



## **FAMILY PERSPECTIVES ON THE USE OF MEDICATIONS IN LONG-TERM CARE FACILITIES**

**A REPORT FROM WOMEN AND HEALTH  
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## 1. Introduction

Women and Health Protection, a national working group based at York University, has had a long-standing interest in the uses of prescription medications and the implications for women. In this project, we sought to build on our previous work – as well as that reported by others -- and learn about the experiences of people who have family members<sup>1</sup> in long-term care (LTC) facilities<sup>2</sup> who may be taking prescription drugs. It has been well documented that older residents in LTC facilities are often given multiple drugs and that many of the individual drugs, as well as the combinations given, have not been fully tested for their safety and effectiveness in these populations. Because family members often have the most direct knowledge about the medications given to their relatives, they have much to contribute to a discussion of these issues. This is especially important information given growing attention to and concern about the ways in which medications are under/over and mis-used for the elderly, a majority of whom are women.

Our goals in this project were (1) to assess the current state of knowledge about family's perceptions about the use of drugs in LTC facilities using a scoping study of the literature to identify relevant research and (2) to obtain these perceptions directly through an online survey directed at family members of those currently in long-term care placements in Canada. We expected that the information from both would then serve as a basis for developing appropriate recommendations with regard to medicine use among/for seniors in care. Because the use of psychotropic medications in LTC facilities had already raised concerns reported in the literature, we also focused on this group of drugs.

The general intent of the project, therefore, was to facilitate public engagement in a key health policy issue – medication (especially psychotropics) use with seniors in long-term care facilities - and to draw attention to the particularly gendered implications of this issue.

The sponsors for this project were the National Network on Environments and Women's Health at York University, Toronto, and the Canadian Women's Health Network, Winnipeg.

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<sup>1</sup> We used an open definition of family, encompassing those who may not necessarily have blood or marriage ties to the person in long-term care.

<sup>2</sup> Throughout this report, we use the term "long-term care facility" to generically describe a range of institutions that go by differing names in each province. Among other terms, it is meant to include : nursing homes, personal care homes (Manitoba), complex care facilities, long-term care homes, auxiliary hospitals, and homes for the aged.

## 2. Rationale

Medications are the most common treatment for many diseases and conditions experienced by older people and persons with disabilities. Medicines now not only treat and cure diseases that were untreatable just a few years ago, they can sometimes modify diseases in their early stages; prevent life-threatening illnesses; relieve pain and suffering; and allow people with terminal illnesses to live more comfortably during their last days. However, they can also be prescribed when a less invasive option might be a better choice for dealing with a problem, and can create ill effects that may render people sicker than when they started, or make them sick when they previously were not. This can be particularly worrisome with the elderly who often take more than one drug, and who may be disadvantaged by declining organ function age-related inability to absorb medications optimally (2).

A 2009 report from Statistics Canada(16), “the first nationwide population-based study to provide benchmarks of medication use and multiple medication use among all Canadian seniors” noted:

*“There is a need in Canada for information about the number of seniors who use medications and those who have an elevated risk of drug-related adverse events from multiple medication use.”*

The research additionally found that in 2005, “pharmacists dispensed an average of 35 prescriptions per person aged 60 to 79, and 74 prescriptions per person aged 80 or older, compared with an overall average of 14 prescriptions per Canadian.” We know from a wide range of reports in the literature that people who take several medications at once are more likely to have adverse drug reactions, and that seniors are particularly vulnerable. Further, and of particular concern given the growing numbers in long-term care facilities, the Statistics Canada survey found that 97% of seniors had taken some form of medication in the past 2 days, in contrast with seniors in households, of whom 76% had done the same.

The growing use of anti-psychotic medication, in particular by seniors in care facilities, has been well documented (10, 14, 17). This is despite evidence that, when matched with placebo controls, users generally have higher rates of both mortality (15) and morbidity (falls, respiratory and urinary tract infections, unfavourable metabolic changes, cerebrovascular events, and accelerated cognitive decline)

(3). Although physicians are not prohibited from prescribing drugs for an off-label use, a 2011 U.S. study documented a very – and worrisome -- high rate of off-label antipsychotic use in nursing homes. In fact, 83% of Medicare claims were associated with an off-label use of antipsychotic medication for seniors in these facilities. Moreover, 51% of claims for antipsychotic medication in nursing homes did not comply with Medicare reimbursement criteria (18). Irish Pharmacy researcher Carmel Hughes asks "...why is 'inappropriate' prescribing accepted in some nursing homes and regarded as the norm?" (9)

There is very little public policy on the issue of medication use among seniors in care facilities, and what there is tends to have little if any gender-based analysis.<sup>3</sup> This is despite the fact that nearly two-thirds of all long-term care residents, and three-quarters of residents 85 and older, are women. As well, most of those providing "informal" care and support to these seniors are themselves women.

The experiences of family members with elderly relatives in long-term care facilities who may be involved in decisions about how their relatives are treated can provide a source of information that would contribute to the research on seniors and medication, and could offer insights for improving public policy. Family members often have direct experiences that would be relevant to a better understanding of how, when, and by whom, decisions about the use of pharmaceuticals are made. Moreover, if family members do have a role, this should be taken into account when policies and practices are developed to best meet the needs of their relatives in long-term care.

### **3. Methods**

The project – and this report – consist of two components that were carried out more-or-less concurrently: a scoping review of the literature and an on-line survey. This dual approach enabled us to learn what was in – or missing from -- the literature regarding family perspectives on medication use in long-term care facilities as well as to explore the extent to which responses to our survey paralleled and added to what had been reported by others.

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<sup>3</sup> For more on gender-based analysis in a health policy context, see Clow, B., Pederson, A., Haworth-Brockman, M., and Bernier, J. (Eds.). (2009). *Rising to the Challenge: Sex- and gender-based analysis for health planning, policy and research in Canada*. Halifax: Atlantic Centre of Excellence for Women's Health.

### 3.1 Scoping Study of the Literature<sup>4</sup>

To determine what is known regarding the experiences and attitudes of family members in relation to medication use among their elderly relatives in long-term care facilities, we carried out a scoping review of the literature. We sought to evaluate what is already known and to identify gaps in the literature on this topic. We were particularly interested in psychotropic medications, since these are more often used in a discretionary (and off-label) fashion (e.g. as sleeping medication) than other drugs, as well as about whether or not gender had been considered as a possible determinant or moderating factor in research that has been conducted.

#### i) Scoping Study

A scoping study takes an approach to reviewing the literature that differs from other types of reviews (e.g., systematic reviews and meta-analyses). Scoping studies are primarily used to investigate the breadth of a research topic, to identify gaps in the existing literature, and to summarize a broad range of evidence that includes both published and grey literature (11). In contrast to a systematic review, scoping studies typically do not include an assessment of the quality of the evidence included in the review. The scoping study methodology fit well with our objectives, which were to summarize what has already been studied, identify gaps in the evidence, and provide a basis to inform further study around this issue.

#### ii) Database identification

This scoping study involved systematic searches through selected databases. The database search strategy was constructed, reviewed, and amended with the assistance of reference librarians at McGill University who helped with our database selection. We also considered additional databases included in a list of “Public Health Bibliographic Databases” published by OPHLA (the Ontario Public Health Libraries Association). The final list of databases for searching was reached by consensus, and comprised the following:

1. PsycINFO
2. CINAHL
3. Canadian Research Index
4. Social Services Abstracts
5. Medline<sup>5</sup>

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<sup>4</sup> We gratefully acknowledge the contribution of Martine Elbejjani, Britt McKinnon and Jessica Gallinger to this section of our report.

### iii) Database search

All major databases (PsycINFO, CINAHL, Medline) contain four major search concepts we planned to use: family, medication, long-term care, elderly. These concepts were linked with the Boolean term “AND” so that any retrieved publication would contain a word or database tag to each of the four concepts. Each concept contains an extensive list of synonyms; for example, “long-term care” synonyms include “nursing home” and “residential care.” However, these search terms varied slightly by database and so we sometimes adapted the planned search terms to meet the idiosyncratic structures of each database. On those occasions when a database’s tags were superior to our self-generated synonyms, we accepted that database’s own categorization system. For example, in CINAHL we replaced our long-term care synonyms with a number of selected database categories: “(MH “Nursing Homes+”) or (MH “Ambulatory Care Facilities”) or (MH “Skilled Nursing Facilities”) or (MH “Long Term Care”).” Because the minor databases had search character limitations and other features that constrained our ability to conduct a precise search, it was not efficient to include all four search concepts when using them. However, because of their smaller size, the results generated by our broader search were manageable.

To complete the literature search, we also examined references in relevant articles that had not been otherwise captured. Throughout, we were attentive to both peer-reviewed and “grey” literature.

### iv) Study reviews and selection

We exported the results of the database searches to a bibliographical tool, EndNote, where the studies were further sorted through a standardized process. First, duplicates were eliminated and the results were limited to publications post-1995. In the first screening level, we then reviewed titles and abstracts to eliminate publications that were not directly relevant to our research question of interest. In this category were, for example, studies regarding end-of-life decisions

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<sup>5</sup> The original list also included SCOPUS, Social Sciences Index, through Web of Science, PubMed and AgeLine, but upon further review these were removed either because they were not readily available, or were not found to be sufficiently valuable for our work. We also replaced PubMed with Medline (through Ovid) because the intrinsic database properties of Medline were far more suited to our needs than were those of PubMed.

and the treatment of certain specific conditions (diabetes, respiratory symptoms, etc.). We then retrieved and reviewed the full content of the remaining studies to identify those to include in the scoping review. At least two independent readers took part in this screening in which we excluded studies that lacked information on family members' perceptions of psychotropic medication use in long term care facilities or where the full text was not available in English or French. The studies that remained were then re-read (again by at least two independent readers) and findings related to family members' views of their relative's medication with psychotropic drugs were summarized individually and combined in a global summary.

#### v) Summary of findings

Despite our extensive search of the literature, we found very little research that pertains directly to the involvement and experiences of family members in making decisions about the use of psychotropic medications by their elderly relatives in long-term care facilities. Only five articles were found to be even somewhat relevant to our question and in none of these was gender considered in any way. The five studies are summarized individually in Appendix 1.

Overall, we identified the following key points with some policy relevance:

- In general, family members did not have a comprehensive understanding about why, how, or for how long the psychotropic medication was deemed necessary for their relatives. For instance, some thought that treatment with sleeping pills or anti-agitation medication meant that, from then on, their relatives would not be able to sleep or be relaxed without the pills. Moreover, they often had many faulty assumptions about psychotropic medication and its discontinuation (13).
- Two studies reported that family members were involved in roughly half of treatment decisions for elderly relatives in long-term institutions (5, 8). However, in both studies, treatment in general, which included but was not specific to medication, was described. Furthermore, in one of these studies family involvement was described only by the physician making the treatment decision and so cannot provide information on the perceptions of the family members themselves (5).
- Family members' perceptions of their relative's pain and distress often did not correspond to the medications prescribed for their relatives in long term care facilities. Family members expressed concern over both over-medication and under-medication of their relatives (7).



- Family members tended to rely on information provided by medical staff and generally trusted the latter for making decisions regarding the use of psychotropic medications (12, 13). One study emphasized how family members' perspectives regarding the use of psychotropic medication was highly dependent on how the nursing staff framed the treatment, the need for medication, and the symptoms of their relative (13).
- Family members also relied on medical staff for information and decisions about the use of psychotropic medications as means of restraint for their relatives (12). Thus, when staff lacked knowledge and training in alternative treatment, family members were also ill informed about the most safe and effective (non-pharmacological) treatments. As well, family members were not aware of the challenges and the limitations that the nursing staff list as barriers for reducing the use of restraints (e.g., lack of time, lack of resources, limited continuity of care staff, inadequate follow-up, lack of resources for training in alternative methods, etc.).
- Physicians treating nursing home residents reported that family involvement and the consideration of the family's wishes related to treatment increased when the elderly relative was more cognitively impaired (5).

#### vi) Discussion

We were unable to identify any study that focused specifically on reporting or analyzing family members' perceptions of the use of psychotropic medication by their elderly relatives in long-term care facilities. Moreover, no studies specifically examined the role of gender in either the decision-making process or the perceptions of family members related to treatment decisions. In none of the five studies retained for analysis were the views of family members regarding psychotropic medication a primary objective. Rather, these were included as part of larger investigations exploring, for example, the use of psychotropic medication for pain or for restraint in long-term care facilities and what relatives thought of all this was not directly examined.

There are, however, some recurrent themes in these studies: family members were found to be generally ill-informed about different aspects of psychotropic treatment and they also had an erroneous impression of the resources staff had and of the constraints on their work that might affect the use of psychotropic medications. They also relied extensively on the medical staff for information and trusted the health care personnel for making treatment decisions.

If we are truly to understand family members' perceptions of their older relatives' psychotropic treatment, more focused research is needed. This should be designed to allow for identifying the full range of these perceptions, the reasons behind them, and how they consequently affect the health and daily life of one's relatives – and one's self. Moreover, these studies must be planned so that gender issues can be explored appropriately.

### **3.2 Online survey:**

Following consultation with selected experts in the field, and concurrent with the timing of our Scoping Study, we developed a 38-question instrument that could easily be completed online, using the survey software, SurveyMonkey . The full survey, which can be found in Appendix 2, was prepared for anonymous completion in both English and French allowed for responses of both a quantitative and a qualitative nature. The survey was reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conformed to the standards of the Canadian Tri-Council Research Ethics guidelines. Management of the on-line survey was facilitated by the Canadian Women's Health Network.

The purpose of the survey was to better understand how key family members (such as adult children, spouses, partners, and others) are involved in the medication decisions for their relatives in long-term care facilities and whether they have a role in how prescription drugs are used by these seniors.

More specifically, we were interested in:

- family members' experiences of participation in how medication decisions are made;
- their expectations about medication use, especially the use of psycho-pharmaceutical drugs (i.e., medications used to alter or improve a person's mood or treat, reduce, or remove behavioural problems. Some examples are anti-anxiety drugs [such as Xanax, Ativan, Valium]; sleeping medications [such as Ambien, Lunesta]; anti-psychotic drugs [such as Risperdal, Haldol, Seroquel]; and anti-depressant drugs [such as Zoloft, Prozac, Paxil, Celexa].)

#### **i) Survey Tool Development**

An advisory committee to the research project - with experts working in the areas of clinical research involving seniors and medication, service

provision in LTC facilities, and individuals involved with resource centres for the elderly – helped guide the development of the research tool. Most of the questions required only short answers that could be tallied quantitatively but, where appropriate, there was space for longer responses; it was the "qualitative" information we obtained this way that was most useful and informative.

Once the electronic questionnaire was developed, it was put up online using SurveyMonkey and a range of approaches - mostly circulating information to websites and listservs (e.g., Par-L, CWHN, RQASF, Biojest, et al.) about it - were employed to invite people to take part. We also created a pdf version of the questionnaire so that those without easy internet access could take part in the survey. The material was online for four weeks, with reminders sent out on listservs to encourage participation.

At the close of the survey, we used a range of software programs (SurveyMonkey; Word, Excel) to summarize responses in tabular and graphic forms according to coding that ensured the anonymity of participants. As per the research proposal, data were analyzed and are reported here in aggregated form (quantitative) and by thematic category (responses to open-ended questions and spontaneous comments).

## ii) Survey Results

Fifty-eight individuals completed all or most of the questionnaire, 51 in English and 4 in French online, and an additional 4 in English in the pdf version. The vast majority (72%) were women between 50-70 years old, responding about female family members (their mothers [54%], mothers-in-law [11%], and grandmothers [9%] predominantly). Most family members in LT care were over 80 years old (85%); about half (54%) of whom were reported to be in good to excellent health, with the remaining 46% reported to be in very poor to fair health.

Most respondents and their family members lived in Ontario (40%), with the others mainly from BC (19%) or Alberta (21%); all were usually located in larger urban centres. About one-quarter of the family members had been in care for under one year, while a third had been there for 1-3 years. About 70% of those in care were said to have cognitive problems, and in most cases this had been diagnosed by a health professional.

Almost  $\frac{3}{4}$  of respondents stated that they made medication decisions for their family member in care because the latter was not competent

to do so herself. Moreover, it was quite usual for the respondents to review care plans regularly, albeit the regularity varied.

Of those reporting that they were responsible for making decisions for their family member, considerably more respondents (about 2 times as many as not) indicated they felt that at some point there had been a problem associated with a family member's use of medication. Most respondents who had a concern about a medication being taken were aware of someone to whom they could take their concerns and, when they did so, reported getting responses that were, for the most part, satisfactory, though not always as quickly as they might have liked. The expressed concerns covered a wide range of drugs - prescription and OTC - and most did not seem related to a concern about any serious risk of the substance taken. This is in line with the responses indicating that about just over half of those completing the online form were generally satisfied with their roles in decision-making about medications (54%).

Nonetheless, more respondents who had decision-making authority for their family member reported NOT being consulted about changes in their family member's medication (57%) than those who were (46%). And where the LT care resident had her own decision-making authority, only 12% were said by their relatives to have been asked for informed consent when a medication was being introduced or changed: 62% were not asked for this and 27% of family members reported not being sure about what happens. These findings should be viewed with caution, since we weren't able to confirm the reports with the actual experiences of the individuals in LT care.

Full results of the quantitative findings are summarized in table form in Appendix 3.

### iii) Further discussion from the qualitative findings

To analyze the many comments participants provided - sometimes in response to prompts for details to a multiple choice question, sometimes spontaneously - we first read through all the material and then grouped it by themes that captured the area of concern. We then explored the extent to which these themes seemed to echo those that emerged as key points in the scoping review, and "tagged" those that were closely tied to one or more of these. We also made note of those issues and "themes" in the questionnaire responses that were not evident in the literature review. Examples of all of these are provided as evidence of how respondents reported their experiences of medication decisions and use by their family members.

## **Involvement in care and decision-making varies**

Family members indicated a broad range of involvement in decisions regarding the use of medications. Some seemed to want to be more involved, while others were content with treatment being decided on by the medical staff.

*“The facility has provided me with a list of the medications that my mother is on, at my request. However, I would prefer that the GP attending my mother consult me about her medications as well as other treatment issues.”*

*“It was written up in his chart, but the doctor on duty would ignore it and prescribe sleeping pills and laxatives. Then the nurses would follow the doctor's orders without checking with me.”*

*“I went to the head of the facility and complained. She wrote a note on his chart that I was to be informed of all changes in meds. It did no good.”*

*“If my mom was residing in the community and I took her to her family physician, I would be involved and have a say in how she is medicated.”*

## **Concerns about both under-medication and over-medication**

Survey respondents expressed concern about both over-medication and under-medication of their family members in care. Mention of over-medication was heard most often with respect to psychotropic medications.

*“She is given anti-psychotics to sleep, anti-depressants, proton pump inhibitors, others, for no reason I can sustain. When she was at one time taken off many, she was clear headed and much of herself again. She was put back on most as soon as she was under the care of the centre doctor.”*

*“She is on over 17 pills a day and that feels like over-drugging.”*

*“We have all noticed a correlation in the deterioration in Mom's mental state with the increased doses. [...] Mom has retained her sweet, soft temperament, but has not been able to recognise us for*

*2+ years. We believe this is the result of overdosing with strong drugs.”*

Concerns about under-medication tended to centre on pain management. Family members’ perceptions of their relative’s pain and distress often did not correspond to the medications prescribed to their relatives.

*“Mom had pain but would not ask for PRN medication. I intervened to make it a regular dose so she would get enough.”*

*“At other times when I have visited and mother has complained of headache (which is chronic for her) I’ve asked if they could give her some tylenol and because she gets tylenol regularly[...] each day they would not give her anything for the pain.”*

*“My mother recently passed away and was allergic to morphine so the last 10 days were brutal trying to find a medication to deal with her pain, it was awful and I wouldn’t have put an animal through the agony she went through.”*

There was also concern about the use of medications for sleeping.

*“[Relative was] Put on a sleeping medication by the family physician but was not told about side- effects.”*

*“Sleeping pills that were too strong were given. He was completely drugged out all the next day, and I did not know why until the day nurse checked his chart.”*

Comments revealed that family members sometimes did not understand why their elderly relative was receiving psychotropic medication and, furthermore, had misconceptions about psychotropic medication and any need for discontinuing its use. Nevertheless, those who did comment often flagged the multi-medication problem described with concern in the literature on medication use in the elderly.

### **Family attitudes framed by LTC staff and medical personnel**

Family members tended to rely on medical staff for information and decisions about the use of psychotropic medications when these were used as means of restraint for their relatives.

*“The nurse phones my sister, who has POA, and she always agrees with the Facility staff’s recommendations.”*

*“When I asked, the owner discussed it with me, and told me why she had been given - or taken off - the med, and it made sense to me, so I accepted it.”*

*“[The] nurse mentioned to me that the doctor had taken her off of her medication and that mom was agitated scared etc so we got in touch with her doctor . In the meantime the nurse asked the doctor on call to authorize her to be on her medication. Everything is fine now.”*

### **Concerns about quality of life for residents**

Many family members provided comments about the quality of life in the facilities where their relatives resided. These tended to centre on the quality of food, access to activities that improve quality of life, and frequency of bathing. Others mentioned the lack of attention to the psychosocial, spiritual, and emotional needs of long-term care residents.

*“The staff are caring but there are so few of them due to decreases over the years that residents who do not have family close by to see them regularly are left alone without any human contact for much of the day and evening. The emotional impact tends to increase behaviour problems leading to more medication.”*

*“There seems to be a current trend towards simply seeing residents as patients who need their physical needs tended to. The closer to end of life and the more dependent a resident becomes the more they need to feel they are being cared for on an emotional level.”*

*« Maman me semble très bien « soignée » sur le plan médical, mais l'alimentation est pitoyable. »*

*“I am quite appalled to see the prevalence of high-glycemic foods--or rather anti-nutrients. Desserts consist of glue: starch*

*puddings made with white flour. Mashed potatoes come out of a box. The food is mostly reheated stuff from boxes: ham with its plethora of nitrates and nitrites is on the menu at least once a week, juice is commercial, undiluted and overly sweet. Snacks are always starch-based, blatantly high-glycemic.”*

*« ...la qualité de vie serait meilleure si les repas étaient de meilleure qualité. »*

There was general awareness of how understaffed most facilities are and how this results in the potential use of medications rather than other non-pharmacologic treatments for a range of conditions.

*“The staff are working to their limit and beyond. I don’t know how they do it.”*

*“I was at X’s rehab hospital when my uncle was there. They had rec[reational] therapists playing games with the residents-- games designed for wheelchair-bound patients. Why not involve co-op students? --they need the credit to graduate; it would be mutually beneficial: give them some basic training in geriatrics and let them get creative... They could use a properly-trained music therapist who addresses specific brain functions via music... What are we waiting for? There are highly qualified, unemployed music therapists out there.”*

*« On nous parle de « milieu de vie »... mais le milieu reste très hospitalier... J'apprécie votre souci face aux médicaments. Ils ne sont que la tête de l'iceberg... de la vie en institution, malgré la bonne volonté certaine de la plupart des membres du personnel et de la direction. »*

*“The current trend of decreased staffing seems to increase the need for medications. A more holistic approach is needed.”*

It was noteworthy that many respondents, even those with some of the concerns quoted above, still expressed satisfaction with the care – including medications -- provided for their relatives.



*"The facility was very helpful in explaining anything I didn't understand."*

*« Chaque fois qu'une question se pose, même s'il ne s'agit pas d'un « problème », il est possible de rejoindre le médecin ou l'infirmière le jour même. »*

*"They have appeared to be very transparent about all decisions regarding my grandma's care."*

*"I have no concerns over the centre staff. Very proactive and caring."*

*"This place is very well run and family is the first consideration. They contact us even if we don't contact them, keeping us informed in a timely fashion of any issues. We are also frequently there, for events, parties, etc, and the staff know us by name."*

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## **LIMITATIONS**

Our study was constrained by the limited literature available as well as the reduced number of participants in the online survey. The use of SurveyMonkey meant that quantitative analyses of the data were also more difficult than need be, albeit the low number of responses allowed manual analyses. Nevertheless, the written responses to the questionnaire and the material in the literature we did find, do provide a sufficiently clear sense of where policy may be needed.

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## **4. Discussion**

At the least, the findings from our online survey underscore what others doing research in this area have been saying for at least a decade: there is need to give consideration to non-medication approaches for managing problems of those in LT care and to ensure that those drugs which are given have shown evidence of their effectiveness and safety, and are used properly, especially when used in combinations. However, while some of the more obvious approaches to address these issues appear simple, they will require adjustments in long-term care institutions that aren't always easy to make: the low-funding of these institutions and their usual medicalized orientation can interfere with person-based management.

For example, and based on some of the comments provided in the online survey, rather than (mis/over)use sleeping medications, consideration can be given to allowing residents to have variable sleeping hours. Similarly, incorporating daily social activities that include physical activities as well as those that offer a pleasurable alternative to sedentary isolation may reduce the need for daytime napping as well as offer the stimulation so many seek for their family members. Importantly, this may also obviate the need for – if not make unnecessary – anti-depression medications (4). As well, more rounded meal offerings with less use of processed, low-fibre food, might provide dietary constituents that would make laxatives unnecessary, improve cognitive function and make residents generally more alert (1).

We make these comments with the full understanding that change in the long-term care setting is not easily realized. In addition to funding issues, these institutions are complex social entities in which, as Avorn notes, “physicians, nurses, consultant pharmacists, other health care professionals, aides and administrators must interact to make decisions about drug use for patients who generally are frail and have numerous co-morbid conditions” (2).

In general, however, the comments from family members do suggest that in all cases of medication, those with decision-making roles need to be fully informed about what problem is to be treated, what all the appropriate alternatives for treatment (drug and other) are. They need to know how the choice will be made and, if a drug is to be used, what its adverse effects and effectiveness are. This will require much more research, since unfortunately, most drugs have been studied only one-at-a-time (and usually with only those under 70 years of age in the clinical trials) and so there is little if any evidence of their effectiveness in seniors in LT care; there are few data on the safety and effectiveness of multi-drug “cocktails.”

A recent U.S. report of the Inspector General examining use of psychotropic medication in nursing homes recommends to: “Explore alternative methods beyond survey and certification processes to promote compliance with Federal standards regarding unnecessary drug use in nursing homes.” (18) These recommendations would seem to be germane to Canada, too.

To facilitate this level of change, there will be need to review the roles and responsibilities of those providing care in LTC facilities to ensure they are appropriately trained, respectfully paid, and otherwise included when care plans are made for an individual. Hughes refers to

the need for change in the “organizational culture” in facilities for seniors (9). And data from our project tends to underscore this.

Furthermore, it will be important to involve families in ways that acknowledge the roles individuals want to and are able to play, with these varying with the gender, age, health, physical ability, economic privileges, and other dimensions that differ between them. Decisions about medication use and other health care interventions are one aspect of their role; they also act as advocates and provide social stimulation and personal care -- and meet other needs of LTC residents (6). The gendered nature of these roles – something that we weren’t able to analyze in itself because of limits in the data and the apparent lack of much heterogeneity in those responding to the online survey – is in particular need of attention, since most likely these will be women caring for older female relatives, with their roles and ability to carry them out differentially distributed. Of course, these issues need to be examined not only in themselves but also with regard to their impact on the well-being of LTC residents.

Finally, there also needs to be more directed research on the effects of multiple drugs in the elderly, with clinical trials directed toward this population and also towards effectiveness (“real world”) rather than efficacy (“ideal world”) outcomes.

## References

- (1) Arvanitakis, M. et al. "Nutrition in care homes and home care: How to implement adequate strategies (Report of the Brussels Forum 22-23 November 2007)". *Clinical Nutrition* Vol 27 No 4 August 2008, 481-488.
- (2) Avorn, J. and Gurwitz, J.. "Drug use in the nursing home". *Annals of Internal Medicine* Vol 123 No 3 August 1995. 195-204.
- (3) Ballard C, Creese B, Corbett A, Aarsland D.. "Atypical antipsychotics for the treatment of behavioral and psychological symptoms in dementia, with a particular focus on longer term outcomes and mortality". *Expert Opin Drug Saf* 2011; 10(1):35-43.
- (4) Blumenthal et al. "Effects of exercise training on older patients with major depression". *Archives of Internal Medicine* Vol 159, No 19, October 25, 1999.
- (5) Cohen-Mansfield, J. and S. Lipson. "Medical staff's decision-making process in the nursing home. *Journals of Gerontology Series A-Biological Sciences & Medical Sciences*, 2003. 58(3): p. 271-8.
- (6) Gaugler, J. E.. "Family involvement in residential long-term care: A synthesis and critical review." *Aging & Mental Health*, March 2005, vol 9(2), 105-118.
- (7) Hall-Lord, M.L., et al. "Family members' perceptions of pain and distress related to analgesics and psychotropic drugs, and quality of care of elderly nursing home residents". *Health & Social Care in the Community*, 2003. 11(3): p. 262-74.
- (8) High, D.M. and G.D. Rowles. "Nursing home residents, families, and decision making: Toward an understanding of progressive surrogacy". *Journal of Aging Studies*, 1995. 9(2): p. 101-117.
- (9) Hughes, Carmel, et al. "Does organisational culture influence prescribing in care homes for older people? A new direction for research". *Drugs Aging* Vol 24 No 2, 2007, 81-93.
- (10) Huybrechts KF, Rothman KJ, Silliman RA, Brookhart MA, Schneeweiss S.. "Risk of death and hospital admission for major medical events after initiation of psychotropic medications in older adults admitted to nursing homes". *Canadian Medical Association Journal* 2011; 183(7):E411-E419.
- (11) Levac, D., H. Colquhoun, and K.K. O'Brien. "Scoping studies: advancing the methodology". *Implementation Science*, 2010.

- (12) Moore, K. and B. Haralambous. "Barriers to reducing the use of restraints in residential elder care facilities". *Journal of Advanced Nursing*, 2007. 58(6): p. 532-540.
- (13) O'Connor, C.S. and B.P. O'Connor. "Reducing consumption of psychotropic medication in nursing homes: contextual obstacles and solutions". *Clinical Gerontologist*, 1999. 21(1): p. 21-35.
- (14) Rochon PA, Stukel TA, Bronskill SE, Gomes T, Sykora K, Wodchis WP et al. "Variation in nursing home antipsychotic prescribing rates". *Arch Intern Med* 2007; 167(7):676-683.
- (15) Schneider LS, Dagerman KS, Insel P.. "Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials". *JAMA* 2005; 294(15):1934-1943.
- (16) Statistics Canada. "Medication use among senior Canadians". *Statistics Canada Health Reports*, vol 20, no 1, March 2009
- (17) Stevenson DG, Decker SL, Dwyer LL, Huskamp HA, Grabowski DC, Metzger ED et al. "Antipsychotic and benzodiazepine use among nursing home residents: findings from the 2004 National Nursing Home Survey". *Am J Geriatr Psychiatry* 2010; 18(12):1078-1092.
- (18) U.S. Department of Health and Human Services, Office of the Inspector General. "Medicare atypical antipsychotic drug claims for nursing home residents". OEI-07-08-00150 , April 2011.

## Appendices

1. Summary of articles used in Scoping Study
2. Questionnaire (on-line survey)
3. Tables showing results of on-line survey

### **APPENDIX 1**

#### **Summary of the relevant articles identified in the scoping review**

- 1- Cohen-Mansfield, J and Lipson, S. (2003) Medical staff's decision-making process in the nursing home. *Journal of Gerontology*. 58(3), 271-278**

This article describes the medical decision-making process that occurs when nursing home residents experience an event that changes their medical status. The study involved 70 nursing home residents in a large suburban nursing home in the United States. Physicians and nurse practitioners completed questionnaires related to the status change event and the decision-making process, which included the involvement of family members in the process. The physicians surveyed claimed to be familiar or very familiar with family wishes in 51% of cases where a decision was made with respect to treatment of the resident. Treatment options that were considered in the study included medication, but also hospitalization, diagnostic testing and comfort care. From the physician's perspective, the family's wishes were one of the most important considerations in making treatment decisions, along with the resident's quality of life and the relative effectiveness/futility of the treatment options. For residents who were more cognitively impaired, physicians considered family wishes as more important to the decision-making process. As this article only presents the decision-making process from the perspective of the physician, the authors suggest further research to elucidate relatives' perspectives on the process and how it compares to the physician's perception.

- 2- Hall-Lord, ML, Johansson, I, Schmidt, I, Larsson, BW. (2003) Family members' perceptions of pain and distress related to analgesics and psychotropic drugs, and quality of care of elderly nursing home residents. *Health and Social Care in the Community*. 11(3), 262-274**

This article examines how family members' perceptions of nursing home residents' pain and distress relates to the residents' use of psychotropic drugs and analgesics. Participants in the study were 232 family members of elderly people in 10 Swedish nursing homes. Findings of the study suggest that many family members consider the help and support their relative receive for pain and distress to be insufficient. Furthermore, the prescription of analgesics and psychotropic drugs among residents often did not correspond with the family member's judgment as to whether the resident suffered from pain or worry. For example, 43% of the residents whose family members perceived as not experiencing any worry were prescribed psychotropic drugs. On the other hand, 11% of residents whom the family members perceived as worried had no psychotropic drugs prescribed. The study found that family members were not generally satisfied with the information provided to them and made the recommendation that family members should be provided with better information; however, what information is necessary and how the information could better be disseminated was not discussed.

**3- High, DM and Rowles GD. (1995) Nursing home residents, families, and decision-making: toward an understanding of progressive surrogacy. *Journal of Aging Studies*. 9(2), 101-117**

This study examines the involvement of various individuals in the process of making decisions about the treatment and health care of nursing home residents. This was an in-depth anthropological investigation that collected qualitative and quantitative information about the care of residents over the age of 75 in four nursing homes in the United States over a period of three years. With respect to decision making about the use of medications, the study found that family members were involved in 53% of the decisions made about their relative's treatment, which included primarily medication decisions, but also decisions about other kinds of health care and physical therapy. The study found no evidence that family members' involvement in decision-making declined with increasing length of stay of the resident family member. On the contrary, participation of family members in decision-making tended to remain high or increase during the first four years of stay in the nursing home. These results are encouraging in suggesting that family members are quite involved in decisions about treatment; however, involvement may be overestimated as it is probable that decisions that were reported to researchers may tend to be those that the family member remembers as a result of their involvement.

- 4- Moore K. And Haralambous B. (2007) "Barriers to reducing the use of restraints in residential elder care facilities". Journal of advanced nursing. 58(6), 532-40.**

This study compares perspectives of staff with those of residents and family members about the barriers for reducing the use of physical, chemical, and environmental restraints. Chemical restraint was defined as using psychotropic medication for discipline or convenience of staff. The authors used a qualitative approach and conducted their study in 3 elder care facilities in Melbourne, Australia. All parties perceived restraints as means of safety and prevention of physical harm. Most family members and residents relied on information provided by staff and trusted them in making decisions regarding restraints. For instance, family members were not bothered when they were not asked permission for using medication for aggressiveness; they felt that staff was working in the best interests of the resident and assumed that the doctors' permission was obtained before administering treatment. Family members and residents identified fewer barriers to reducing the use of restraints than staff members. Moreover, family members were not aware of most of the barriers that were described by the medical staff: lack of time, lack of continuity of care staff, lack of equipment, poor practices (poor monitoring and reviewing), inadequate follow-up for issued restraints, poor knowledge of alternative methods, and lack of resources for training in alternative methods. Some family members reported that they were not well informed on the safety and restraint devices available and that they were interested in learning more about other approaches and equipments that could potentially be safer. The authors found that most staff members also reported poor knowledge of alternative methods and limited resources for appropriate training in those alternatives; this consequently affected family members because they relied on staff to be provided with such information.

In general, family members were not found to be well informed about the need for and the different options of restraints. Their judgement of their relatives' safety and needs seemed to be highly dependent on the staff's perspective. They trusted the staff for information and decision-making. So, when the staff lacked knowledge and training in alternative methods, the family members were also ill informed about safer and more effective methods.

- 5- O'Connor C.S. and O'Connor B.P. (1999) "Reducing consumption of psychotropic medication in nursing homes: contextual obstacles and solutions". Clinical Gerontologist. 21 (1), 21-35.**

In this manuscript, the authors discuss strategies that they have implemented in one of the authors' practice to reduce the use of



psychotropic medication. They successfully reduced the consumption of psychotropic medication and attributed their successful outcomes to certain key tactics: communicating correct and engaging information to all the parties involved; clear communication between the different parties; and most importantly, “framing” the medication reduction strategy as a short-period and a case-by-case trial with clear reassessment dates and objectives. Even though the article was not focused on relatives’ perspective on the use of psychotropic medication in nursing homes, the authors described how their strategy was perceived by family members and noted the importance of the way information was shared with the families. Most family members were receptive to the strategy following the explications of the physician who reassured them that their relative is carefully followed and involved them in monitoring behavioural changes. The role of the nursing staff was crucial with regards to the family members’ perception of the project depending on whether their comments appeared concerned or negative (“I really don’t know why the Doctor stopped it”) or positive (“she did get some sleep, we’ve been keeping an eye on her”). One major element in dealing with the families was to correct some faulty assumptions about medication (e.g. stopping sleeping pills does not mean that their relative would not sleep); the authors also noted that some family members were told by physicians in the community that their relative would always need some type of medication. The concerns of family members were most effectively reduced by framing the project as a short-term health-enhancing test period based on careful monitoring. Family members were further reassured when they saw the physician present in the unit and checking up on their relatives and particularly when they, themselves, began to notice positive changes.

## **Appendix 2**

### **ON-LINE QUESTIONNAIRE: FAMILIES, MEDICATION AND LONG-TERM CARE FACILITIES**

**TITLE:** Family Perspectives on the Use of Medications in Residential Long-Term Care Facilities

**INVESTIGATORS:**

Anne Rochon Ford and Abby Lippman

**SPONSOR:**

National Network on Environments and Women's Health at York University, Toronto, and the Canadian Women's Health Network, Winnipeg.

Funding has been provided through the Women's Health Contribution Program of Health Canada

This information sheet is intended to give you a basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned here, or would like information not included here, please ask us ([nnewh1@yorku.ca](mailto:nnewh1@yorku.ca)).

### **BACKGROUND**

#### **WHAT IS THE PURPOSE OF THE STUDY?**

Medications are the most common treatment for many diseases and conditions seen in older people and persons with disabilities. Medicines now not only treat and cure diseases that were untreatable just a few years ago, they can sometimes modify diseases in their early stages; prevent life-threatening illnesses; relieve pain and suffering; and allow people with terminal illnesses to live more comfortably during their last days.

However, for older adults and people with disabilities, medications—both prescription and over-the-counter drugs - can also come with problems.

The purpose of this study is to better understand how key family members (such as adult children, spouses, partners, and others) are involved in the care of their relatives in long-term care facilities and whether they have a role in how prescription drugs are used by people in long-term care facilities. We hope that, over the long term, the information we gather from this survey will directly benefit families and seniors in long-term care

facilities by helping to positively influence policies within institutions and at the government level.

We are interested in

- family members' experiences of participation in how medication decisions are made, and
- their expectations about medication use.

We would like to explore who makes the decisions about medications and how they are made. We are interested in learning about

- what individuals know about the medications used for their family relatives in long-term care
- what they want to know about the medications and how and if they want to participate in decisions,
- what they are told about the medications.

In this study, we are specifically interested in psycho-pharmaceutical drugs. These are medications used to alter or improve a person's mood or treat, reduce, or remove behavioural problems. Some examples are anti-anxiety drugs (such as Xanax, Ativan, Valium); sleeping medications (such as Ambien, Lunesta); anti-psychotic drugs (such as Risperdal, Haldol, Seroquel); and anti-depressant drugs (such as Zoloft, Prozac, Paxil, Celexa).

#### **WHAT WOULD I HAVE TO DO IF I TAKE PART IN THIS SURVEY?**

We are asking you to respond online to a series of questions that address the issues outlined above. It should take about 15 to 20 minutes to complete this survey. All responses are collected anonymously and you will not be asked to provide your name on the survey. However, if after completing the survey, you would like to provide further information in a follow-up telephone interview, you will need to provide your name so we can contact you.

Participation in this study is completely voluntary and you may choose to stop participating at any time. Choosing not to participate, choosing not to answer any particular questions or lack of completion of the survey will not affect your relationship with the researchers, York University or any other group associated with this research study.

#### **WHAT HAPPENS WITH THE RESPONSES TO THIS SURVEY?**

The survey is anonymous. Your name is not attached to any data collected and the study researchers will not be able to identify any individuals who take part.

- The responses to questions will be coded so that they are not associated with any individual.
- Information that is supplied in the survey will be held in confidence and the participant's name will not appear in any report or publication of the research.
- In all situations, confidentiality will be provided to the fullest extent possible by law.
- The data will only be analyzed and reported in the form of total numbers and percentages (aggregated form). That means individual responses will not be included in any reports.
- Only group (aggregated) data will be included in any reports to government agencies, funding agencies, or scientific groups and in any published results.
- The survey is prepared using software known as "Survey Monkey" which uses SSL-encryption to protect information as it is sent. Only the researchers will have access to the anonymous data on the Survey Monkey site.
- Data from this survey will be securely stored in locked cabinets in the offices of the research team at York University and will only be accessible to them. Files will be shredded after 7 years.

Results from the survey will be made available through our websites <[www.whp.apsf.ca](http://www.whp.apsf.ca) and [www.nnewh.org](http://www.nnewh.org)> at a future date when all information has been collated and summarized.

If you have any questions about the survey, please call Anne Rochon Ford, principal investigator on the study, at 416-736-2100, ext 20713 or by e-mail at [annerf@yorku.ca](mailto:annerf@yorku.ca).

If you have an interest in talking with us further about your responses, please feel free to contact us at: 416-736-2100, ext 20715 or by e-mail at [nnewh1@yorku.ca](mailto:nnewh1@yorku.ca).

Please note that the online survey is hosted by Survey Monkey which is a web survey company located in the USA. For information about the security and privacy policy for Survey Monkey, go to: <http://www.surveymonkey.com/>

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for

the Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail [ore@yorku.ca](mailto:ore@yorku.ca)).

If you want to continue, please go to .... We hope you will answer all the questions, but you are free to skip any that you prefer not to answer.

### **SURVEY QUESTIONS:**

We are interested in your responses to questions about your experiences with a relative who is currently living in a Canadian residential long-term care facility . “Long-term care facility” is a term used for a range of facilities that are funded by government, and are primarily for seniors with significant physical conditions or mental conditions such as dementia .

Long term care facilities have different names in different provinces and include: *nursing homes, personal care homes (Manitoba), complex care facilities, long-term care homes, auxiliary hospitals, and homes for the aged*. In general, these are facilities of various sizes that have available around the clock care. The caregivers may include nurses, personal service workers (PSWs), residential care aides, etc.. These do not include: retirement homes where residents have only minimal medical needs or services, or psychiatric institutions.

**Please note that we are interested in responses from those individuals whose relatives are CURRENTLY in a long-term care facility or, if the relative has recently died, WAS IN ONE WITHIN THE LAST 12 MONTHS.**

#### **A. YOUR RELATIONSHIP TO THE RELATIVE IN A LONG-TERM CARE FACILITY**

**IF YOU HAVE MORE THAN ONE FAMILY MEMBER IN A LONG-TERM CARE FACILITY, PLEASE CHOOSE TO ANSWER ALL THE FOLLOWING QUESTIONS FOR ONLY ONE MEMBER.**

**(PLEASE NOTE:** Throughout the questionnaire we will refer to this person as “your family member” or “your relative”.)

1. What is your relationship to your relative who is living in the long-term care facility?

My relative in the facility is

My mother

My father

My husband (married or common-law) or partner

My wife (married or common-law)

My sibling  
My mother-in-law  
My father-in-law  
My aunt  
My uncle  
My grandmother  
My grandfather  
Other \_\_\_\_\_

2. My family member is  
Female  
Male

3. The age of my relative in long-term care is now:  
under 50  
50-59  
60-69  
70-79  
80-89  
over 90

4. My family member has been in the long-term care facility for:  
Under 6 months  
6 to 12 months  
1 to 3 yrs  
3 to 5 yrs  
More than 5 years

5. The main medical reason(s) my relative is in the facility is (check as many as apply):  
Cognitive problem (e.g. Alzheimer's, dementia, etc.)  
Difficulty with mobility  
Difficulty seeing or hearing  
Other chronic physical health condition  
(Specify: \_\_\_\_\_)  
Other mental health problems  
(Specify: \_\_\_\_\_)  
Other:  
\_\_\_\_\_  
\_\_\_\_\_

6. The general health of this relative is:  
  
Excellent

Very good  
Good  
Fair  
Poor  
Very poor

**B. FACILITY**

1. The type of facility my relative is in (or was in) is called (e.g. long-term care facility, nursing home, etc):

---

Not sure

2. The facility is part of a hospital

Yes  
No  
Not sure

**C. GEOGRAPHY**

1. This facility is in (Check as many as apply)

Drop-down list of provinces

A large urban centre  
A small city  
A rural part of Canada  
A remote or northern part of Canada

**D. FACILITY FUNDING**

1. This facility is

Government -owned (also called “public”, where health care costs are paid by government, although additional fees are usually charged for the room, etc.)

For profit (private pay)

A combination of public and private

Other \_\_\_\_\_

Not sure

**E. DECISION-MAKING AUTHORITY + MEDICATION ISSUES**

1. Are you making decisions for your family member because they were assessed to be incapable of doing so themselves?

Yes  
No  
Not sure

2. If this is the case, have they been formally assessed as being incapable to make their own decisions?

Yes  
No  
Not sure

3. If so, by whom:

Doctor  
Nurse  
RPN

Other: \_\_\_\_\_

4. At the time of admission, was your relative asked to sign a consent form for medical treatment?

Yes  
No  
Not sure

5. If they signed such a form, did they specifically mention the use of medications? (both kinds and amounts)

Yes  
No  
Not sure

6. Were YOU (or someone else close to your family member) asked to sign such a form at the time of admission?

Yes  
No  
Not sure

If you answered "yes" to the above question, please provide any details you may recall about the form that you signed (name of form, questions asked, assistance in filling it out, explanations offered)

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7. Long-term care facilities are required to have care plans describing such thing as your family member's routines, assistance they need, medications they use, other treatment plans, etc.). Has the facility reviewed the care plan they have for your family member with you or someone else in your family?

Yes, on a regular basis  
If so, how often \_\_\_\_\_  
Yes, but only when there's a major change in care  
No



Not sure

***In the following questions we want to know more about informed consent with respect to medications. Informed consent includes being given information about the treatment, including side-effects, benefits, etc., as well as having questions answered.***

8. Have you ever been asked by a member of the staff (nursing, medical, other) for your opinion or thoughts about a medication that was being proposed for your relative whether this was to begin, end, or change some medication?)

Yes - to begin a new medication (If so, what was the medication?

\_\_\_\_\_)

Yes – to end a medication (If so, what was the medication?

\_\_\_\_\_)

Yes – to change a medication (If so, what was the medication?

\_\_\_\_\_)

No

Not sure

Comments:

\_\_\_\_\_

9. Have you ever been asked by a member of the staff (nursing, medical, other) for your permission regarding a medication that was being proposed for your relative whether this was to begin, end, or change some medication?)

Yes - to begin a new medication (If so, what was the medication?

\_\_\_\_\_)

Yes – to end a medication (If so, what was the medication?

\_\_\_\_\_)

Yes – to change a medication (If so, what was the medication?

\_\_\_\_\_)

No

Not sure

10. If your relative is capable of providing his or her own consent to treatment, do you know if they are asked for informed consent when a new medication is being prescribed or a medication is being changed?

Yes

No

Not sure

Please provide details

---

11. If you are the substitute decision-maker for your relative's care (such as with Power of Attorney), do you know if medication has ever been given to them without your consent?

Yes

Please provide details (medication, reason for giving, etc.)

---

No

Not sure

12. Have you ever thought/felt there was a problem associated with your relative's use of some medication? (e.g. they seemed to be getting not enough; too much; there were side effects; they seemed to be getting something not necessary; etc.)

Yes

Please provide details

---

No

Not sure

13. If you thought/felt there was some problem related to medication, what did you do? (check all that apply)

Spoke to staff soon after (nurse, doctor, other facility personnel)

Got an outside opinion (e.g. an outside health professional, Alzheimer's Society, family member, consulted the internet, etc) and then spoke to staff

Wrote a letter of complaint to the management of the facility

Complained to the health professional's governing body (e.g. College of Nurses/Physicians)

Complained to a government office

Discussed it with other relatives or friends

Did nothing

Please provide details

---

14. If you had a concern about a medication currently being prescribed to your family member in the facility, was there someone to whom you could take your concerns ?

Yes

No

Not applicable

15. If yes, to whom:

Family Council

Patient Ombudsman

Patient Advocate

Other:

---

—

16. If you followed up with staff, did they: (check all that apply)

Deal with your concern immediately to your satisfaction

Deal with it immediately, but not to your satisfaction

Deal with it to your satisfaction but not right away

Pass responsibility on to someone else

Ignore your concern

Other

Please provide details \_\_\_\_\_

17. If you followed up with someone in the facility, was this person easy to reach? ( by phone, in person, by e-mail)

---

18. Are there any changes in long-term care facilities that you think would improve the quality of life for people living there? (Please check as many as you feel apply)

More staff

More skilled staff

Better programmes for residents

Less medication

More medication

More cheerful setting/facilities

Better family access to those who make decisions

Other: \_\_\_\_\_

19. Overall, do you consider your participation in decisions about medication use by your relative in a long-term care facility to be:

Satisfactory

Unsatisfactory

Not sure

Please explain

---

20. Is there anything else you'd like to tell us about your experience with your family member in a long-term care facility for which we have not provided a question?
- 
- 

### **DEMOGRAPHIC INFORMATION**

Please tell us a bit about yourself.

1. Age

Under 30

30-39

40-49

50-59

60-69

70-79

over 80

2. Sex

Female

Male

3. I live in: (Please check as many as apply)

Drop-down list of provinces

A large urban centre

A small city

A rural part of Canada

A remote or northern part of Canada

THANK YOU!

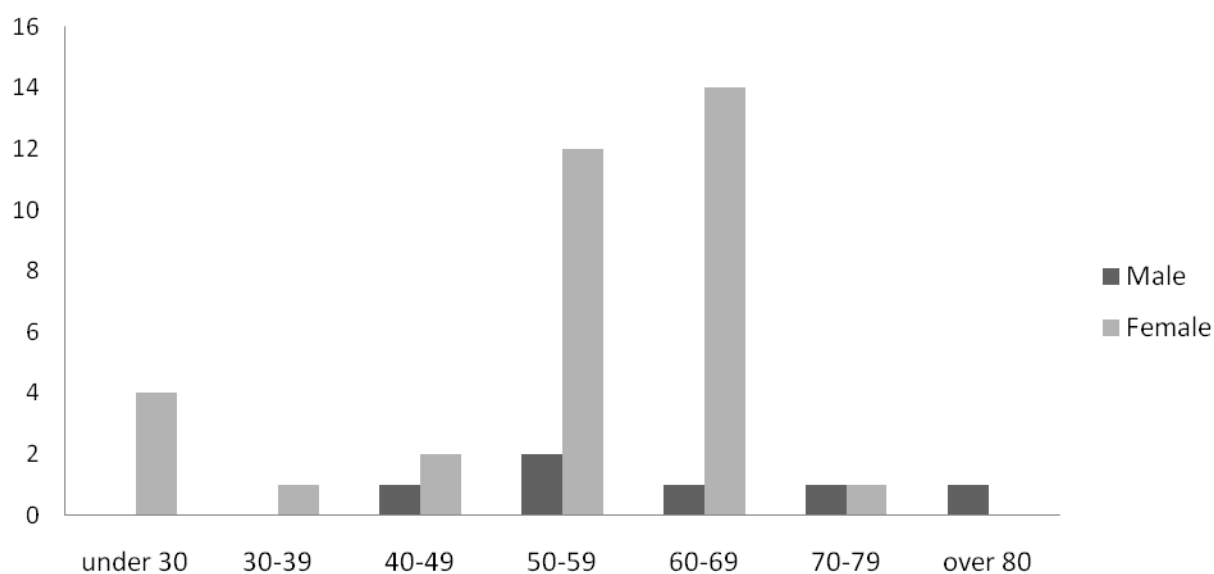
Jan 17/11

## Appendix 3

### Select Tables from Online Survey

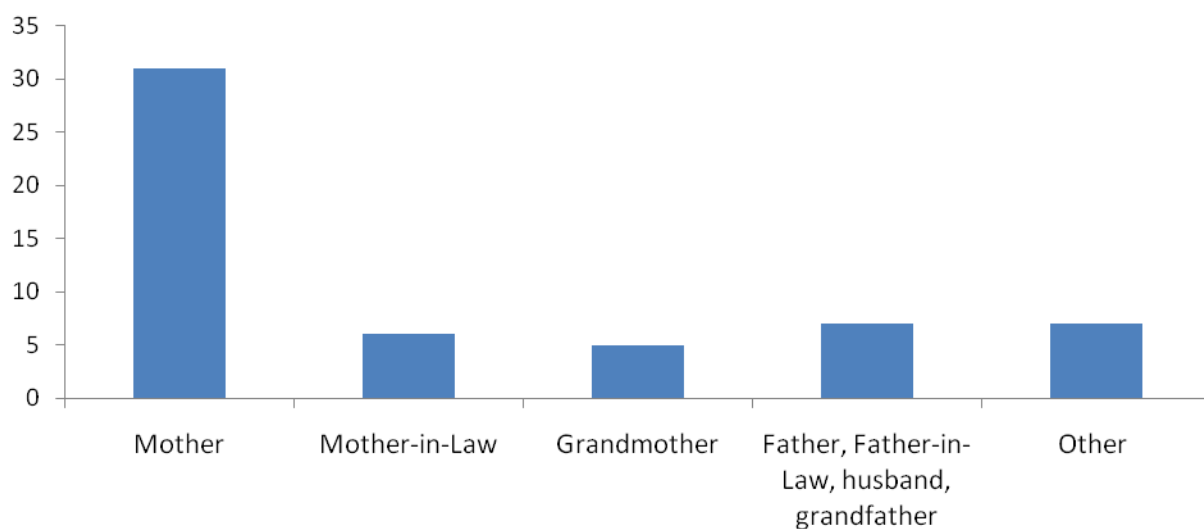
Percentages and numbers are based on those who responded to the questions. Non-respondents were not included in the totals.

**Table 1: Respondents by Sex and Age (n=40)**



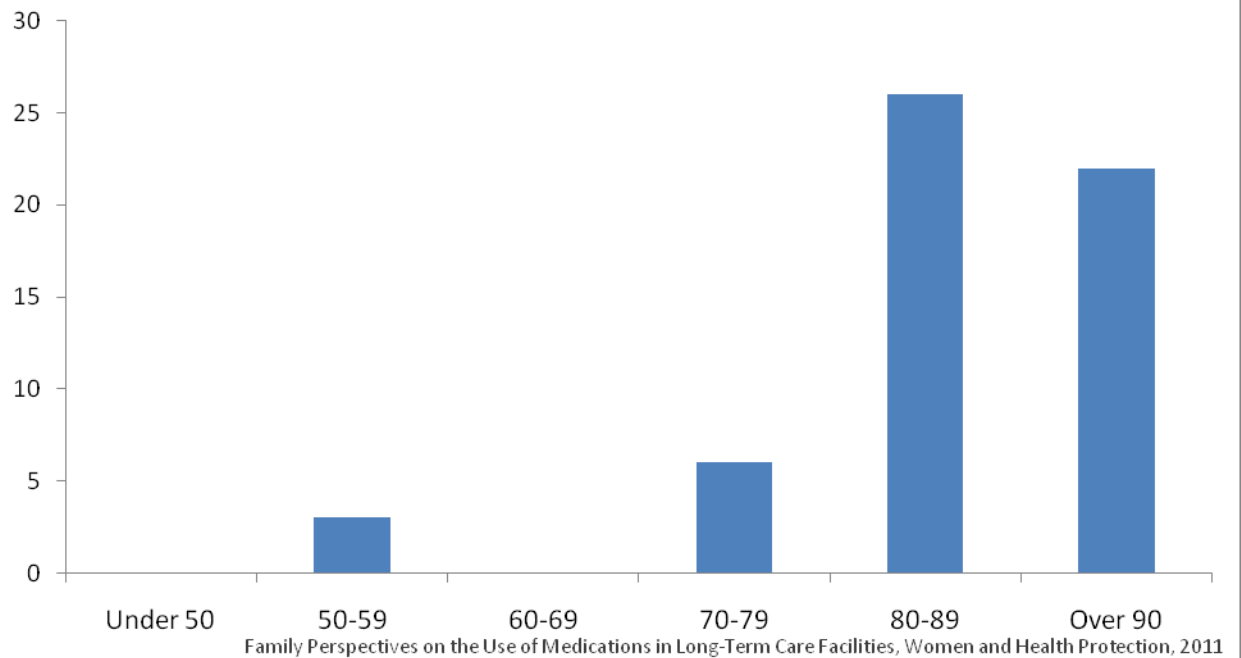
Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 2: Family Members in Care (n=56)**

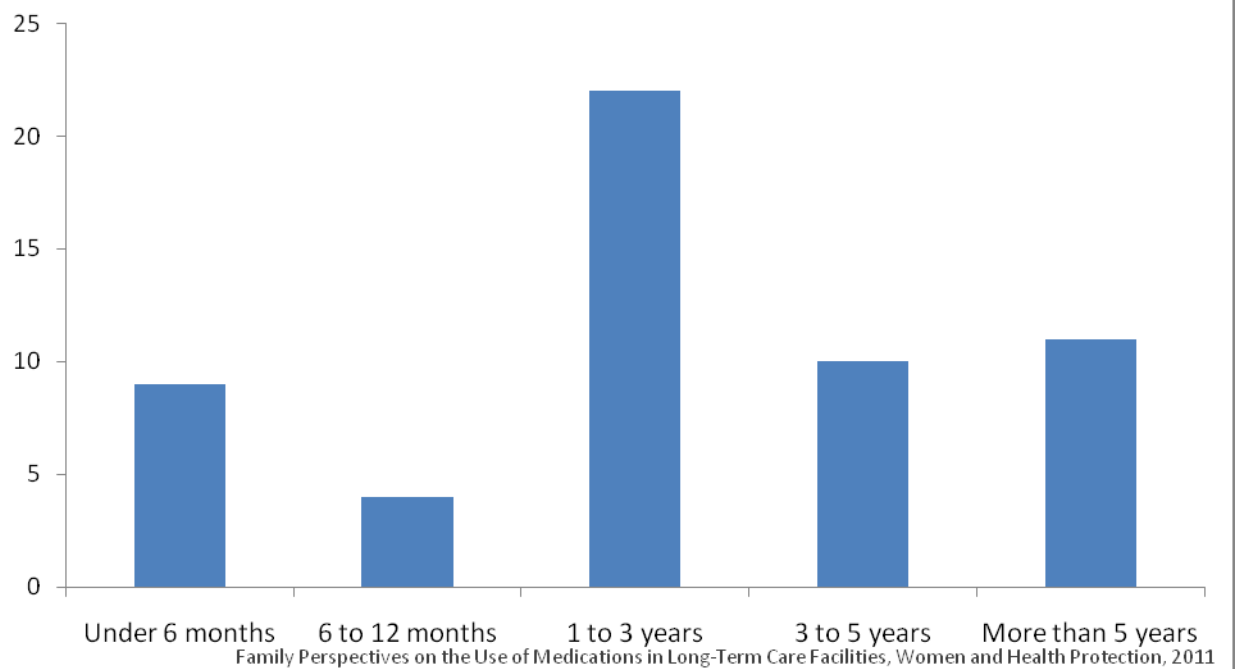


Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

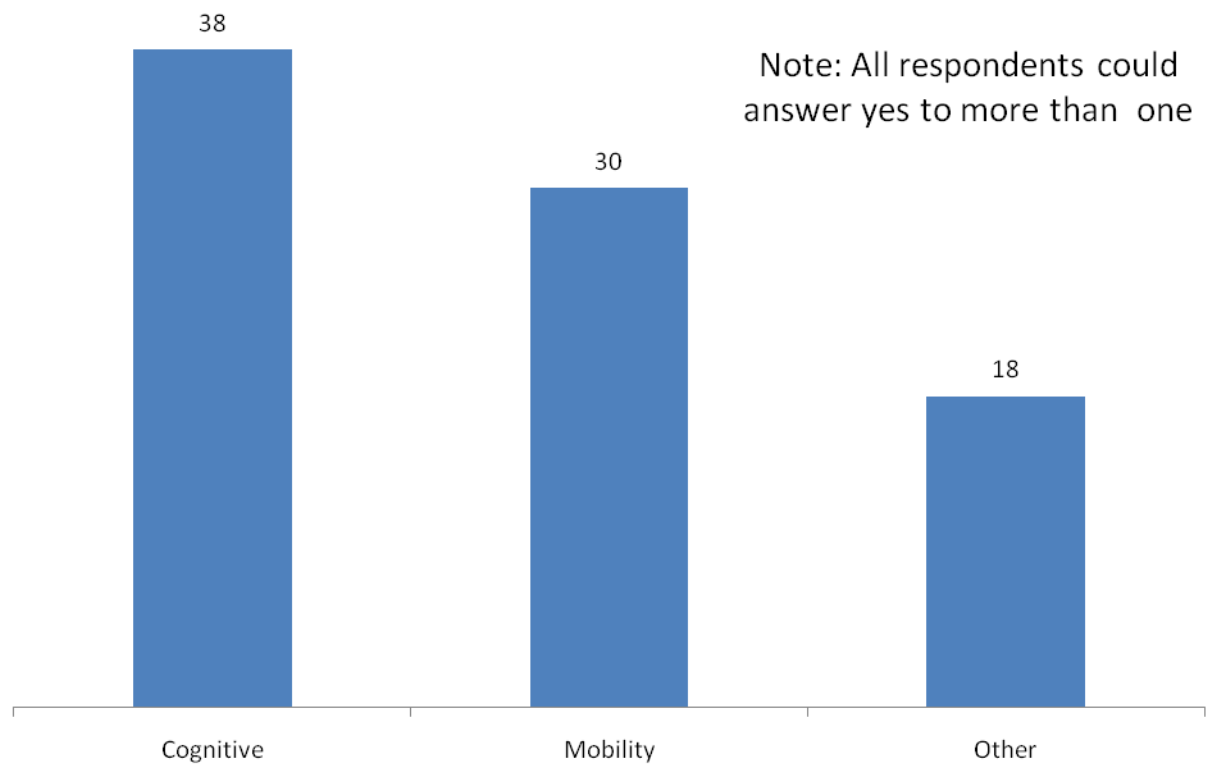
**Table 3: Age of Family Member in Care (n=57)**



**Table 4: Duration of Stay of Family Member in Care (n=56)**

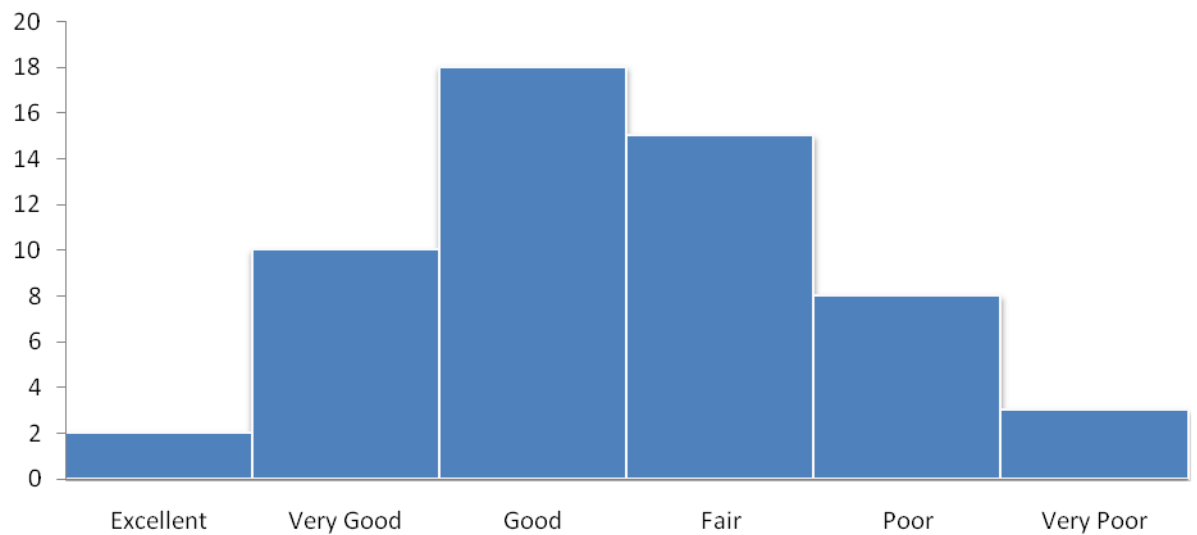


**Table 5: Medical Reason for Stay (n=57)**



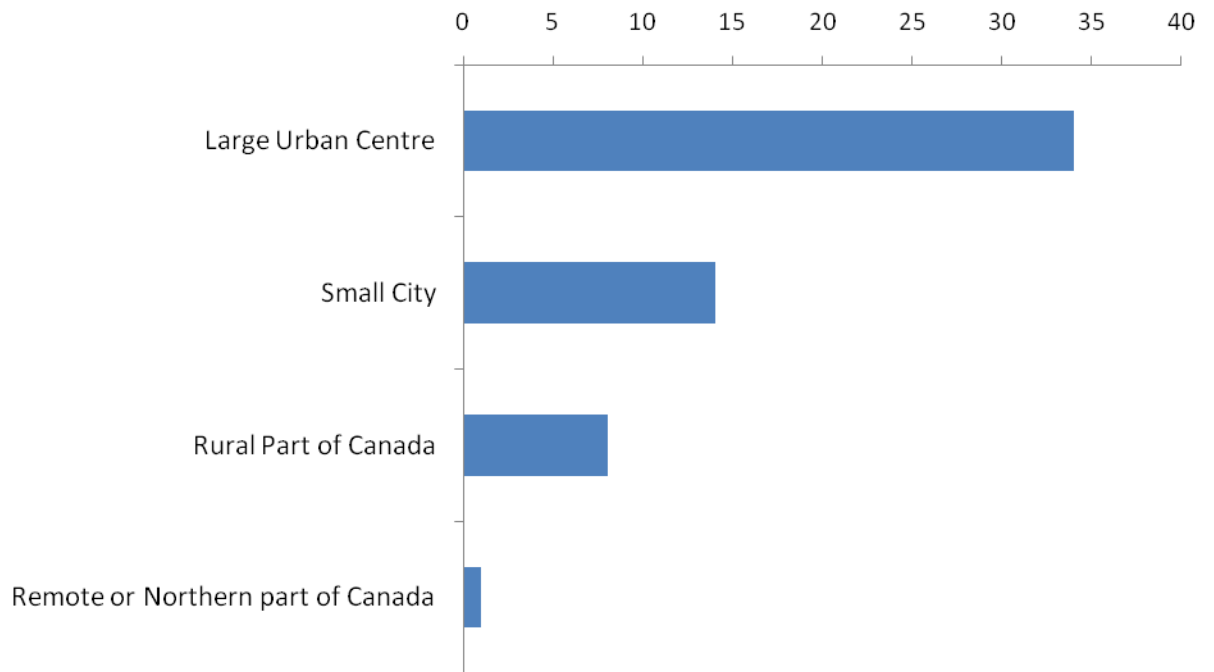
Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 6: General State of Health of the Family Member In Care (n=56)**



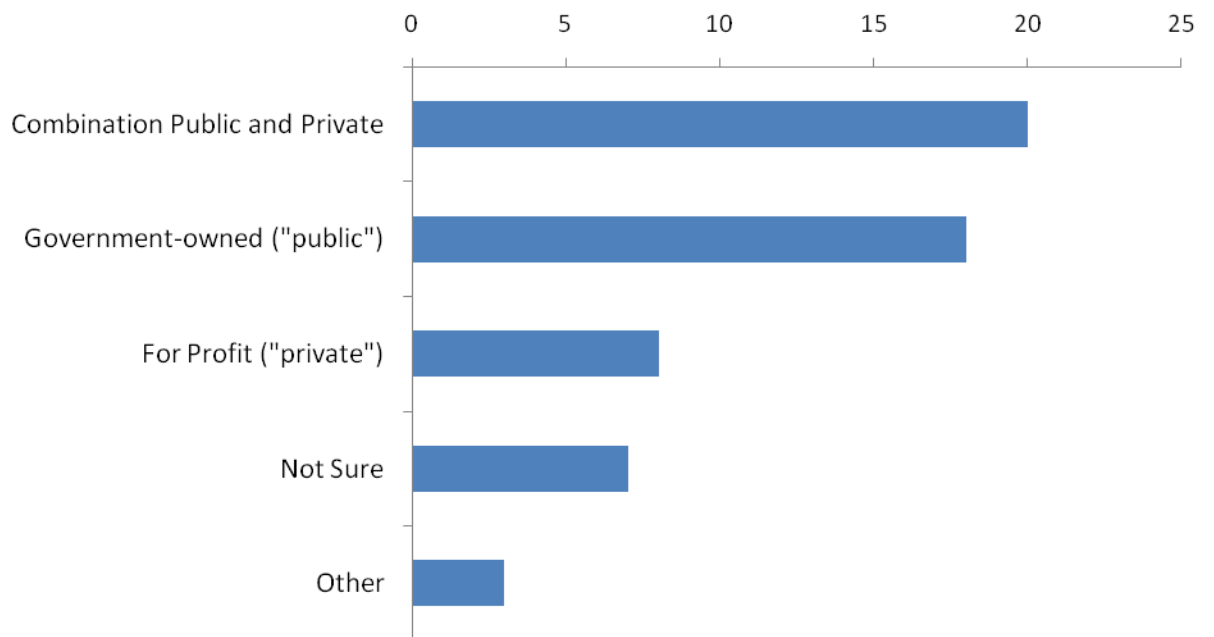
Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 7: Location of the Facility (n=57)**



Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

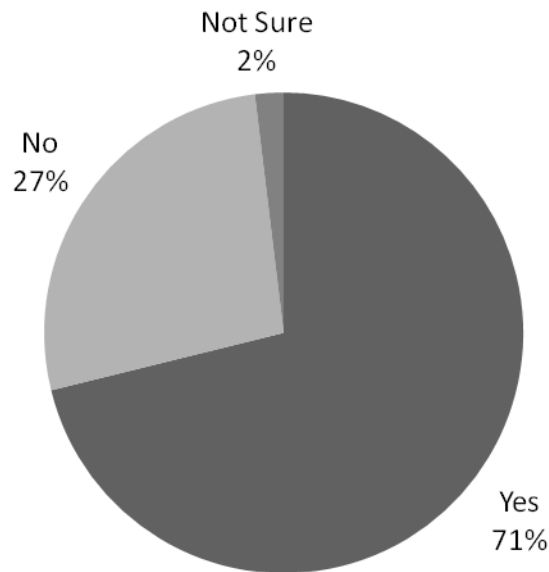
**Table 8: Type of Management of Facility (n=56)**



Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

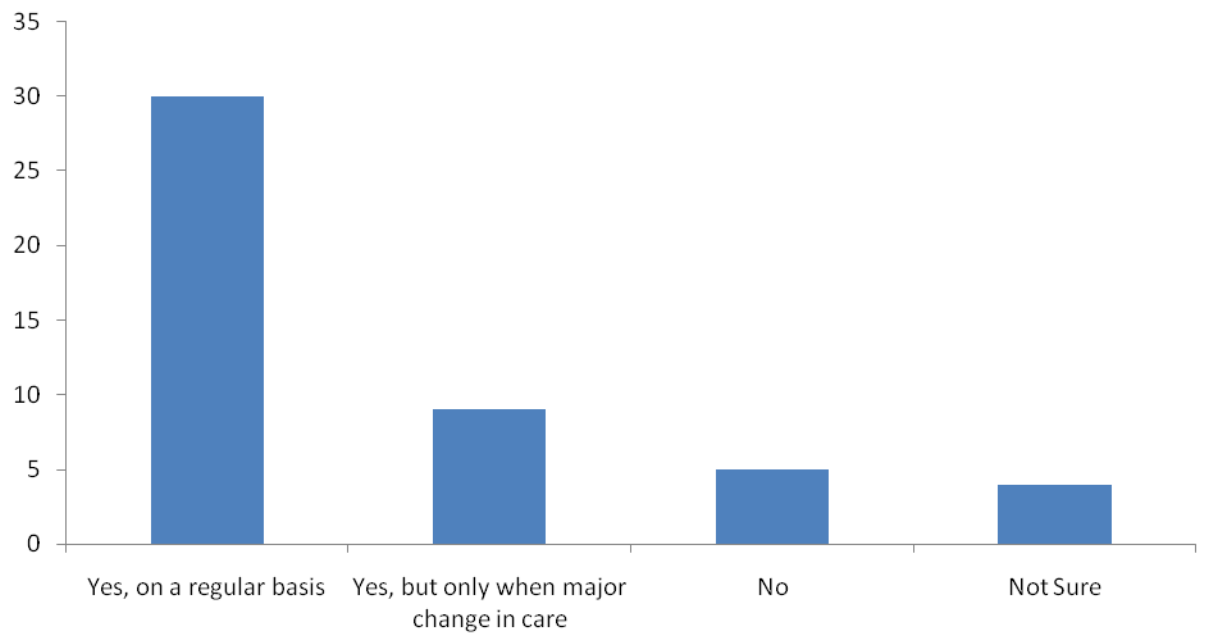


**Table 9: Respondent has Decision-Making Power for Family Member (n=52)**



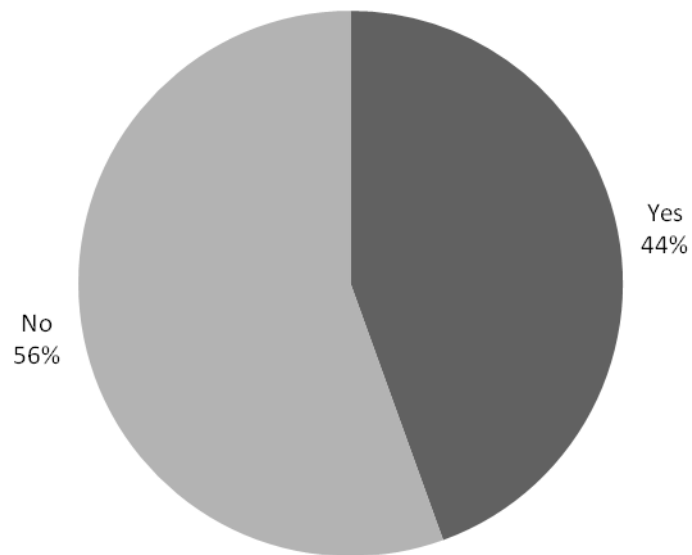
Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 10: Care Plans Reviewed on a Regular Basis (n=48)**



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**Table 11: Respondent Was Consulted by Staff Regarding Some Medication Issue (n=44)**

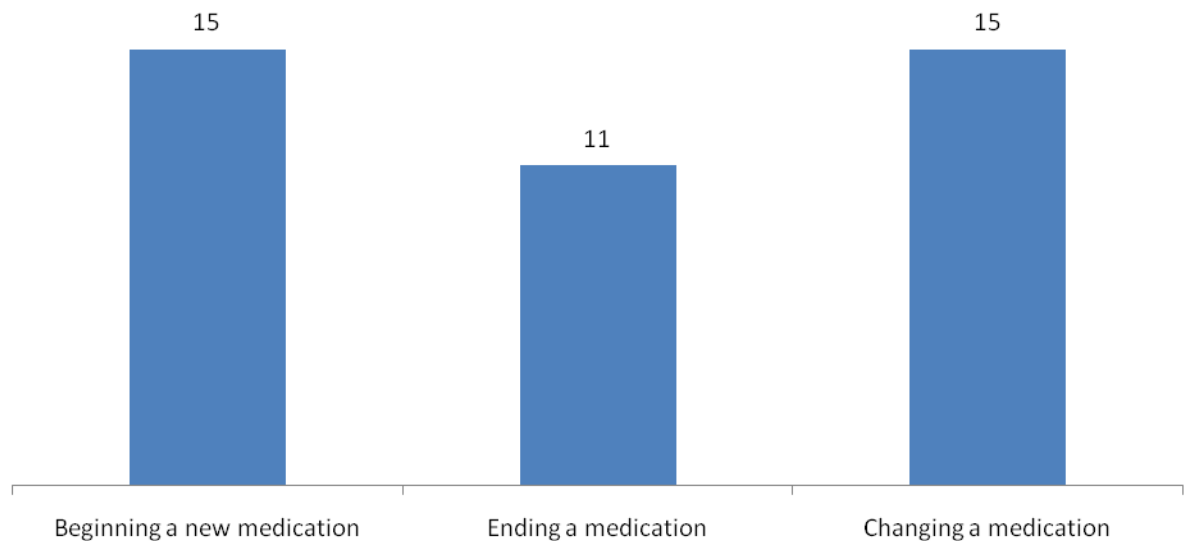


Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 12: Nature of Consultation Regarding Medication Use (n=19)**

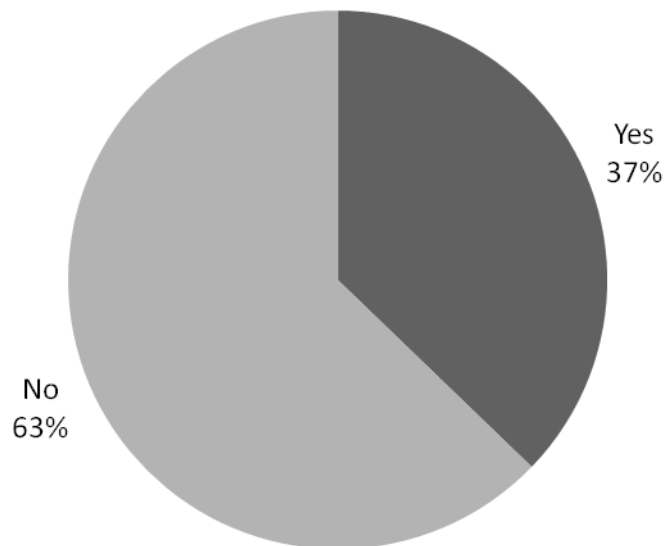
Note: Of those who answered "yes" in Table 11

Note: There could be more than one reason for consultation



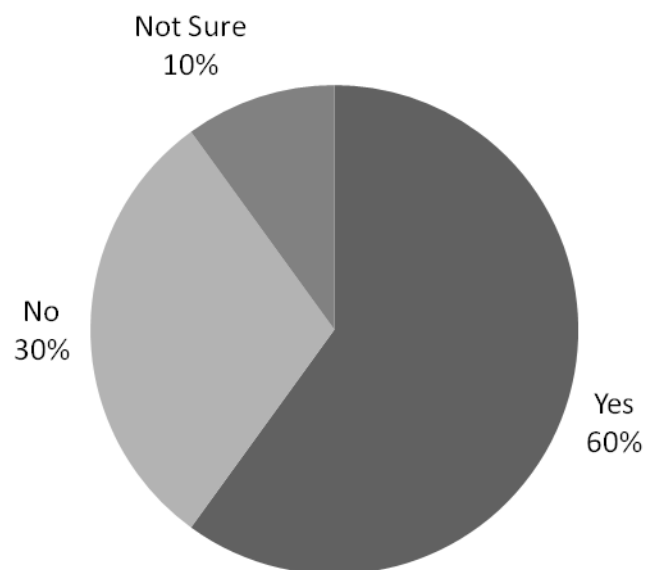
Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 13: Permission Was Requested of Respondent Regarding a Medication (n=43)**



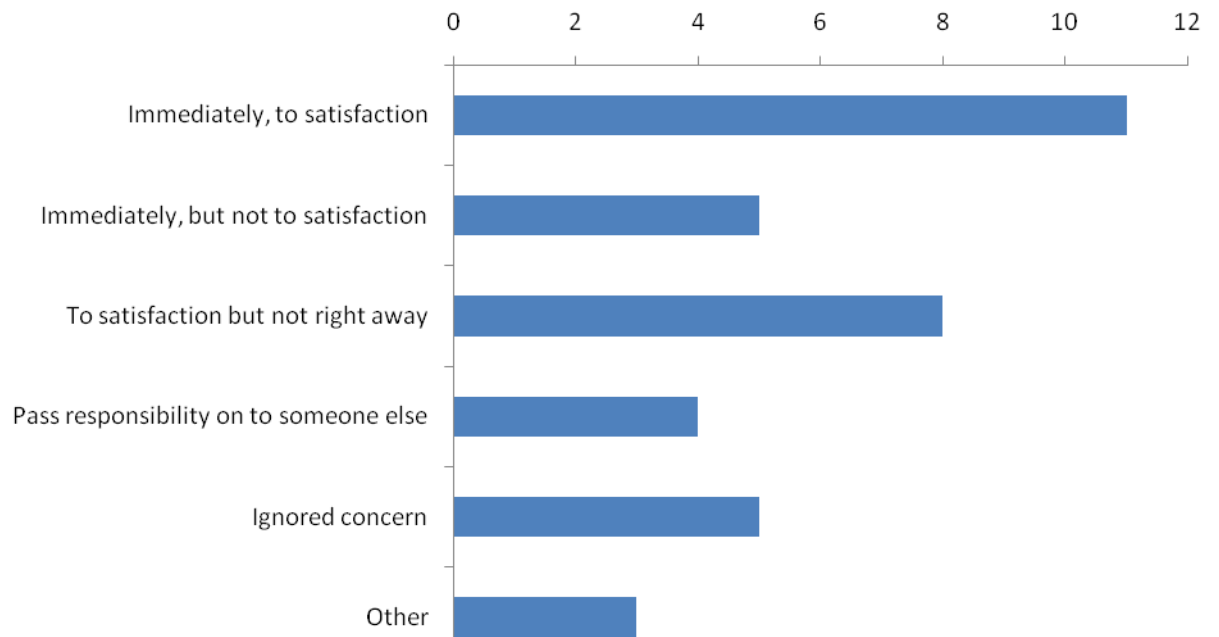
Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 14: Perception of Problem Relating to Medication Issue (n=40)**



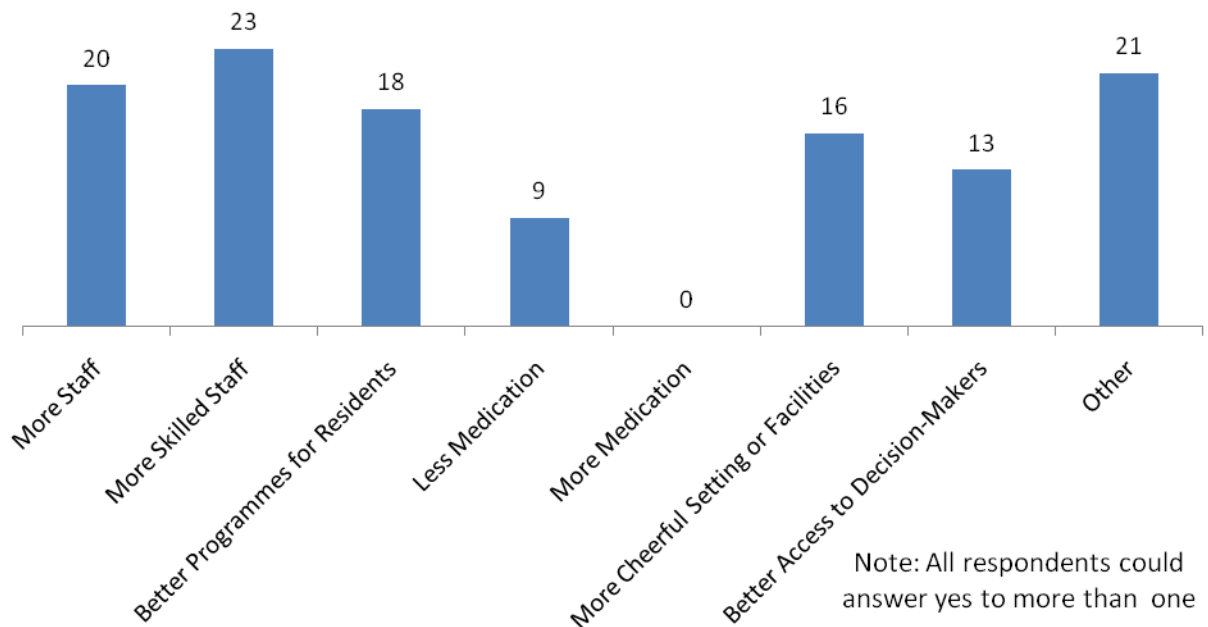
Family Perspectives on the Use of Medications in Long-Term Care Facilities, Women and Health Protection, 2011

**Table 15: How Problem Was Dealt With (n=32)**



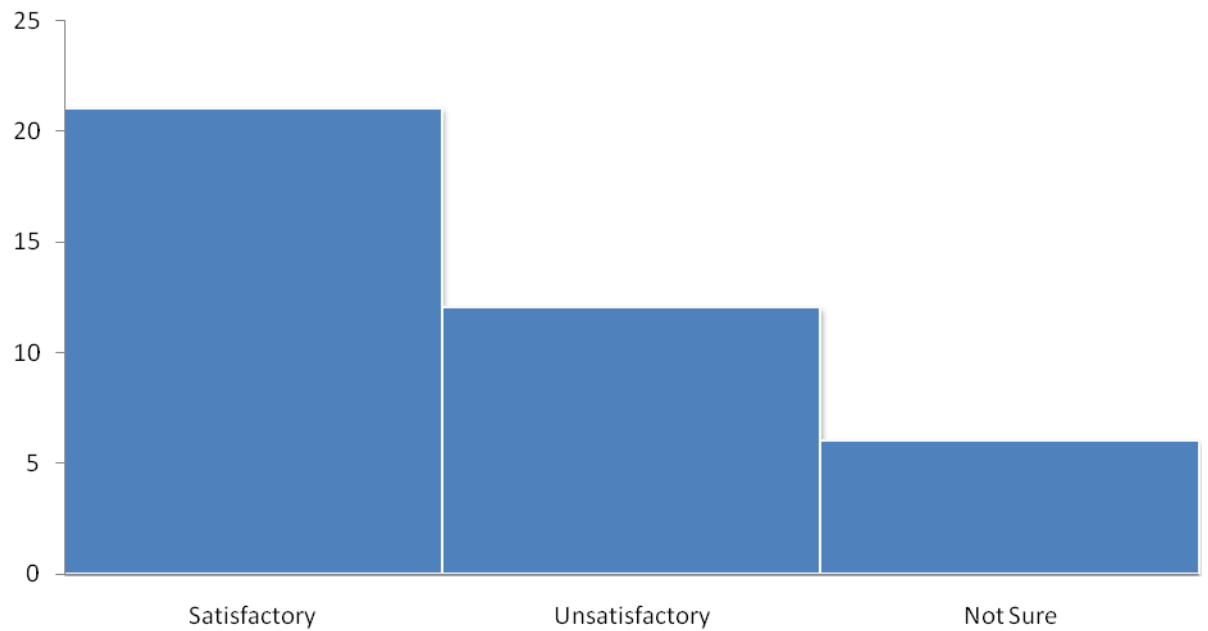
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**Table 16: Changes Needed in Long-Term Care (n=40)**



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**Table 17: Overall Satisfaction With Decision-Making Regarding Medication (n=39)**



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