisions made with families are documented and due process is followed, the risk to providers is minimized. It becomes a shared responsibility between care providers, residents, and families.

- A rural audience member noted that the direction she had received around this issue has been much more rigid than that suggested. *Hopes for the future*
Mr. Cloutier suggested to the audience that the debate we really need to have is: how do we expand our community models of care so that we don't have to have so many people in institutionalized care?

Dr. Kane agreed with an emphasis on community models of care, and suggested that the future will include a model which combines the best of the assisted living model combined with the capacity for heavier care. She related an anecdote, referenced in the work of Joanne Rader, a nurse from Oregon and the author of *Bathing Without a Battle*. In it, a former nurse who was somewhat obstreperous due to dementia ended up sleeping under the nursing desk in a personal care home because that's where she felt comfortable. The staff was able to meet her needs through making space for her with pillows and blankets etc.

Dr. Kane emphasized that as mentioned, organizational structure is important. She also suggested that we need a new kind of nursing leadership, saying nurses need to be coaches, teachers, and role-models. She suggested also that nurses need to support the skill development of care aides. She commented on the incredible growth of the care attendants in the Mississippi Greenhouse model, even though the nurses involved weren't necessarily comfortable with the increased responsibility the aides assumed.

An audience member from the Independent Living Resource Centre in Winnipeg noted that many of the changes suggested by Dr. Kane are already happening in their program which is based on a self-managed care model.

Informal sharing over refreshments

Following thank yous to the speakers and participants, Laurie Thompson invited all in attendance to share further comments with each other while enjoying refreshments. Several people stayed and provided positive comments about the session. Someone noted: "it really got me thinking about what will happen for my relatives and myself - and about what I'd like for myself". Two ladies who are residents of Deer Lodge commented that they enjoyed the session and were happy to point out that they have exceeded the average length of stay of many PCH residents and intend to do so for some time to come!

Further information

The *Living in Care: Balancing Risk and Safety in Long Term Care Public Forum* synopsis and the presenters' slides are available on the Manitoba Institute for Patient Safety (MIPS) website at: <http://www.mbips.ca/wp/category/event-review/> . To borrow a copy of the DVD of the event, please contact MIPS at (204) 927-6477.