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COMMISSION DU DROIT DE L'ONTARIO

# **UNDERSTANDING THE LIVED EXPERIENCE OF INDIVIDUALS, CAREGIVERS AND FAMILIES TOUCHED BY FRAILTY, CHRONIC ILLNESS AND DEMENTIA IN ONTARIO**

## **Improving the Last Stages of Life**

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## EXECUTIVE SUMMARY

Care in the last stages of life is an urgent societal issue with impact on an increasing number of Canadians. The aging of the population ensures that a growing number of Canadians will be living longer with chronic illness and many will be affected by end-of-life concerns, whether as patient, family member or provider. When considering economic and health policies regarding end-of-life care, what is often missing are the voices of the individuals, family members and professionals with lived experiences of the system. The purpose of this research was to listen to, understand and integrate the perspectives of individuals aged 65 and older struggling with end-of-life complexities, their key family caregivers and supports. Frailty was the common denominator linking those surveyed, as the aim was to explore the experiences and care needs of individuals defined by increasing frailty rather than closeness to death. Patients and caregivers interviewed came from diverse backgrounds with regards to patients' health conditions, socioeconomic status, culture and geographic location. Their own narratives, which touched upon a wide range of issues, were captured so that the individual voices of patients and caregivers could be heard. By interviewing a diverse group of patients and caregivers, we heard from "the source" about their needs and the barriers and supports they have encountered while attempting to navigate Ontario's system during the last stages of their lives.

To better understand the perspectives of those working within the system and how changes may be incorporated into the existing systems, a multi-stakeholder approach was adopted. Consultation and input were sought from a group of informed and interested stakeholders from the fields of medicine, ethics, law and public policy working in the system.

The research was undertaken in a two-stage, multi-perspective qualitative model using the "Appreciative Inquiry Approach". This form of action research begins by identifying where opportunities lie, and can be connected and used to motivate a path and vision for change. Within this research framework, the first stage of the research consisted of obtaining an in-depth understanding of the personal experience, needs and perceptions of patients and caregivers with regards to the system of care in the last stages of life. The second stage involved interviews with an expert advisory panel of stakeholders from different professional fields. Each stakeholder was presented with the summary findings from the first stage and asked to provide specific commentary and recommendations for changes that respond to and may improve the end-of-life experiences of the representative patients and caregivers.

The perceptions and wisdom of patients, family caregivers and professionals were integrated and a number of key themes regarding optimization of care for frail elderly patients and their caregivers towards the end-of-life emerged:

1. Communication between professionals, particularly physicians, and frail elders and caregivers was a central concern of all those who took part. When dreaming of a more effective system, patients and caregivers emphasized the critical importance of effective communication of diagnosis and prognosis, as well as clear understanding of the illness and what to expect. However, equally clear was the common failure of this communication process;
2. Patients and caregivers perceive the system of care to be fragmented and uncoordinated. Problems with navigation of the system, particularly at moments of crisis or transitions of care, were highlighted. This is in line with clinical experience. Stakeholders also recognized this fragmentation and expressed moral distress at the inadequacy of the system in which they work. The wish for interaction and coordination between the patients, families, health care providers and the legal profession was also dreamt of by all involved;
3. The system of care for the frail and particularly demented elder in the community was not always equitable or equally accessible by all despite efforts to make it so. Numerous factors were found to affect equity of health care delivery including socioeconomic status, gender, culture and race and geographic location;
4. While autonomy and independence are highly valued elements in medical care, the presence of dementia impairs the ability of the patients themselves to participate fully in decision-making. Consequently, while individual autonomy is a key ethical norm in health care decision-making, considerations of decision-making in this population must integrate the substitute decision-makers into the practical and ethical process of decision-making;
5. Palliative care emerged commonly as a focus of discussion amongst stakeholders, patients and caregivers. This issue is more complex in dementia. Most individuals living in the community with dementia are not in the terminal stages of illness and palliative care is not indicated. When those suffering dementia become severely ill and near the end of their life, palliative care approaches appear to be appropriate but are not always accessible. Ensuring equitable access to supportive models of care that reflect the needs of frail individuals and their caregivers is paramount;
6. Advanced planning for end-of-life care is essential but, in the majority of cases, a discussion of this planning did not occur. Stakeholders were aware of the legal issues associated with the caregiving role and matters of assignment of powers of attorney, wills and capacity, and substitute decision-making.

However, caregivers and patients themselves did not seem very concerned about these matters nor were they highly knowledgeable about them. There was very little mention of legal matters by patients and caregivers. Caregivers appeared to be guided by their own values and beliefs, rather than formal legal guidelines;

7. While often characterized as looking after a "loved one", caregiving in late life is characterized by much more complex emotions including feelings of being cheated, intense feelings of isolation and dislocation from the normal stream of life, depression and hopelessness, sense of loss and role transformation. Caregivers are highly vulnerable to psychological and medical burdens directly associated with the stress of caregiving. Consequently, when considering system requirements for care of elders with significant frailty and dementia in the last stage of life, recognition and attention to the needs of informal caregivers is critical.

Numerous reports have been produced examining end-of-life care and the need for improved care at this stage of life.<sup>1</sup> These reports drew on population-based statistics such as health utilization data or findings from opinion surveys. The current study is notable in hearing from patients, family caregivers and stakeholders in their own words about their experiences in dealing with end-of-life issues and their creative ideas as to how to address the emotional, practical and legal complexities associated with the last stages of life.

The focus was on generating evidence regarding the needs and wishes of patients, caregivers and stakeholders about care at the end of life to promote informed dialogue on appropriate changes to consider within (and across) the health, social and legal systems in Ontario. This innovative project provides valuable insight into the lived experiences of those engaged in end-of-life care and serves as a prompt for further discussions on this topic. There is now the opportunity to translate this experience and knowledge into action that can impact public policy and positively influence the social, legal and economic fabric of Canadian society.

## TABLE OF CONTENTS

<b>I. INTRODUCTION .....</b>	<b>1</b>
A. Purpose of Research .....	1
B. Scope of Research .....	1
C. Rationale of Research .....	1
D. Research Questions .....	2
<b>II. LITERATURE REVIEW .....</b>	<b>3</b>
A. Aging, Frailty and Chronic Illness .....	3
1. Models of Frailty.....	4
2. Frailty, Chronic Diseases and Death in Older Persons .....	4
3. Prognostic Implications of Clinical Frailty.....	5
4. Rockwood Canadian Study of Health and Aging Frailty Index and Clinical Frailty Scale .....	6
5. Ontario Statistics on Frailty, Dementia and Chronic illness.....	7
6. Direct Costs of Frailty .....	9
7. Indirect Costs of Frailty, Chronic Diseases and Dementia .....	10
B. Communication between Physician and Patients, Caregivers and Families Touched by Frailty, Chronic Illness and Dementia .....	11
1. Physician Factors .....	12
2. Patient and Caregiver Factors .....	14
3. Summary .....	16
C. Access to Health Care for Vulnerable Populations in Ontario in the Last Stages of Life.....	16
1. What Shapes the Health Equity Framework?.....	17
2. Health Equity Framework.....	19
3. Vulnerable Populations in Ontario and Access to Health Care Services in the Last Stages of Life .....	20
4. Access to Home Care Services at the Last Stages of Life .....	21
5. Initiatives to Address Health Inequities and Disparities at Last Stages of Life in Ontario .....	22
D. Last Stages of Life and Caregiving .....	24
1. Specific Areas of Need.....	26
2. Indicators of Quality of Care.....	28

E. Current State of the “System” and Identified Gaps .....	29
1. Identified Gaps .....	30
F. Conclusion .....	30
<b>III. THE LIVED EXPERIENCES OF PATIENTS AND CAREGIVERS IN ONTARIO AND EXPERT STAKEHOLDERS’ RESPONSES TO THEIR LIVED EXPERIENCES: A QUALITATIVE STUDY .....</b>	<b>32</b>
A. Introduction .....	32
B. Conceptual Framework and Methodological Approach .....	32
1. Study Population .....	33
2. Data Collection and Management.....	34
3. Data Analysis .....	34
4. Research Ethics Approval .....	35
<b>IV. QUALITATIVE STUDY FINDINGS.....</b>	<b>36</b>
A. Introduction .....	36
B. Lived Experience of Older Adults Living with Frailty, Multiple Chronic Illnesses and/or Dementia, and Their Caregivers .....	37
1. Demographic Information .....	38
2. Lived Experience of the Patients and Caregivers.....	40
C. Interactions between Dyadic Microsystem and External Systems of Care .....	50
1. Overarching Theme: Effective Communication.....	50
D. Professional Stakeholders’ Lived Experience: Struggling within a “Non-System” .....	58
1. Characteristics of the “Non-System” Experienced by Professional Stakeholders .....	59
E. Building a Responsive System for Individuals Living with Frailty, Chronic Illnesses and Dementia ..	69
1. Humanizing the Experience .....	70
2. Engage Family Caregivers as an Integral Part of the System .....	72
3. Expanding Professional Education and Training.....	75
4. Public Education and Awareness.....	78
5. In a Nutshell.....	79
<b>V. DISCUSSION OF MAIN FINDINGS FROM LITERATURE REVIEW AND CURRENT QUALITATIVE STUDY, AND CONCLUSION .....</b>	<b>80</b>
A. Communication: Diagnosis and Prognosis .....	81
B. Communication and Decision-making .....	81

C. Equity and Access.....	82
D. Enabling Factors for Support and Access .....	83
E. Advocacy and Fragmentation .....	85
<b>VI. APPENDICES .....</b>	<b>87</b>
A. Stages of Research Guided by Appreciative Inquiry and Study Populations for Each Stage.....	87
B. Professional Groupings and Names of Interviewed Stakeholders .....	88
C. Patient/Caregiver Dyad Interview Guide .....	88
D. Stakeholder Interview Guide .....	90
E. Programs, Services and Policies to Support Caregivers and Patients .....	91
<b>VII. ENDNOTES.....</b>	<b>95</b>

## **I. INTRODUCTION**

This research study explored how the last stages of life are experienced by elderly patients over the age of 65 and their family caregivers from their own narratives, which touched upon but were not limited to the following issues: knowledge gaps regarding disease, system navigation, needs for advocacy, wills and powers of attorney, consent and capacity, caregiver self-care and caregivers' feelings of loss and closure.

### **A. Purpose of Research**

The purpose of this research paper was to describe and understand the lived experience and needs of individuals in the last stages of life, as well as those of family caregivers who support these individuals, and to promote dialogue to inform changes that may be implemented within and across the health, social and legal systems in Ontario.

### **B. Scope of Research**

The current research focused on the lived experience and needs of individuals aged 65 and older dealing with severe frailty according to the criteria of the Canadian Study of Health and Aging Clinical Frailty Scale<sup>2</sup>, and their family caregivers. To understand how changes may be incorporated into the existing systems, a multi-stakeholder approach was adopted. Consultation and input were sought from a group of informed and interested stakeholders from the fields of medicine, ethics, law and public policy.

### **C. Rationale of Research**

Numerous documents have been produced locally, nationally, and internationally on palliative and end-of-life care which were instrumental in focusing attention on the need for improved care at this stage of life.<sup>3</sup> While previous reports have approached the definition of the problem using population-based statistics such as health utilization data or findings from opinion surveys, the current research paper adopted a qualitative research design. By interviewing patients and caregivers (together called "patient/caregiver dyads") of different socioeconomic, cultural, geographical and disease backgrounds, we heard from "the source" about their needs and the barriers and supports they have encountered while attempting to navigate Ontario's system during the last stages of their lives. The focus was on generating evidence regarding the needs and wishes of patients and caregivers for last-stages-of-life care to promote informed dialogue on appropriate changes to consider within (and across) the health, social and legal systems in Ontario.

## **D. Research Questions**

Given our approach to research, mentioned above, our paper sought to answer the following research questions:

1. What are the clinical, psychosocial, and information needs of frail elderly patients and their family caregivers during the last stages of life?
2. What are the factors that affect the ability of patients and their family caregivers to positively perceive and appropriately access available services and supports in the current system of care in Ontario?
3. What are the opportunities for change within Ontario's law and policies to stimulate necessary law and policy reform to improve the quality of care currently available?
4. What are the possibilities for enhanced advocacy supports with regards to improving access to information, rights advice and system navigation?

## II. LITERATURE REVIEW

This section presents a review of the existing literature covering these topics:

- A. Aging, frailty and chronic illness;
- B. Communication between physicians and patients, caregivers and families touched by frailty, chronic illness and dementia;
- C. Access to health care for vulnerable populations in Ontario at the last stages of life;
- D. Last stages of life and caregiving;
- E. Current state of the system and identified gaps.

The research that forms the body of this report provides a unique and invaluable description of the experiences of those currently engaged in end-of-life care as providers, patients and families. This review synthesizes a survey of current knowledge to provide context for the work that follows. The literature review also guided the formulation of the interview questions posed to patients, caregivers and stakeholders.

### A. Aging, Frailty and Chronic Illness

While the World Health Organization (WHO) has promoted a model of aging in which older people remain healthy and active, a focus on robust aging should not lead us to neglect those who are frail, suffer from dementia and are approaching the end of their lives.<sup>4</sup> Frail elderly persons often suffer from a combination of chronic diseases that jointly produce disability, reduce homeostatic reserves<sup>5</sup> and limit their ability to care for themselves. Physical, cognitive and emotional capacities gradually decline with age with the frequency and severity of limitations increasing in older age groups, particularly beyond age 85.<sup>6</sup> As many as 7 to 12% of people aged 65 and older may be affected by frailty and be vulnerable to adverse outcomes.<sup>7</sup> In the face of acute illness and other stressors, they are at greater risk of health destabilization, institutionalization and death.<sup>8</sup> When designing optimal care tailored to the individual, it is important to understand the concept of frailty and its impact on the aging process, chronic disease experience and mortality. When designing systems for society at large, it is equally important to understand the concept of frailty to ensure services are aligned with and responsive to new clinical and social needs.

## **1. Models of Frailty**

Three models of frailty, the Functional Domains, Biologic Syndrome and Burden models, have direct applicability to clinical settings and population-based research and have been critically examined and compared using a nationally representative population sample from the 2004 wave of the Health and Retirement Study (HRS).<sup>9</sup>

The Functional Domains model of frailty originated from the Alameda County Study<sup>10</sup> and is rooted in the theory that “a group of problems and losses of capability would render an individual more vulnerable to environmental challenge”. Under this model, frailty is operationalized as a syndrome of deficiencies in four domains of functioning (Physical, Nutritive, Cognitive and Sensory) represented in 16 self-report items. A patient is identified as frail if they encounter difficulties in two or more domains.

In the Biologic Syndrome model, frailty is defined as a “biologic syndrome of decreased reserve and resistance to stressors resulting from cumulative declines across multiple physiologic systems”. Frailty is operationalized as a phenotype—the observable physical characteristics of an individual, as determined by his/her genetic makeup and environmental influences—using five criteria: weight loss, exhaustion, low energy expenditure, slowness and weakness. A patient is identified as frail if they have three or more symptoms.<sup>11</sup>

The Burden model is a cumulative deficit approach based on a summation of markers of impairment that are inseparable from chronic disease. The Frailty Index (FI) developed under this model is comprised of 70 items which may be categorized as diseases, cognitive impairments, mood, mobility and function.<sup>12</sup> A patient with a calculated frailty index of 0.2 or above would be identified as frail. The Burden model of frailty is adopted for the purpose of this study, due to its emphasis on the linkage between chronic illnesses and frailty and its established application in the geriatric population.<sup>13</sup>

## **2. Frailty, Chronic Diseases and Death in Older Persons**

Geriatric medicine specialist, Dr. Carlos Weiss, asserted that “frailty and chronic diseases are prime modulators of a person’s health trajectory in later life”.<sup>14</sup> The presence of multiple conditions (referred to as “comorbid diseases”) may also contribute to the development of frailty, depending on the severity of an individual disease or the degree of interaction of the multiple conditions.<sup>15</sup> With the concurrent presence of two or more chronic diseases, patients also face risks associated with taking multiple medications (“polypharmacy”) and other adverse outcomes, such as social isolation and death.<sup>16</sup>

While the mechanisms linking frailty to aging and chronic disease may not be entirely clear<sup>17</sup>, most frail persons have at least one chronic condition<sup>18</sup> and close to half (46.2%) have multiple conditions.<sup>19</sup> Figures from North American studies, particularly the *Women's Health and Aging Study I*, showed that frail older women are particularly affected, with the prevalence of chronic diseases twice as high compared to the rest of the population.<sup>20</sup> In the representative sample of moderately to severely disabled, community-dwelling women aged 65 to 101 year, 28% were found to be frail, with an average of 4.3 chronic diseases reported<sup>21</sup>; 74% reported difficulty walking two to three blocks and 15% were homebound—evidence that they struggle with the illness burden and limitations associated with having multiple chronic conditions. More recent studies suggest that frailty is more prevalent in patients with certain chronic conditions, namely osteoarthritis, diabetes mellitus, chronic lower respiratory tract disease, hypertension, myocardial infarction, congestive heart failure and other cardiovascular diseases.<sup>22</sup> Not coincidentally, these chronic conditions are among the leading causes of death for Canadians aged 65 and over.<sup>23</sup> An understanding of the impact of multiple chronic diseases and frailty offers insight into the complex care needs of this population, in the context of last stages of life.

### **3. Prognostic Implications of Clinical Frailty**

There appears to be a continuum between not-frail and frail.<sup>24</sup> However, progress along the continuum is usually in one direction only with those identified as frail unlikely to return to their previous state.<sup>25</sup>

In the last decade, frailty research has focused on ascertaining the extent to which frailty may be used as a clinical concept, for example, in assisting with treatment decisions and yielding useful predictive information regarding prognosis.<sup>26</sup> There are ongoing efforts to identify frail patients clinically. As frail older adults appear to have lower ability to tolerate stressors such as medical procedures or hospitalization,<sup>27</sup> identifying patients as frail may better stratify them as appropriate or inappropriate for certain interventions,<sup>28</sup> including palliative care. The duration of frailty may be short in comparison with most diseases and disabilities. In a study that examined how and whether community-living older persons transition between frailty states, it was found that in 1.5 years, up to 20.1% people with frailty died.<sup>29</sup> Thus, identifying frail patients may allow slowing of the frailty process and prolongation of life. Prognostic indexes for mortality for the general population<sup>30</sup> and specifically for the frail older adult population<sup>31</sup> have been developed for this purpose. These tools are becoming especially relevant in primary care settings in Canada, where primary care physicians are commonly required to formulate prognoses for frail patients of increasing complexity, including those with dementia.

An ability to estimate life expectancy would be beneficial to allow delivery of the most appropriate treatment, including palliative care, and to allow patient and caregiver to prepare for the end of life. Patients with cancer consume most palliative care resources, partly because prognosis is easier to formulate. At the same time, patients with other chronic illnesses may be denied what might be the most suitable and cost-effective service for them,<sup>32</sup> in part because prognosis can be difficult to formulate in chronic illness including dementia.<sup>33</sup> This can lead to a mismatch between the interventions offered and the clinical situation.<sup>34</sup> The patient may be treated actively when this is not appropriate given her prognosis, or, conversely, the patient may be excluded from palliative care because she does not meet the criteria for entry which, in Ontario, vary by service provider.<sup>35</sup> For example, criteria for entry into palliative care often include a requirement that death is expected within six months, an estimate that may be impossible to make in chronic illness and dementia.<sup>36</sup> The Ontario Ministry of Health and Long-Term Care recognizes the importance of including palliative care in the management of patients with chronic disease and has pledged to adopt this approach.<sup>37</sup> Part of ensuring that this goal is met may be the adoption of standard criteria for eligibility for palliative care. Measurement of frailty might form part of the assessment.

#### **4. *Rockwood Canadian Study of Health and Aging Frailty Index and Clinical Frailty Scale***

Based on the Burden model of frailty, Kenneth Rockwood and others developed the Frailty Index (FI), which is a systematic approach to count an individual's clinical impairments or accumulative burden of symptoms, diseases, conditions and disability.<sup>38</sup> The FI is a count of 70 clinical deficits noted during history taking and clinical examination including these items: presence and severity of current diseases, ability in the activities of daily living, and physical and neurological signs of vulnerability.<sup>39</sup> The FI is replicable and correlates highly with mortality. However, it may be time-consuming to complete and, thus, not practical for clinical use.<sup>40</sup>

In 2005, Rockwood and others developed the Clinical Frailty Scale (CFS). Rooted in the same theoretical model of fitness and frailty they used to develop the FI, the CFS was initially a 7-point scale that was further refined and updated to 9-point scale, ranging from 1 (Robust Health) to 7 (Severely Frail—completely dependent for personal care, from whatever cause, physical or cognitive) to 9 (Terminally Ill—approaching the end of life including those with a life expectancy of less than six months who would not be categorized as frail based on other factors). The 7-point version was tested in 2,305 elderly patients who participated in the second stage of the Canadian Study of Health and Aging (CSHA-2), and was found to correlate well with the FI and to better predict entry into institutional care as well as to predict death. Applying the CFS to patients relies on the clinical judgment and skilled interpretation of the clinician conducting the history-taking and clinical examination.<sup>41</sup> Thus it may be best used by

clinicians experienced in the care of the elderly. Reliance on the judgment of the individual completing the scale means that different clinicians may emphasize different aspects of the patient's presentation. The developers of the CFS argue that this subjectivity is a strength of the tool, since it allows different clinicians to validly identify a patient as frail by distinct processes.<sup>42</sup>

## **5. Ontario Statistics on Frailty, Dementia and Chronic illness**

Although the prevalence of frailty varies greatly depending on the method of measurement<sup>43</sup>, it is estimated to affect 10.7% of community-dwelling adults aged 65 and older in the United States.<sup>44</sup> In Ontario, the Institute for Clinical Evaluative Sciences (ICES) highlighted the characteristics of four cohorts of frail seniors in their 2011 report *Health System Use by Frail Ontario Seniors*.<sup>45</sup> The four vulnerable cohorts examined were: older women, medically complex home care clients, community-dwelling older adults with dementia and older adults recently placed in long term care. Understanding the demographics and characteristics of these subsets of community-dwelling older Ontarians offers insights into their complex health and social care needs. Thus, highlighted data of the first three cohorts defined in the ICES report are presented in the following sections as they provide relevant context for our paper. The group of patients newly admitted to long-term care will not be reviewed as it falls outside the main focus of this study.

### **i. Older Women**

In an Institute for Clinical Evaluative Sciences (ICES) report, Andrea Gruneir, Minnie M. Ho and Ximena Camacho<sup>46</sup> noted that women comprise a majority of the population over age 65 in Ontario, with the gap widening among the oldest of older adults: In the cohort over age 85, there were approximately 100,000 women for every 50,000 men. These older Ontario women were reported to have a high burden of chronic disease with fewer than 7% having no chronic conditions and 75% having two or more. The prevalence of frailty also increases with age in this group, from 7.6% among women aged 76 to 79 to 16.4% among those aged 90 and older. By comparison, prevalence of frailty in a similar group of American men and women increased from an estimated 15.7% of those aged 80 to 84 to 26.1% of those aged 85 and older.<sup>47</sup> Rates of poverty also increase with age. The combination of burden of illness, frailty and economic hardship may put older women at particular disadvantage as they enter their last stages of life.

## **ii. Medically Complex Home Care Clients**

Older Ontarians who are medically complex—that is, with multiple chronic conditions, impaired cognitive functioning or both—are increasingly being admitted to hospital, and 16.9% of this cohort dies during hospitalization.<sup>48</sup> Post discharge, 48.1% return to their homes in the community, frailer than prior to hospitalization and at higher risk of readmission. Although not a large number, 4.5% of medically complex patients discharged home received no home care in the two weeks following discharge. This represents a significant gap in support for this extremely vulnerable population in need of targeted enhanced care and case coordination, especially during transitions between different levels of care.

## **iii. Community-Dwelling Older Adults with Dementia**

Of community-dwelling Ontarians aged 66, 6.8% had been diagnosed with dementia by a physician.<sup>49</sup> This prevalence is lower than the 14.9% reported by the Alzheimer Society of Canada<sup>50</sup> as the ASC estimate also included unconfirmed diagnoses and institutionalized individuals. The proportion of older adults affected by dementia was similar across the sexes and increased with age, rising from 2.7% of women aged 66 to 74 to 20.3% of women aged 85 and older. Older adults with dementia are more likely to be identified as low income: 25% of those with dementia versus 18% of those without.

In the ICES report it was found that markers of frailty were more common in the dementia group, with 21.2% exhibiting diagnoses related to frailty compared to only 5.2% of those without dementia.<sup>51</sup> The burden of chronic disease was also found to be higher in older Ontarians with dementia: almost all individuals in the dementia group (90.8%) had been diagnosed with two or more medical conditions, compared to 69.9% in the group without dementia.<sup>52</sup> The complexity of disease in these older adults was also reflected in their medication use in the preceding year. Older adults diagnosed with dementia were prescribed, on average, two more drugs than their counterparts without dementia over the course of the prior year, with an average of 9.8 medications in the dementia group compared to 7.5 medications in those without dementia.<sup>53</sup>

This specific cohort of frail Ontarians depends heavily on informal assistance with their basic and instrumental activities of daily living.<sup>54</sup> Eighty per cent of the care needed by frail seniors, including those with dementia, was provided by informal (unpaid) family caregivers, usually a child (or child-in-law) or spouse. Among those diagnosed with dementia, 98.7% were reported to have an informal caregiver.<sup>55</sup> The contribution of informal family caregivers in dementia is significant in both financial and emotional terms. Caregivers spent an average of 21 hours a

week providing care for family members with dementia, 6 hours longer than the time spent by caregivers of persons without this diagnosis;<sup>56</sup> 26.7% of family caregivers living with the individual with dementia experienced distress compared to 14.3% of live-in caregivers of family members without dementia.<sup>57</sup> These data suggest that the lived experience of those caring for someone with dementia in the last stages of life should be taken into account so that potential opportunities to improve their caregiving situation may also be identified.

## **6. Direct Costs of Frailty**

Health care expenditures account for the majority of the direct costs of frailty in the last stages of life. There is evidence that frail elders visit primary care physicians, specialists and the emergency department (ED) more frequently than elders not identified as frail and incur higher medication costs.<sup>58</sup> Similar findings were reported in the 2011 ICES report<sup>59</sup>, where it was noted that frail seniors in Ontario have more physician visits, ED visits and acute hospitalizations, and are higher consumers of home and long-term care services and medications than those who are not frail. Community-dwelling older adults with dementia consume more health care resources than those without dementia, including more family physician visits (13.6 versus 9.1 visits annually). Among this population, 45.9% visited the ED over the course of one year and 12.2% of these visits were for a potentially preventable condition, compared to 6.2% in older adults without dementia. About one quarter of frail elders with dementia were hospitalized annually with an average length of stay of 18.6 days.<sup>60</sup> With the average cost of an acute care hospital bed estimated to be \$842/day<sup>61</sup>, the cost of an average hospital stay is, therefore, \$15,661, and the estimated annual cost of hospitalization for 25,444 elders with dementia in Ontario would reach at least \$39.8 million.<sup>62</sup> Costs for palliative care must also be considered when tabulating the costs of frailty, particularly as the population lives longer with severe frailty and chronic illness.<sup>63</sup> The cost of providing specialized palliative care in the last month of a person's life averages about \$33,000 in an acute-care hospital.<sup>64</sup> In comparison, similar care provided in a palliative care unit costs \$18,900 to \$23,100 and \$13,800 in a hospice bed. In-home palliative care costs under \$3,000 per day (where available) and might include nursing, physiotherapy, occupational therapy, personal support and homemaking services.<sup>65</sup>

The cost of providing home care to frail elders must also be accounted for. According to the *13th Annual National Report Card on Health Care* published by the Canadian Medical Association<sup>66</sup>, 55% of Ontarians will need to rely on the public system for home health care, supplemented by care provided or privately purchased by family, friends or both.<sup>67</sup> The expectation (and necessity) that family and friends bear more of the responsibility and cost for the home care of frail elders is partly driven by evidence from health economic analyses comparing the costs of formal and informal care. For example, in the Netherlands, the hourly

cost of informal home care was estimated at €9.3 an hour—equivalent to about \$13.50 Canadian dollars—which is much less than formal care provided at public expense.<sup>68</sup> While the provincial government continues to promote home care as an alternative to institutionalized care in acute care hospitals and long-term care facilities in an effort to reduce costs associated with health care expenditures, it is also imperative that a well-resourced and funded home care system be provided so that frail elders and their family caregivers are not pressured to shoulder direct and indirect costs of care, as detailed in the next section.

### **7. Indirect Costs of Frailty, Chronic Diseases and Dementia**

One approach to measure indirect cost of frailty is to assess the number of hours that family caregivers spend on caregiving and then estimate the value of their unpaid labour. Approximately 8 million Canadians provide care to a frail or dying elderly relative every year<sup>69</sup>, allowing them to remain at home. As noted above, family caregivers provide 15 to 21 hours of unpaid care weekly or 780 to 1,092 hours annually.<sup>70</sup> Additionally, the Ontario Home Care Association (2013) estimates that an average frail elder (or her family caregiver) purchases an extra 133 hours or visits of home care annually for services that they are not trained or equipped to provide. Significant out-of-pocket travel expenses are also incurred by family caregivers, as informal caregivers travel to the care recipient's home in another city or province to provide live-in care.<sup>71</sup>

During a frail elder's last stages of life, the indirect costs of care absorbed by family caregivers significantly increase. In a study evaluating the experiences of caregivers providing end-of-life care<sup>72</sup>, it was found that 24% of informal caregivers retired early because of their caregiving responsibilities and over 20% of informal working caregivers reduced their hours of employment. The demands of informal caregiving are especially intense during the last month of life, with an average of 340 hours of care provided by the primary family caregiver.<sup>73</sup> In their 2002 study, Lorriane Greaves, Olena Hankivsky, Georgia Livadiotakis and others<sup>74</sup> estimated that \$5,749.40 of unpaid labour would be provided in a one-month period, assuming the average wage of a caregiver is \$16.91 per hour. These extrapolations validated the economic valuations calculated on a replacement cost basis<sup>75</sup> which suggested that the value of unpaid labour provided by caregivers in Canada was approximately \$5 billion per year. In a more recent economic valuation study, Marcus J. Hollander, Guiping Liu and Neena L. Chappell<sup>76</sup> estimated that it would cost more than \$9.7 billion per year in Ontario to reimburse families and friends for their caregiving service. Another significant indirect cost was the loss of future pension entitlements and reduced retirement savings as a result of the caregiver having fewer years in the workforce.<sup>77</sup>

Not all costs are as readily quantifiable. One such cost is the price paid by caregivers who develop “caregiver burden”, an umbrella term for the physical, psychological, social and financial impact of caregiving.<sup>78</sup> Caregivers experiencing burden have poorer physical and emotional health and suffer worsening of health conditions, such as diabetes, hypertension and depression. As a result, they access the health care system more often and consume more health care resources than their non-caregiving counterparts.<sup>79</sup> Additional costs for caregivers include loss of income and missed vocational advancement. Indirect costs of caregiving are also felt by Canadian employers through caregivers’ absenteeism, presenteeism and low productivity, the result of distraction, distress and fatigue. These costs may be as high as \$1 billion annually<sup>80</sup>, which may have negative financial impacts on the governments as family caregivers who depart the workforce may pay less income tax while consuming social assistance and accessing refundable tax credits.

## **B. Communication between Physician and Patients, Caregivers and Families Touched by Frailty, Chronic Illness and Dementia**

The sharing of information between physician and patient is essential<sup>81</sup>, no less when the patient is frail. There is an extensive literature regarding communication during the last stages of the lives of cancer patients. Less has been written about communication between physician and patient when the patient is a frail, elderly individual with or without dementia.<sup>82</sup> This section primarily references the cancer literature but the basic concepts regarding communication and its importance are applicable when the patient is aged 65 and older and identified as being severely frail. Information about communication with this patient group and their caregivers is included when available.

Before beginning the discussion of physician-patient communication, it is important to note that open communication is not only good practice but it is also enshrined in law in Ontario under the *Health Care Consent Act*.<sup>83</sup> The *Act* stipulates that informed consent is necessary for all treatment, except in emergencies. Thus, patients must be given information regarding the risks and benefits of accepting or refusing any treatment so that they may provide informed consent. Of course, good communication is desirable for reasons beyond the provision of consent, as will be discussed below.

Physician-patient communication is a reciprocal process that continues throughout the duration of the therapeutic relationship. It begins at the first encounter between physician and patient when the patient describes her health concerns and the physician shares his understanding of the problem at hand and the most appropriate remedy. This dialogue is

ongoing, allowing for continuous refinement of understanding on both sides as the disease progresses and patient needs evolve. The physician requires comprehensive information to formulate an accurate diagnosis, treatment plan and prognosis. Equally, the patient requires a complete picture of her health status. Information regarding her illness, its prognosis and the implications of choosing or refusing treatment are essential in allowing the patient to choose and provide informed consent for interventions at every stage of her illness.<sup>84</sup>

While it may be the ideal, open communication between physician and patient can be difficult and not always achieved.<sup>85</sup> Historically, medical paternalism meant that the physician held the health care information and decided unilaterally what the patient would be told.<sup>86</sup> Physicians tended to be reluctant to disclose accurate prognostic information, portrayed the situation in more optimistic terms than were warranted and sometimes avoided discussions of prognosis at all, unless specifically asked.<sup>87</sup> Today, patient autonomy and independence are highly valued both in the information received and in the application of that knowledge in medical decision-making.<sup>88</sup>

In dementia, physicians are guided by the same principles of respect for patient autonomy and desire to provide information in a way that is tailored to individual needs.<sup>89</sup> The nature of the dementia itself raises additional issues that factor into the physician's decision about how much to disclose. Depending on the severity of the patient's cognitive impairment, she may lack the ability to process and understand the diagnosis and there may be no benefit in making the disclosure.<sup>90</sup> Furthermore, cognitive function may fluctuate so a patient may be able to receive diagnostic and prognostic information at one time and not another<sup>91</sup>, making it important to assess the patient's level of impairment and tailor the disclosure to her ability on that occasion.<sup>92</sup>

Studies in all medical specialties confirm that patients wish for open sharing of medical information empathically delivered.<sup>93</sup> Further, good communication can improve patient outcomes and satisfaction with care received.<sup>94</sup> Unfortunately, despite the wishes and efforts of both the provider and receiver of the information, communication sometimes breaks down due to factors within the physician or patient, or the relationship between them.

### **1. Physician Factors**

There are many reasons why physicians fail to provide accurate information to patients. Some believe that negative health information, so called "bad news", can be devastating to patients and withhold information in what they regard as a benevolent effort to ease suffering and foster hope.<sup>95</sup> Euphemism is sometimes used to soften the news, leading to confusion and

misunderstanding.<sup>96</sup> The diagnosis of dementia is sometimes withheld from the patient and family. The physician may use vague or inexact terms that are not formal diagnoses<sup>97</sup>—for example, “mild dementia”, “cognitive impairment” or simply “dementia” without specifying the type. Again, this approach is taken in order to spare patient and family suffering and perpetuate hope in the face of a serious diagnosis.<sup>98</sup>

One way of describing the discrepancy between what is known by the physician, what is conveyed to the patient and the reality of physician withholding is provided by Elizabeth B. Lamont and Nicholas A. Christakis<sup>99</sup>, who speak about the “formulated” versus “communicated” prognosis. The former is the “most accurate estimate of how long patients have to live” and the latter is “what they would tell their patients if the patient insisted on obtaining an estimate of how long they had to live”. Lamont and Christakis reported that physicians surveyed would communicate their formulated prognosis only 37% of the time, even when patients specifically asked about prognosis, and in the remainder of cases would communicate a prognosis different from their formulated prognosis or would not speak about prognosis at all. This has obvious implications for patient autonomy and decision-making.

Breaking bad news may be stressful for physicians<sup>100</sup>, who may experience troubling emotions (for example, anxiety, grief, exhaustion, guilt and a sense of failure) that they lack the ability to tolerate and manage.<sup>101</sup> They may feel equally unequipped to contain the patient’s emotional response.<sup>102</sup> Consequently, the physician may consciously or unconsciously fail to make a frank disclosure to spare himself emotional distress.<sup>103</sup>

It’s possible to understand why incomplete prognostic diagnostic information might be provided, at least initially. Predictions regarding the course of chronic illness are difficult to make both because of the nature of the conditions themselves and the unique way each individual patient responds to the illness and its treatment.<sup>104</sup> Population-based estimates of the expected course may be available but do not necessarily apply in the individual case. The physician might justifiably hold back simply because he cannot make an accurate estimate of survival time.<sup>105</sup> The difficulty in establishing prognosis is particularly difficult in chronic illness and dementia, sometimes leading to a greater reluctance to make predictions.<sup>106</sup>

Another barrier to effective communication lies in the fact that physicians are not adequately trained in the skill of sharing health information with patients.<sup>107</sup> They may be too blunt, too emotional, too distant and generally inattentive to patient needs regarding what they want to know, and when and how they want to know it.<sup>108</sup> The physician may focus on the facts regarding illness and prognosis, areas of greater expertise and comfort, and neglect the patient’s emotional needs.<sup>109</sup> This approach has been observed in taped conversations in which

a diagnosis of dementia was made to a patient and caregiver. The physicians used few emotional rapport-building behaviours, such as expressions of empathy.<sup>110</sup> It was suggested that the physicians may have had difficulty including expressions of emotion in a conversation about such a serious diagnosis. Alternatively, the patients' cognitive impairment might have made it necessary for the physicians to focus more on conveying the facts of the diagnosis with little time available for attention to the patient's affect.<sup>111</sup> Regardless of the diagnosis, patients and caregivers certainly want to know the facts, but also want and need attention paid to their affective state and to know how the illness will affect them emotionally, areas that may be neglected by the physician.<sup>112</sup>

Physicians acknowledge that they are often unprepared for the sharing of difficult news, particularly at the beginning of their careers, and wish for more training. Fortunately, communication is a teachable skill.<sup>113</sup> Many courses have been designed and integrated into medical education to try to correct identified deficits, including in Ontario medical schools.<sup>114</sup> It is unclear if this training has translated into improved skills among professionals or better experience for the patient and family receiving the news. What is more certain is that experiential training in which learners are given the opportunity to practice breaking bad news is more effective than the provision of written guidelines.<sup>115</sup>

## **2. Patient and Caregiver Factors**

Communication difficulties can also arise on the patient's side of the interaction. Patients vary in their informational needs and their needs often change over the course of the illness.<sup>116</sup> Unfortunately, there do not seem to be consistent patient or disease characteristics that allow predictions about what information a specific patient would want to know and how she would like to receive it<sup>117</sup>, underlining the need for individualization in information sharing.<sup>118</sup> It seems that the only reliable way to determine individual patient preferences is by enquiring of the patient.<sup>119</sup>

When working in a multicultural context, the patient's ethnic background has to be considered.<sup>120</sup> For example, one study found that patients belonging to Korean and Mexican communities wanted less information regarding prognosis compared to their peers from other communities.<sup>121</sup> The point is not to highlight the informational needs of patients belonging to these two ethnic groups, but rather to highlight that caution is needed as assumptions cannot be made about patient preferences based on culture alone.<sup>122</sup> Again, it's essential to ask and individualize what is shared.

Patients wish for honesty, empathy and the use of simple, unambiguous language when the physician is sharing health news.<sup>123</sup> There is a desire and a need for factual information regarding diagnosis, prognosis and treatment as well as clarity around how the disease will impact the lives of both the patient and his family members. Patients want to know how their illness will compromise their independence and lead to changes in their role within their family. They fear loss of control.<sup>124</sup> They wish for an experienced and knowledgeable physician who provides information in understandable, non-technical language and is competent, empathic and attentive to their emotional needs.<sup>125</sup>

Patients are often in conflict internally, both wanting full disclosure of information but also not wanting bad news.<sup>126</sup> It can be very difficult for the physician to balance honesty and optimism while being open but not blunt, sensitive but professional, emotionally engaged but not overwhelmed.<sup>127</sup> Nonetheless, the physician's obligation is to strive for this balance in communicating with each patient.

Even if the health care provider does communicate the diagnosis, it is often not "heard". Patients may deny the news they are receiving or fail to appreciate its implications.<sup>128</sup> Several studies demonstrate that despite the physicians' belief that they had accurately disclosed that their patient had metastatic disease for which palliative care was most appropriate, a significant minority of patients believed they had localized disease and their treatment was aimed at cure.<sup>129</sup> Confusion regarding prognosis can have serious implications as holding an unrealistically optimistic view of the prognosis may lead the patient to choose an inappropriately aggressive treatment rather than a palliative approach better suited to his situation.<sup>130</sup>

Beyond what specific information is provided, patients have preferences regarding the process through which information is shared.<sup>131</sup> Ideally, the conversation should occur in a quiet place free of interruptions.<sup>132</sup> Family should be included, particularly in dementia<sup>133</sup>, if that is the patient's wish. The discussion should start with enquiry into what the patient knows already and what they would like to be told.<sup>134</sup> Adequate time should be available to provide the information, allow for questions and ensure understanding.<sup>135</sup> The expression of emotion should be welcome and responded to empathically. In dementia, it may be preferable to disclose the diagnosis over several meetings to allow for questions and education of patient and caregiver about the diagnosis, prognosis and treatment planning.<sup>136</sup> Patients and caregivers should be assured that future meetings are possible to clarify what has been shared and update information as needed.<sup>137</sup> The discussion should end with a brief summary about what has been shared.

Just as patients need information and vary in their preferences regarding the provision of information, families also require timely and accurate information.<sup>138</sup> They require factual information to provide appropriate care for their family member, to make informed decisions about treatment and to help in preparation for the future including the patient's death and their bereavement.<sup>139</sup> Like the patients they care for, each caregiver's needs for information are unique and change as the caregiving situation changes. Some common themes include concerns about pain control, prognosis, system navigation, respite, and the availability of timely and reliable information.<sup>140</sup> The work of Latifat Apatira, Elizabeth A. Boyd, Grace Malvar and others<sup>141</sup> also revealed that families view themselves as resilient and disagree with the notion that negative information should be withheld in an effort to sustain hope. In addition, the timely provision of information may ease the suffering of bereavement.<sup>142</sup>

### **3. Summary**

In summary, communication between physicians and patients with chronic illness, dementia and other conditions in the last stages of life is essential but complex and not always well executed. Communication falters because of factors in both physician and patient. Patients often lack the critical information regarding their illness and prognosis needed to exercise their autonomy and make informed choices regarding their care. Similarly, patients' emotional needs and quality of life concerns are not always well attended to. Fortunately, both sides recognize that problems exist and share a wish for improvement. Communication skills can be taught and significant efforts have been made to improve physicians' expertise in providing health information in a manner that is sensitive to the needs of the individual patient.

## **C. Access to Health Care for Vulnerable Populations in Ontario in the Last Stages of Life**

The *Canada Health Act* governs the provision of health care in all provinces across Canada and is guided by five principles: *universality, comprehensiveness, portability, accessibility* and *public administration*.<sup>143</sup> The intention behind these principles is to eliminate financial barriers to health care for the individual. Each province is responsible for the delivery of health care and the health care system is governed by provincial legislation. Access to health care continues to be an issue for sub-populations, which face multiple barriers to care. There have been ongoing efforts to address the needs of, and barriers to, care faced by vulnerable populations at the last stages of life, including individuals who belong to one or more of the following groups: Aboriginal peoples; visible minorities; lesbian/gay/bisexual/transgender/queer/two-spirit

(LGBTQ2S) peoples; individuals living in rural and remote communities; Francophone peoples; women and informal family caregivers. Drawing upon the health equity framework, access and needs of these sub-populations will be discussed in relation to access and health equity in the Ontario health care system.

## **1. What Shapes the Health Equity Framework?**

### **i. Social Determinants of Health Paradigm**

The World Health Organization set out to establish actions to improve health inequities through the social determinants of health paradigm.<sup>144</sup> The parameters for this paradigm and its practice are set using a socioeconomic approach.<sup>145</sup> The paradigm seeks to define and dismantle the conditions in which risk occurs.<sup>146</sup> Conditions that perpetuate risk include: poverty; gender, racial and sexual inequality; environmental stressors, such as weather and toxin exposure; housing and living conditions; education and early child care; food security; employment and working conditions; social inclusion and exclusion; and globalization.<sup>147</sup>

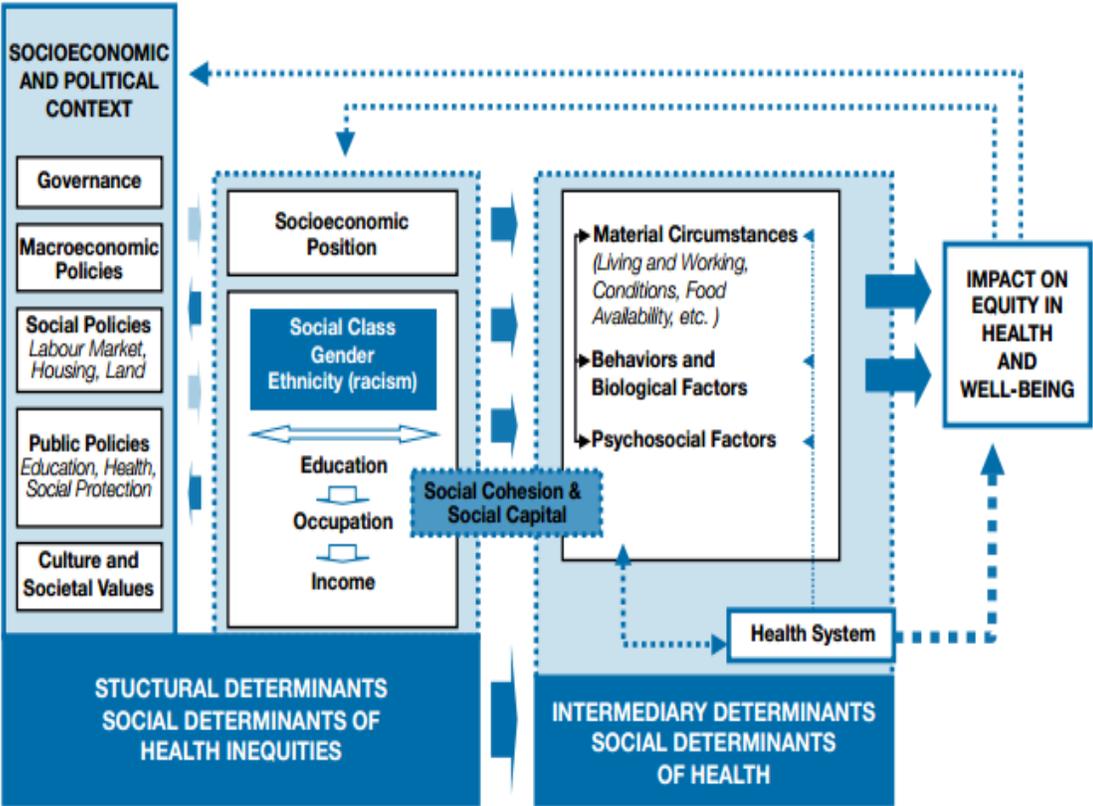
Rachelle Ashcroft explains that there are three dominant perspectives within the social determinants of health paradigm: materialist, neo-materialist and social comparison. The materialist perspective, “assumes that the key to understanding and promoting health is attending to material living conditions, which affect health by influencing social environments, relationships, and an individual’s physical, psychological and educational development”.<sup>148</sup> The neo-materialist perspective, “assumes that living conditions and social infrastructures—including those that determine how economic and social resources are distributed—account for individual health outcomes and differences in health levels between larger populations”.<sup>149</sup> The social comparison perspective “emphasizes the impact of social hierarchies on health and assumes that perceptions and experiences of social inequality result in stress and negative health outcomes”.<sup>150</sup> Social determinants of health provide a fundamental framework within which to address health inequities, which are heavily influenced by social, economic and political systems, as well as environmental and biological factors.<sup>151</sup> The social determinants of health and these three perspectives inform one another within the social, economic and political environments in which health interventions are formulated and practiced.

### **ii. Social, Economic, Political Structures**

Social determinants of health operate within social, economic and political structures that govern the implementation of health programming and services. They function within the context of funding bodies, community diversity and societal practices.<sup>152</sup> Figure 1 illustrates

how social and economic policies, societal and cultural values, governance and the positioning of a community have a cyclical effect on health and well-being.

**FIGURE 1—CONCEPTUAL SOCIAL DETERMINANTS OF HEALTH FRAMEWORK (WHO, 2010)**



**iii. Intersectionality Theory**

Intersectionality theory was developed by legal scholar Kimberle Crenshaw (1989)<sup>153</sup> and revised with contributions from bell hooks (1990)<sup>154</sup>, Patricia Hill Collins (1990, 2002, 2005)<sup>155</sup>, and Agnes Calliste and George Sefa Dei (2000).<sup>156</sup> Intersectionality theory recognizes that oppressions are experienced as interlocking, simultaneous and interchangeable, rather than as “additives” to or in isolation from one another.<sup>157</sup> An intersectional approach to health and social care captures the complexities of the lived experiences of communities that encounter lack of access to health services and programs and the social and material necessities of life, due to factors like age, culture, disability, ethnicity, gender, immigrant status, race, sexual orientation, social class and spirituality.<sup>158</sup> Olena Hankivsky and Ashlee Christoffersen state that, “Intersectionality moves beyond the assumption that health outcomes may be caused by

a number of contributing causes, by asserting that numerous factors are always at play” and that, “intersectionality examines gender, race, class and nation as systems that ‘mutually construct one another’”.<sup>159</sup> Intersectionality encourages a contextual analysis that examines beyond singular identities, experiences and social locations to consider a range of differences, which allows better understanding of any situation of disadvantage.<sup>160</sup> Intersectionality is a crucial consideration in health care settings when addressing social determinants of health, formulating interventions that facilitate social justice and developing policy development initiatives that address the needs of communities.

#### **iv. Oppressions**

Oppressions are deeply embedded in dominant discourse and society, and are often not visible but affect everyone.<sup>161</sup> Interlocking systems of oppression include racism, xenophobia, classism, sexism, homophobia and heterosexism, ableism and ageism, which all have detrimental effects on an individual’s health. Vicente Navarro states that, “the oppressions of sexism, racism, heterosexism, and ageism, to name a few, can and do happen together to produce a complex synergy of material and social disadvantage”.<sup>162</sup>

## **2. Health Equity Framework**

The health equity framework, which is based on social justice principles, is an effort to address health disparities. Health disparities are the differential and, often, inferior health outcomes experienced by vulnerable populations. The four health disparity indicators commonly used within Canada are socioeconomic status (SES), Aboriginal identity, gender identity and geographic location<sup>163</sup>. Individuals within a population are stratified according to these indicators, which influence their positioning (social, economic, political etc) in a society and their access to health care resources.<sup>164</sup> Geographic location may further restrict one’s access to health care since availability of resources, levels of poverty and crime rates may vary by location.<sup>165</sup> Health equity seeks to reduce or eliminate these disparities by providing a standard of care for all individuals within society.<sup>166</sup> It explicitly takes into account the four health disparity indicators for the purpose of improving health care accessibility and addressing the needs of vulnerable populations through and beyond the present disease or health condition. The main difference between health equities and health disparities is that the former are the historical and structural components that shape an individual’s access to health care and the latter refer to indicators of how the disease (health-based) unfolds for vulnerable populations.<sup>167</sup> The health equity framework seeks to provide a structure for addressing the lack of access to health care experienced by vulnerable populations. Health disparity indicators are used to measure how well a society is achieving health equity.<sup>168</sup>

**3. Vulnerable Populations in Ontario and Access to Health Care Services in the Last Stages of Life**

Health outcomes depend on the complex interplay between the health inequities and health disparities experienced by the individual. Members of vulnerable populations in Ontario may be further marginalized when they are older, frail or in the last stages of life. All frail elderly patients and their informal family caregivers may experience difficulties accessing health care services. Additional factors may compound the effects of frailty and age and further compromise accessibility.

Women’s health may be impacted by geography, power differentials, race, culture and lack of access to services.<sup>169</sup> Access to health services can be made more difficult for women by the multiple roles women are expected to fulfill in Canadian society (such as mother, partner, employee, caregiver of aging parents). Faithful fulfillment of these roles may prevent women from addressing their own health care needs in a timely manner. This holds true for both the elderly frail patient and the informal family caregiver who identifies as a woman. Persons identified as LGBTQ2S encounter barriers due to socioeconomic, ethno-racial, age, gender, disability, religious, geographical location, educational and relationship factors.<sup>170</sup> For frail elderly immigrants, the realities of economic inaccessibility are illustrated when the patient does not have health insurance and is unable to afford prescription medication.<sup>171</sup> The growing aging populations in rural Ontario struggles to access services as health care resources are not expanding at a rate parallel to the growing demand.<sup>172</sup>

**TABLE 1—INDIVIDUALS WITHIN 4 VULNERABLE POPULATIONS IN ONTARIO AGES 65+ (STATISTICS CANADA, 2011)**

Aboriginal peoples	82,690*
Francophone	88,770**
Immigrants	763,655
Visible minorities	1,752,435

\* Number based across Canada. The Aboriginal population in Ontario accounts for 2% of the overall population within the province; however, they experience higher levels of health inequities.<sup>173</sup>

\*\* Number based on Statistics Canada. More than half of Francophone seniors in Ontario are women.<sup>174</sup>

Older persons who are homeless have higher levels of physical and mental health issues and often require specialized, complex care interventions, which are often not provided in shelter settings. The work of Amanda Grenier, Rachel Barken, Tamara Sussman and others<sup>175</sup> documented this reality in the experiences of older persons, over age 42, experiencing higher rates of homelessness and more frequent, severe and complex mental-health challenges.

A study in the greater Toronto area revealed that access to culturally appropriate health care among immigrant populations increased when services were spread geographically and provided by health care professionals fluent in diverse languages.<sup>176</sup> For immigrants in the last stages of life, it is important to consider the cultural distinctions between Western and non-Western medical practices within palliative care. Culturally determined values, wishes and perceptions of illness, health and death are paramount particularly for frail elderly patients accessing palliative care in the last stages of life.<sup>177</sup> Easy geographical access is also crucial for frail elderly patients as it minimizes their travel times to appointments, gives health care professionals more ready access to patients' homes<sup>178</sup> and can decrease stress for informal family caregivers responsible for transporting elderly patients and ensuring care is received in a timely manner.

Those suffering from mental illness often struggle with multiple disadvantages such as poverty, immigration status, sexual orientation, ethno-cultural identity and geographic location.<sup>179</sup> These may be compounded by other barriers including: language and the lack of culturally appropriate services for immigrants, refugees and visible minorities; lack of provincial health insurance coverage for those individuals without citizenship; and inadequate mental health supports in remote areas of Northern Ontario.

#### **4. Access to Home Care Services at the Last Stages of Life**

Ontario's *Home Care and Community Services Act*, 1994, SO 1994, c 26 is provincial legislation that outlines a person's rights when receiving home care. Home care is currently administered by Community Care Access Centres (CCACs) across Ontario. The *Act* sets out the right for home-based care to be free of charge, although fees may be charged for services administered through other programs.<sup>180</sup> Access to health care by patients and families may be improved with the passage of Bill 210, *The Patients First Act*, 2016, which was recently introduced in the Ontario legislature and amends the *Home Care and Community Services Act*, 1994, and the *Local Health System Integration Act*, 2006. If passed, this *Act* would eliminate CCACs and expand the role of the Local Health Integration Networks (LHINs) with the goals, among others, of shortening wait times for primary care, enhancing integration and continuity of care across

the spectrum from primary care to hospital to home, and improving access to and uniformity of home care across the province of Ontario.

Frail elderly patients with multiple chronic conditions, including Alzheimer’s disease and related dementias, currently have difficulty accessing adequate home-based care due to the complexities of the disease, the structure of care, funding models and the hours that are allocated for care<sup>181</sup> Home-based care is often distributed based on medical needs only. As a result, the holistic needs of frail elderly patients, particularly those with dementia, at last stages of life may go unmet.<sup>182</sup> This inequity may be compounded by other factors such as SES. For example, it has been shown that home-care is utilized at higher rates in higher income homes.<sup>183</sup> This is at least in part due to the fact that higher income households have the resources to hire private home care. Another study documented barriers encountered by rural elderly patients with dementia, including having little to no access to home care, compared to patients without dementia.<sup>184</sup> Similarly, immigrant populations may be at a disadvantage, as reported by Audrey Laporte, Peter C. Coyte and Ruth Croxford<sup>185</sup>, who documented less utilization of home care among immigrant populations.

##### **5. Initiatives to Address Health Inequities and Disparities at Last Stages of Life in Ontario**

There are various initiatives in Ontario that are intended to address health inequities and disparities, which could potentially improve services for persons with chronic illness, dementia and frailty in the last stages of life.

For instance, the Ministry of Health and Long-Term Care developed a comprehensive assessment tool for health institutions and organizations to ensure compliance for achieving health equity. The *Health Equity Impact Assessment (HEIA)*:

...is a decision support tool which walks users through the steps of identifying how a program, policy or similar initiative will impact population groups in different ways. HEIA surfaces unintended potential impacts. The end goal is to maximize positive impacts and reduce negative impacts that could potentially widen health disparities between population groups—in short, more equitable delivery of the program, service, policy etc. Effective use of HEIA is dependent on good evidence.<sup>186</sup>

In addition, there is a home-based primary care model for the frail elderly in the greater Toronto area that aims to “[provide] access to ongoing primary medical care; maximizing independence and function; enhancing patient safety and quality of life; linking patients to supportive home care services; and reducing emergency department and hospital admissions”.<sup>187</sup>

The sustainability of the model has been enhanced by the implementation of the Care of the Elderly Alternative Funding Plan, which funds primary care physicians who take into their practices frail elderly patients unable to travel in and out of their homes.<sup>188</sup>

Furthermore, the community health-centre model of care seeks to eliminate systemic barriers to accessing health care, including: “poverty, geographic isolation, ethno- and cultural-centrism, racism, sexism, heterosexism, transphobia, language discrimination, ageism, ableism and other harmful forms of social exclusion, including issues such as complex mental health that can lead to an increased burden or risk of ill health”.<sup>189</sup> This model of care focuses on primary illness prevention, health promotion, community capacity building and service integration. The model is informed by the following principles: accessibility, client- and community-centred care, inter-professional service delivery, community governance, inclusion of the social determinants of health and utilization of a community development approach.<sup>190</sup>

Finally, Hankivsky and others describe the interconnectedness of intersectionality and social determinants of health and the benefits of integrating intersectionality to better address fundamental causes of illness and disease. Documenting lived experiences of community members based on an intersectional analysis can provide the insight needed to develop effective programs and services within the health care system. Intersectional analysis can provide a multi-dimensional understanding of the complex impact of social locations and the social determinants of health on health outcomes.<sup>191</sup> Hankivsky and others also recommend consideration of the impact of racism, classism and sexism on health inequities. The creation of a collaborative policy or assessment which addresses the complexities of systemic oppressions, identities and social determinants of health, may help eliminate health inequities. Elizabeth McGibbon and Charmaine McPherson outline an integrated approach to begin discussion of oppressions, social determinants of health, and intersectionality as illustrated in Figure 2.

**FIGURE 2—SYNERGIES OF OPPRESSION: A FRAMEWORK FOR ADDRESSING SOCIAL DETERMINANTS OF HEALTH INEQUITIES (MCGIBBON & McPHERSON, 2011)**

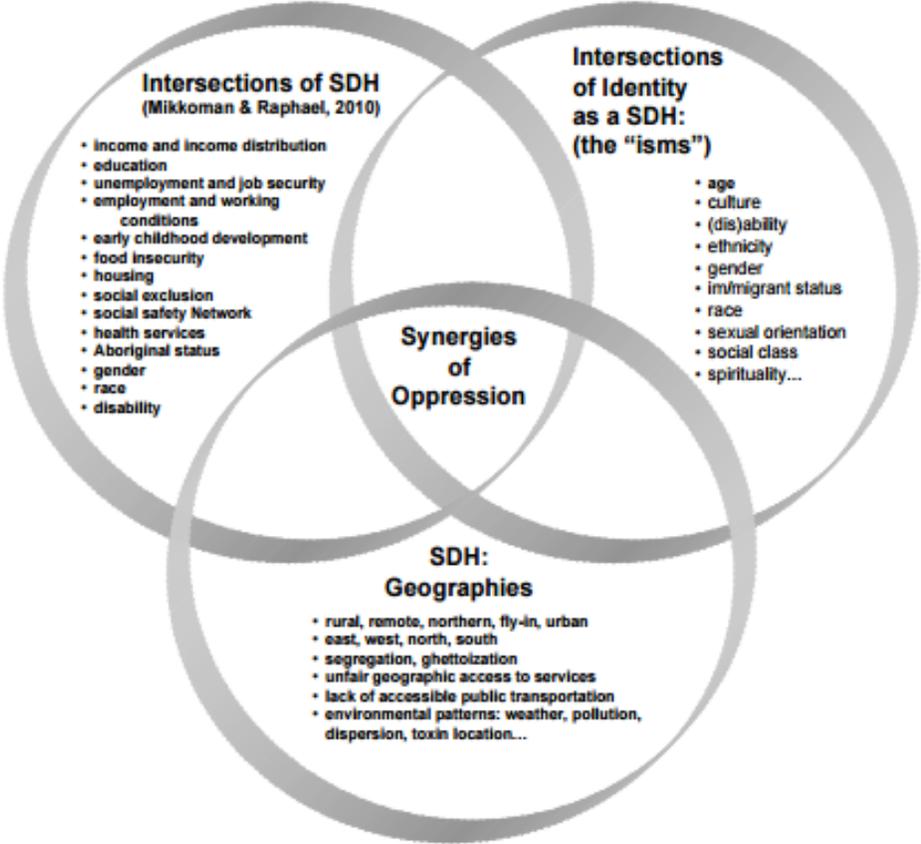


Figure 2 illustrates that oppressions, intersectionality and social determinants of health do not operate in isolation from one another. An inquiry to create a theoretical framework to explain and implement practices, which demonstrate the interrelationships of social determinants of health, resiliency of communities and lived experiences, oppressions and intersectionality would support evolution of health care practices to better serve patients’ and families’ needs.<sup>192</sup> Understanding how frail elderly patients within vulnerable populations are affected by health inequities will provide a comprehensive way forward to addressing their health needs.

**D. Last Stages of Life and Caregiving**

Family caregivers play a significant role in the dynamic and complex process of caring for the frail elderly in the end stages of life. Various factors impact the ability of family caregivers to provide the often complex care required for frail elderly persons. These factors include decline

in physical and cognitive ability, co-morbidity, increased dependency, lack of advance treatment planning, limited access to services, family dynamics and relationship with health care providers. The resulting complexity complicates what is required by family caregivers and creates a need for care that is consistent yet individualized.<sup>193</sup> A call for care that is specific to the often complex needs of both patients and their family caregivers is found in Sharon Carstairs' Senate report on the state of palliative care in Canada. She states that, "Canadians are living longer, but they are living longer with complex conditions. Canadians at end of life and their families need the right interdisciplinary health and social services care, at the right time and in the right setting, based on their needs".<sup>194</sup> Concerns raised by Carstairs are consistent throughout global literature (regardless of context) where researchers have identified the need for an integrated and comprehensive approach to end-of-life issues in the frail elderly.<sup>195</sup>

Perhaps most importantly this research suggests, as Carstairs calls for, a paradigm shift with respect to our collective understanding of palliative care, which has traditionally been associated with cancer and short term prognosis.<sup>196</sup> Palliative care provides supportive treatment at end of life that ensures pain and symptom management, decreased suffering, and psychological and spiritual support to patients and families to enhance the quality of life for people who are both living and dying at the same time. People with life-limiting illnesses, such as dementia, have traditionally had limited access to palliative care, possibly because of extended and uncertain disease trajectories<sup>197</sup> and health care policies that have restricted access.<sup>198</sup>

The barriers to accessing quality palliative care for those with advanced chronic disease was identified in the Joint Declaration of Partnership (2011) between the Ontario LHINs, the Government of Ontario and the Quality Hospice Palliative Care Coalition of Ontario. The Declaration acknowledges that care for the elderly is currently fragmented, location dependent and disease-focused, rather than integrated and person-focused. Like Christopher Frank and C. Ruth Wilson<sup>199</sup>, who review and call for shared care models that integrate family practice with geriatrics, the LHIN declaration pledges to integrate primary, geriatric and palliative care. This declaration makes a strong case for care that fits the needs of individuals and their family caregivers rather than asking individuals to fit existing care or program models that may or may not be available.

## **1. Specific Areas of Need**

### **i. Decision-making: Consent and Planning for Future Care Needs**

Planning for future care needs is a major contributor to healthy aging in Canada, is identified in the National Senior's Strategy and appears as a major component in research on end-of-life care.<sup>200</sup> Planning for the future assists families and health care providers in making important decisions that can guide treatment at the end of life and has been found to have a significant effect on lowering the number and length of ICU admissions in elderly patients.<sup>201</sup> Factors that can complicate end of life decision-making include: moral distress; invasive suffering (a particular issue for the frail elderly where treatment may inflict unnecessary suffering); negotiating tensions and preparedness<sup>202</sup>; cultural, religious and socioeconomic values with respect to concerns about quality of life; mistrust of the system; spirituality; and an understanding of who belongs in the conversation about care planning.<sup>203</sup> Multiple reviews and studies indicate a need for better communication regarding advance care planning from both the patient and health provider perspectives with a general consensus that family practice is a practical location for these conversations, even though family physicians cite a lack of skill in this area.<sup>204</sup> Robin Sekerak and Jonathan Stewart suggest it is important to distinguish whether goals of care are to promote the quality or quantity of one's remaining life.<sup>205</sup> However, these distinctions may not be evident to families prior to the crisis points when decisions are often made. Michelle Howard, Carrie Bernard, Amy Tan and others capture some of the complexity of advance planning:

Ideally, advanced care planning is an ongoing process . . . The presence of an advance directive does not guarantee that a patient has reflected on a variety of health states that might be experienced in relation to his or her desired quality of life, or that the patient has communicated his or her values and preferences to the SDM [substitute decision maker]. In the moment of crisis, the applicability of decontextualized choices to the patient's unique situation and the extent to which outcomes of such decisions align with the patient's preferences might be unclear.<sup>206</sup>

In an attempt to understand why these conversations are so difficult for physicians, Kristy S. Deep, Sharon F. Green, Charles H. Griffith and others investigated the attitudes and perspectives regarding end of life discussions with patients among physicians during their residency training.<sup>207</sup> Their findings were consistent with findings of others that show that patients and families desire shared decision-making but are often dissatisfied with the quality of communication.<sup>208</sup> Deep and others identified that the conversations are often content-based (disease- and treatment-focused, attention to task) rather than process-focused (inclusive of values, fears, taking enough time, listening, paying attention to body language).

The physicians described being challenged by their own emotions and those of their patients, frustration with family members who were not unified, mistaking grief for denial, ideas around death and dying and internal conflict that arose with faith-based beliefs or uncertainty around goals of care. They suggest a need for increased education and practice with highly charged discussions. Howard and others recommend several tools and programs that have been implemented in Canada to assist with the promotion of advance care planning in family practice.<sup>209</sup>

Making treatment decisions is often complicated by ethical questions, particularly when these decisions are made by proxy. Perceived quality of life is a major factor influencing treatment choice in the last stages of life when family members may be making decisions for the patient who can no longer communicate his own preferences.<sup>210</sup> Without knowledge and understanding of the patient's values, wishes and treatment preferences, physicians may tend to propose treatment options that are disease specific rather than based on the individual.<sup>211</sup> According to Barbara L. Kass-Bartelmes and Ronda Hughes:

Predicting what treatments patients will want at the end of life is complicated by the patient's age, the nature of the illness, the ability of medicine to sustain life, and the emotions families endure when their loved ones are sick and possibly dying.<sup>212</sup>

Further complicating this, Dawn Allen, Valerie Badro, Laurie Denyer-Willis and others found that in complex illness (in this case kidney disease) treatment options are often presented to patients as a binary do/don't do decision, which often cannot be applied to complex illness.<sup>213</sup> Their research promotes whole person decision-making, which may include factors such as functionality, life circumstances and care goals that are not captured by such binary choices.

## **ii. Collaboration and Integrated Care**

A number of studies suggest that the highest priorities of patients with serious end-stage conditions—such as cancer, end-stage kidney disease, or limitations in the ability to perform the activities of daily living—are pain and symptom relief with the goals of optimizing quality of life, limiting burden to family, making relationships with family closer and maintaining a sense of control.<sup>214</sup> This requires a collaborative relationship between patient, family members and health care providers built on trust and an understanding of patient and family values.<sup>215</sup> Collaboration leads to more integrated and effective care for the frail elderly at the end stages of life when their needs are most complex.<sup>216</sup> A multidisciplinary collaboration, including both medical and supportive services, may best promote successful community living at the end of life with increased independence and fewer symptoms.<sup>217</sup>

### iii. Support for Family Caregivers

Support for family caregivers, extended family and friends have a significant impact on a person's ability to remain in the community. Support to caregivers can include financial assistance, employment programs, training to enhance capacity, bereavement support, integrated care and respite.<sup>218</sup> In a paper on ethical family-physician relationships, Sheryl Mitnick, Cathy Leffler and Virginia L. Hood suggest that:

Caregivers require information, access to resources and support to facilitate their role. Physicians can positively affect the caregiving experience by recognizing and addressing caregivers' physical, psychological, spiritual and emotional needs and acknowledging the value of the caregiver role.<sup>219</sup>

Serge Dumont, Lise Fillion, Pierre Gagnon and others have developed a tool that assesses burden in the end stages of care and their research suggests that caregiver burden can negatively impact a person's ability to remain at home in end stages of life.<sup>220</sup> While respite care is often suggested as a means to mitigate burden, a systematic review of respite care in the United Kingdom<sup>221</sup> suggests that respite does not affect burden but does provide improved satisfaction for caregivers of people with end-stage dementia. This reflects that the heavy burden placed on caregivers of persons with dementia may not be easily relieved.

## 2. Indicators of Quality of Care

Consensus across the literature is for pain and symptom relief, optimized quality of life (QOL) autonomy and connection. However, patients with dementia or cognitive decline may not be able to articulate that they are in pain or determine many of the other factors that contribute to perceived or experienced quality of life. It then falls upon the family caregiver to make these determinations. While definitions of quality of care (QoC) can differ, there are consistencies across end-of-life literature that suggest that satisfaction is increasingly considered to be a reliable measure of QoC<sup>222</sup> Factors shown to increase satisfaction are treatments that are less invasive<sup>223</sup> and non-hospital based. In the U.S., care that is hospital- or office-based versus care at home was found to lower costs by 25% and increase patient satisfaction outcomes.<sup>224</sup> A comprehensive U.S. report by John Mitchell found that over 80% of patients prefer to avoid hospitalization and intensive care during the terminal phase of illness and that more invasive care often led to more suffering.<sup>225</sup> Research in Japan by Setsu Iijima, Nobuko Aida, Hideki Ito and others<sup>226</sup> promoted quality care as treatment that is appropriate to the patient without over or under treating and that includes care and support for family and friends caring for the elderly.

### **i. Satisfaction Level with Services**

The most significant contributor to patient satisfaction is access to palliative care and hospice care.<sup>227</sup> The same research suggests that improving satisfaction entails understanding which elements of palliative care are important for which patients and families to ensure end-of-life interventions are tailored to the individual. Patients with end-stage dementia often do not receive hospice care in spite of hospice care being identified as a measure of QoC.<sup>228</sup> A Cochrane review of the cost effectiveness of palliative care found small but significant evidence that palliative care increases the chances that a person will die at home and strong evidence that symptom burden is lower in at-home palliative care.<sup>229</sup> However, the same review showed no effect on caregiver grief. It is important to note that persons with end-stage dementia may have difficulty communicating or understanding their pain and therefore it is more difficult to predict symptom relief in this population.

With an aging population and an increase in the number of frail elderly being cared for by family members who may themselves be aging, it is necessary develop new perspectives on death and dying and revise models of care to meet patients' needs.<sup>230</sup> While there is a clear need to improve the experience of patients and caregivers at the end of life, it is important that policy and best practices move toward less fragmentation and equal access while at the same time creating flexible policy that expands how we understand treatment, values and accountability in end-of-life care for the frail elderly. Canada Research Chair Harvey Max Chochinov suggests making a distinction between health care and health caring as a means of distinguishing the kind of care that truly makes a difference to patients because it informs treatment goals unique to the individual and promotes trust between professionals and patients.<sup>231</sup>

## **E. Current State of the “System” and Identified Gaps**

Ontario's health care system for frail elderly patients is shifting from the current institutionally based model of acute and long-term care for complex patients to providing a continuum of care in the community. The system is seeking to address health care needs by using a holistic approach for last stages of life, taking into account other aspects of life that patients value, such as spirituality, social, housing and familial or community needs.<sup>232</sup> The Ministry of Health and Long-Term Care in Ontario has recently introduced Bill 210, *The Patients First Act*, 2016, which has the goal, among others of enhancing integration and continuity of care and improving access to and uniformity of home care across Ontario. Planning for an integrated approach to hospice and palliative care for frail elderly patients will also be needed.<sup>233</sup> (See Appendix E for

current programs, services and policies addressing the needs of caregivers and patients at last stages of life.)

### **1. Identified Gaps**

The gaps in providing quality care in the last stages of life include limitations specific to the geographic locations of services, funding structures and eligibility criteria for receiving benefits for caregivers. Allison Williams and Valorie A. Crooks completed a pilot evaluation of the Compassionate Care Benefit (CCB) offered by Employment and Social Development Canada and found limitations to the benefit.<sup>234</sup> For caregivers that are caring for someone with non-malignant advanced chronic illness, it is difficult to project the trajectory of the illness so there is uncertainty about when to apply for CCB. Williams and others recognize that the CCB is a beginning point to address the extensive burden and stress faced by family caregivers.<sup>235</sup> Implementing palliative care principles in current services and models of care will provide a systematic way to increase quality of care at last stages of life. For example, The Way Forward Project (See Appendix E) is informing provinces such as Alberta in the creation and implementation of a provincial palliative care framework. Alberta has successfully completed the first stage of implementation by embedding its framework within its current health services system, leveraging current funding structures and resources and collaborating with communities within the province to inform policy and programming details to provide quality care informed by palliative care principles. The Way Forward Project provided a framework to begin implementation in primary care, long-term care settings and home care services.

## **F. Conclusion**

Care in the last stages of life is an urgent societal issue which impacts an increasing number of Canadians. The aging of the population will give rise to an increase in the number of people confronted by end-of-life issues, either individually or through involvement in their care. Elderly persons are living, often for many years, with severe frailty and chronic illnesses and struggle to gain access to needed services from a fragmented, unresponsive system. As outlined above, needs and perspectives of this group and their caregivers are not well characterized. Their voices are missing from the conversation. To address this gap, a two-stage, multi-perspective qualitative study, described below, was undertaken. In the first stage, frail elderly persons in the last stages of life and their caregivers were given the opportunity, perhaps for the first time, to describe their lived experience in their own words. A full appreciation of the lived experience of this population means hearing not only from patients and caregivers but also those involved in the provision of care. To capture this perspective requires a multi-

stakeholder approach to survey individuals, industry, government, community and non-governmental organizations. Thus, in addition to hearing directly from patients and caregivers, consultation and input were sought from a group of informed and interested stakeholders from the fields of medicine, ethics, law and public policy. This innovative research has the potential to provide new insights to inform public policy and positively influence the social, legal and economic fabric of Canadian society.

### **III. THE LIVED EXPERIENCES OF PATIENTS AND CAREGIVERS IN ONTARIO AND EXPERT STAKEHOLDERS' RESPONSES TO THEIR LIVED EXPERIENCES: A QUALITATIVE STUDY**

#### **A. Introduction**

Building on the literature review, a focused qualitative study was proposed and conducted to explore the lived experience of frail elderly patients, their caregivers and family members with Ontario's system of care, as well as opportunities for enhanced supports as identified by professionals working directly and indirectly with these patients and caregivers. In the sections below, the research methodology and framework (Appreciative Inquiry), study population and protocol adopted for the current study are describe in detail. In Chapter V, the extensive findings of this two-stage qualitative study are presented. Specifically, findings are presented in two major sections below in accordance to the two stages of the research:

- Stage I: A purposive sample of 12 patients and 14 caregivers was interviewed using a semi-structured guide developed for this project (Appendix C). The first set of findings highlighted the personal experience of these patients and their primary family caregivers, and their need for and perception of the system of care that they encountered.
- Stage 2: Individual interviews with 11 members of an expert advisory panel were conducted. The panel was made up of stakeholders from these professional fields: medical, allied health, legal and ethics, administrative and policy. Each expert stakeholder was presented with the summary findings from Stage I and asked to provide recommendations for changes that respond to the experiences of the representative patients and caregivers interviewed.

#### **B. Conceptual Framework and Methodological Approach**

A two-stage, multi-perspective study employing "Appreciative Inquiry (AI)" was conducted. "Appreciative Inquiry" is a form of action research that begins by identifying where opportunities lie, which may be used to motivate a vision and path for change. The strength of AI lies in its "generative capacity", which is a "capacity to challenge the guiding assumptions of the culture, to raise fundamental questions regarding contemporary social life, to foster reconsideration of that which is 'taken for granted' and thereby furnish new alternatives for social actions".<sup>236</sup>

AI is a four-step, action research approach traditionally used to stimulate organization and system transformation. It is well-suited to guide the current research as it allows participants to Discover, Dream, Design and Realize their Destiny:

- Discover—an “appreciative” phase which allowed interviewees to tell us the “what has been”. Interview questions were written to generate stories, to enrich inner dialogue within the last-stages-of-life care system and the population interacting with it, and bring the opportunities for change and improvement more fully into focus.
- Dream—a “provocative” phase where interviewees were invited to think outside of the boundaries of what had been in the past, open-endedly discuss the “what might be” and explore realistic developmental opportunities.
- Design—an “applicable” phase for interviewees to make choices about “what should be”, and generate solutions that would align with “what has been” and “what might be” and be concretely beneficial to the system under review (the last-stages-of-life care system).
- Destiny—a “collaborative” stage focused on determining how the solutions identified in the Design stage may be applied and validated in action. It elicited personal and organizational commitments to bring about changes in the system, and participants’ thoughts on how they can contribute to the development of “what will be”.<sup>237</sup>

## **1. Study Population**

Stage I of the study involved 26 patients and caregivers (of which 12 were patients and 14 were caregivers). Community-dwelling frail older patients (aged 65 and up) and their nominated key informal caregiver were purposively recruited to include a variety of patients/caregivers dyads of different backgrounds with regards to such variables as patients’ health conditions (problems), socioeconomic status, culture/ethnicity, geographical locations and informal care arrangements. The intention was to have a representative sample of dyads, which provided a multitude of different perspectives and contexts as well as an enriched account of issues commonly encountered by this population in Ontario. Initial field access was obtained via the network of local academic teaching practices and clinics in Ontario, with which the authors and confirmed stakeholders (Appendix B) may be affiliated. These professionals then referred patients aged 65 and older, in Stages 7 or over on the Canadian Study of Health and Aging (CSHA) Clinical Frailty Scale<sup>238</sup>, to the research team.

Stage II of the study involved focused interviews with 11 expert stakeholders from various professional groupings: medical, allied health, legal and ethics, administration and policy. Findings from Stage 1 were reported to the expert stakeholder panel, and these patient/caregiver case studies were considered in a broader context. Each member on the panel was interviewed individually and invited to discuss the key findings of the first stage, draw conclusions and point out opportunities for implementation of the results with respect to education, services, law/policy change and process management. This section resulted in a specific commentary and recommendations for changes that may improve the current situation as experienced by the 26 representative patients and caregivers interviewed.

Further details regarding how the Appreciative Inquiry approach was adopted in the current two-stage research and the study population may be found in Appendix A.

## **2. *Data Collection and Management***

Interviews from both research stages were digitally recorded for transcription with the consent of the interviewees. Three experienced qualitative researchers (MC, SM and LJN) conducted all interviews and made comprehensive field notes to facilitate the contextualization of the data. Verbatim transcriptions were outsourced to a professional research transcription service. The software program NVivo-11 was used for data management, coding and subsequent qualitative data analysis.

## **3. *Data Analysis***

Three experienced qualitative researchers in the team (MC, SM and LJN) participated in data analysis. As illustrated in the timeline, analysis of the patient and caregiver interview and field notes began soon after the first interview and took place in parallel to the ongoing data collection. This ensured that emerging themes and first key concepts were included and further developed in subsequent interviews. Interviews were iteratively analyzed using the inductive and narrative approach, and interpreted on different levels to allow for longitudinal analysis across the cross-sectional cases.

Thematic analysis guided the analysis of stakeholder interviews. All stakeholders received a draft of the condensed main themes and recommendations and were invited to provide additional comments in order to validate the results.

#### **4. *Research Ethics Approval***

Research ethics approval was received from the Toronto Academic Health Science Network (TAHSN) research ethics board at Sinai Health System. Written informed consent was obtained from all participants. Consent included the option to withdraw from the study at any time. Interviewees were aware of the risk that they might develop a personal relationship with the interviewer and erroneously expect that the interviewer was available to them in a therapeutic role.

## IV. QUALITATIVE STUDY FINDINGS

### A. Introduction

In this chapter, the extensive findings of the two-stage qualitative study are presented:

1. Sections B and C with results from patient and family caregivers' interviews, and
2. Sections D and E with findings from interviews with expert stakeholders.

Specifically, in Section B, which is guided by the “appreciative” phase under the Appreciative Inquiry (AI) approach, patient and caregivers told us the “what has been”—in other words, their experience living with frailty, multiple chronic illnesses or dementia: the psychological processes they undergo, the loss they endure, the unpredictability and uncertainty of their diagnoses and disease processes. Patients and caregivers also discussed at length the coping mechanisms—both effective and not—that they utilized to counterbalance the discouraging aspects of their lived experiences: through gaining knowledge about the system of care, advocating for themselves (in the caregivers' case, advocating for the patients), maintaining some sense of autonomy and retaining normalcy. Patients and caregivers find themselves in a constant tug-of-war between maintaining “order” at this stage of life, and falling into the “chaos” of managing crises. Since most of our interviewees were being cared for at home, that is, not receiving institutionalized care—for example, in a long-term care facility or in an alternative-level-of-care bed in the hospital—they described specific challenges associated with home care in Ontario and the resulting “chaos” that ensued. A figurative representation summing up the lived experiences of patients and caregivers may be found in Figure 4.

In Section C, the data collection and analyses were driven by the “Dream” phase from the AI approach. This is a “provocative” phase, inviting patients and caregivers to think outside of the boundaries of what had been in the past, open-endedly discuss the “what might be” and explore realistic developmental opportunities. The data, as summarized in Figure 5, focused on specific points of encounter by patients and their caregivers with the system of care in Ontario as they search for a diagnosis and prognosis; are being clinically and functionally assessed at various time points; struggle with uneven distribution of resources; and attempt to access resources and advocacy groups. As evident in the data presented in this section, patients and caregivers had trouble “dreaming” of what would improve their situations, as they often felt powerless when pitched against a fragmented system that lacks cohesion and effective communication between sectors. Also, these individuals are very much consumed by the suffering from their dire physical complications, so that they may not have the capacity to reflect on what could alleviate their conditions. They dreamed, however, about having an entity—an individual or team—that has a

thorough and comprehensive understanding of their personal situations, which can guide them in system navigation and advocate for them as they interact with the Ontario system of care.

Section D presented an “unplanned data set” as expert stakeholders from different jurisdictions spontaneously reflected upon and commented on the inefficiencies in the systems (or lack of a system). The resulting collective “lived experience” of professionals from the legal, health care and policy fields candidly validated and complemented the lived experiences of patients and caregivers. The “lack of systemic coordination and supports” (“non-system”) implied in the patients’ and caregivers’ interviews, was clearly described by stakeholders across all professional groupings. The characteristics, consequences and impact of the “non-system” on the professionals, patients and caregivers were summarized in Figure 6. The “non-system” is characterized by its reactivity, non-collaborative relationships between legal and medical sectors, scattered resources and access inequity. It is further complicated by communication gaps or miscommunications between professional sectors and between the system and the patients and caregivers, which may contribute to patients’ and caregivers’ unrealistic expectations of what the system can or cannot do for them, leading to increasing pressure on and moral distress experienced by frontline professionals.

The chapter closes with Section E, guided by the “Design” and “Destiny” steps from AI. Expert stakeholders were asked about how existing systems and infrastructures may be leveraged and optimized to improve the conditions and lived experiences of individuals at their last stages of life and their family caregivers. In response, they described the conceptual and practical elements required to build a “responsive system” of care that is compassionate, collaborative and cohesive and encourages communications (Figure 7). The four pillars essential to the structure of this system are: humanizing the experience, engaging family and caregiver, expanding professional education and public awareness.

## **B. Lived Experience of Older Adults Living with Frailty, Multiple Chronic Illnesses and/or Dementia, and Their Caregivers**

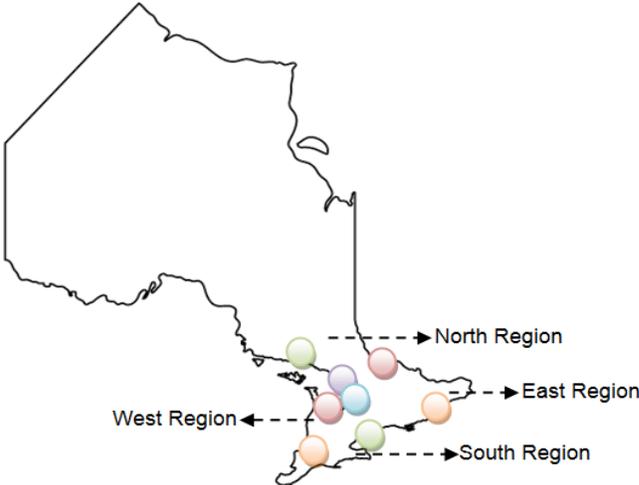
Individuals in the last stages of life may have one and sometimes multiple chronic, life-limiting diseases which lead to increased frailty (physical and/or cognitive), and may not be faced with imminent death. In Stage 1 of the study, we examined the lived experience of 26 of these individuals (age 65 and older; known hereafter as “patients”) and/or their caregivers (note: caregiver only if the patient was “cognitively frail” according to the CSHA Clinical Frailty Scale<sup>239</sup>) by interviewing a purposive sample (please see Table 2 for demographic information) living in different regions in Ontario.

**1. Demographic Information**

Twelve clinically frail elderly patients and 14 family caregivers, for a total of 26 participants, were interviewed. All patients interviewed had a frailty score of 7 or over and were considered in the last stages of life by that definition. Table 2 shows the demographic characteristics of the patients-and-caregivers dyad interviewed, with these key features:

- 67% of patients and 92% of caregivers were female;
- 31% of interviewees belonged to a visible minority;
- 83% of patients were receiving home care (that is, not living in a long-term care facility or receiving care in a hospital at the time of interview)

**FIGURE 3—DISTRIBUTION OF PATIENT AND CAREGIVER INTERVIEWEES IN ONTARIO**



As seen in Figure 3, 11% of our participants resided in Northern Ontario, 31% in Southern Ontario, 23% in Western Ontario and 35% in Eastern Ontario. One thing of note is that all interviewees were either Canadian born or have resided in Canada for more than 25 years. As discussed in extensive detail in Section C, their unfamiliarity with the system of care that was supposedly built to meet their needs at this stage of life highlighted the urgent need for re-examination of and closing system gaps.

**TABLE 2—DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS (CG = CAREGIVER, PT = PATIENT)**

CG/PT	Age	Region	Sex	Marital Status	Ethnic-origin	Visible minority	Years in Canada
CG	30	Peterborough	F	Married	Scotland/England /French Canadian	N	Canadian born
CG	51	GTA	F	Married	Eritrea	Y	25
PT	58	GTA	M	Married	Eritrea	Y	25
CG	78	Toronto	F	Married	Scotland/England	N	Canadian born
PT	91	Waterloo	F	Widow	Canadian	N	Canadian born - lived in Bolivia in young adulthood
CG	66	Waterloo	F	Married	Canadian	N	Canadian born - lived in Bolivia in early life
CG	38	Algoma	F	Single	Polish/Welsh	N	Canadian born
PT	66	Algoma	M	Married	Polish/Welsh	N	Canadian born
CG	58	Durham	F	Married	Guyana	Y	38
PT	78	Scarborough	F	Married	Guyana	Y	30
PT	84	Toronto	F	Widow	Canadian	N	Canadian born
CG	63	Toronto	F	Married - recent widow	Canadian	N	Canadian born
CG	68	Kawartha Lakes	F	Married	Canadian	N	Canadian born
PT	69	Kawartha Lakes	M	Married	Canadian	N	Canadian born
PT	90	Kawartha Lakes	M	Married	Canadian	N	Canadian born
CG	88	Kawartha Lakes	F	Married	Canadian	N	Canadian born
PT	82	GTA	F	Married	England	N	61 years
CG	50	Peel	F	Married	Indian (India)	Y	over 40 years
PT	77	Peel	F	Widow	Indian (India)	Y	over 40 years
PT	77	Durham	F	Single	England/Ireland	N	Canadian born
CG	58	Durham	M	Married	England/Ireland	N	Canadian born
CG	46	Algoma	F	Married	French Canadian/Ireland	N	Canadian born
PT	84	Toronto	F	Widow	Canadian	N	Canadian born
CG	66	Toronto	F	Married	American	N	30
PT	93	York	F	Widow	Asian	Y	35+
CG	64	York	F	Married	Asian	Y	35+

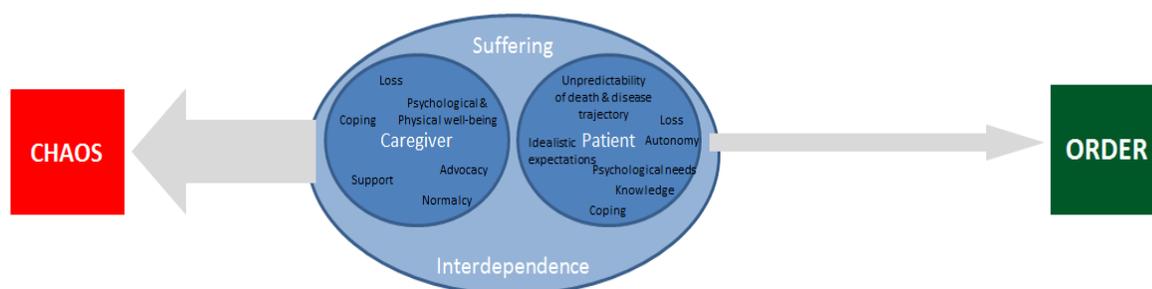
## 2. Lived Experience of the Patients and Caregivers

In presenting the data, we considered the patient and caregiver as a dyad, and took their combined lived experience into account whenever possible. The overarching theme within the dyad was that of suffering and interdependence: while suffering is inevitable and a key feature during the last stages of life, interdependence presented as both the consequence of and the humane response to suffering. This was evident in the interactions within the dyad—a microsystem set up between the patient and the family caregiver(s)—and in ways the dyad reached out to external systems (such as social circles, allied health, medical, legal), depending on them to provide support that would ensure a dignified way to live the last stages of life.

### i. Characteristics of the Dyadic Microsystem Made Up of the Patient and Caregiver

The dyad, as a microsystem, has characteristics as illustrated in Figure 4 inside the small dark blue ovals. As patients and caregivers are “thrust” into their specific roles, they each exhibit different intrinsic characteristics that continually shape and construct their roles. Patients go through a psychological process of either accepting their prognosis or continually struggling with the uncertainty of the disease trajectory and the unpredictability of death. This process evolves throughout the last stages of life, and may cause patients to have idealistic expectations of life and of what the systems can or cannot do for them. As a coping mechanism or to exercise autonomy, patients go to great lengths to learn about and manage their illness (knowledge). In some cases, especially where the patient is incapable, the caregiver has to do the same in order to advocate on behalf of the patient.

**FIGURE 4—CHARACTERISTICS OF THE DYADIC MICROSYSTEM**



Caregivers also support the patients in practical ways, assisting them in their daily living, at the same time attempting to maintain their own well-being and the normalcy of the household. Both patients and caregivers experience a sense of loss such as mobility and other functions, roles and relationship. By the nature of the context they are situated in, the dyadic microsystem is vulnerable and prone to chaotic circumstances such as medical crises, although they may desire “order”, where events can be in their control, be carefully planned and occur in a systematic or “orderly” manner.

In their interviews, patients and caregivers provided extensive details regarding treatment options they explored on their own, the frequent emergency-room visits, the difficulties they experienced during transitional phases as they were discharged from acute care, and how they scrambled to find resources they could access. However, most interviewees could not articulate or comment on issues such as legal preparations, final wishes, consent and the relationship between a power of attorney (POA) and substitute decision maker (SDM), and the implications of decision-making regarding care within these roles. The disconnection from this aspect of planning highlighted how complex the medical conditions faced by the patients were, and the complications that surround these conditions were so all-consuming that the dyads had no time to reflect on, discuss or plan “other” matters that were equally relevant at this stage of life.

Another salient theme so ironically loud and clear, yet not verbalized, was the absence of cohesive and responsive external systems which the dyads could rely on. Without these systems, everyone attempted to find support in their own ways, with some having better luck than others. This put patients or dyads in a precarious position or close to chaos.

## **ii. Chaos in the Context of Home Care**

As the majority of our patient-interviewees were receiving home care, our data set specifically revealed their experience of chaos with regards to the coordination and implementation process of home care services. Interviewees described the multiple times they had to repeat their needs to different health care administrators and professionals, which resulted in feelings of distress and in receiving minimal help and services that did not match the needs of the patient.

Frail elderly patients with diagnoses such as dementia may have moments in the day where they may not appear to require personal care, but actually require intensive personal care much of the time. Having a case manager assess the patient’s needs at a given moment in the day may not adequately reveal the full care-needs picture of the patient, leading to inaccurate assessment of service requirements and inadequate allocation of hours of home care service.

This inappropriate downloading of responsibility onto the caregiver contributes to caregiver burnout and distress as they have to take time off of work, find alternative care, and be left to figure out who to call and where to go in a time of crisis.

Another contributor to chaos is the cost of home care services for caregivers. As discussed in the literature review, some home care in Ontario is provided free of charge and currently facilitated by centres for community access. Caregivers who have low to middle socioeconomic status experience barriers to this service because they cannot afford additional home care services to supplement the limited, publicly funded time allocated to them through these centres. Navigating the system to find alternative forms of care, such as day programs, is often done with uncertainty and not knowing what is available in their community. Although Ontario is filled with many resources in certain regions, this is not the reality in regions further from urbanized areas. In this case, the chaos experienced by these caregivers and patients is two-fold, having limited to no access to a much-needed service both to alleviate the caregiver from distress and to provide quality of life for the patient. This intersecting experience of the caregivers' socioeconomic status and their geographic location was especially highlighted in the interview data from the Northern region of Ontario.

In the next sub-sections, representative narratives from our interviewees are presented to further elucidate each dyadic characteristic summarized in Figure 4.

### iii. Psychological Process

Living with multiple chronic, life-limiting illnesses, elderly patients in our sample expressed several psychological responses: disappointment, depression, isolation, hope or hopelessness and sense of loss. These may fluctuate and change from day to day.

Having to interact frequently with the health care system, many patients may become bitter or disappointed in what it cannot offer, in its fragmentation and in its insensitivity. Some patients felt that they have been “cheated”—that is to say, if only the system were more responsive to their needs, they would have a better chance of survival:

**Patient:** I felt like the health-care system has failed me.

**Patient:** I would get annoyed and I'd say, well, you guys have got to speed this up. It's already too late at this point, but I didn't really know, and they play you along. I'm saying “play you along” because I think they're not sure about what they're supposed to do, and so they don't . . . pay attention to my symptoms. If there's a chance you can save someone in that initial treatment, it's in that beginning of the

disease, you know, the survival rate is much better than somebody who did not start treatment early.

Throughout the course of disease, patients may toggle between states of hope and hopelessness. From time to time, patients are dragged down by periods of hopelessness. When they are having a “good day”, patients may feel energized by hope: hope for a cure, hope for a longer life.

**Patient:** I go to the doctor, no hope. Just they let me stay home. Just they let me stay home until I die with no hope, with no medication, with nothing. All our hope, all our life, gone. I never knew this would be such a fast-changing situation.

**Patient:** We’ve got some lovely children and grandchildren. They are my source of joy and hope, give me hope . . . maybe I’ll be given more time in life, you know.

Patients may also experience isolation as they interact with their social circles less when their frailty worsens. As one caregiver observed, “Loneliness is a terrible thing and when terrible things are going on it’s worse”. Patients, and at times caregivers, become depressed as a result of isolation:

**Caregiver:** He doesn’t have any other friends in the community; his friends were all his family. He had seven brothers; they were very, very close. Unfortunately he’s lost one almost every year for the last, like, five years, so there are two left besides him and he’s the oldest of all of them. He’s mostly on his own now. But so yeah, so . . . sorry, I just need to grab a Kleenex.

One prominent psychological process that our caregiver-interviewees experience is the sense of loss. This is especially true in caregivers caring for someone with dementia. Patients with dementia, as observed by their caregivers in our study, experience a variety of symptoms which increase as their disease progresses. These range from an initial difficulty with complex tasks and forgetfulness, to their loss of ability to carry out basic daily living activities such as dressing and eating. As articulated by our caregiver-interviewees, their relatives with dementia may experience behavioural and other changes such as loss of mobility and ability to communicate. Witnessing this slow and agonizing progression of dementia, caregiver-interviewees experience a sense of loss as they may feel that a part of the person is being lost every day, and caregivers are left with the idea of how it used to be like with the person, and what it could be if only dementia did not happen.

Patients with different life-limiting conditions experience loss as well: physical function, cognition, and autonomy. They may also experience a loss and transformation of their roles, such as from wife/husband/daughter to a dependent.

#### iv. Unpredictability and Uncertainty of Disease Trajectory

Both patients and caregivers discussed the ambiguity and uncertainty that surrounds the diagnoses and, later on, the disease process. Certain diagnoses may be hard to define or confirm, and when health care professionals could not provide an answer, the uncertainty becomes that much more worrisome for the dyad:

**Caregiver:** And then finally when he was having difficulty breathing, I said to him, “Let’s go to emerge doctors because we’ve been going to our doctor, nothing happening.” And then I took him to emerge. Then doctor saw him. He said, “But I did all the tests, there’s nothing. But I see you not comfortable, go check with your doctor.” So we went to another hospital. A young doctor was there, she said, “I know he has something but I cannot diagnose it because we run all the tests. There’s nothing.” I was exasperated.

As they continue on with the course of the disease, the dyad may have difficulties in predicting or adapting to the progression of disease. For the patient, there is uncertainty around “What symptoms am I going to experience next?”, “When will the pain stop?”, “When will I get better, or not?”:

**Patient:** As I told you, this kind of disease, it changes every day. Before it was okay, I can walk upstairs. Now, I basically stay here. I sleep in the dining room in a hospital bed.

Caregivers find themselves in unpredictable illness situations in which they are uncertain and bewildered but still forced to cope with new responsibilities in managing the outcomes of these situations. Emotionally, it can be nerve-racking for the caregiver to witness a relative falling repeatedly or worry about the effects of dangerously fluctuating blood sugar levels:

**Caregiver:** His sugars were good and now they’re getting out of whack. The blood pressure is getting high, his sugars are going up. They’re wondering if all this infection on his stomach and his gallbladder, is it all combined together. Everything is up in the air and anything can happen in the next second.

**Caregiver:** Every day is different. Last week, he fell. He was just getting up from the washroom and then all of a sudden, he ended up on the floor.

## v. Unrealistic and Idealistic Expectations

Unrealistic expectations may propel the dyad in the direction of “chaos” (feelings that they lack control), by promoting denial or poor understanding of their situation, inadequate planning or ineffective problem-solving. For example, patients may have unrealistic expectations about their condition—they hope, they fight and believe they will conquer. As one patient put it, “I just have to think that I’ll get through it”. Little energy and time, therefore, are put towards reflecting on and making preparations for the “alternative”—death.

**Patient:** We hope always when we go there; we go every three months, every two months. We believe something will come up to cure or to do something or treatment. They’re doing the research now. They said there is two [new] medicines to come maybe next year.

The health care system may also feed directly or indirectly into these unrealistic expectations. For example, patients and caregivers sometimes rely heavily on the attitude to the future. If a doctor conveys a message of unrealistic hope to the caregiver, it may be misinterpreted as “everything is fine” or “it will get better”:

**Caregiver:** So yeah, so the dependency has grown quite a bit. I remember asking my doctor, I said “Oh my gosh, she's getting forgetful. Is she going to forget me?” And she's like, “No, that won't happen 'cause she's so attached to you. She may not remember your name.” I don't want her to forget me.

**Patient:** So originally, when there was a spot in the kidney, but the results came back negative for cancer, the doctor had said, “Oh, go ahead, go to Florida, we'll test again when you come back”. So we were led to believe that it wasn't a big deal. “Oh, in four months come back and look again, and when we find it we'll deal with it then” and that sort of thing. Yeah, but it turned out to be a rare aggressive form of cancer, it progressed extremely quickly.

Some patients may feel their increased frailty was not an issue because they have done their duties by consulting with many health professionals, and they expect things to turn around for the better. Conversely, many of our caregiver-interviewees were exceedingly worried about the outcomes for the patient. This was especially true in the case of dementia patients. Emotionally, the caregiver does not want to lose the patient and has unrealistic expectations of what “needs to” happen. This may lead her to structure her daily life to ensure she is always with the patient, further reinforcing unrealistic hopes that “things will be okay”, that the

patient is resilient and that they will adapt. The unrealistic expectations that health will get better in time are highlighted in this dialogue:

**Patient:** Yeah. But the shoulder doesn't hurt me per se. It doesn't bother me. The hand, yes. The grip because I had just really—had very limited—I used to be a good cook and I used to like to cook. I can't do that anymore. I'm afraid to hold anything in my hand because I can't hold. I don't know whether I've got it or not. So that's frustrating, very frustrating, and now I'm getting to use my left hand more.

**Caregiver:** You've adapted.

**Patient:** I have good health, no more ill health. Bad enough. I don't like it.

Lastly, many of our elderly respondents have idealistic expectations on the trajectory of life in general—they worked hard their whole lives and are entitled to enjoy a good retirement. They saw their parents go through it and, by following suit, they expect the same long, happy life:

**Patient:** I mean, I think we all want to live a happy, healthy life. You know, my mother worked extremely hard throughout her life and, you know, accumulated a nest egg and a nice home and, you know, retired. I think I've done the same thing so I can have a retirement period where I enjoy the fruits of my hard work, you know. Forty years ago when I started to work that was the case. That's what people expected, is if you worked hard and you saved and you were smart, you know, you would have a comfortable retirement where you could enjoy life, right?

## vi. Coping Mechanism

For most interviewees, adaptive coping (that is, positive coping mechanisms) such as being practical, thinking ahead, making plans, being organized and keeping their schedule on track is used to manage the stress that comes with living through the last stages of life. They also sustain their psychosocial well-being by depending on their faith or connecting with close relatives and friends.

**Patient:** Support is from our community people, they come and pray always. You see this house, it's always full. Today you lucky you came—there was a guest this morning even when he's in bed. But it's always, the church people, they come.

**Caregiver:** I call my granddaughter often, and talk to her on the phone. I mean, she is one of the three most important people in my life that I would talk to. And I knew they'd give me the support. Sometimes, I just had to hear their word. I had

made up my mind, I knew what I was going to do, I knew I had to do it. It was just the fact of hearing them say, yeah, that's what you should do.

A few caregivers discussed maladaptive coping (that is, negative coping mechanisms) such as not being realistic about their situation, denial and wishful thinking. These coping mechanisms tend to lead individuals to chaotic situations and unsustainable lifestyles:

**Caregiver:** So I've had to change my routine in that I will work in the evenings and overnight and then still have to get up in the morning. I have to keep going, keep going, but then some days I just kind of crash.

## **vii. Autonomy**

For many of our frail elderly patients autonomy is severely eroded in their last stages of life when family members and health care professionals make decisions for them constantly. The extent to which autonomy is exercised by the caregiver is related to the patients' mental and socioeconomic status. Some patients try to exercise autonomy and make decisions for as long as they can:

**Caregiver:** He doesn't . . . he won't sign the POA papers

**Patient:** I don't want to go there. I mean, why say that. I may be weak physically, but my mind is sharp . . . as long as I can think, I would like to have that little bit of benefit to call the shots.

Most caregiver-interviewees expressed their loss of autonomy in the sense that their lives are centred on the patient and revolve around his care. The sense of "entrapment", defined clinically as when the situation and demands of caregiving make it impossible to exercise decision-making independent of the patient and the demands of the disease—is highlighted in this quote by a caregiver:

**Caregiver:** For me, whereas in the past he used to come out and just of his own initiative he'd come over to the house, he'd come and stop by, he'd come in you know for coffee, have dinner, things like that, he can't do those things anymore. So I've changed my way of doing things to make sure I'm over there more often, to get to his house and to bring dinner to him. I usually bring two or three other meals with me at that time so that he has some others.

### **viii. Knowledge and Advocacy**

Knowledge and advocacy are two closely related functions in our dyads. In most cases, the caregiver-interviewee is the advocate within the micro-system. The caregiver's advocacy extends beyond medical care. It includes supporting the patient's values, ideas, beliefs and faith, because he is entering into a decision-making process with health care professionals and the caregiver is often the only person navigating for that patient.

**Caregiver:** I have to do all of the talking, all of the translating in every discussion about every—you know, whether they're asking him if he wants a DNR [do-not-resuscitate] order, you know, and having to explain to him what that means.

Caregivers who take on the advocacy role educate themselves and do their own research to quickly learn about the system. They feel a sense of accomplishment and are generally satisfied if they are able to represent their relatives and help them through this phase of life:

**Caregiver:** Like, I have to have the knowledge of things. I know what services are available and I make calls and ask and push for things.

**Caregiver:** But if there wasn't someone there to speak for him and to push and to say no, he would have been sent home that day and I don't know what would have happened, you know, because the antibiotic he was on was not working properly and that. Keeping him in the hospital, it didn't make sense. But my father would not have had, you know, the confidence or anything [to speak for himself]; what the doctor says is right according to him.

Although caregivers and patients acknowledge that "knowledge is priceless", they may not have all the knowledge they need to engage in an informed decision-making process with health care professionals. Sometimes, caregivers feel they know their relative very well, but have limited knowledge of the illness and thus may not be able to represent him in that aspect:

**Caregiver:** It's frustrating. It's frustrating and it's upsetting and you feel like you're—I don't have a medical degree but you know the person you care about you know what's best for them, and you know – and this hospitalist is just seeing I don't know how many patients in a day, he doesn't know my grandfather from a hole.

Despite caregivers' efforts to empower themselves with knowledge, there are still many aspects of home care that would be best "left to the professionals" to determine because of

their expertise. For instance, the patient may want to stay at home, but does not realize just what the challenges will be, as conversations with professionals who might better guide the process have not been initiated. Crisis and chaos might have been averted had these conversations occurred at the point of making the decision to stay at home and thereby allowing the dyad to have an opportunity to synthesize the knowledge and engage in informed decision-making.

Advocacy can sometimes be complicated by family dynamics. Family members may not share the same values and beliefs and/or the primary caregiver may be acting more in line with their own values and beliefs than those of the patient.

#### **ix. Retaining Normalcy**

Life becomes increasingly difficult to control as the patient become increasing frail. For the caregiver there are often no openings to care for themselves and the needs of other family members. The chaos stemming from the unpredictability during these stages may be overwhelming. Caregivers—especially female caregivers in our data—often attempt to restore normalcy in life by engaging their children or grandchildren in their lives and routines:

**Caregiver:** Yeah, it's the logistics. Yeah, it just becomes logistics, right, that the kids have to be at swim practice at 5:30 a.m., that I want to be up at the hospital, that you know then I have to pick them up at school, whatever, get one to dance, pick them up. It's just like a lot and then to also want to be at the hospital because you don't know when the doctors are going to come by and you want to know whatever your tests results are from that day or from the day prior.

Sometimes, caregivers learn to adapt. When they do, the caregiving role and the stressors it imposes become a more normalized, albeit still difficult, part of life:

**Caregiver:** So, every once in a while, we do get the guitars out, and instruments out, and would have a tune. My son plays. It's me trying to get a little bit of enjoyment. Then I go back to emptying his ostomy bag, getting his blood sugar checked.

#### **x. In a Nutshell**

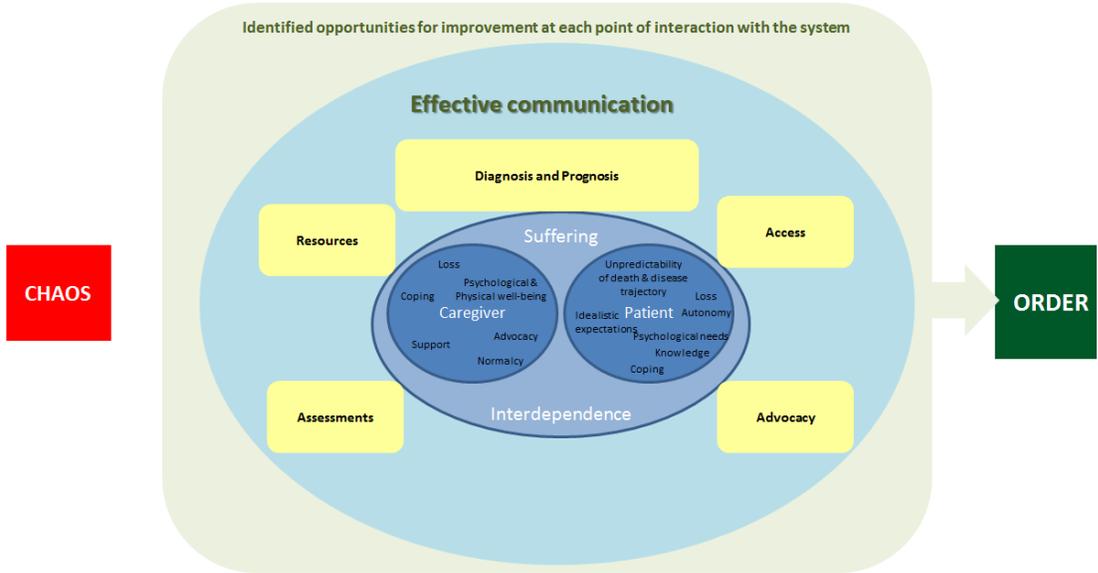
The collective lived experience and the characteristics of patients with frailty, multiple chronic illnesses or dementia and their caregivers were presented, as informed by research interviews with a purposive sample of 26 patients and caregivers in Ontario. In Section C, we look closely at

how patient and caregiver dyads currently interact with the Ontario systems of care, and what some of their wishes are within this context.

**C. Interactions between Dyadic Microsystem and External Systems of Care**

The interaction between the patient and caregiver dyad and the external systems took place at different time points. The specific points of encounter by patients and their caregivers with the Ontario system of care are represented in Figure 5 as small boxes surrounding the oval representing the patient and caregiver dyad. Interviewees shared in great detail their needs, the barriers they faced and the support they received while attempting to navigate Ontario’s system for care. As detailed in this section, at each point of interaction—diagnosis and prognosis, assessments, resources, access and advocacy—patients and caregivers also attempted to identify potential opportunities for positive changes that would lead them towards a more orderly state.

**FIGURE 5—INTERACTION BETWEEN THE CAREGIVER AND PATIENT DYAD AND EXTERNAL SYSTEMS**



**1. Overarching Theme: Effective Communication**

Communication, when done effectively, is an overall facilitator in all processes. When health professionals communicate the diagnoses clearly to patients and caregivers, and educate them about it—not only at the doctor’s office when the diagnosis was made, but during follow up appointments—ambiguity and the sense of uncertainty may be reduced. When prognosis is honestly and empathically communicated, patients and caregivers may have a realistic

expectation as to what may happen to them physically, emotionally and financially, and thus may plan accordingly. When there is cohesive record-keeping so that results of different assessments may be clearly accessible to all parties involved in the care of the patients, patients would not have to be subjected to unnecessary and duplicative assessments. Developing an effective communication structure and format is viewed as necessary to create an environment or space conducive to the discussion of the patient's values and desires, ultimately resulting in positive outcomes.

### **i. Diagnosis and Prognosis**

The point of diagnosis is often where patients and caregivers begin to experience chaos. Our interviewees spoke at great length about the long process of learning about the patients' diagnoses. The ambiguity they perceived during communication about diagnoses was often frustrating and anxiety-provoking, as illustrated by quotes from various interviewees:

**Patient:** This is an unexpected disease and took too long to diagnose [. . .] it started when I was complaining of the chest pain. Then it was one doctor after another. Back and forth, back and forth.

**Caregiver:** The process that he went through, that it's not just a clear-cut "Do this test and then this will occur". And getting a lot of different information and there's no consistency of who we were seeing and people leaving or having to travel, and then that delayed that process further, you know.

**Caregiver:** The doctor said this disease starting with movement, difficulty movement, to move your legs, to move your hands. Unfortunately, he's started with breathing. That's why the doctors took them so long to diagnose.

When different, unpredictable and at times new symptoms arose as they waited for a diagnosis, patients and their caregivers became helpless in the face of mysterious suffering from a nameless condition, which initially may not be diagnosable by physicians. Older patients with multiple chronic diagnoses may have to endure this process repeatedly:

**Patient:** Well, it's hard to explain to you, because it took a number of years to get a diagnosis of dementia. He [husband] was becoming delusional, and losing his mobility and ability to communicate clearly. And one day, my son's friend that is my young friend—and she's been a godsend to me, believe me—she was sitting here and she says "I think he's having a stroke. We should get him to the hospital". That was the worst thing we could have ever done.

All of our patient-interviewees have life-limiting, chronic illnesses and struggle with the complexity, ups and downs, and the uncertainty of extended disease trajectories. Throughout

the course of the illness, they can experience a range of physical and psychological symptoms, which they may not understand. Patients and caregivers appreciate it when physicians or health professionals take the time to explain a diagnosis in clear, understandable and relatable terms and language, and when they speak openly and honestly to them about prognosis and symptoms as the disease progresses. Patients and caregivers often use the information to make informed decisions and to plan for their final stage of life.

**Caregiver:** This doctor came in, one day, they had taken him for an X-ray and he came in and he said, “Has anybody talked to you about what multiple system atrophy is?” And I said, “No.” And he proceeded to take, like, about 15 minutes to describe the progression of the condition and some days are going to be like this and some days are going to be like that, but he said, “The mental aspect of it—the dementia tends to level out”, he said, “but the physical condition will have good days and he’ll have bad days, but the little ups, there will be more down, you know, so it’s just a gradual decline”. I was grateful for that.

**Caregiver:** He did do some chemo treatments to try to slow it down. Now we do radiation just to manage pain, for the bone pain, and stopped all chemo treatments because it wasn’t really beneficial, and it made him feel so horrible. His doctor has told us that the chemo’s not really going to do anything at this point. It may slow it down a little bit, but it’s just prolonging what we already know is going to happen. So that [stopping the chemo] was a choice we made—my dad made—as a family.

With clarity regarding prognosis, the patient and caregiver may better monitor their conditions and identify any symptoms that may be out of the ordinary and seek help accordingly.

**Caregiver:** You were taking Didrocal for years. I had to take you for X-rays and you had to go on a table and have X-rays, and you found it was really bad so that’s why they give you the needles now. But now, the needles only one every six weeks.

## ii. Assessments

Functional assessments done in patients and caregivers’ homes may be perceived as stressful and as a form of gate-keeping rather than responding to patients’ needs. For example, community access coordinators may rely on irregular snapshot assessment of patients’ functions to determine how many home care hours may be granted to the patients. This may cause patients and/or caregivers to “put on” their worst behaviours, so that they can access much-needed home care. Sometimes, despite obvious needs for services, resources may not be available, thus outcomes of assessments may not be acted upon:

**Patient:** I don't feel like I have a case manager who can provide us as a family with a holistic type of an idea what are the resources we should be accessing. It's like she comes in sporadically for her assessments, we'll have a conversation, and then that's it.

During the course of the disease, different health care professionals may administer different assessments in different settings. When the reasons for the assessments are not well explained, some tests may seem to the patients and caregivers to have no apparent utility; as one patient remarked, “I don't know why she did an assessment, no. I told her my symptoms and that was it”. On the contrary, sometimes assessments appear to the dyad to be necessary but are never carried out, as illustrated in this quote:

**Caregiver:** The one thing, though, I would say is that I did have a—like, after the initial assessments and everything they did at the house, when I talked to the care coordinator about him getting some additional physio, like, having some actual physiotherapy. She said she'd send someone but they did not send anyone. I found that kind of strange, you know.

### iii. Resources

Most of our patient-interviewees were living at home and relied on some form of home care. Community and home care resources were perceived as inflexible, and the provision of services may be rigid and insensitive to their needs:

**Caregiver:** I appreciate the five hours. But they split it up from two to three hours. I don't know how to put this. Like, I appreciate it but sometimes I feel it's not enough. Sometimes I think . . . ugh, God . . . because I have to set the alarm and get up at 4, 4:30 and come down and empty [patient's] ostomy bag myself.

**Caregiver:** The PSW, the one who comes, they're not supposed to lift, too. I guess liability issues and stuff like that.

Invited to “dream” about what may be improved, interviewees imagined the benefits of a system in which providers were empathic, sensitive and responded to their unspoken yet evident needs, regardless of the setting. It can be “anxiety provoking” if the provider is not empathic and does not understand a patient's abilities and needs, especially when the patient is incapable of communicating his or her needs. When providing home care, service providers and health professionals who exercise empathy make getting necessary support with daily living activities, medical care and symptom control in the home a more bearable experience:

**Caregiver:** The nurse is here so when there is a change in my dad's condition at that stage or his movement and that sort of thing, that they can encourage him as

well. She can tell him, “Yeah, it’s okay to take the Ativan” or “No, it’s okay to take those Oxy[Contin]s for pain, or we’ll manage your pain.”

Interviewees were also appreciative when the resource they accessed was responsive to their evolving needs. For instance, during the last stages of life many symptoms—physical and behavioral—can appear unpredictably, putting caregivers and patients under duress if they do not have the skills and knowledge to manage the symptoms, as is so often the case:

**Caregiver:** We were lucky to have a nurse that does come daily, because there are many things that he needs checked on. The nurse can make the phone call right away to the doctors, to the palliative doctor, and they can get a change in medication as needed, and that’s excellent.

**Caregiver:** I’m pretty sure I called his case coordinator a couple of times in a panic about something that happened to [patient] or whatever, and she called me back and put my mind at ease.

By providing empathic and responsive professional contact and resources, providers can foster a trusting relationship between themselves and the patient. A few patients commented on how this kind of constructive relationship can “ease decision-making” as they become more comfortable to ask questions and to get relevant information:

**Caregiver:** I really enjoy our case manager. I can leave her a voicemail, she responds to me right away. I’ve informed her of needs to change PSW schedules or what we need and she’ll just call and leave me a voicemail back or call the home and talk to my mum and give her the information that she might need.

Dyads acknowledge that the emotional aspect of care is as important as the physical. As one caregiver put it, “You know, having all these things in place and making sure that the physical care is being addressed is great. The emotional part, too, also needs to be addressed”. While most of our interviewees rely on personal resources such as family and friends to provide emotional comfort, they are appreciative when there is someone from outside of their social circles who understands—be it a nurse, a hospice volunteer or a personal support worker (PSW). Some patients developed meaningful relationships with individuals who come into their homes, with whom they talk about their aspirations and fear, and their small triumphs and defeats along the path of living with life-threatening chronic diseases. Caregivers appreciate this resource as a respite, a time to take a break from the straining situations they are physically and emotionally tied to:

**Caregiver:** The respite workers are PSWs and they’re not allowed to administer medication, or make that decision on what to give him, but there’s someone that can be sitting with him and talking. It’s his little bit of social time because it’s somebody other than our faces that he sees so it’s nice for him to have someone different to talk to, and then help him with his personal care.

**Caregiver:** The nurses are excellent, they're great, because they sit mostly with him and talk through certain things. They help support the family, more of an emotional support, as well.

#### iv. Access

**Caregiver:** If you're not aware of these services you can't use them, right? If you're not aware that you need the service, you don't access them, right? If you're not aware how they work, you're not going to know how to get that service into your home if you need it, right?

Patients and caregivers may not be able to access a particular resource for a variety of reasons including if:

1. The resource is not available in a particular region in Ontario;
2. Patient or caregiver does not have knowledge of the resource (as illustrated by the above quote);
3. Patient or caregiver does not meet certain criteria or systemic requirements.

Regardless of the reason, inability to access a certain resource that a patient/caregiver needs at a certain point of the disease trajectory leads to duress. For example, there are certain parts of Ontario where it is difficult to access palliative care at home. One caregiver-interviewee, whose profession allows her to have a wealth of knowledge of resources in the city, was frustrated to learn that she could not find home palliative care for her father outside of the city. This led to distress when she tried to honour her father's wish to stay and die at home:

**Caregiver:** There's no home call doctors, or things like that, that we we've been able to find or access. That's really hard, because, you know, the doctor can't come to us, we can't go to the doctor, but you're stuck in this limbo of, you know, we don't want to go to the hospital, but we don't want him to die in pain either. So ...

In some cases, access may be offered or promised to a patient, but due to communication breakdown between various sectors, services may not be set up:

**Caregiver:** We've been offered a social worker to come and meet with the family. They offered it and we said yes, that would be great, but the people who were offering it haven't actually just taken the initiative in setting it up.

As detailed in the "Chaos" section, one's socioeconomic status may be a barrier when trying to access service. This aspect of "Access" was highlighted by this quote from a caregiver from Northern Ontario:

**Caregiver:** I'm sure there's other services available in [northern region of Ontario], but it wouldn't be covered. It might be something that we'd have to pay privately if we were to go a different route, right? So we haven't looked into any other options, just whatever [Ontario home care service] will provide is what we go with, because financially it's covered, the services are covered that way.

Patients and caregivers from our study had particular difficulties when accessing financial support. Although they understand that certain restrictions exist as resources are scarce, they find the limitations frustrating. In other cases, they wonder if some criteria are unreasonable:

**Caregiver:** ALS Society . . . They came, they visit him. So they ask us if we have benefit if we can afford it at the beginning of these symptoms. They cover some percentage. They gave him [medications] to slow the symptom, about \$700 medication for three months they give him. So after that, nobody ask about nothing, as if they think he would be dead by three months and wouldn't need the meds.

**Patient:** They said they will help, the government will help, if your income is \$37,000 and less. But how can I be living in the house with only \$37,000 income? It's tough. Something they said it's help, but it's not really help. So we didn't even ask them when we see the form, they gave us the form. When we read the form, "\$37,000?" [. . .] we didn't ask them to help. We just did it ourselves.

**Patient:** One of the doctors mentioned that he should be able to access blind pension. So we called different numbers, something to do with the government, they say, "Do you own your home? Oh, you own your home? And do you have a bank account? Oh, yeah? You don't qualify."

When invited to "dream" about how things may be made easier for them, a number of interviewees independently mused about having an individual or a team who can "navigate" and guide them through their last stages of life, no matter where they may be in Ontario:

**Patient:** It would be a person or a team who is more a listener than a talker, who knows what resources you would need, whatever it may be depending on your situation; [who knows] people who can help you whether it's some kind of therapy or treatment or home support. Somebody who can connect you and can connect you fast with the right person or service as needed.

**Caregiver:** Someone who can kind of take us out of the hot seat of having to make those decisions, someone who can communicate with the medical professionals. And you know, what if we're missing some piece? It's that they can see it firsthand and they can help us navigate that system a bit more. So, how to get the bed, or how to get things paid for, whatever it is, that they can do some of that system navigation with us in this last stage.

## v. Advocacy

“Advocacy” is closely related to “Access”. Caregivers oftentimes have to do their own research in order to coordinate care and advocate for the patient. As mentioned in the Discover stage, some caregivers may use advocacy as a coping mechanism and find satisfaction in advocating on behalf of the patients, to ensure that their needs, wishes and dignity are honoured:

**Caregiver:** Like, you have to have the knowledge of things. My father has me, someone who knows how to advocate for his needs. In someone else’s situation—who doesn’t have knowledge of services that are available and that—they wouldn’t know to call and ask and push for things.

Nonetheless, this constant process of coordination and managing someone else’s life can be emotionally charged and may lead to caregiver strain and burden. This is the point when community advocacy support could be of immense value, for patients and caregivers to learn about their health and legal options, and to advocate for their needs:

**Caregiver:** Is there a community clinical place you can go? Is there a sign on somebody’s door that says if you’re facing somebody’s death enter here? You know, is there?

**Caregiver:** I know in the Greater Toronto Area there's this Advocacy Centre for the Elderly that provides legal services regarding wills, power of attorney, things about elder abuse, you know, capacity to consent, and what those things mean for seniors that may not know about that legal language and how to go about doing advanced care planning etc. It would be nice if we had it out in Kitchener-Waterloo.

As mentioned previously, chaos often manifests in the context of home care. Patients sometimes feel helpless and abandoned, especially when insufficient care is provided, or when the situation has changed and new needs have arisen. An advocate would be a helpful resource in these cases to call attention to the need for reassessment:

**Patient:** What they are giving me now it’s really tough. I don’t know how people do it at home with two hours care. To wait for somebody the whole day, for them to be here for two hours, to help me out from bed and to clean me up . . .

Interviewees suggested that a coordinator or a case manager could take on the role as a patient advocate, as “a great case manager that is aware and checking in and asking the right questions” can advocate for the right services for patients, especially when people don't know what services they need.

## vi. In a Nutshell

It is evident that patients in our study sample—individuals with frailty, multiple chronic illnesses or dementia—and their family caregivers experience many barriers as they interact with a fragmented system of care. As prefaced in the introduction to this chapter, however, they may find it challenging to articulate what improvements they would like to see. In the next few sections, their predicaments are presented to expert stakeholders: individuals who have extensive frontline knowledge about the system of care this particular group of patients and their caregivers are drawn into at this stage of life. Their comments are presented in Sections D and E.

### D. Professional Stakeholders’ Lived Experience: Struggling within a “Non-System”

Take for example a patient of mine, 82 years old, who has vascular dementia. [. . .] They need to go to a long-term care facility because they’re wandering and there’s some risk of violence. They’ve been kicked out of day programs, they have a co-morbid medical illness, which puts them at very high risk of falls, and the only place, if I wanted to send them for emergency access to any supervision, is to the emergency room. Because of their problems, crisis support in terms of long-term care, they were given I think it was 12 weeks access to a secure unit, which is many months. And that’s with someone like me trying to advocate for them. And so what that means is you have people struggling within a non-system.

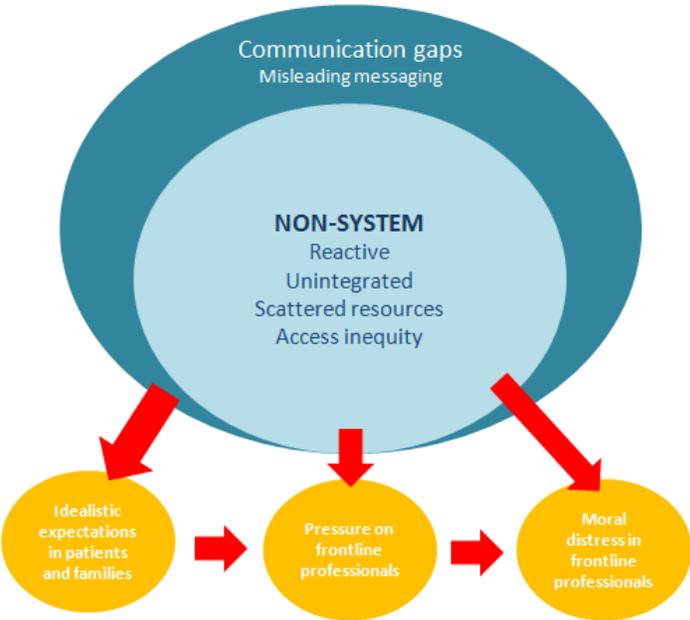
As part of the Design stage of AI, stakeholders were asked about how existing systems and infrastructures may be leveraged and optimized to improve the conditions of patients and family caregivers living with frailty, multiple chronic illnesses or dementia. Instead of responding directly to that inquiry, however, stakeholders from different jurisdictions spontaneously commented on the inefficiencies in the systems (or lack of a system) and their impact on this specific group of patients and caregivers. The “non-system”, implied in the patient-caregiver dyad interviews, was clearly described by stakeholders across all professional groupings. It was portrayed as one within which patients “don’t feel like they know who to call if X happens or if Y happens”, and one in which “patients and families who see three or four doctors and 10 or 12 nurses and maybe a social worker and maybe somebody else and a [physical therapist] and an [occupational therapist], and they would have heard something different from every single one of those people”.

People at the end of life or [with] advanced illnesses, [they struggle with] their pain, their nausea, their vomiting, but there’s this whole other element which is that they don’t feel safe and they don’t feel like they are cared for within the system. I actually think that causes a lot of suffering.

**1. Characteristics of the “Non-System” Experienced by Professional Stakeholders**

The “non-system” was characterized as reactive (rather than responsive), non-collaborative between legal and medical sectors, with scattered resources and plagued with access inequity. It is further exacerbated by communication gaps in and between all sectors and the at-times sensationalized and misleading messages of fundraising campaigns. These inefficiencies as lived by our stakeholders, summarized in Figure 6, are detailed in the following sub-sections. The findings presented in the section may serve as impetus for change.

**FIGURE 6—THE “NON-SYSTEM” DESCRIBED BY EXPERT STAKEHOLDERS**



**i. Lack of Communication or Miscommunication—An Overarching Characteristic of the “Non-System”**

Enveloping the “non-system” is the overarching theme of communication gaps, which compound the detrimental effects of the “non-system”. One of our stakeholders fittingly analogized the resulting breakdown to a “growing dysfunctional forest”:

Clearly, one of those points of origin is at that very beginning. There is certainly inherited ambiguity in diagnosis and [ . . . ] in prognosis. So the seeds of chaos are planted at that point. When you take that inherited uncertainty, and you layer on top of it a less-than-ideal communication, or lack of communication altogether, you then have germinated that seed of chaos and you now have a little, you know,

leaflet. Then, as you move through the illness trajectory and we water and fertilize that chaos, it grows, right? So you get to that state, where it's clearly end of life and the needs are the greatest, you have already got a dysfunction built in.

Lack of communication or conversations may happen when health and legal professionals fail to provide clear information for the patient and/or family caregiver to make informed decisions, or have a conversation about dying in general. Ironically, despite the desire of patients to have such discussion and the positive effect on those who had them, only a small percentage of patients have had a discussion about their prognosis with their physicians.<sup>240</sup> This lack of honest and open discussion, regarding a patient's illness trajectory and about the dying process, may lead to conflicts and distress in future interactions between the health care system and patient/caregiver dyads.

What was most striking about my visits with these patients is that, they really, really appreciated talking with me about the end of their life and death, things that people want to talk about.

Directly linked to the "accountability" theme discussed below, communication breakdown may also occur between disciplines (i.e., medicine and the law). This results in barriers to care as the patient/caregiver dyad would be put in the middle of a dispute:

You have lawyers who quite fairly say, "I don't advise my physician to go to the consent and capacity board anymore" because [chances are they will] lose the hearing and appeal, and it's going to take six months to get it resolved.

Lastly, there is a lack of conversations regarding death and dying in the public realm. "Death is part of life", and yet the public "don't talk about dying" and "live as though we're going to live forever", and the impact of this is far reaching as more individuals run the risk of getting into situations where they or their family members would have to make difficult decisions, not guided by any plans or expressed wishes.

I deal with capable, very intelligent people who have a POA. I would ask if they have talked to their husband or daughter about end-of-life wishes. The answer would be, "No, why would I do that?"

Instead of it being something that I think should be normalized, where, you know, sort of a marker of early adulthood: we've got a plan in place in case something happens to us and then we're just going to keep updating that plan as the years unfold; [. . .] we push it off and we push it off and we think it's something that old people do or we think it's something we do because we get sick or something like that.

Other stakeholders wondered if public health may play a role in encouraging that kind of conversation in the general public, to correct faulty assumptions and beliefs on what health care can or cannot do:

Ministry of Health and other public health [agencies] could do a much better job of messaging to the general public the reality that we all get sick and die. And so in light of that reality there are times when our high tech, very expensive system works very well for people, and there are times when a low tech supportive hand is just as worthy.

A subtheme here is “misleading messaging”. The effects of communication gaps in different contexts as described above are compounded by the often unintentional, but nonetheless misleading or sensationalized, messages used in fundraising campaigns, which may contribute to the generation of unrealistic expectations in patients and caregivers:

We’re very good at blaming patients for having unrealistic expectations without realizing that we’re the ones that are often the creators of those expectations.

Our stakeholders commented on the moral and ethical concerns regarding certain forms of advertising and/or fundraising campaigns:

But putting a life-sized sign on a building that promises to do something that we have absolutely no ability to do, at this stage, is, in my mind, morally problematic.

“We’re going to conquer XXX in your lifetime.” So now, as a patient, what are my expectations [of] that organization?

## ii. Reactivity

Everyone is watching and waiting for the inevitable hip fracture. That is profoundly frustrating.

Patients living with frailty, chronic illnesses and/or dementia often encounter medical crises that may be preventable. The quote above by one of our stakeholders captures the essence of a “reactive” system where health care professionals are waiting for a crisis to happen, allowing patients to present themselves in critical conditions, instead of assessing what patients need and taking the proactive steps to facilitate an advance-care planning conversation with them. The stakeholder, cited above, continued to explain why everyone is “waiting”:

[. . .] because all the mental health legislation and the legal framework for caring for people at risk, if you will, in the community, comes out of a mental health

autonomy perspective, which is good, except that assumes that the illness is essentially episodic and that there are various types of treatments that are available and people can kind of achieve some kind of wellness with support.

This is especially frustrating in the case of, for example, a dementia patient, where there is “a steady, progressive decline, no matter what happens, and intervening at an early stage actually allows someone not to have the hip fracture”. With the system set up to be reactive, however, one is essentially allowing the patient “to have the hip fracture”. Ironically, although the health care provider(s) would be “satisfying legal requirements that were set up for a different context” by acting at a crisis point, the health of the individual would be compromised, and substantive costs would be introduced into the system.

Within a reactive system, patients may also miss the window of opportunity to receive appropriate care—such as palliative care—to maintain their quality of life, as again, “it often takes a crisis to actually signal a palliative care referral by a physician”:

Say the person in front of me, they have stage-four cancer or they’re stage-three but they look fine. So, I’m not going to talk about it today. And then, two days later, they’re in the emergency department, in crisis mode or with an acute exacerbation or heart failure. And then that’s when the patient is admitted and that’s when the referral to palliative care is made, which, in many cases would be too little, too late.

As pointed out by a few stakeholders, there is another layer to “reactivity” within the health care consent context, played out in the role of the attorney for personal care. The attorney acting under a POA for personal care is expected to make decisions on behalf of patients who are found to be incapable of doing so. The law requires that the attorney for personal care consult with other supportive family members and friends in six areas of decision-making—health care, shelter, clothing, hygiene, nutrition and safety. In reality, however, the attorney for personal care oftentimes is called to make a decision for patients who have no prior expressed wishes, or for those who have not had open transparent conversations about their prognosis, their values and beliefs, or what sort of care they prefer:

The role for an attorney for personal care is very reactive. If I’m called upon as the attorney to make the decision, I make the decision. Say a patient falls, breaks his hip, goes into the hospital, and becomes delirious. Somebody needs to make the decision and sign the papers for him to have surgery. The attorney for personal care is called upon to do that because the health care professional doesn’t think that the patient is capable of making the decision. So the attorney has to react and make that decision on the spot.

Adding to the complexity is the fact that the *Substitute Decisions Act* and the *Health Care Consent Act* also state that the attorney for personal care “does not have custodial power” and thus, “does not have the right to enforce a decision upon a person who’s objecting”. This is when accountability becomes an issue as it may be confusing who is ultimately responsible for the patient’s well-being.

### iii. **Unintegrated Approach: The Law within Health Care in Ontario**

So I might have the authority to determine that my mother should move from her home that she’s living in to a retirement home because she’s no longer safe living in a home with multiple levels, because her balance is poor and she keeps falling, but if she objects to that I have no legal authority to force her to go to the retirement home. I can’t forcibly remove her from her house and take her to the retirement home and tell her she has to stay there.

Stakeholders highlighted perceived barriers when the legal system and health care systems in Ontario interact, often leading to the experience of moral distress by the health care professional, and chaos experienced by the patient-caregiver dyad.

It’s the health care practitioner’s responsibility to make sure they’re getting informed consent and their responsibility to determine if the patient has the capacity, and it’s their responsibility otherwise to go to a substitute.

The above quote highlights the view of a stakeholder from the legal field about the health care professional’s responsibility for keeping the patient informed of their rights.

You don’t actually need a power of attorney for personal care in the province of Ontario, as you have a substitute decision maker if you’ve made one or not. But the existence of power of attorney for personal care appears on the checklist for when you walk in the door, and if you don’t have one you’re an anomaly and nobody knows what to do with you and then it’s a problem.

Frail elderly patients and their caregivers may not know this information on the relationship between an attorney acting under a POA and substitute decision maker—more specifically, may not know how this is a facilitator in their health care needs when they require complex care at last stages of life.

I remember going with my mother-in-law to emergency and my sister-in-law was there, and the doctor kept saying “Is there a DNR order? Is there a DNR order?”, which had nothing to do with why my mother-in-law was in emergency. My sister-in-law was in a mad panic because she said, “Well they keep asking for it and we don’t have it” and I kept saying “That’s because [my mother-in-law’s] substitute

decision maker—who was unable to come to the hospital right away—hasn't done one". She continued to be in a panic because somebody's asking for it, and they keep coming back and asking for it again and again and again, because they didn't get the answer they wanted. So they pigeonhole everybody instead of thinking about the patients as individuals and what their needs are.

The quote above highlights the distress a stakeholder experienced in a crisis situation when addressing the care needs of a loved one who was in her last stages of life. This quote represents two layers: 1) The stakeholder, who is an expert in the legal system within Ontario, felt distress in this moment due to the patient being in a crisis point and the health care system needing a specific person to address their care needs, and 2) The health care provider sought to have a decision made in the absence of the legal substitute decision-maker, because of the urgency of the situation, causing chaos for family members. Overall, this quote is an example of when the legal and health care systems interact with one another in a moment of crisis within a health-care setting.

Lots of lawyers doing it [advising on wills and POAs] are also just doing real estate or family law or a little bit of corporate or this or that. There are even criminal lawyers who will dabble in doing wills for clients; not the people who do mergers and acquisitions on Bay Street, perhaps, but just about everybody else. What happens is lawyers spend all kinds of time talking about what's going to happen to the money after the client is dead and they talk about powers of attorney for property and they don't spend enough time to talk about the importance about the POA for personal care.

This quote represents the informed conversation needed to advise patients and their caregivers on their rights in decision-making for their health care needs. Having a power of attorney for property and/or personal care, and a substitute decision maker in place, is not enough to reduce chaos in the patient-caregiver dyad experience at last stages of life. Learning what these legal components do, and how and when they interact with their health care needs, is crucial to reducing the distress for the dyad and the health care professionals involved in carrying out their care.

#### **iv. Scattered Resources and Access Inequity**

Inadequate resources and access inequities were highlighted in this section and echoed many of the same elements that emerged from the patient-and-caregiver interviews as presented in Section C. The following factors were highlighted:

1. Geography and physical location: the interaction of the physical location of the patient, the physical location of the program and/or service, and the availability and physical presence of the health professional attached to the program and service all affect accessibility.

I think the ethics of it is we actually should have more resources available from a support point of view for patients and caregivers in rural areas than we would have in urban areas, but we generally tend to see that they're clustered, the supports are clustered in the urban areas.

Palliative care in Toronto, you've got pretty good coverage in Toronto. Outside of that, it's a totally different story. You are talking about two, three family docs doing home visits with limited coverage.

Cultural factor in the context of physical location may also be a barrier. For example, individuals living in rural areas may represent a group of individuals defined by a common life experience, as pointed out by a stakeholder:

You have a rural mentality of we take care of ourselves, we take care of our own, and so there's no culture of seeking help.

2. Structural and systemic barriers: For example, poverty and the “-isms” can limit or deny accessibility of health and social care.

There's been a real challenge with regionalization, and ethically, what it does do is, it places extra strain on the system that supports the patient.

Because we're regionalized, if you have any high acuity needs—cancer, dialysis, any of those things—you can be from two hours out in the countryside and have to come into town to get your cancer treatment, or any other number of things.

3. Transportation: Although a common barrier in rural areas, as stakeholders pointed out that “some people in those rural areas have no way of getting into town to the hospital”, this is equally a problem for some in urban areas who are isolated, housebound, unsupported and without means to access the outside world.
4. Policies and procedures at the organizational level: Policies and procedures within health care facilities, such as hospitals can limit the professional in linking patients to resources:

When someone is in hospital [the patients' and the organizational] interests may be misaligned. [ . . . ] In the community those interests can be aligned so that everyone in the community can agree we need to do everything we can to help you be safe in your home. That means we're going to do X, Y and Z. But at the current time the resources simply do not exist. The irony is that it's cheaper to do that than if the person's in the hospital.

#### **v. Impacts of a “Non-System” on Frontline Professionals**

As seen in Figure 6, the “non-system” described by expert stakeholders contributes to patients and caregivers’ false assumptions and unrealistic expectations. Frontline workers and professionals attempt to meet these expectations by designing programs to fill gaps and/or navigating, on behalf of the patients, care pathways that may not exist. This results in siloed programs and contributes to the moral distress of the health professionals. Specifically, when health care professionals recognize gaps or feel the pressure of patients and caregivers for services that do not exist, they sometimes create local solutions which may be locally helpful but contribute to the “non-system” because they are not developed collaboratively or coordinated with other resources.

#### **vi. Expectations and Assumptions**

Stakeholders perceived that patients and families have somewhat idealistic expectations of the health care system, stimulated by societal perceptions of and attitudes about death and dying—the sociocultural valuing of youth and productivity diminishes the place of end-of-life struggles, imposes negative values on aging and death, and does not incorporate dying as a “natural” part of life. The resultant relative societal silence about the realities of end-of-life issues, together with the limitations of the “non-system” and lack of constructive conversations, contribute to idealistic or unrealistic expectations.

This happens all the time, in that until a patient and their family are struggling with dementia and frailty, people assume that there is a system that functions and then when they're in it, they're like, “What do you mean I have to wait a year to get the long-term care place that I need?” And that's just—that's very, very problematic.

People still expect magic from the health care system. I mean, we trust you. We believe in you. We think you can always make us better. We don't know that you can't.

## **vii. Pressure on Health-Care Professionals Leads to Moral Distress**

One of the things that facilitates the system to work better is the remarkable devotion and commitment of health care providers in a system without enough resources.

This quote reveals a key factor that contributes to moral distress among health care professionals—that is, altruistic dedication to patients at end of life often is not matched by accessible resources to care for them, putting the health care professional in the position of recognizing need, wanting to do more, but being unable to do so because of external factors often caused by funding constraints, among other things:

I have friends who graduated and want to go to, like, Oakville, they want to start a palliative care program, but they have trouble recruiting folks because it's based on a fee-for-service model. How are you going to get people out there and start a program based on fee-for-service service for something that doesn't even exist?

Primary care practitioners are under particular stress when dealing with palliation often associated with end-of-life care. For example, primary care teams are responsible for helping decide when active curative interventions are no longer likely to be effective, identifying end-of-life issues, introducing palliative care, providing psychosocial support and bereavement counselling, and making timely referrals to specialized palliative care services such as symptom control, but may not be well trained or structured to carry out these duties:

Family docs are graduating all across the country with a lack of comfort to manage primary palliative care!

We need to make primary care accountable for the palliative needs of the population. Not just the cradles, the pediatric needs; not just the preventative needs, but palliative care, too.

Patients' and caregivers' unrealistic expectations described above, the high demands and needs, and the lack of a flexible funding structure make it ever more challenging to serve patients effectively:

I think for those who are home-bound or for whom it's difficult to access care, I think we can create a team that does this in the home. I know of a family physician who does home-based palliative care and he takes care of chronically unwell patients for whom getting into a clinic is not impossible but it's really hard.

The implications and complexity of initiating palliative care also make it difficult for health care professionals and especially the primary physician or the most responsible physician to discuss it with their patients, as illustrated by this quote:

Oh, like, I only have 15 minutes for this appointment. If I make a referral to palliative care, this is going to take 35 minutes to explain why I'm abandoning my patient or why I'm giving up.

The pressure on frontline professionals to put in extra effort to compensate for what the system cannot provide during end-of-life care sometimes leads to moral distress, as evident in the following quotes:

In a health care system where we hold ourselves out as providing a reasonable level of care for every citizen in our province or in our country, we're not living up to that standard because we're letting people fall through the cracks.

People in palliative care are so passionate we want the best for our people. Quality of life is what we do all day. We acknowledge the full dignity of each person beyond the stigma of their own marginalization. So when we don't see that happening, we get frustrated.

All of the above factors may contribute to moral distress among health care professionals when interacting with patients and caregivers dealing with frailty, multiple chronic diseases and dementia.

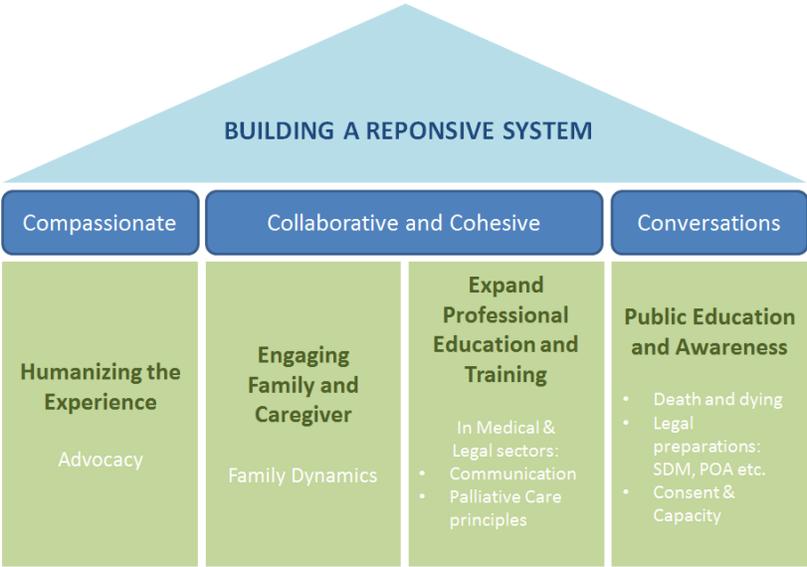
#### **viii. In a Nutshell**

“Palliative care” is often equated with “specialized palliation” delivered to patients who are faced with imminent death—that is, a prognostication of death within three to six months. Since older adults with chronic illness, dementia and frailty have longer durations of disease, they are underrepresented in terms of access because the Ontario system is not structured and equipped to deliver palliative care on a continuum. Individuals living with frailty, chronic illness or dementia may not be eligible for specialized palliative care in a palliative care unit; however, this population would benefit from information and care guided by palliative care principles, such as having early discussions regarding their prognoses, and setting and updating goals of care. Without a system that would support the delivery of appropriate type or level of care for this population, the existing system of care resorted to waiting for and reacting to crises, and is perceived as “chaotic” by patients and caregivers. Health care practitioners, especially in primary care, experienced moral distress as they provide care out of altruism that is not supported by the infrastructure. In the next section, expert stakeholders attempted to

generate solutions in response to the inefficiencies they witnessed and experienced within the current Ontario system of care. Specifically, under the sub-section “Expanding Professional Education and Training”, stakeholders made recommendations as to how palliative care principles may be more broadly applied to situations involving frailty, advanced chronic illness and dementia.

**E. Building a Responsive System for Individuals Living with Frailty, Chronic Illnesses and Dementia**

**FIGURE 7—STRUCTURE AND ELEMENTS OF A RESPONSIVE SYSTEM BASED ON STAKEHOLDERS’ DATA**



“Design” is an AI phase in which interviewees can generate solutions to problems that emerged in “what has been” and “what might be” inquiries, while “Destiny” focuses on how these solutions may be applied and validated in action. Interview data from these two phases of AI were analyzed and are presented here blended together.

Expert stakeholders considered both patients’ and family caregivers’ and their own lived experience, and made recommendations on how to motivate and implement a path and vision for system change. Stakeholders across all sectors called to attention the need to train professionals to communicate sensitive issues to patients and families affected by frailty, chronic illness and dementia; to educate this specific population of patients and their families

about, and elevate their awareness of, hospice and palliative care; to enhance advocacy supports; and to create an expanded model for applying palliative care principles. They also highlighted the need for different professional sectors to work collaboratively towards these goals.

A “Destiny” of “building a responsive system” was envisioned (Figure 7, Building a Responsive System) characterized by compassion, collaboration, cohesiveness and healthy conversations supported by four pillars:

1. Humanizing the experience;
2. Engaging family and caregiver(s);
3. Expanding professional education and accreditation;
4. Public awareness.

### **1. *Humanizing the Experience***

The practical solutions discussed under the “Humanizing the experience” theme will contribute to the “Compassionate” quality of the “responsive system” envisioned.

Stakeholders pointed out opportunities to “humanize the experience” of the patient during his/her last stages of life when, aside from struggling with physical and medical issues, the patient may also experience profound losses and have psychological, social and spiritual needs that require support. Studies have shown that individuals in their last stages of life are more satisfied with their care if they have had a discussion with a physician and have received honest information about their condition.<sup>241</sup> Our stakeholders echoed these findings and emphasized the need to have early, frequent and transparent conversations between health care providers and patients about death, the process of dying, and what gives people meaning and a sense of comfort in the process:

What was so striking to me is that on reflection, when a palliative care nurse or physician goes into the home and they’re there for half an hour or an hour, just by virtue of the job, people will spend most of that time thinking about physical symptom control—you know, pain, nausea, constipation, whatever. And those are all very important and interesting, but they’re not necessarily engaged in talking about the important questions about the end of someone’s life, and I think people are hungry for that.

Professionals from different sectors may play a part in “entering into the experience of the patients” and “journey” with them. Creating a care framework led by palliative care principles as discussed in the literature review is implicated in our data.

The best palliative care I've seen provided is what would be considered by other health professionals as being, you know, at a snail's pace. It's slow and it's time-consuming. But I would argue holding a patient's hand while they die is as valuable as an open heart surgery.

Concrete suggestions from our stakeholders include having informed conversations with patients at end-of-life phases of illness about disease trajectories and prognosis, instead of simply referring patients; talking to patients and their family caregivers about advance care planning; and listening to and regularly revisiting the patient's goals of care.

Really listening to their goals and then, once they can actually express their goals and you can actually hear their goals, [they may] feel cared for.

Having a goal-of-care conversation with a patient is to provide psychosocial support. Reassuring the patient along the way, saying "You are doing the right thing, you're on the right track", is a very reasonable approach. Spending more than 10 minutes with them, holding the patient's hand, that kind of thing, is valuable.

#### **i. Sub-theme: Advocacy**

An important sub-theme under the "Humanizing the Experience" theme is "Advocacy". An advocate is an individual or a team of individuals committed to a transformative role meant to enhance both the system's principles and the patient's values and outcomes, rather than fixating on public health discourses and an action "to do" item. One stakeholder described the agent of advocacy as someone who "has health literacy, the knowledge, social network and social capital to be able to connect". Other stakeholders pointed out the need of advocacy:

Sometimes it's not necessarily that the patient and the caregiver lack energy or lack intelligence, it's that it's really hard to know how to get the right help at the right time. So, an advocate role, whether formal or informal, is extremely helpful.

Stakeholders' data contain solid evidence that advocacy may be manifested in a POA, family caregiver or team of health professionals, and is most effective when not activated during a time of complex decision-making or crisis. The best approach is to start the conversations early:

Good approaches include talking to all family members and solicit input and then make decisions in accordance with the best interest tested under the law and prior capable wishes.

The goal of the advocate is to increase the participation and commitment of patients, family caregivers and health/legal professionals in last stages of life, by encouraging conversations and facilitating connections to resources, which in turn facilitate smoother transitions and preparedness for patients and family caregivers. Ultimately, advocates represent the patient's wishes and goals of care, and ensure that the patient is provided with the kind of care she/he wants during the last stages of life. This was evident in the case of Mr. D, as told by one of our stakeholders, who told the health care team "very clearly" that he wanted to "die at the shelter". The advocates' role was to ensure that the health care team was not imposing their own ideas about dignity and quality of life onto Mr. D, but rather, to coordinate resources to support Mr. D's wishes to die at the shelter.

The role of the advocate may also take the form of a "navigator" as discussed in both the Dream and Design phases of the data. One stakeholder described what an ideal navigator would do:

Helping with access, helping talk about prognosis, helping to translate what's been said, helping people understand the uncertainty, helping people to live in the uncertainty, helping them to access resources; but just to kind of be there to answer all those gazillion questions that come up that there's really no structure to answer.

Another stakeholder talked about the humanizing characteristics of a system navigator in great detail:

A system navigator role . . . it takes somebody who has an active interest, but not necessarily an emotional stake, and puts them in a position of assisting the dyad or in navigating the system [. . .] It enables the provider to communicate directly with the patient, but having this passionate third-party presence to help clarify and, at a later date, revisit the same information with that patient, with the dyad. And so patients and caregivers won't come out of meetings with physicians saying, "I don't know what they said." [. . .] Having this sort of system navigator to be eyes and ears [. . .] they can advocate for the patient.

## ***2. Engage Family Caregivers as an Integral Part of the System***

The family caregiver is an important part of all aspects of the patient's care. Family caregivers are unpaid and may provide ongoing care and support—physical, cognitive or mental—for the patient. Based on an Ontario study, palliative care patients were cared for primarily by their

spouses or partners (57%), or their children or children-in-law (29%). In our study, stakeholders emphasized the importance of having family caregivers “on board” and to “take ownership”.

The system and providers need to be able to do things for patients and families, but patients and families also have to take ownership.

Things tend to go well for the patient's family when the interests of the health care provider and support staff are aligned with the patient and family; the way you have people access the system is you actually make it accessible in a way that makes sense to the patient and caregiver, for example in the city we have the Crisis Outreach Service for Seniors, or Community Navigation and Access Program (CNAP).

It is of utmost importance, therefore, to support family caregivers with education and training and to provide them with practical tools so that they may be sustained in their role as effective advocates for the patient. Professionals from both the legal and health care sectors can play a part in educating family members:

When a client comes to you to draw up a will or to sign forms to appoint a POA for personal care, [the lawyer should be] explaining the importance, and for that matter, telling the client, okay, you appointed your daughter as your attorney for personal care; you better have a chat with her about how you want your life to end.

Timing is also important in providing relevant information. Different stakeholders identified “transition points” as critical time points for education:

We need to look at these transition points for the patient and for the caregivers and be able to provide some sort of information.

When something changes, or something around their health changes, or something changes around their setting of care—that they needed to go into long-term care, or they were hospitalized, or they were sent home from the hospital—or, you know, the caregiver has changed. Those are your opportunities where they’ve become less invincible or they’re interfacing with the health care system, in some way. You know, those are the best opportunities, you know?

Technology may also be used to enhance accessibility and keep everyone on the care team—family caregivers included—informed and engaged. Technology may be leveraged—for example, by incorporating a caregiver assessment as part of the electronic records—so that “the family caregiver does not have to retell his/her story over and over”. Successful models such as the “Partners Advancing Transitions in Health Care” (PATH) that the Change Foundation

implemented in Northumberland, Ontario in 2011 involved more than 250 elderly patients and their family caregivers, who “shared care” with a community coalition of cross-sector providers:

They are given tablets with these easy-to-use tools and apps [that] keep a running record of what’s said, when it’s said and who said it. So they can go back and revisit it and review it. They can use tools to email a physician about things that was discussed and it would be answered in a timely manner . . . wouldn’t have to wait for the next appointment. When the next appointment comes around or when patient visits a different professional, and they say, “What happened at your last appointment?” the patient/caregiver can provide the information in an accurate way.

Despite the promising potential of technological tools, various stakeholders have strong words of caution against the use of self-directed tools or websites that are intended for passive use, as these “dehumanize the experience”:

There needs to be a central place where caregivers can get information in a timely manner with respect to support services and how to access them. A website alone will NOT do it—caregiving is a very human experience and they need to connect with “a person” who can help them navigate.

Stakeholders also suggested looking at other successful models to support caregivers in a “humanizing” way:

A New York hospital has a Caregiver Centre on site that offers a place where caregivers can meet with a social worker, receive counselling, make a cup of tea, decompress, meet privately with family members and the medical staff etc.

There is this hospital-based program in the U.S. where volunteers (screened and trained) seek out family caregivers on the various hospital floors and encourage them to visit the caregiver centre. Having a centre like this in our hospitals would help—if there is one place you can find family caregivers, it’s in the hospital corridors!

#### **i. Sub-theme: Family Dynamics**

Family dynamics play a role in making or breaking the healthy alliance between professionals and patients and family caregivers. This sub-theme was subtly observable in body language during patient-caregiver dyad interviews and clearly emerged from the stakeholder’s data. Stakeholders described what an older patient may consider as she/he identifies someone who can take care of the patient’s estate and personal matters during the last stages of life:

I think more and more clients are really struggling more on the property side than the personal care side, but they are struggling about who is suitable to assist them in making decisions [. . .] they feel [their family] may not be around or is far away, or they think that it's going to be too onerous.

Quite frequently, an older client may choose not to involve certain members of the family in something because of what their previous experience with that person has been or how they think the person will react, or how they think they will interact with other members of the family.

Differing perspectives and past experiences of individuals can influence advance care planning. Professionals need to take family dynamics into consideration when engaging caregivers in advance care planning, decision-making and other discussions relevant to patient's well-being rather than assuming family members will harmoniously support decision-making.

Together with the "Expanding professional education and accreditation" pillar discussed in the next section, "Engaging family caregivers" will ensure that the envisioned "Responsive system" be "Collaborative and cohesive".

### ***3. Expanding Professional Education and Training***

Aligning with the compassionate characteristics of the envisioned responsive system, cross-sector frontline practitioners should be equipped with the skills and knowledge to care for people in the last stages of life. One stakeholder suggested that the Academic Health Science colleges should provide training to practitioners in various settings. Training would include communication skills, decision-making skills and care planning skills:

Medical trainees have significant exposure to dying patients. They may not, however, be comfortable communicating with them important issues such as wishes and goals of care. Communication skills need to be taught and practiced, over and over.

Secondly, palliative care principles may be more broadly applied to situations involving frailty, advanced chronic illness and dementia. Palliative care principles aim to promote both the physical and psychosocial well-being of patients and family caregivers and may be routinely delivered by family physicians, medical and nursing staff, and other allied health professionals such as social workers in both community and hospital settings. Currently in the Ontario health care system, palliative care requires referral by a physician. This may be problematic for those without access to primary care.

I think that the gap in care may be addressed by teaching practitioners to recognize the combined effect of multiple chronic conditions in persons as they get older and goals of care often change with some chronic conditions.

Most people have had, toward end of life, more than one chronic condition and often there are competing objectives or competing guidelines, that suggest competing ways of managing. Health professionals may be steered to focus on what's meaningful for the person towards end of life and the goals of the management, and then encourage them to tailor the management of the disease accordingly.

Palliative care principles such as “applying a holistic approach to care that considers a person’s life experience and current situation” may also be applied in the legal arena. For example, the Canadian Hospice and Palliative Care Association partnered with the Canadian Bar Association to have lawyers trained to give advice to clients on the importance of thinking about end-of-life issues, such as advance care planning, earlier on in life:

We partner with the Canadian Bar Association through our Advance Care Planning Project. Wouldn't it be great if every person that went in to see a lawyer to do a will—you know, at a point of transition, right? Something had changed in their life and they'd seen a lawyer—that lawyer would broach the subject of advance care planning. So that it's on people's radar and that they are thinking about it. They may even have it drawn up early on and update it later.

Beyond palliative care principles, health professionals may also participate in cross-specialty training and other informal training conducive to collaboration. This may arise through initiatives such as formal and informal meetings and joint case conferences that provide opportunities for colleagues to seek advice from one another:

LOOP, which is an online, secure, web-based collaboration tool, has the Daily Huddle where the docs are all on the phone and the nurses and the case managers, and they just go through patients for an hour. They make a plan and they figure out who needs what and who's going to see who, every day.

The shared care approach—especially among specialists from the acute-care setting and health providers in the community-care setting—is responsive to the care needs of the patient throughout the disease trajectory. This approach also enhances the skills of health care professionals involved, and can lead to mutual respect and understanding of their respective roles:

We actually have a program where we've trained the palliative care docs on administering IV Lasix at home with the backup of a cardiologist. So the home care doc feels comfortable running an IV Lasix, the cardiologist is thrilled because

they're not in emergency and the patient is thrilled because they're at home getting IV Lasix, which is what they'd be getting in emergency.

As mentioned in Section D, there is an expectation that family physicians will provide primary palliative care in the community and in patients' homes ("home-based medical teams with expertise in palliative care"). One stakeholder estimated that around "65% of Ontarians die of dementia or frailty or diseases with unpredictable trajectories, who often do not need a specialist care program, but would benefit from having a sort of palliative approach to primary care". In order for primary physicians to feel competent, Continuing Medical Education could offer credit courses that focus on helping primary care clinicians "better diagnose the chronic complex conditions that are very challenging to diagnose and manage early on, specifically dementia, heart failure, COPD, falls etc." Having chronic conditions managed earlier on in the illness trajectory may avert "a cascade of events" resulting in repeated hospitalization and premature institutionalization. Instead, we can have a cohesive and responsive system:

Earlier accurate diagnosis, especially in dementia, would allow family physicians to better care for these persons, and manage them in an interdisciplinary way. This would reduce the number of referrals to specialists.

One evidence-based model in Ontario that has been particularly successful in achieving the above is the primary care-based memory clinic model, led by one of our stakeholders.<sup>242</sup>

One stakeholder pointed out the lack of "common language" between the medical and legal fields, contributing to "much confusion and negative perceptions on both sides". To rectify this, the importance, implications and relevance of the "substitute decision-making provisions in the *Health Care Consent Act*" should be made clear to health professionals. The function and value of the Consent and Capacity Board should also be emphasized. These measures may generate a more collaborative—rather than opposing—environment between these closely related sectors, so that they may better respond to the needs of patients in their last stages of life:

This past year, there's an annual event at the Law Society called the Estates and Trusts Summit, and for the first time ever, they had a palliative care physician come and talk which [. . .] is a really positive, useful thing to do.

#### **4. Public Education and Awareness**

Only about 20% of deaths in Canada are sudden or unexpected and most Canadians die in old age.<sup>243</sup> There are ample opportunities to discuss death and dying and to plan for the last stages of life, and 80% of Canadians agreed that people should start planning for end of life earlier on. As mentioned previously, only 9% of Canadians have discussed end-of-life care with their physicians.<sup>244</sup>

One of the key elements in the envisioned responsive system is public education, which is intended to generate public awareness of these important issues, and to create opportunities for frequent and healthy conversations about death and dying. Some of the existing initiatives, as pointed out by a stakeholder, aim to “start the conversation on end-of-life care”. These conversations affect positive change in public attitudes toward dying as they encourage people to reflect on their desires and hopes, to make a record of them, and to communicate these to their family and caregivers. With these documented wishes, individuals can revisit and update them as life circumstances change, ensuring that at points of crisis documented wishes are honoured.

Our stakeholders also pointed out the importance of educating the public on the value of long-term care facilities. While “the government is pushing for people to age in place and die at home, the reality is not everyone will spend their last days at home”. Long-term institutional care is an important element in the “continuum of care”, and “some people actually thrive in long-term care, as they gain weight, become more social etc”. Therefore, the pros and cons of the long-term care option and home care option should be presented “to allow families and patients to make informed choices in the care setting that’s best suited to their needs and situations”.

The difference is between going to a retirement home and a long-term care home. There’s a lot of pressure now on people who have relatives in a hospital, in an acute care bed, to agree to a discharge to a retirement home and sometimes they’re not presented with other options, even; and you know, but they don’t know, the difference between the two. They don’t know that one is part of the health-care system and the other isn’t. Nobody tells them these things.

Another dimension to public education focuses on legal preparation:

This whole idea that somebody else may assist somebody in making decisions because that person may lose capacity to make their own decisions is something that may seem straightforward. However, most people aren’t even at the level of understanding it.

The creation of kits that accurately outline key terms associated with legal documents and preparations related to last stages of life may also prove to be useful. Another initiative that may be more broadly adopted and disseminated in Ontario, as pointed out by our stakeholder, is a “voluntary trusteeship program run by the City of Toronto. If a person has enough insight to say they need some help, but they don't have a family member to become the power of attorney for finances, then the agency will take on their financial capacity assessment”.

Last but not least, there needs to be public acknowledgement and awareness of the important role of family caregivers. The emotional, financial and physical costs of caring for elderly parents are enormous and caregivers require appropriate support to carry out their role.

Raising awareness of caregiving issues is key. Most people, in my opinion, do not truly comprehend the issues around caregiving until they are “in” the situation themselves. More “awareness raising” is important, plus any economic analysis that demonstrates how caregiving is impacting the labour force (lost wages, lost productivity, etc) or costs to the health care system is important.

With more Ontarians discussing issues surrounding death and dying, legal considerations and caregiving, a grassroots movement may gain traction. Only then may the public, as a collective, capitalize on the “policy windows” that are currently open, and mobilize political changes and influence funding decisions to improve the conditions of family caregivers and patients in their last stages of life:

I understand that much of the programs and services fall within the provincial/territorial domain. That said, the new federal government is negotiating a new Health Accord with the provinces/territories. Given this window, this would be the point in time to try to influence change.

## **5. In a Nutshell**

The data set presented here is generated by a research process guided by social construction principles and represented the collective strengths across different sectors (that is, health, legal, social, policy) in envisioning and developing a better care pathway for patients and caregivers living with frailty, chronic illness and dementia, who may be cared for in their homes. Professional stakeholders from different sectors were engaged in provocative conversations regarding how to transform the system on the ground. Recommendations from our stakeholders presented in this section challenge us to think and work beyond the health care system when providing timely care and support to this particular population of patients and their family caregivers, and to understand how the legal, social and policy sectors may all contribute to support this transformation.

## **V. DISCUSSION OF MAIN FINDINGS FROM LITERATURE REVIEW AND CURRENT QUALITATIVE STUDY, AND CONCLUSION**

While aging, frailty, dementia and chronic illness are clearly major social, economic and health system concerns, they first and foremost impact individuals, family members, health professionals, counselors and consultants. This study is a ground-up examination of the perspectives of individuals struggling with end-of-life complexities, their key family caregivers and supports, together with the perspectives and experience of stakeholders, who included ethicists, policy makers, legal and health providers. The study is notable in that the data derives from hearing the perspectives of patients, family caregivers and stakeholders in their own words about their experiences in dealing with end-of-life issues and their creative ideas as to how to address the emotional, practical and legal complexities associated with the last stage of life.

It is well-recognized that many individuals with dementia and other serious age-related frailties are cared for by a significant other who is a primary caregiver and support. In the community, the majority are family members, hence they have both a significant obligation of care as well as intense emotional connections that complicate the process of managing difficult situations while dealing with the often wrenching experience of watching somebody with whom they are deeply tied gradually fade as the chronic illness, perhaps most especially dementia, erodes their life. While each aged individual and each family member have their own experience, they are also linked as a unit as the forces of the illness require daily, hourly and moment-by-moment attention. For this reason, the person with the illness, together with his or her key family member, must be viewed not only as individuals but as a dyadic unit.

About 99% of the frail elderly require support from informal caregivers, often women who are themselves elderly with high rates of physical frailty and economic hardship. Frailty is a particularly complex phenomenon in elders who also have dementia. Family caregivers are generally untrained and unprepared to provide care for complex frailty and dementia, yet are in the forefront of the system, contributing billions of dollars annually in unpaid services that support the health care system. In addition, caregivers are highly vulnerable to psychological and medical burdens directly associated with the stress of caregiving, leading to increased health care costs in this population. Consequently, when considering the system requirements for care of elders with significant frailty and dementia in the last stage of life, the equation must include the needs of informal caregivers without whom the caregiving system would collapse.

## **A. Communication: Diagnosis and Prognosis**

Our data, supported by background literature, indicate that communication between professionals, particularly physicians, and frail elders, caregivers and families is a central concern of both patients and stakeholders. The data are clear that families and frail elders themselves want and require open communication from professionals about the nature of the illness, its likely course and the implications of treatment decisions. However, equally clear is the common failure of this communication process. Sometimes this arises from the lack of training of physicians in conveying this kind of information to patients and engaging with them in an effective manner. There may be a tendency to try to blunt the impact of the “bad news” with euphemisms. The outcome for families and patients is lack of clarity and uncertainty, which further impair other decision-making regarding matters such as substitute decision-making on behalf of the patient. Overall, the data suggest that physicians are not adequately trained in the skill of sharing health information with patients, and are often unprepared for addressing these issues, particularly at the beginning of their careers. Concurrently, patients may vary in their need for information and some are ambivalent about what they want to know. On the one hand, the data suggest that the patients generally are in favour of hearing news directly and bluntly, but it is also true that family members may be uncertain about whether to allow physicians or other health professionals to convey a bad prognosis to vulnerable frail elders. The wish for information and conveyance of bad prognoses are particularly influenced by cultural norms with some ethnocultural communities wanting less information regarding prognosis compared to members of other groups.

Communication between health care practitioners and patients is further complicated by data that indicate that commonly individuals do not hear information accurately even when it is conveyed to them. This is evident, for example, when “informed” consent is solicited from patients or caregivers. Additionally, it is common clinical experience that caregivers who may have been told in detail about matters such as diagnosis and prognosis, come away from such information-sharing sessions with fragmented knowledge and poor understanding of what they have been told. This suggests that the nature of communication must be tailored to the emotional state of the individual and caregiver and that it is important to recognize that communication may have to be provided more than once.

## **B. Communication and Decision-making**

While autonomy and independence are highly valued elements in medical care, the presence of dementia impairs the ability of the patients themselves to participate fully in decision-making. Consequently, while individual autonomy is a key ethical norm in health care decision-making,

considerations of decision-making in this population must integrate the substitute decision-makers into the practical and ethical process of making decisions. Often substitute decision-makers have to make decisions on very serious matters, sometimes regarding life and death, without fully understanding their obligations, the laws or the particular autonomous wishes of the person with dementia. Under the circumstances, a careful and detailed discussion between the health care provider, usually the physician, and the substitute decision-maker is important, but commonly does not occur.

The ability of physicians to accurately predict outcomes in some circumstances is highly variable. Uncertainty about prognosis leaves substitute decision-makers in a precarious position when having to make decisions about significant medical interventions, including life-saving procedures in frail, chronically ill or demented individuals. Frank discussions about prognosis, the experience and level of suffering of the person with the illness or dementia, and the impact and benefits of treatment are critical.

Because of the importance of communication, health care professionals are wise to give careful consideration to the circumstances in which information is conveyed and to include the important decision-making members of the system, particularly the family caregivers who are intimately connected with the frail and possibly demented elder. These interactions, which, in a busy health care environment are often rushed and performed under the pressure of time, may be inadequate processes given the seriousness and implication of the decision-making process.

### **C. Equity and Access**

Numerous factors affect equity of health care delivery, including economic status, culture and race, environment, social factors, and access to basic necessities of life such as food and clean water. Families of frail elders who have more resources are able to engage services outside the public health care system in Ontario. For dementia care in particular, the available services from the government-funded systems are generally inadequate to meet the needs of care provision, given the 24-hour requirements of care required by many such patients in the community. This is further exacerbated in rural areas where services may not be locally available.

While the Ontario system strives for equity and accessibility, the system of care for frail and particularly demented elders in the community is both fragmented and inadequate for their needs. This increases the reliance on the family caregiver and further highlights the importance of considering the nature of caregiver burden and the need to address this issue with effective

interventions. Cultural factors also increase the equity gap. Seniors in poorly resourced ethnocultural and rural communities are reliant on their families, who are often overburdened in their capacity to provide care.

Gender is a particularly important factor in consideration of late-life chronic illness and dementia. The majority of informal caregivers are women, and this gender disparity may have important implications for the nature of system response.

While often characterized as looking after a "loved one", caregiving in late life is comprised of much more complex emotions, including feelings of being cheated, intense feelings of isolation and dislocation from the normal stream of life, depression, sense of loss, and role transformation as caregivers deal with feeling trapped and hopeless in the grip of the inexorably progressive disease. Dementia provokes guilt in caregivers since the disease can never be adequately addressed and always leaves the caregiver with a feeling of inadequacy in the face of symptoms and behaviours that are uncontrollable and progressive.

Health care professionals themselves are often poorly equipped to diagnose, understand and advise on more specialized aspects of care, including diagnosis, understanding legal issues or advising on the availability of services in the system, leaving the patient and caregiver in the position of having to navigate a highly complex system of services without much guidance or skills training. Particularly striking amongst stakeholders was the moral distress caused by the pressures on health care professionals, particularly those in primary care.

#### **D. Enabling Factors for Support and Access**

To be sure, there are effective models for addressing the needs of the chronically ill population at the end of life. These models often incorporate palliative care principles, including relief of suffering, and addressing psychological and spiritual needs. While palliative care emerged commonly as a focus of discussion amongst stakeholders, patients and caregivers alike, this discussion is controversial when addressing the issue of dementia, which is a complex phenomenon that requires additional consideration. When those suffering dementia become severely ill and near the end of life, palliative care approaches appear to be appropriate. However, most individuals living in the community with dementia are not at the terminal stages of illness, since dementia is a slowly progressive disease which goes from very mild to severe. In the intervening years, until it progresses to very severe levels of impairment, the quality of life of an individual with dementia may be quite good. While there is always a burden on the family caregiver under these circumstances and supports are essential, viewing these individuals as terminal or in need of end-of-life care does not coincide either with their own

self-image or that of the family. Consequently, it is unwise to attempt to create a blanket approach to both the philosophy and implementation of services for dementia. Each individual requires a careful determination of the stage of the disease and of the caregiving process and implementation of interventions based on those factors, rather than on a simple diagnostic paradigm. Ensuring equitable access to supportive models of care that reflect the needs of frail individuals and their caregivers is paramount.

Advanced planning for end-of-life care is intuitively necessary. However, our data indicate that, in the majority of cases, a discussion of this planning, either between the patient and family members or with health care practitioners, is not undertaken. Indeed, advance care planning is often not part of the consideration when caregivers have to make substitute decisions for frail elders. Under these circumstances, the caregiver family member who is struggling with his or her own emotions and uncertainties is often guided by factors that do not accurately reflect the wishes of the individual with the disease process. Clinical experience suggests that even when the wishes of the patient are known, it is difficult for families to actually carry out these wishes when they run counter to the family caregivers' thinking and beliefs.

Interestingly, while professional stakeholders are highly aware of the legal issues associated with the caregiving role and matters relating to powers of attorney, wills, capacity, advance care planning and substitute decision-making, caregivers and patients themselves do not seem very concerned about these matters, nor are they highly knowledgeable about them. Consequently, there is often a disconnect between the patient and caregivers' understanding of the legal system, the role and obligations of the physician, and such things as the *Substitute Decisions Act*. In our data, there was very little reference to legal matters amongst patients and caregivers. Indeed, the guiding principles for caregivers appeared to be their own values and beliefs, rather than formal legal guidelines. All stakeholders, including health care workers, legal experts and policy makers, noted the lack of common language between the fields of medicine and law that makes it sometimes difficult for professionals to work together to address legal and ethical aspects of health care related to end of life in the frail elderly.

Legal experts emphasized that while adequate laws are in place to ensure equitable health policy, these laws are not always optimally reflected or understood by those who work in and use the health care system, pointing to a need for enhanced collaboration amongst policy makers, health care providers, lawyers and those who use the health care system.

Just as health care professionals often fail to communicate clearly to patients and caregivers, so the legal profession often fails to provide clear information in order to enable informed decisions. In this regard, there are often communication breakdowns between medicine and

the law, with physicians frequently unaware of the important elements of the relevance of the *Substitute Decisions Act* and *Health Care Consent Act* in determining their responsibilities. Here there may be a difference between the perspectives of the health care practitioner, particularly the physician, and the legal system. While physicians often struggle with the risks inherent in working in complex and often crisis-ridden situations with patients and caregivers at end-of-life, those in the legal profession have expressed the opinion that professionals need to be more accountable and bound by their legal obligations. This is particularly evident in the realm of obtaining informed consent, when health care professionals are often ill-equipped to fully assess the capacity of patients or to engage appropriately with substitute decision-makers. Both the literature and the physician stakeholders called for enhanced training in legal issues and their communication.

## **E. Advocacy and Fragmentation**

Patients and caregivers perceive the system of care to be chaotic and uncoordinated. Problems with navigation of the system, particularly at moments of crisis or transitions of care, were highlighted. This is in line with clinical experience. Stakeholders also recognized this fragmentation and expressed moral distress at the inadequacy of the system in which they work. This is perhaps particularly evident in the nature of supports for home care when patients are discharged from acute care services such as hospitals. Often, the institution is under pressure to ensure rapid turnover and disposition of patients back to the community, where resources to meet the needs of patients being discharged are often inadequate. Stakeholders, when they are aware of this discrepancy, are highly troubled by the reality.

When dreaming of a more effective system, patients and caregivers emphasized the critical foundation of effective communication around conveying diagnosis and prognosis, as well as clear understanding of the illness and what to expect. They highlighted the importance of coordinated assessments and the wish for better communication not only between them and their health care professional, but also amongst health care professionals, so that the burdensome duplication of repeated assessment processes is reduced. The wish for interaction and coordination between the legal profession and health care providers was also dreamt of by stakeholders. This included concepts such as training of lawyers to advise clients on the importance of end-of-life issues and advance care planning, and public education on the relationship between health care and legal matters. Additionally, better coordination between the legal profession and health care professionals around establishing a common base of communication, language and understanding was wished for to avoid confusion and negative perceptions on both sides.

The top-down approach to the design of services is perceived by caregivers as non-empathic and unresponsive to them as individuals. They dream of a flexible and sensitive system that can respond to them and that is accessible and responsive to their specific urgent needs when these arise, regardless of socioeconomic status and geographic location. This would ensure that patients and families living in rural areas have access to services in the same way as those in urban areas. An accessible system would include dissemination of accessible information about available resources and services. An effective system would include attention to provision of system navigation support and guidance.

In a complex legal health care environment, patients and caregivers dream of the availability of advocacy services that will be available when they require more expert legal opinion and options. An effective system of care would be flexible enough to change based on the changing clinical landscape that is universally present in progressive chronic illnesses. For example, one-size-fits-all solutions do not take into account the needs of patients and caregivers in the serious phases of illness as compared to the more mild or moderate stages when requirements are quite different.

Similarly, stakeholders struggle with the uncoordinated inefficiencies in the system, and are highly aware of scattered or unevenly distributed resources, access inequities and communication gaps. Stakeholders also were aware of the common breakdown in communication between legal practitioners and patients and caregivers around issues of assignment of power of attorney and advising on other end-of-life legal matters, such as wills. Highlighted was the absence of specific training for legal professionals in this regard.

When imagining the design of a more effective system, stakeholders, like the patients and caregivers, spoke of humanizing the experience. They emphasized the importance of effective communication between health care providers and patients about key elements of the process of dying and, implicitly, communication with caregivers when the patients themselves are unable to participate, such as those patients who are impaired by dementia. Stakeholders emphasized the engagement of family caregivers as an integral part of the system, recognizing their need for “support”, education and the appropriate use of communication advances such as technology.

This innovative project provides valuable insight into the lived experiences of those engaged in end-of-life care and serves as a prompt for further discussions on this topic. There is now the opportunity to translate this experience and knowledge into action that can impact public policy and positively influence the social, legal and economic fabric of Canadian society.

## **VI. APPENDICES**

### **A. Stages of Research Guided by Appreciative Inquiry and Study Populations for Each Stage**

#### *Stage 1*

The first stage of the proposed study was guided by the “Discover” and “Dream” steps from AI, with the aim of obtaining an in-depth understanding of the personal experience, needs and perceptions of family caregivers/members and elderly patients aged 65 and older with moderate to severe frailty, with regards to system of care in the last stages of life. These lived stories of patients and caregivers or family members were drawn out by a semi-structured interview guide (Appendix C), aimed at “discovering” the enablers and barriers these individuals encounter in their journeys related to care in the last stages of life, and to “dream” of what might be. Lived experiences from the representative sample of caregiver/care-recipient dyads were analyzed using inductive coding in an iterative process by three experienced qualitative researchers in the team (MC, SM and LNJ).

#### *Stage 2*

The second stage of the study was guided by the “Design” and “Realize the Destiny” steps of AI, and involved interviews with stakeholders from different professional fields: medical, allied health, legal and ethics, and administration and policy, using a focused interview guide (Appendix D). Eleven individuals confirmed their interests and availability to participate in this stage of research (Appendix B). These individuals were selected to encompass a broad range of expertise and were interviewed to comment on Ontario policies, laws and health acts relevant to the issues identified by the patient/caregiver dyads.

## B. Professional Groupings and Names of Interviewed Stakeholders

Professional groupings	Stakeholder names
Administration and Policy	Sharon Baxter
	Sandra MacLeod
Allied Health	Dr. Oona St-Amant
Legal and Ethics	Tom Foreman
	Jan Goddard
	Mark Handelman
	Gilbert Sharpe
Medical	Dr. Naheed Dosani
	Dr. Mark Lachmann
	Dr. Linda Lee
	Dr. Leah Steinberg

## C. Patient/Caregiver Dyad Interview Guide

### Stage I Data Collection: Patient/Caregiver Dyad One-on-One 60-90-Minute Interviews

#### Biographical and social background

Tell me about yourself.

- Probes: Geographical location, cultural background, age, connection to community
- Probe: What is the relationship between caregiver and care recipient? [Question to caregiver]: How long have you been taking care of care recipient?
- Take notes on caregiver-care-recipient relationship dynamics
- Based on observation made on relationship dynamics and capacity of care recipient, the option to continue the interview separately will be provided.

#### Health conditions

Please describe the health issues you are managing at the present time.

- Probes: When were you diagnosed and by whom? What is your everyday experience living with these issues? (Ask for a concrete example)
- [Focus: On assessment tool/how did you get diagnosed?]

#### Challenges and coming to terms with health problems/impairments in daily living

What changes occurred in your life since your diagnoses?

- Probes: How did these changes impact you? How has your routine shifted?

### **Perceived support: informal/family versus formal/professional**

Who in your community/family do you draw support from?

- Probe: Why were these individuals approached for support? What kind of support do you expect from them? What is your experience thus far? How does this type of support assist you in your daily life?
- 

What is your experience with regards to seeking care from health care professionals?

- Probes: How far are your physician(s) from you? How do you travel to your appointments? How long do you wait for your appointments?

Are these supports provided to you according to your will—and if not, please elaborate.

What other supports are you aware of that are available to you?

- Probes: Do you draw upon supports from what you have mentioned? Why or why not?

### **Decision-making**

Who makes the decisions for the patient?

- Probes: What kinds of decisions? When/how did you come into the role of decision-making? Focus on: personal choices and daily life [social; emotional; recreational; systemic]

### **System navigation**

What services have you accessed? How often do you access these services?

- Probes: When did you start accessing these services? What were/are the diagnoses at the time of accessing these services?

What are the barriers/challenges that you have encountered?

What might be/have been helpful that you did not receive?

What in the system is working for you?

### **Future prospects, concerns, and wishes with regards to Ontario's system of care**

What are your wishes for the future? What are the plans in place to fulfill these wishes?

Have you discussed issues such as advanced care planning/financial, housing arrangements, and power of attorney? If not, please explain. What may facilitate these conversations?

## **Advocacy**

<http://www.ontariocaregivercoalition.ca/our-history.html>

<http://www.dyingwithdignity.ca/about>

Example of an advocacy group: Advocacy Centre for the Elderly

<http://www.advocacycentreelderly.org/services.php>

“ACE serves people 60 years of age and over in the Greater Toronto Area, and may also provide services to seniors outside of Toronto if the case is of significance to the seniors' community. ACE also works with the local community clinics across the province to provide legal services to seniors living in these other locations.

“Please note that while ACE primarily provides legal services to low-income seniors, we do not have the resources to provide legal services to all eligible low-income seniors. ACE will consider several factors in deciding whether it will provide legal services to you, including your income level, the importance of your case to legal issues affecting the seniors' community, and the availability of a community legal clinic within your geographic area. If ACE is unable to assist you directly, we will make every effort to refer you to someone who can. Please note that you will not become a client of ACE unless ACE agrees to represent you.”

What do you think of this group? Why or why not is it useful for you?

What kinds of advocacy groups/activities would support participation/reaching out to the services you mentioned in the community?

## **Conclusion**

Is there anything you would like to add?

Thank you.

## **D. Stakeholder Interview Guide**

Expert in related field (legal/administration/policy, medical, allied health, ethics) is provided with a summary of Stage I data analysis prior to the interview.

1. Were there any surprises (ie information missing, information you anticipated) after reviewing the summary?
2. What were your initial responses to the summarized data?

3. What are some of the approaches that may be applied to address the issues experienced by the caregiver and patient?
4. What changes need to be made within the system as you know it to implement what was presented?
5. What is in the existing infrastructure that can contribute to a solution? (Utilizing existing capital.)
6. What are the barriers/facilitators in your own daily work? Probe: What is your agency/capacity in your daily work?
7. What are the challenges to implement these changes?
8. Is there anything else you would like to add?

## **E. Programs, Services and Policies to Support Caregivers and Patients**

### Public Awareness Initiatives

- **The Pallium Project**  
The Pallium Project is a collective arrangement of leaders and individuals with the overall goal to develop tools, resources, professional development and initiatives for hospice and palliative care. Their goals are focused to improve access, enhance quality of care and build longer-term system capacity (<http://www.pallium.ca>).
- **Canadian Virtual Hospice**  
The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators.<sup>245</sup>
- **The Way Forward Project**  
A road map for an integrated palliative approach to care which includes meeting a person's and family's full range of needs—physical, psychosocial and spiritual—at all stages of frailty or chronic illness, not just at the end of life.<sup>246</sup>

### Social Policies

- **Compassionate Care Benefit**  
The Compassionate Care Benefit is a federal program under Employment and Social Development Canada where a family caregiver may apply for financial benefits when providing palliative and end-of-life care for up to 26 weeks leave, which can be shared among other family members.

## Models of Care

- **PATH Forward Model**

Integrating palliative care principles in current care models for frail elderly patients with dementia will address their current health care needs prior to crisis. Mallery and Moorhouse<sup>247</sup> call for mandating palliative care within geriatric medicine using the Palliative and Therapeutic Harmonization (PATH) Forward Model, which focuses on three steps: 1) Understanding (by completing a comprehensive geriatric assessment, or CGA), which will provide a holistic view of the individual's health and take into serious consideration frailty; 2) Communicating to ensure knowledge transfer is transparent and thoroughly explained to the patient and/or decision-maker; and 3) Empowering, which supports the decision-making process for the patient and caregiver.

- **Primary-care-based memory clinic**

A primary-care memory clinic model and training program, which is based on collaborative care, evidence-based care and capacity building, has been implemented in 78 primary-care settings throughout Ontario. The model has supported patients with cognitive issues (such as dementia) in seeking medical and social care, including access to specialized care.<sup>248</sup>

## Services

- **CNAP, Community, Navigation and Access Program**

The Community Navigation and Access Program (CNAP) is a network of over 30 community support service (CSS) agencies in the Toronto area that are collaborating to improve access and coordination of support services for older adults, their care providers and health care stakeholders. The CNAP Network Agencies' aim is to ensure that every door leads to service so that older adults can reach the care they need and live independently. CNAP is supported by the Toronto Central Local Health Integration Network (TC LHIN) through the Ontario Aging at Home Strategy.<sup>249</sup>

- **Community Care Access Centres (CCAC)**

CCACs deliver home and community health care and connect people to other services in their community. The centres work with seniors, adults, children and their families to help determine and provide the right care and health supports to keep them at home for as long as possible.<sup>250</sup>

- **Crisis Outreach Services (Woodgreen)**  
Crisis Outreach Service for Seniors is an on-call mobile crisis intervention and outreach service for seniors who have suspected or diagnosed mental health and/or addictions, including dementia, that provides short-term response 365 days a year, 9 a.m. to 5 p.m. Call the COSS team at (416) 640-1459 to make a referral. The COSS team makes every effort to make direct in-person contact with the client in the community the same day or next day, depending on urgency.<sup>251</sup>
- **The Temmy Latner Centre for Palliative Care**  
A centre within Toronto's Mount Sinai Hospital that is dedicated to providing palliative care, including quality end-of-life care, to those who are dying from a life-threatening illness and making support available to their families. Services include providing patients with end-of-life care in patients' homes. Through a Home Care Program, a doctor is available to patients seven days a week, 24 hours a day.
- **Inner City Health Associates**  
Inner City Health Associates (ICHA) is a group of more than 60 physicians working in over 40 shelters and drop-ins across Toronto. ICHA provides primary, mental health and palliative care to those who do not otherwise have access to care. We serve people living on the street and in shelters, as well as those who are precariously housed. ICHA is funded by the Ontario Ministry of Health and Long Term Care through an alternative payment plan.<sup>252</sup>
- <http://www.homecareontario.ca/home-care-services/about-home-care/hospice-palliative-care>  
This website provides a basic overview of publicly funded and privately retained home care in Ontario.
- <http://www.advancecareplanning.ca/>  
A resource for families and patients called SPEAK-UP, which provides information and guidance regarding advanced care planning.
- <http://www.prepareforyourcare.org>  
This is an interactive Web-based tool that assists people in making medical decisions for themselves or others; helps determine appropriate care; and advises how to talk to doctors to get the information and assistance with decision-making that they may need.

- <http://www.thecarenet.ca>

The Canadian Researchers at the End of Life Network (CARENET) is a group consisting of health care professionals from across the country who collaborate with each other to understand and improve palliative and end-of-life care. This website has separate pages for researchers, patients and families, and health care providers.

## VII. ENDNOTES

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<sup>246</sup> CHPCA, note 1; Quality End-of-Life Coalition of Canada, *Blueprint for Action 2010 to 2020* (Ottawa: CHPCA, 2010) 1-20. Online: [http://www.chpca.net/media/7607/ENG\\_progress\\_report\\_2010.pdf](http://www.chpca.net/media/7607/ENG_progress_report_2010.pdf) (last accessed 4 July 2016).

<sup>247</sup> LH Mallery & P Moorhouse, "Palliative and therapeutic harmonization: Expanding the orientation of geriatric medicine" (2012) (2)1 Canadian Geriatrics Society Journal of CME 5-8.

<sup>248</sup> Lee, and others, note 242.

<sup>249</sup> Community Navigation and Access Program, "About Us" (Toronto: CNAP 2016). Online: <http://www.4seniors.org/aboutus.aspx>.

<sup>250</sup> Community Care Access Centre, "About Toronto Central CCAC" (Toronto: CCAC, 2015). Online: <http://health.careathome.ca/torontocentral/en/Who-We-Are/About-CCAC>.

<sup>251</sup> Woodgreen Community Services, "Service Detail" (Toronto: Woodgreen 2010-16). Online: <http://www.woodgreen.org/ServiceDetail.aspx?id=192>.

<sup>252</sup> Inner City Health Associates, "Who We Are" (Toronto: ICHA, 2016). Online: <http://www.icha-toronto.ca/>.