

There is no “I” in Team: Nursing in a Patient-Centered Health Care System

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Introduction

The increasing demand on health care due to the growing needs of the aging population and the anticipated constraints of the health care system require policy makers and government to strike a balance between ensuring universal access to services while ensuring the sustainability of the system. Although advances in medicine are allowing for people to live longer lives, their needs are requiring care of a different nature than what is provided in acute care. This implies that not everyone is reaping the benefits of the medical advancements. The demographics of the peoples utilizing health services like primary care, outpatient clinic, hospitals and emergency services, most frequently are older adults whom 80% of which live with a chronic disease and 50% of them whom live with co-morbidities (Cooper and McCarter 36).

Not only are the needs of those seeking medical resources transforming but so is the role they play in a health care context. In health care today, the patient is viewed as a client or a consumer of services. In fact, the term “patient” has been criticized for implying submissiveness and mistakenly portraying the characteristics of a health care user who is in fact someone who is assertive, informed and empowered in their care. For this reason, terms like “customer”, “consumer” or “client” are regularly used instead of “patient” to symbolize the freedom and power patients possess (Childress, *The Place of Autonomy in Bioethics*). This has obviously shaped how health care organizations perceive the role of the patient and has also changed the manner in which care is delivered. Inevitably, change is often accompanied with unfamiliar and new issues that arise, requiring deliberation and resolution.

The nursing role today is multi-faceted and encompasses responsibilities of advocacy and active care for patients, their families, health organizations and the health care profession.

Specifically, “nurses provide the main connection with patients, act as advocate with other care providers, give physical care to patients and offer emotional support to both patients and their families” (Leiter, Harvie and Frizzell 1612). Given the breadth of a nurse’s responsibilities, it is troublesome to learn that traditionally, the ethical frameworks that are in place for nurses that are intended to support and guide moral action and decision-making are derived from dramatic biomedical ethical dilemmas of which are unlike the issues nurses witness and manage in their everyday practice and therefore the proposed guidance is irrelevant, inadequate and potentially obstructive (Varcoe, Doane and Pauly 317).

The concept of patient autonomy as it is interpreted in patient-centered care, and as it relates to modern medicine has been a focus for discussion in clinical and medical ethics groups, and for valid reasons. Although there is recognition that the role of patient autonomy is a fundamental component in health care decision-making, challenges and ethical dilemmas can arise in its interface with the moral and professional obligations of health care professionals. When considering values such as patient autonomy and the duty to care and avoid undue harm to patients, the prioritization of principles and moral duties can become ambiguous (Lantos, Matlock and Wendler 495). From an ethics perspective, it can be unclear under what circumstances an act is considered right or wrong. For instance, an act may be judged as the right act provided it fulfil an established obligation however an opposing act may alternatively also be judged as right based on the consequences it will render. This deliberation and justification is complicated and highly contentious even amongst skilled ethicists, yet somewhat expected of individuals in the health care profession. It is clear that given the already inherent complexities of the nursing role and nurse-patient relationship, nurses and consequently the patient suffer when there are conflicting practice and standards to service delivery.

An example of an approach with potentially conflicting principles is the respect for patient autonomy in the context of patient-centered care. It is within the parameters of respect for patient autonomy that patients have the freedom and the means to individualize a personal care plan ultimately independent from any input by a medical professional. This freedom strikes the public, policy makers, public organizations and the government as an integral element to receiving health care when in reality it leaves nurses and potentially the patient, unsure, disadvantaged, and unsafe. Carrying out patient-centered expectations can make health care professionals vulnerable as it pressures them to dismiss the standards of the medical profession, to accept requests for non-beneficial, unnecessary or unsafe interventions as well as to accept the responsibility of having to assist in carrying out the less than optimal care plan goals (Brett and McCullough 149). For this reason, this paper will begin with an analysis of the major ethical principles in medical and bioethics and their interplay with patient autonomy. The Principlism approach developed by Beauchamp and Childress will be used as a guide to evaluate patient autonomy within a clinical context. Beauchamp and Childress provide a structure in which “there is appreciation of the limits of principles as well as the need to give them additional content, while attempting to render consequent rules and judgments as coherent with other commitments as possible” (Beauchamp and Childress). I will then examine in later chapters how the expectations from patient-centered care in the context of home care conflicts with clinical judgments as well as personal and organizational values and standards of health care providers.

The context in which the principles of biomedical ethics are applied and the manner in which services are allocated and provided, may vary across regions, settings and occupation as each province is responsible for governing health care within their own jurisdiction. This arrangement is based on the conditions in the Canada Health Care Act of 1984 which stipulates

that each of the ten provinces and two territories are responsible for administering a health insurance plan which collectively provides universal health care coverage to approximately 31 million people across Canada (Ridic , Gleason and Ridic 112). Health care in Canada is a service provided to all citizens universally and rarely requires a patient to incur a cost from the services and care received (Health Canada). This paper will focus specifically on health care in Ontario and particularly in the home care sector and will provide an overview of pertinent legislation and practices that are believed to exacerbate or contribute to particular issues.

A primary focus however, will be to analyze the impact of patient choices in the context of respect for patient autonomy on the nursing role and individual nurses. Individuals who chose to become a nurse have a natural, innate desire to help others in need or to enhance their well-being and when there are barriers that exists that impede fulfilling their professional role expectations, emotions such as frustration, distress and dissatisfaction and consequently, staff burnout can occur (Leiter, Harvie and Frizzell 1615). This paper will contribute to a better understanding of the consequences that less than ideal patient choices has on home care nurses. The results of a questionnaire administered to home care nurses for the purpose of this paper and to evaluate the hypothesis that patient autonomy challenges the scope of the nursing role will be discussed in later chapters.

Finally, this paper concludes with recommendations for re-alignment of the patient-centered care framework with nursing standards and principles of autonomy, beneficence and non-maleficence. I will provide evidence that the policies and practice standards that are in place have conflicting elements and therefore are potentially obstructive in the provision of health services. In today's era of limited health care resources, increasingly demanding health care needs and evolving methods for service provision, I believe the discussion about the impact of

expectations such as respect for patient autonomy is crucial. Addressing only the *consequences* of these expectations, such as moral distress and risk to nurses and the potentially poor outcomes for patients, is not sufficient. A more proactive approach is required and thus a systematic investigation in the many facets of frameworks such as patient-centered care and respect for patient autonomy is warranted. This paper will contribute to a better understanding of the possible risks at the patient, provider, employer and system level and what is required to mitigate the risks from both a moral and practical standpoint. This will ultimately allow for patients to exercise their rights in a manner that acknowledges their role but ensure their safety and furthermore, ensures adequate care is provided throughout their care trajectory while the integrity of the nursing profession is upheld.

Part I:**Chapter One: Principlism**

Autonomy

Autonomy and autonomous behaviour are terms scattered throughout literature and are particularly relevant to those in the field of medical and bioethics. Some proponents of autonomy assert that the right to autonomy should prevail over all other ethical considerations and for other bioethicists like Tom Beauchamp and James Childress, autonomy is only one facet of a complicated web of equally important ethical principles and considerations.

Generally speaking, it is understood that autonomy is defined in terms of self-governance and independence. Similarly, in health care the terminology and philosophy has been adopted and signifies “individual or personal autonomy” (Beauchamp and Childress 99). Interestingly, although there is recognition of its importance and the potential benefits relating to autonomous behaviour, there are various interpretations. Although the scope, definition and characteristics of autonomy and autonomous decision-making remain unclear, significant focus is placed on achieving this ideal, especially in patient-centered health care. As a result of the variance, explicit guidance on how to approach and ensure patient autonomy as well as acknowledgment of its potential limits remains unresolved.

Some understandings of autonomy emphasize skills and characteristics of an autonomous person and other versions emphasize the importance of the authenticity of the individual’s choice and or actions (Beauchamp and Childress 100). According to Beauchamp and Childress, autonomy is defined as behaviour and meaningful choice made by an individual for themselves, free from any external influence such as policy, members of the public, government etc., and is also not impacted by limitations such as access to information (Beauchamp and Childress 99). It

should be noted that this will be this definition that will be used throughout the paper when referring to autonomy and or autonomous behaviour. Nevertheless, autonomous behaviour will naturally be exercised differently across settings and situations by virtue of it being behaviour, choice and person specific. In health care for example, autonomy may be a means for a patient to request, accept or refuse a certain course of treatment independent from medical advice or involvement.

Of course, the goal of promoting autonomous behaviour is important in the provision of any health care service but certainly a primary driver in the home care sector. The Home Care and Community Services Act of 1994, for instance, clearly states in the Bill of Rights that as a recipient of community care services, the person “has a right to be dealt with by the service provider in a manner that respects the person’s dignity and privacy and promotes the person’s autonomy” (Ontario Government). Additionally, the Act also states that “any person receiving community services has a right to be dealt with by the service provider in a manner that recognizes the person’s individuality and that is sensitive to and responds to the person’s needs and preferences, including preferences based on ethnic, spiritual, linguistic and familial and cultural factors” (Ontario Government). The directive from the Government of Ontario stipulates that the health care professional ought to provide the patient a space to express choice autonomously and subsequently, the health care professional is to assist the patient in carrying out their choices. Patients and their families are informed of these practice standards and educated about ideals such as “autonomy” and “dignity” at the onset of receiving services. This in turn creates precedence for nurses who are expected to uphold this vague and ambiguous expectation which will be interpreted and exercised differently by each patient by virtue it being an individual choice.

Fortunately, guidelines exist to help nurses better understand the characteristics of autonomous behaviour. Beauchamp and Childress for example, propose that autonomous behaviour should satisfy only three criteria: 1) the actor must have acted intentionally, 2) with a reasonable degree of understanding, 3) and free of manipulation or control (Beauchamp and Childress 101). The authors recognize that one either acts intentionally or not but that the latter two criteria are a matter degree and exist on a spectrum. Since each situation is unique and would be difficult to establish an acceptable standard level of understanding and intensity of influence or control, a patient need only have *some* level of understanding and be free from only a *reasonable* degree of external force, but not all (Beauchamp and Childress 101).

Although influence is permitted to a certain degree in this framework, the patient nevertheless may choose to decline a comprehensive discussion and theoretically, this is acceptable as he requires only *some* understanding of the context in which the decision is being made and the possible consequences of each respective choice. For example, a patient who demands a medically futile treatment may not accept the alternative options or be open to learn the rationale for why their requested treatment is unnecessary or futile but because the patient has some understanding of the situation and choices, his wishes would ultimately need to be accepted as it meets the definition for autonomous behaviour. This precedence leaves the provider and ultimately the greater system at risk as it promotes a careless use of limited resources based on potentially minimal deliberation and decisions that are unfounded.

The definition of patient autonomy is logical in theory and so the assumption is that it is straightforward to apply in practice. The interplay of autonomy with other key principles such as non-maleficence and beneficence is where the challenges lie in the field of medical and bioethics. By simply satisfying the three conditions outlined by Beauchamp and Childress, the

right to patient autonomy is not always guaranteed to a patient nor should it be. This is an important consideration for the provision of patient-centered care and respect for patient autonomy. Despite a patient acting independently, intentionally and with some understanding, the provision of an autonomously chosen treatment plan may be ethically and practically difficult to accept and facilitate.

Beauchamp and Childress make a distinction between autonomous behaviour and an autonomous *choice*. According to the authors, a person may not have the capacity to act autonomously but is still able to make an autonomous choice (Beauchamp and Childress 100). A patient with advanced dementia and severe cognitive impairment for example, is a condition often cared for in the home care sector given its chronic nature. A person with such a condition in which decision-making is impaired and is not able to function fully independently or provide informed consent to treatment is still able to express autonomous choice in areas such as medication refusal, meal preferences etc. However, somehow the autonomy of these individuals is at times dismissed because of their reduced ability to *exercise* their autonomy and expression of choice.

As stated by authors Susan Sherwin and Meghan Winsby (2010), this phenomenon is likely due to the lack of recognition of the limits of opportunity of certain autonomous choice. According to the authors, there is a required shift in focus to what they refer to as relational autonomy (182). Relational autonomy refers to “a cluster of approaches to autonomy, which emphasize (rather than ignore) the socially embedded nature of agents” (Sherwin and Winsby 182). Essentially, the concept of relational autonomy acknowledges the social context in which the autonomy is being exercised recognizing that there are factors that limit and or endorse varying degrees of autonomy depending on the conditions. The fundamental underpinnings of

relational autonomy, as stated by the authors is grounded in social justice and is believed to be an appropriate shift as the traditional view of autonomy “assumes that agents can step back from this social web and engage in a process of rational deliberation that is not importantly complicated by the details of their particular social circumstances” (Sherwin and Winsby 184). According to the authors, this concept of independence and freedom as stipulated in the conventional understanding of autonomy has been shown to be problematic for three reasons: “1. They ignore the important fact that we are all interdependent and rely on one and another in multiples ways; 2. They serve to devalue efforts to care for others by denying the urgency and frequency of such work and; 3. They devalue persons who are clearly highly dependent, such as children and people with serious disabilities” (Sherwin and Winsby 185).

The concept of relational autonomy and its relationship with social justice is an important perspective for issues of stereotypes, biases, discrimination etc., and its impact on the expression of autonomy. A group that is often stereotyped or oppressed in various ways are persons of old age. Seniors who experience oppression, abuse or are stereotyped as result of their chronological age are said to have experienced “ageism” (Sherwin and Winsby 186). Ageism is a serious issue for consideration, especially in the context of health care decision-making and autonomy given its characteristics and possible impact. Furthermore, given the demographics of the most frequent users of the health care system, the concept of relational autonomy becomes especially important.

To account for certain factors inherent to old age such as the need for assistive services, diminished cognitive abilities, weakened ease to communicate, decreased physical and mental functioning etc., the concept of relational autonomy encourages acknowledgement yet accommodation for the challenges so that informed consent and expression of autonomous

behaviour remains a standard practice. If the integrity of autonomy is going to fully recognized, the autonomy of those who are not able to express their wishes freely such an elderly or vulnerable person will need to be protected and empowered.

The choices an autonomous person makes based on the rightness or wrongness of the options presented for him or her is considered as first-order autonomy and is the type of autonomy understood to be central in the field of health care. A patient who decides independently to undergo another round of chemotherapy treatment rather than a proposed mastectomy based on information related to risks and benefits would be an example of first-order autonomy. Second-order autonomy however is also legitimate. Beauchamp and Childress assert that second-order autonomous choices would entail a person making the choice to transfer the decision-making powers to a physician or religious institution for example, and although relinquishing in a sense their decision-making powers, this should not be mistaken for a loss of autonomy. The person is simply exercising second-order autonomy (Childress, *The Place of Autonomy in Bioethics* 13). A patient selecting a hospital or institution in which they would prefer to receive and have their care directed, is also an example of second-order autonomy. In this view, the likelihood of a conflict between autonomy and external influence would not be of great concern since the patient selected independently the members of their health care team therefore exercising second-order autonomy. The selected members and institution would likely share similar views and beliefs with the patient which would translate into acceptable treatment analogous to what the patient would select themselves anyway (Beauchamp and Childress 102).

From a rights-based perspective, the right to exercise personal autonomy would fall in the category of a negative freedom; one should have the right to be free of any coercion from others (Cohen 391). Although a person has the right to be free of any coercion, one also has the right to

request and be provided with adequate amounts of information in order to make an informed decision, which is a positive freedom and is the basis of informed consent (Cohen 392). The disclosure of information is crucial in facilitating informed, competent and voluntary decision making. (Ogbogu and Brown 519). Naturally, it is the health care professional who delivers information to the patient and assists the patient in developing care plan goals. A patient has a right to accept, refuse or request any treatment plan for any reason at any time despite whatever consequences or alternative treatments that are available based on the understanding that they have been informed of all relevant information in order to make a decision in relating to risks and benefits.

Nevertheless, although there may be high risks involved, the patient has a right to make risky, potentially harmful decisions. Deciphering the threshold at which the risk of a less-than ideal choice is no longer acceptable and thus requires external control and ultimately the necessity to place limits on patient autonomy, can be complicated for various reasons. The case of *Malette vs. Shulman* for example, demonstrates how a patient's decision could literally mean life or death and how ambiguous the scope of respect for patient autonomy can be for a health care professional.

Ms. Shulman was a patient who was brought to the emergency room in critical condition, semi-unconscious and confused due to her injuries. Ms. Shulman was a Jehovah's Witness and carried with her a card indicating that for religious reasons, under no circumstances should she receive a blood transfusion. As the patient's condition continued to quickly deteriorate, the physician (Malette) decided to order a blood transfusion despite having knowledge of the advance directive. The physician justified his actions based on the fact that the blood transfusion would save the patient's life and that all other non-blood interventions had been attempted and

failed. Furthermore, it was his opinion that without the context, a signature, or conditions in which the care was signed, compounded by the inability to consult with the patient, the validity of the card was questionable and so the blood transfusion was administered.

Although it is unintuitive to believe that a physician could be punished for saving a patient's life, the Ontario Court of Appeal upheld that "no medical procedure may be undertaken without the patient's consent obtained after the patient has been provided with sufficient information to evaluate the risks and benefits of the proposed treatment and other available options and to act otherwise would be unlawful battery" (Ogbogu and Brown 518). The physician in the case was found guilty battery. The physician acted wrongly given the advance directive but argued that he did so because of his professional and moral duty to care. In this example, clearly the patient's wishes whether questionable or not, were at odds with the physician's own clinical and professional judgment about what would be in the patient's best interests. The Court's rationale for its position was "grounded in the patient's right to self-determination by which is the patient, not the medical professional who has the final decision on whether to undergo treatment" (Ogbogu and Brown 518).

Capacity and Informed Consent

The case of *Malette v. Shulman* highlights the significance of patient autonomy and its connection with informed consent. Certainly, consent to treatment is critical in delivery of health care services as it is a goal of care and also a legal requirement of a health care professional prior to administering any treatment or intervention. Although assessing capacity to determine whether informed consent can be provided plays a crucial role in the delivery of health care services, it is in fact a legal process rather than clinical and thus, grounded in a legal framework (Wahl 8).

According to the Health Care Consent Act of Canada, “a person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequence of a decision or lack of decision” (Service Ontario 6). This definition is similar to the definition of autonomy by Beauchamp and Childress insofar as there is a required level of understanding of possible risks and benefits of accepting or refusing the proposed treatment plan. The Act also stipulates that it is the health care professional who is recommending the treatment who is responsible for assessing capacity and that a patient is presumed capable until evidence determines otherwise (Service Ontario 6).

Legislatively, capacity for decision-making is separated by decisions relating to property and personal care and treatment. For the purpose of this paper it will be decision-making capacity for personal care that will be the focus. The crucial element of the process of obtaining consent is the reasonable effort that is made to inform the patient of the nature of the treatment, expected benefits, risks and side effects of accepting or refusing the treatment and alternative treatments that are available. The process rather than the decision itself is of upmost priority in health care. A patient may agree with elements of a proposed treatment plan but may in fact choose not to provide consent to receiving the treatment and alternatively, a patient may disagree with the information provided but may nevertheless consent to accept care in light of it; the decision itself is somewhat irrelevant.

Similar to the standard set out in the Health Care Consent Act of Canada, Beauchamp and Childress assert that determining a person’s capacity to provide consent to treatment is based on the grounds of whether or not they are able to “understand the material given, to make a

judgment about this information in light of their values, to intend a certain outcome and to communicate freely their wishes to caregivers or investigators” (Beauchamp and Childress 113). Capacity for decision-making is critical from the perspective of respect for patient autonomy. Clearly in order to meet Beauchamp and Childress’ criteria for autonomy as stated earlier in the paper, it would require that the individual be assessed to in fact have the skills and knowledge required to meet the standard level of understanding and appreciation. In reality, this is a challenge given the status of health literacy in Canada.

A study done by the Canadian Council on Learning (2008) found that 60% of Canadian adults in fact do not have the skills necessary nor the ability to use them concurrently as required to adequately manage one’s health (Canadian Council on Learning 2). According to the Canadian Public Health Association, health literacy is defined as “the ability to access, understand, evaluate, communicate information as a way to promote, maintain or improve health in a variety of settings across the life course” (Canadian Council on Learning 9). Interestingly, a correlation is found to be strongest between the level of a person’s health literacy and the outcome related to the management of chronic conditions such as diabetes, arthritis, stress etc. The stronger a person’s health literacy is, the less likelihood a person will develop the condition and or have it poorly managed (Canadian Council on Learning 3).

The Canadian Council on Learning set out to measure and validate the health literacy of Canadian adults by conducting the Adult Literacy and Life Skills (ALLS) survey. Literacy related to written text, numeracy and problem solving were areas specifically targeted in the survey. A total of 191 tasks were developed based on varying degrees of difficulty across situations and were assigned a score based on a scale of 0-500. The scale was broken down into five levels to capture specific sets of skill and knowledge. It is assumed that level three (276-

325) is the minimum level of ability required to actively and successfully engage in the management of one's health. The study found however that the average Canadian fell below the minimum and possessed the skill set of a level two. Level two is defined as "the ability to sort through "distractors" (plausible but incorrect pieces of information), integrate two or more pieces of information, compare and contrast information, and interpret simple graphs", while level three is "the ability to integrate information from dense or lengthy text, integrate multiple pieces of information and demonstrate understanding of mathematical information represented in a range of different forms. Tasks typically involve a number of steps or processes in order to solve problems".

The authors of the study assert that these findings are significant because "without these abilities, ill-informed decisions may be made, health conditions may go unchecked or worsen, questions may go unasked or unanswered, accidents may happen and people may get lost in the health care system" (Canadian Council on Learning 5). This view is obviously critical in the context of respect for patient autonomy and informed consent.

Medical decision making clearly requires a developed skill set and awareness. This will naturally relate to a person's capacity. Capacity can fluctuate throughout the day, from day to day and between decisions and therefore capacity is said to exist on a spectrum (Beauchamp and Childress 114). A person is not usually deemed as globally incapable as capacity is decision-specific (Service Ontario). For example, a person may be incapable to make a decision about personal finances or whether to undergo surgery but is capable to express wishes about meal preferences.

Because capacity fluctuates within a range, the threshold for capacity versus incapacity is important, especially when it dictates decision-making powers. A very important consideration

both from a clinical and moral standpoint is the fact that a person is not incapable simply for making a less-than ideal choice or a decision that would not maximize their own best-interests (Wahl 9). However, because we assume capacity until proven otherwise, the pressure to uphold respect for patient autonomy could potentially overshadow indicators that would trigger a need for further assessment or conversely, mislead our view of the person's capacity for decision-making.

The issue of capacity and informed consent as it relates to patient autonomy should be highlighted in order to foster discussion so that a standard of understanding and appreciation can be established. This is especially important considering the less than ideal or potentially harmful decision a patient may choose to make. By doing this, the likelihood that patients will be protected from undue harm will be enhanced, and nurses will be protected against delivering potentially unnecessarily, unsafe or negligent care.

Fortunately, Beauchamp and Childress have developed a list of incapacities to assist in identifying the markers of incapacity. The range of incapacities include: 1. "the inability to express or communicate a preference or choice; 2. The inability to understand one's situation and its consequences; 3. the inability to understand relevant information; 4. The inability to give a reason; 5. The inability to give a rational reason (although some supporting reasons may be given); 6. The inability to give risk/benefit-related reasons (although some rational supporting reasons may be given); 7. And the inability to reach a reasonable decision (as judged, for example, by a reasonable person standard)" (Beauchamp and Childress 114). The standards fall into three main categories: the ability or lack thereof to express a preferred choice, to understand and appreciate and to deliberate on possible consequences and its impact in life (Beauchamp and Childress 115).

The implied understanding in the criteria by Beauchamp and Childress is that if the patient were capable, the patient would *acknowledge* the risks but have the ability to articulate the reason for choosing to accept the risks should he refuse care, rather than simply believing that the risks do not apply or are not relevant to their situation. For example, a patient with a terminal illness may choose to refuse a third round of chemotherapy in order to avoid the discomfort associated to the therapy while another patient may refuse care simply because he or she does not believe they are dying. The latter is not a person who meets the genuine sense of consent and capacity. The role of the health care provider is crucial in this sense to help the patient truly understand and appreciate the risks so that the integrity of autonomy and consent can be upheld. Hence, the relationship, openness and honesty between the patient and the health care provider are legal, professional and moral imperatives.

Despite the importance of patient autonomy and consent I will examine now whether it is the health care professional's moral duty to simply *inform* a patient of possible harm or does this duty expand further to remove and or prevent the harm. Nevertheless, regardless of the theory of autonomy used, the theory is adequate as a guide only if it matches the moral standards selected to govern decision-making (Beauchamp and Childress 101).

Non-Maleficence

Two prominent principles that are quite familiar to nurses in their everyday practice are non-maleficence and beneficence. The two principles play a very important role in nursing ethics and help ensure that respect, dignity, well-being and truthfulness remain at the center of nursing practice. Beneficence and non-maleficence share similar characteristics but subtle differences in practice. In attempt to clarify the principles, writers have attempted to categorize the two, some

have combined the two to create a single principle, others have placed each feature into an order of importance and authors like Beauchamp and Childress have developed a set of norms for each, without forming an order of priority (Beauchamp and Childress 151).

Non maleficence is characterized as a person “ought not to inflict evil or harm” (Beauchamp and Childress 151). It requires that a person refrain from action in order to intentionally avoid harm to a person. Non-maleficence is also known as due care and can be further expanded into specific moral obligations such as “do not kill, do not cause pain or suffering, do not injure, do not cause offense and do not deprive others of the goods of life” (Beauchamp and Childress 153).

The majority of the rules are fairly straightforward. It would not require much training to understand the basic rule “do not kill”. Some can be more difficult to grasp though in terms of scope, especially for nurses in a patient-centered health care system where the requests made by an autonomous patient can have varying degrees of risk or may very well be unknown. Although the expectations are clear insofar as that the nurses can refuse blatant risky acts such as intentionally administering a lethal dose of medication, the grey area is when a patient is requesting a particular treatment plan that may in fact be the cause of harm.

Nurses are bound by their professional standards and are required to uphold a level of care and quality of service that are both ethically and clinically-sound to avoid risk or undue harm to a patient. Although not all treatment options that a patient requests would explicitly contra-indicate with care goals, or conflict with best practices guidelines, the risk of *potential* harm may not be explicit. Nevertheless, the nurse accountable for all aspects of care she provides. As a result of the patient-centered care philosophy, the concept of negligence becomes especially important. The term negligence can comprise of a nurse either intentionally imposing

harm (or risk of) to a patient but can also involve unintentionally imposing undue harm as a result of carelessness. In the cases of negligence, the nurse is said to have failed the duty for due care (Beauchamp and Childress 154).

The scope of due care within the patient-centered care framework is difficult to clearly establish. Due care is defined as taking a reasonable degree of precaution necessary to avoid harm (Beauchamp and Childress 153). In the cases where a patient makes a request for a treatment that lacks scientific evidence, or supporting best-practice guidelines, the nurses may be uncertain about possible contraindications or what results the treatment would produce but is pressured to respect a patient's wishes. By administering unregulated treatment, the nurse could diminish the chances of improving or curing the patient's condition or worse, possibly causing harm. In the event an adverse event occurs, although the outcome may have been unintentional, the nurse would have "failed" to remove the risk of harm despite the fact the treatment was demanded by the patient.

Once again there are potentially conflicting priorities. When an individual enters the health care profession, there is an implied agreement that they accept to treat and care for patients using their expertise and clinical judgment. Implicit in the statement about negligence is that nurses are in agreement of the treatment that is being provided and that progress and potential complications can be measured and planned for. Without a better understanding of the limits of patient autonomy, nurses are at risk of dismissing this responsibility and potentially disregarding possibly negligent acts.

To assist in clarifying particular nuances of non-maleficence and negligence, authors Beauchamp and Childress have developed a framework drawing from legal aspects of negligence and due care to help clarify when a person (e.g. nurse) would be morally blameworthy for a

negligent act. The list includes: the professional must have a duty to the affected party, the professional must breach that duty, the affected party must experience harm, and the harm must be caused by the breach of duty (Beauchamp and Childress 154). According to the authors, the duty of the health care professional in relation to the patient is to “adhere to the professional standards of care. By entering into the profession of medicine, professionals accept a responsibility to observe the standards specific to their profession” (Beauchamp and Childress 154).

The criteria outlined by Beauchamp and Childress are similar to that of Canada’s legal approach to standards of negligence and informed consent. For example, the Supreme Court of Canada case of *Zamparo v. Brisson* resulted in a physician (Brisson) being found guilty for professional negligence based on the conclusion that he neglected to provide sufficient and explicit guidance relating to whether or not the patient should undergo a surgery. The patient chose to undergo surgery which resulted in paralysis to her face. It was asserted that should the physician had explicitly guided the patient, she would have chosen to decline the elective surgery based on the possible risks and physician input. The Judge found that the physician neglected to *recommend or oppose* the surgery. According to the Judge, “it is part of a surgeon’s responsibility to give the patient his opinion as to whether or not surgical intervention, although maybe useful, should be performed in an individual case” (Baylis, Downie and Freedman 211).

The *Zamparo v. Brisson* case highlights the complex relationship between respect for patient autonomy, informed consent and professional liability. Ultimately, it is the patient’s informed decision that informs the health care team about the appropriate treatment intervention to administer, however, there is an understanding as demonstrated in the *Zamparo v. Brisson* case that the patient’s decision should only be made following explicit physician advice. For this

reason, respect for patient autonomy could potentially mislead the health care professional as it promotes a decision-making process in which the patient is free of any external influence. Nevertheless, the nurse is expected to carry out the therapeutic intervention as chosen by the patient. Should the nurse choose not to help carry out the specific treatment but continue to provide other aspects of care and symptom management for the less than ideal treatment, there may be a perceived sense that the nurse has relinquished liability for that particular aspect of care because she is not physically assisting the patient carry out the risky treatment. This is a narrow view of due care and liability. It would be analogous to the argument that a health care professional did not contribute to a patient's suicide simply because she did not *physically administer* a lethal amount of medication herself but knowingly prescribed the medication to a patient who planned to use it to end their life. Although the topic of physician-assisted suicide is outside of the scope of this paper, it does highlight the potential nuances of patient autonomy and professional liability. It forces us to consider the point in which a nurse is no longer responsible or liable for due care or non-maleficence when the ultimate decision about how to care belongs to the patient. Patient autonomy may suggest a duty to treat, yet this ought not to imply an obligation to treat with a contra-indicative, sub-optimal or futile treatment (Beauchamp and Childress 167).

Beneficence

From a patient's perspective, they are informed from the beginning that they are at the center of the health care team and that their autonomy will be respected and preferences and wishes will be accepted. Patient autonomy is obviously held at high regard given its emphasis in policy and practice standards but like non-maleficence, so is the principle of beneficence. The principle of beneficence adds an element of difficulty for nurses, especially within a patient-

centered care model. Unlike non-maleficence which requires refraining from an act that could pose risk of harm, beneficence requires an individual to take action (Beauchamp and Childress 197). In the context of health care, this could involve a nurse acting in a way that improves a patient's welfare or enhances benefit for the patient (Beauchamp and Childress 197).

Returning for a moment to the case of *Malette v. Shulman*, according to the patient, receiving a blood transfusion was considered harmful given her religious views but from the physician's perspective, the possible harm was death which would have inevitably resulted without the blood transfusion. The blood transfusion caused harm from the patient's perspective but was the action taken by the physician in order to prevent the loss of life.

Childress and Beauchamp define beneficence as "the character trait or virtue of being disposed to act for the benefit of others" and the authors define principles of beneficence as "a statement of moral obligation to act for the benefit of others" (Beauchamp and Childress 197). Although the term 'obligation' is used in the definition of principle of beneficence which could suggest that this duty is non-negotiable, according to some writers, not all acts of beneficence are an obligation. Beauchamp and Childress propose that the obligations for nurses with respect to beneficence is to promote benefits, to avoid and eliminate harm and to assess an actions benefits against the possible harmful consequences (198.) Unlike non-maleficence, failure to fulfill the obligations should not result in legal or moral responsibility (Beauchamp and Childress 198).

Beauchamp and Childress further stipulate that a person has an explicit obligation to act beneficently towards another person when the following five conditions occur (let us assume that X is the nurse and Y is the patient): the first is "if Y is at risk of significant loss of or damage to life or health or some other major interest", the second is if "X's action is necessary to prevent

the loss or damage”, thirdly if “X’s action has a very high probability of preventing it”, the fourth, if “X’s action would not present very significant risks, costs or burdens to X” and finally, “the benefit that Y can be expected to gain outweighs any harms, costs, or burdens that X is likely to incur” (Beauchamp and Childress 202).

Although a nurse’s obligation to care is non disputable in most cases, within the context of respect for patient autonomy, the understanding and the final assessment of harm and benefit will be interpreted and determined by the patient. In this view, the criteria of obligated beneficence will likely look quite different than from a clinical perspective given the difference of training and expertise between a patient and a health care professional regardless of how much dialogue there has been to inform a patient.

With respect to the conditions listed by the authors, the first four are fairly straightforward to interpret and apply in a clinical context given that they are clinical in nature and refer specifically to the nursing role. For instance, the very nature of health care implies that a person (i.e. person Y) will be at risk for loss of damage of life, health, if the nurse does not act, by virtue of their need being a health related need. The second condition is also quite clear. The provision of health care requires a particular expertise and training with the ultimate goal to cure and prevent future deterioration and so the need for action by the nurse is indisputable in this context. It is the final three conditions that could distort the nurse’s understanding of their obligations for beneficence and required action in the context of patient-centered care and respect for patient autonomy. Implicit in the third condition is that the nurse has the control over what appropriate action to take in order to prevent the loss of or damage to the patient’s life. When respect for patient autonomy is viewed as a priority however, the decision regarding

appropriate action belongs to the patient and not the nurse's which ultimately will impact the risk, burden and benefit rendered.

A case example that highlights the issue of the primacy of patient autonomy is one in which a patient is discharged from the hospital with an Intravenous-Therapy (IV) line. Once at home, the assigned home care nurse becomes aware that the patient is known drug user and is using the IV line for his personal drug use. Because of where the IV line is inserted, the patient is at a very high risk for drug overdose (i.e. loss of or damage to life). In order to mitigate the risk, the IV line would need to be removed and the patient would be required to visit the clinic daily so that the medication could be administered under supervision and for its intended purpose only. Drawing on the conditions of obligated beneficence, this scenario would appear to be simple to resolve and would affirm that the nurse does have an obligation for beneficence and thus should remove the IV line and transfer the patient to the clinic so that the medication can be administered safely. The nurse's rationale would meet the criteria outlined by Beauchamp and Childress: the patient is at a significant risk for harm of overdose (condition 1) and the nurse removing the IV line is necessary to prevent the risk of overdose (condition 2) and it is essentially 100% probable that doing this would avoid the risk (condition 3) which would not create much burden or costs for the nurse because the alternative of the clinic is available (condition 4) and the benefit in ensuring the patient's well-being outweigh any possible harms that would be incurred (condition 5). This example appears straightforward in terms of duties and obligations to the patient, however when it is evaluated through the lens of respect for patient autonomy, it becomes difficult to discern the obligations for beneficence and the duty to respect patient autonomy.

When the patient ultimately has a right to be autonomous and live at risk and define for himself what actions would benefit him most, the outcome can be quite different than when interpreted clinically. For instance, if the IV patient states that he will not visit the clinic, the nurse may have an obligation to respect the patient's choice to live at risk. Obligated beneficence suggests that it is a moral duty and thus an obligation to prevent harm by taking action within the parameters of the stated criteria. The first two criteria refer directly to a loss of or damage to life in which only a nurse's clinical actions could prevent. Although a patient's view of benefit may be interpreted differently than that of the nurse's, in the context of obligated beneficence, the prevention of harm is considered the presumed benefit. In the view of patient autonomy however, it is unclear if we are obligated to remove the patient's IV line and transfer him to the clinic to prevent harm (i.e. overdose) or to respect the patient's choice to live at risk and not remove the IV line but continue providing services in the home. Recognizing that the two options ultimately do have potentially harmful outcomes (i.e. the patient going without care if removed or a possible overdose if maintained), the choice to remove the line and transfer the patient to the clinic is a reasonable step taken to ensure the client's safety (i.e. prevention of loss of or damage to life) rather than dismiss and enable the harmful behaviour.

A point for consideration is that although the patient case described above may involve illegal substances, a third alternative is to tolerate the behaviour through a harm reduction approach which would be adequate to satisfy the criteria of obligated beneficence and harm prevention. Although a highly contentious matter, the Insite Supervised Injection Site in Vancouver, Canada is the first of its kind in North America and is an example of how powerful such an approach can be to ensure patient safety. In order to adopt a harm reduction approach though, organizational support for such practices is required. For instance, provision of clean

syringes to known-drug user patients or education regarding safe injection can prevent harm however may not be practice endorsed by the organization and thus not within the scope of the nursing role. Should the decision be made to not remove the IV line of the known-drug user patient for reasons such as respect of patient autonomy, the duty to also provide harm reduction care should be seriously reflected on and the parameters of organizational guidelines should be expanded.

An improvement in a person's quality of life would certainly be a logical goal as a treatment outcome. Although enhancing a person's quality of life could be said to be a measure of benefit, the scope and characteristics are difficult to define especially if the patient and the health care professional have conflicting views. To provide insight on this issue, authors Wooden, Nair and Tang (1997) identified quality of life indicators from the perspective of patients and health care professionals with the goal of identifying universal or shared opinions relating to quality of life.

By creating a list with fundamental elements of quality of life gathered from a literature review, the authors built a survey to administer to health care professionals (e.g. physicians, allied health staff etc.), patients and family members of a cardiac rehabilitation program and a pacemaker clinic. Each participant was asked to rate how each element contributed to their quality of life in order of priority regardless of whether it impacted their lives positively or negatively. A total of 24 health care professionals and 58 patients returned the survey (Woodend, Nair and Tang 75). The results were separated into sections in order to identify elements most important from a physical, psychological, social, material, structural, and activity aspect. The differences between responses were quite interesting particularly in the areas of physical, psychological and activity (Woodend, Nair and Tang 76).

For the patients and their family members, the five most important aspects relating to quality of life from a physical perspective was mobility, general health status, symptom relief, diet and time spent in the hospital were integral components to a high quality of life. The latter three listed were especially important according to the patients' ratings. These ratings differed for the health care professionals who rated exercise tolerance, general health status, symptom relief, chest pain and perceived benefits of treatment as the most important (Woodend, Nair and Tang 75). Although general health status and symptom relief were rate as important for both groups, no information was provided in the study regarding how the patient or health care professional in fact defined general health status or symptom relief. From psychological perspective, the most important elements to quality of life as perceived by the health care professionals were depression, anxiety regarding health, fear of recurrence and death among which the latter two did not appear to score highly for patients but rather self-esteem, satisfaction with life and confidence did as the most important areas (Woodend, Nair and Tang 75). For the activity section of the survey, patients rated the ability to live normally, activities of daily living, energy, home management and perception of limitations to activity as important aspects to their quality of life while health care professionals rated areas of employment as a top indicator (Woodend, Nair and Tang 76).

Overall, the survey results indicated that a patient and health care professional's perspective of integral elements for quality of life differ in terms of how negative or positive the impact on their life is and how each area is prioritized. Areas such as chest pain, medical complications, depression and fear of recurrences were rated highly for areas related to quality of life for health care professionals but ranked much lower for patients (Woodend, Nair and Tang 76).

It is reasonable to maintain that if an intervention or treatment is expected to worsen an already perceived low-quality of life, then a health care professional should refrain from administering the treatment (Beauchamp and Childress 169). In a clinical context, the assessment of how low or high a person's quality of life is measured by is usually in terms of the clinical benefits or harms that would contribute to the quality of life and be the primary basis of the deliberation. The trouble is that the assertion that the basis for a quality of life standard be solely clinical conflicts with how quality of life is typically characterized which reaches far beyond simply the medical benefits a patient will render following a treatment (Beauchamp and Childress 170). Beauchamp and Childress recognize that the difficulty in establishing a universal definition for quality of life is secondary to the challenge of establishing a universal understanding of fundamental matters such as "meaning of life" and "dignity" which are often individually interpreted in a variety of ways (Beauchamp and Childress 170).

Of course a patient's preferences are central in the decision about a course of treatment in a patient-centered care model, but acquiescence and delivery of the preferred choice should not result in diminished professional integrity or be a the rational for breaching professional standards (Brett and McCullough 149). As a member of a regulated health profession, there is an implied duty to deliver care and treat a patient in a way that will maximize their health and well-being, as well as understand, express and apply clinical judgment throughout the trajectory of care (Brett and McCullough 149). Based on the conditions outlined for the obligations of beneficence, if a patient's preferences are going to trump the nurse's professional duties, then there is a shift in practice that needs to be discussed and reflected in guiding standard practices and principles.

The theoretical underpinnings of ethical principles such as autonomy, non-maleficence and beneficence are sound but can present controversies when considered simultaneously. There are limits in their practical application, especially within a clinical context like in the home care sector. Traditionally, care is provided in a hospital, clinic or a long-term care home. With the demanding pressures of the current health care system, provision of services such as post-operative care, personal support for hygiene, therapies and ongoing medical support is becoming increasingly predominant in a person's home. With an increase in independence and personal comfort, the benefits for the patient are countless however by expanding the parameters of the traditional care setting, issues for the nurse may arise as conventional standards and procedures may not apply as easily in an uncontrolled environment like a patient's private home.

In a study conducted in Western Canada in 2000-2001 by Varcoe et al. (2004), the limitations and difficulties that nurses experience as a result of the ambiguity were demonstrated. The researchers of the study set out to evaluate how ethical reasoning is actually carried out from the perspective of nurses. Focus groups were held with 87 nurses from across various disciplines and included nurses practicing in both acute and community care. The nurses who were interviewed expressed an ongoing conflict between their own personal values and morals and those of their organization. For example, many described perceiving something as "good" yet were pressured by various organizational restrictions and situational factors to respond to a situation in a way that conflicted with their own beliefs. According to the nurses involved, the differences in moral perception resulted in uncertainty about appropriate responses but also a concern about expectations and assuming moral responsibility for the outcome. The nurses described constant changes in moral reasoning and identity which contributed to both a personal growth as an individual but also increasing concern and tension. The tension, as described by the

nurses, was present mostly between the various disciplines in the health care team as well as the patients their family members, especially in the decision-making process.

While maintaining a focus on the importance of a strong therapeutic relationship but also their alliance with their own profession and also the health care profession in general, nurses experienced a difficulty in what they perceived as dual loyalties, which were often in conflict. Many nurses spoke about “letting it go” or “choosing their battles” when faced with ethical dilemmas, recognizing the possibility of conflict. Like most health care professionals, the nurses would assess the possible risks and benefits, consider their role and responsibility in the team involved relative to the others and the possible significance and the urgency of the situation to guide their decision about whether to enact their own ethical practice.

Another interesting element of the study demonstrated that the nurses’ decision to act was influenced by the possible consequences of doing so. Many described receiving negative reactions and others experienced resistance from their colleagues when they promoted or upheld ethical principles and behaviour. From a practical sense, this type of reaction can be frustrating for a nurse and ultimately may deter her from taking appropriate action. Overtime, this behaviour will inevitably increase the nurse’s feelings of moral distress and burnout.

Interestingly, according to the nurses interviewed, the corporate vision and messaging also contributed to the uncertainty regarding ethical practice. Issues such as limited resources and staff, resource allocation and the increased demand for services shaped the way in which the nurses assessed and decided to act upon a particular situation.

A comment that is particularly relevant to note for the purpose of this paper is the perspective of a community nurse. The nurse recognized the role of community care and its importance in prevention and rehabilitation but argued that although the corporate ideals are

often based on quantitative data, because of the nature of the uncontrolled environment, there is no effective way in the community to truly assess what “didn’t happen” (i.e. prevented) therefore minimizing the success of the program and diminishing the value of the nurse and strength of their decision-making and problem-solving skills. In summary, the authority of others in the team, the contextual features of the situation, support from leadership and the corporate assumptions influenced the nurses’ decision to enact ethical practice (Varcoe, Doane and Pauly 323).

Ethical decision-making and moral reasoning is obviously much more complicated for nurses than simply “respecting a patient’s autonomy and choices” while “doing no harm” and “acting for the benefit of patient”. The perspective described by the nurses in the study provides an important insight into the complexity of applying nursing ethics.

Beneficence and non-maleficence is choice and situation specific in that each individual determines their responsibility for carrying out the duty in relation to each particular patient and clinical decision. However as the study described above demonstrated, the ability to identify a common ethical ground amongst the health care team and with the patient can be challenging. Each discipline and each patient are going to perceive harm and benefit differently. Given the nurse’s role though, it is he or she who is responsible for delivering the care and depending on the outcome is left exposed to the criticism. Despite this possibility however, the opinion that it is less complicated to simply “let it go” is very telling and troublesome from an ethics and professional accountability perspective.

Ethical principles in the medical profession bear significance and are meant to be action-guiding and at the forefront of decision-making and service delivery. The endeavour to ensure ethical clinical practice can be difficult to accomplish however as indicated in the study by

Varcoe, Doane and Pauly, the issue is further impacted by the organizational and system pressures and expectations. The conflicting priorities that occur diminish the nurses' confidence in their clinical judgment and expertise which ultimately impacts patient care.

Justice

A key element that underlies many of the contentious issues frequently debated by policy makers, government officials, ethicists and administration in the field of health care relates to issues of justice in resource allocation as well as sustainability. Justice is interpreted as “fair, equitable, and appropriate treatment in light of what is due or owed to persons. Standards of justice are needed whenever persons are due benefits or burdens because of their particular properties or circumstances” (Beauchamp and Childress 241).

The actual distribution of the resources like health care services in relation to justice refers to term distributive justice which ensures the “fair, equitable, and appropriate distribution determined by justified norms that structure the terms of social cooperation” (Beauchamp and Childress 241). Essentially, distributive justice ensures that all similar cases are treated similarly.

Understandably, matters relating to justice are complex and multi-faceted when considering the fair and equitable distribution of limited resources such as health services and the related benefits and burdens. Standards that establish a framework for the equal distribution of goods refers to material principles of justice (Beauchamp and Childress 242). Material justice can refer to the distribution of goods either by means of “an equal share to each person, to each person according to need, to each person according to effort, to each person according to contribution, to each person according to merit or to each person according to free-market exchanges” (Beauchamp and Childress 243). In health care, the material principle of justice “to

each person according to need” is predominantly how resources, such as health services are allocated.

The distribution of goods based on need can be problematic if the meaning, assessment and classification of the concept is left undefined. Beauchamp and Childress’ interpretation is that a person’s need is referred to as “something that is critically required in order to avoid harm or detriment; a *fundamental need*” (Beauchamp and Childress 242). The concept of fundamental needs sets a threshold for what needs require obligatory fulfillment which presumably would relinquish a health care provider’s responsibility in fulfilling a patient’s *every* need.

The question as to who should receive health care and what level of health care should be provided is relevant to this paper given the standard of patient autonomy and the right to choose the type and level of health care one receives. Policy-makers and government officials debate matters of access, allocation and management of health care resources and its relation to national and provincial health insurance policies which has sparked various contentious discussions (Beauchamp and Childress 258). Although issues of justice and equitable provision of services is not a critical issue in Canada, reports have shown that Canadian of all socio-economical status have equal access to primary care across however this equal access diminishes concerning delivery of services from a specialist which people of higher status are found to have greater access (Romanow 14). Furthermore, aspects such as “the relative poverty or affluence of different regions; the degree of urbanization; the population density; or the ethnic composition appear to correlate strongly with the benefit that an individual will be render by utilizing health services in Canada (Romanow 16).

According to Beauchamp and Childress, the distribution of health care services as it relates to justice can be divided into two perspectives. The first perspective is that all health care

resources should be accessible by all people equally. The authors point out that proponents of this view do not recognize that role of the service *provider* and therefore is not a very compelling view (Beauchamp and Childress 260). Implicit in stating that all people have an equal right to health care implies that society has the capacity to fulfill all needs when required or requested. Another problem with this view is that a right to health care suggests that *any form* of health care should be available equally to all people (Beauchamp and Childress 260). It would be difficult to imagine that the resources that fund the Canadian and consequently the Provincial health care systems could sustain this endeavour and therefore is not a feasible plan.

The distribution of a decent minimum of health care on the other hand, would not impose such high demand to provide as would the right to all health care. The decent minimum of health care is the second category in which health services can be distributed according to the authors. Beauchamp and Childress have separated the concept of a decent minimum of health care into two levels for logistical and practical purposes. Level one would ensure universal coverage for basic and emergency health situations (e.g. acute and primary, disease treatment and coverage for people with disabilities) and the second level would require patients to pay privately for other additional health needs and preferences (Beauchamp and Childress 260).

Although the Canadian context is different than in other developed countries in that health care is essentially universally accessible, the provision of a decent minimum of health care as the benchmark is an interesting concept. The health care system in Canada is shifting; resources are becoming scarce, the number of health care providers is low and the level of complexity of care required is increasing. For this reason, at the center of the discussion regarding health care in Canada are the potential threats to the sustainability of the system. According to the Commissioner Report of the Commission on the Future of Health Care in

Canada, sustainability is defined as “ensuring that sufficient resources are available over the long term, to provide timely access to quality services that address Canadian’s evolving health needs” (Romanow 2). Some contend that the source of risks to sustainability related directly with the distribution of funding and cost of delivering services while others assert that it is due to the inefficiencies embedded within the system.

The Commissioner Report found that there are key elements that impact the successful provision of health care services. The following items were listed in the report as integral components that require systematic examination and action in order to meet the increasing demand and complexity of care. The factors include “limited fiscal resources to address the range of health needs; limited physical resources, equipment and new technologies; imbalance in the supply, distribution and scopes of practice of health care providers; demographic, societal, and technological changes that make some services (e.g., prescription drugs and home care) more important or essential than they were in the past; and Canadians’ growing expectations that an increasing range of treatments will be provided within the public system” (Romanow 9).

In a way, the conceptual parameters of a decent minimum of health care is similar to the Canadian health care system today, however, the respect for patient autonomy as it relates to justice has essentially shifted our view of “decent minimum”. The view that health care providers must respect the wishes and preferences of their patients suggests that the responsibility to accommodate the patient is limitless and without consideration that policy makers and the government need to strike a balance between the provider, the patient needs and the available resources in order for the Canadian health care system to sustain itself.

A Critique of Principlism

Although proponents of Beauchamp and Childress' framework would assert that the principles established are instrumental in the ethical decision-making in the field of medical and bioethics, it is nevertheless important to discuss a major critique of this concept. Authors Danner Clouser and Bernard Gert (1990) sought to highlight the fundamental flaws in using principles as a framework. The authors coined the term Principlism to refer to "all accounts of ethics comprised of a plurality of potentially conflicting prima facie principles" (Beauchamp and Childress 371). Clouser and Gert assert that there are three main arguments against a principle-based frameworks such as the one proposed by Beauchamp and Childress.

According to the authors, the first argument is that the principles serve only a small purpose similar to a checklist, heading or labels are not adequate as a moral guide. Although Beauchamp and Childress do agree that their principle-based framework lacks in providing an explicit moral guiding theory, they also call attention to the fact that although a theory is more comprehensive, a theory does not provide the explicit guidelines that the authors proclaims it does either (Beauchamp and Childress 372). Ethical dilemmas, by virtue of being a dilemma, are complicated, unique to each situation and ambiguous to decipher. The rules that are typically derived from a moral theory, like principles, are general enough that they cover a range of situations. Clouser and Gert contend that rules such as "don't cheat", "don't deceive" and "do your duty", are much more guiding than principle "headings" such as beneficence and non-maleficence. Beauchamp and Childress would agree but assert that rules derived from a theory are essentially principles in a more comprehensive form therefore, not as drastically different than their own framework (Beauchamp and Childress 373).

The second argument is that a principle-based framework causes individuals to act upon a situation however they feel appropriate as there are no specific directions that are established as

moral norms. Clouser and Grant allege that the only direction Principlism offers with relation to the duty for beneficence for example would be “think about beneficence and here’s thirty pages of distinctions and deliberations to get you started” which according to Clouser and Gert, is completely unlike the directives a moral theory would provide (Clouser and Gert 222).

Furthermore, Principlism is said to lack agreement or unison among its principles and advises agents to carry out principles that conflict and are ambiguous both from a moral and practical sense (Clouser and Gert 223). In spite of these assertions, Beauchamp and Childress defend that it is through the process of analyzing each principle that the rules are derived and thus standard moral norms are established (Beauchamp and Childress 373).

Finally, the third main argument is that the fundamental principles as asserted by a framework of Principlism are assumed to be accurate but often conflict with each other and secondarily, offer no guidance regarding which principle should prevail or which act is morally superior to another. Clouser and Gert claim that unlike a comprehensive theory, in a principle-based framework, the user is “given a number of conflicting principles and then told pick whatever combination they like” (Clouser and Gert 222). Beauchamp and Childress defend their position and assert that no theory exists that accounts for all types of scenarios and therefore agents cannot reasonably expect for any theory or framework to settle all ethical dilemmas (Beauchamp and Childress 372)

Despite the criticisms of Principlism, the framework provides a feasible structure to resolve biomedical ethical dilemmas and is the framework most predominantly used in the field of bioethics. Employing general principles rather than concrete rules provides flexibility while establishing a common ground as a basis for discussion; this is especially important for moral

disagreements. From a practical perspective, conflicting priorities and perspectives can be discouraging for an individual however Principlism provides a resource to foster deliberation and discussion amongst differing views. Beauchamp and Childress emphasize that “different parties may emphasize different principles or assign different weights to principles even when they agree on which principles are relevant. Such a disagreement may persist even among morally committed persons who conform to all the demands that morality makes on them. If evidence is incomplete and different sets of evidence are available to different parties, one individual or group may be justified in reaching a conclusion that another individual or group is justified in rejecting” (Beauchamp and Childress 25). Ultimately, Principlism is a useful tool for the focus of this paper to demonstrate that the respect for patient-autonomy in the context of patient-centered care should not be the principal factor dictating what a person ought to do when confronted with a practice or professional challenge relating to biomedical ethics.

Chapter Two: Patient-Centered Care

Autonomy, respect, dignity and professionalism are regularly reflected upon in health care and used in powerful ways to symbolize standards of care. Many institutions such as hospitals and long-term care facilities publicly advertise and maintain in their mandates, mission or value statements that such values are significant and indicative of the services they provide and make up the basis for which the organization functions. The Ottawa Hospital for example, states that the core values of the institution are “compassion, a commitment to quality, working together and respect for the individual” and assert that the members of the hospital will “provide each patient with the world-class care, exceptional service and compassion we would want for our loved ones” (The Ottawa Hospital). Conversely, the mission of the Champlain Community Care Access Centre is to “deliver a seamless experience through the health system for people in our diverse communities, providing equitable access, individualized care coordination and quality health care” (Champlain Community Care Access Centre). Finally, vision statements from the Pearly and Rideau Veteran’s Health Centre include statements such as “we believe everything we do is for the well-being of residents and we recognize and respect their individual needs, which are reflected in their plans of care” and the facility “believes in and respects the uniqueness, diversity and dignity of each person and treat each other with honesty and compassion. We believe we have the right to express and the duty to hear different points of view in a way that respects individual dignity and self-esteem” (The Pearley and Rideau Veteran's Health Centre).

The previous mission and value statements are from similar organization insofar as each institution provides a form of health care service however are unlike one another pragmatically

given the contextual features unique to each setting. Nevertheless, the theme within each statement is consistent which alludes to the culture established within the organization and greater health care system. Patients are promised to be respected as individuals, their well-being protected and are promised to be provided quality and individualized care.

A mission and vision statement provides insight to patients and their families about what they can expect from a health care institution during their health care journey. The challenge is that the over 30 million individuals who reside in Canada and who are prospective users of health care resources at any time are going to prioritize “autonomy”, “respect” and “dignity” differently. For example, a patient at the Ottawa Hospital may interpret autonomy as being “encouraged” to discharge oneself from the hospital against medical advice should he wish to no longer be there. Or a resident at the Pearly and Rideau Veteran’s Health Centre may disagree with the need to take his medication which helps reduce behavioural concerns such as wandering and aggressive outburst and although it may put himself and other residents at risk, he feels his right to decline medication should be respected. Although the Centre promises to respect the “uniqueness and individual needs of each patient” they have also set the expectation that they will “do everything for the patient’s well-being”. There is potential looming conflict should the patient observe the nuances of the statements.

The mission and vision statements establish trust in the organization for its employees as it symbolizes the institution’s moral integrity. The statements also help its clients understand their rights and responsibilities while utilizing the service. For this reason, it is essential to reflect upon the messaging that is created and ensure that in reality, the promises, duties and expectations can be carried out effectively.

Overall, there is recognition that it is beneficial to empower patients to make their own choices regarding the provision of their personal health care services. One of the most significant reforms witnessed gradually over the last few decades is the shift from medical paternalism to a patient-centered care model. Authors like James Childress (1982) have compared paternalism to the concept of fatherhood to demonstrate that the role of a physician often resembles the role of a father. This comparison involves two key elements. The first is that similar to a father who's main concern is their child, a primary driver for a physician's actions are the best interests of his patient and most often are grounded in compassion and care. Secondly, traditionally it is the responsibility of the father to make most if not all of the decisions for his child regarding matters of wellbeing (Childress, *Who Should Decide? Paternalism in Health Care* 4). A father is expected to place great importance on his child's best interest and only wants "what is best" when making decisions concerning his child. The spirit of a physician's decision-making is believed to mirror that of a father's. Other metaphors that have been used in comparison to the role of the physician are priest, negotiator, contractor, technician, engineer, friend, teacher and captain (Childress, *Who Should Decide? Paternalism in Health Care* 6).

Although it is a logical comparison, the role of a physician to other functions such as contractor or priest has been criticized. Critics assert that viewing the physician like an engineer for instance minimizes the moral agency of the physician and conversely, the metaphor proposes a hierarchical-type dynamic insofar as the engineer (or physician) is the appointed individual responsible to make the final decision and "call the shots" (Childress, *Who Should Decide? Paternalism in Health Care* 6). Naturally, the assigned roles in a health care team have witnessed a transformation given the criticisms of paternalism and the emphasis on norms such as only the physician "calling the shots".

The catalyst supporting the shift from medical paternalism to patient-centered care (particularly patient autonomy) stems from many factors but primarily from the criticisms in the literature relating to fundamentals of paternalism. According to Baylis et al. (1995), there are three primary criticisms of medical paternalism. The first claim is that because decision-making involves assessing both facts as well as values, only the patient is naturally best suited to identify, express and evaluate values against their own value system. Although factual based decision-making is crucial in medicine and is appropriate for the role of the health care professional given their training, the value-based decisions are equally as important in the trajectory of care and only the patient is considered best suited for this exercise. This view places emphasis on the fact that it should be the patient's values at the center of the decision and not the values of the physician, nurse, or other member of the health care team.

The second argument that supports patient-centered care speaks to the "fallacy of generalization of expertise" (Veatch, *Generalization of Expertise* 29). The fallacy of generalization describes the phenomenon that occurs when there is an assumed universal expertise of someone in all areas, including moral reasoning. In the context of health care, the scope of the health care professional role is well defined however proponents of patient-centered care argue that this expertise is not all-encompassing and only the patient has the expertise to weigh and compare the associated risks and benefits when selecting or when presented with a treatment plan.

Finally, the third criticism is that simply put, because the treatment will impact the life of the patient regardless of the outcome, only the patient should have the right to choose (Baylis, Downie and Freedman 158). Patients should be given the forum to acknowledge their values and share with the treating health care professional.

Paternalism and Shared Medical Decision-Making

I am not proposing that the health care system return to paternalistic methods of service and care provision as this would be troublesome for various reasons. The shift from paternalism to patient-centered care was warranted. The importance of patient input and the value of gathering patient perspective about their personal health related interests are indisputable. Furthermore, an overly excessive emphasis of a paternalistic approach increases the risk for biased decision-making (on behalf of the health care professional), inadequate exchange of information with the patient and insufficient assessment of a patient's therapeutic status (Quill and Brody 764). Although it was a positive shift insofar as that a patient has an opportunity to express their preferences, the emphasis on the expectation that the preferences will be *respected* has created a transformation of moral norms for nurses. Due to the drastic change in focus, the integrity of the medical profession, particularly the emphasis on beneficence has been impacted.

Paternalism is most frequently described as “the intentional overriding of one person's known preferences or actions by another person, where that person justifies the action with the goal of benefiting or avoiding harm to the person whose will is overwritten” (Zomorodi and Foley 1747). In reality, according to Beauchamp and Childress, paternalism may nevertheless be required in certain situations. To clarify the parameters of this claim, a distinction is made between the different types of paternalism, notably soft and hard paternalism.

Soft paternalism is when “an agent intervenes in the life of another person on grounds of beneficence or non-maleficence with the goal of preventing substantially non-voluntary conduct which would include a condition or situation that precludes rational deliberation and informed consent” (Beauchamp and Childress 208). Since the focus of this paper is on the decision making of capable individuals, we will focus on hard paternalism which only involves the “intervention

intended to prevent or mitigate harm to or to benefit a person, despite the fact that the person's risky choices and actions are informed, voluntary, and autonomous" (Beauchamp and Childress 210). Hard paternalism is controversial because it is the overriding of a person's values and beliefs, for example a nurse's over another's, like a patient's, in order to ensure the nurse's intended outcome.

According to Beauchamp and Childress, hard paternalism is justified if 1) the harm that the patient is at risk for is high however preventable, 2) the probability that the act, although paternalistic, would prevent the harm is high, 3) the predicted benefit to patient if the paternalistic act was performed would offset the possible consequences if it were not performed, 4) restricting patient autonomy is the only reasonable option and finally, 5) achieved my means of the option with the least amount of constraint against autonomy (Beauchamp and Childress 216). As Childress and Beauchamp assert, a nurse would be justified in using hard paternalism if the seriousness of the risk to the patient's well-being increased, including risk of permanent injury (Beauchamp and Childress 216). Within this framework, it would ultimately be justified in certain situation for other principles to prevail appropriately over patient autonomy.

The conditions listed for hard paternalism have underpinnings similar to the principles of non-maleficence and beneficence and especially resemble obligated beneficence. Using the example of the known drug user discharged from the hospital with an IV line, constraining his autonomy to use the IV line for personal drug use by removing the line and transferring him to the patient would be justified. The decision to do so, although paternalistic to the extent that the patient's known preference is overwritten, would only limit the patient's autonomy minimally (he can use drugs as he was prior to the hospital admission) but prevent potentially serious harm. Although the consideration for a patient's right to live at risk from the perspective of justified

paternalism is different than that of the perspective of respect for autonomy, further analysis is certainly warranted.

Influence

Nurses are trained and accountable to ensure that a patient's best-interest remain at the forefront. As stated in the Professionals Standards from the College of Nurses of Ontario, "Each nurse is accountable to the public and responsible for ensuring that her/his practice and conduct meets legislative requirements and the standards of the profession" and furthermore "nurses are responsible for their actions and the consequences of those actions. They're also accountable for conducting themselves in ways that promote respect for the profession. Nurses are not accountable for the decisions or actions of other care providers when there was no way of knowing about those actions (College of Nurses of Ontario 4)". The nurse is said to meet this standard by " providing, facilitating, advocating and promoting the best possible care for clients; advocating on behalf of clients; seeking assistance appropriately and in a timely manner; sharing nursing knowledge and expertise with others to meet client needs; ensuring practice is consistent with CNO's standard of practice and guidelines as well as legislation; taking action in situations in which client safety and well-being are compromised; maintaining competence and refraining from performing activities that she/he is not competent in; taking responsibility for errors when they occur and taking appropriate action to maintain client safety" (College of Nurses of Ontario 4). For this reason, similar to the matter of hard paternalism, according to Beauchamp and Childress there are instances where influencing patient choice is warranted. The authors have listed three types of influence that can occur which include coercion, persuasion and manipulation.

Coercion is said to occur “if and only when one person intentionally uses a credible and severe threat of harm or force to control another” (Beauchamp and Childress 133). An example would be if a nurse threatened to deem a patient as incapable and place them into a long-term care facility against their wishes should the patient refuse a particular treatment. It is noted that coercion is said to be real only when an actual, intended threat has been imposed obstructing genuinely autonomous behaviour as opposed to a perceived threat.

Conversely, persuasion occurs when “a person believes in something through the merit of reasons another person advances” (Beauchamp and Childress 133). This requires a distinction between a person’s logical and emotional interpretation. Although a patient may have rationally deliberated information that was provided about the seriousness of potential harm for refusing care or the benefit of accepting a proposed treatment plan, and subsequently accepts the treatment, the patient would still be considered to have been persuaded based on the information provided by the treating health care professional. The significance of informed consent and assurance that *all* pertinent information related to a treatment decision is logically understood is especially important to prevent issues of persuasion overpowering a patient’s informed consent.

When neither coercion nor persuasion occurs and the patient nevertheless does what the person’s says, the form of influence is considered to be manipulation (Beauchamp and Childress 134). Whether intentional or not, a nurse may inflict influence into the patient in subtle forms such as tone of voice, body language, manner in which information is presented etc. Eliminating any form of influence, as the authors have demonstrated can present both practical and moral challenges. In essence, the form of influence will be based on the way in which the patient interprets the influence.

Regardless of how a form of influence is perceived as real or not, patient-centered care can be a significant change in practice and accepted by some with apprehension. Experts in the medical profession and critics of the patient-centered care philosophy voice concerns with inviting patients to play such a key role while asking the health care professional to avoid nearly all forms of influence. Critics stress that without the expertise that health care professional acquire through years of training and education, the integrity of the medical profession is at risk of being discredited (Keating, McDermott and Montgomery 13). Alternatively, proponents of patient-centered care maintain that by enhancing information giving, promoting open and honest communication and improving active listening to the patient's perspective, all those involved in the health care team will benefit (Keating, McDermott and Montgomery 14).

It goes without saying that patients who are well-informed, empowered and educated will be better equipped to participate in their care. Alternatively however, the health care professional responsible for facilitating the interactions must also have acquired the expertise, have the necessary information, time and resources to act accordingly and to manage the clinical aspects appropriately (Wagner, Austin and Davis 68).

Health care professionals are accountable and have the professional duty to practice respectful, ethical and evidence-based medicine. This acquired expertise grants them a unique set of rights and obligations (Lantos, Matlock and Wendler 498).

With the shift in focus from a paternalistic delivery of care to patient-centered care, patients are led to believe that this philosophy equates to the absolute permission to choose. Although patient-centered care does not guarantee this right or the right to behave in a manner irrespective of standards or care, organizational policies and guidelines, empirical evidence, resource allocation or competency (Brett and McCullough 149), anecdotal reports indicate that

this is perhaps the perception. The mission, vision and value statements of various organizations and legislations as previously discussed, no doubt contributes to this expectation.

There is no doubt that the nature of health care has changed. The complexity of care needs is becoming greater and so is the demand for health care professionals who have the capacity for ethical-decision making and specific skill sets to cope and carry out with service standards. Without special attention to this and the resources and clarity required to help foster it, the ethical principles of justice, reasonableness, beneficence and non-maleficence is at risk of being diminished.

Nurse and Physician-Patient Relationship

Although paternalism and unwarranted influence can be serious threats to the therapeutic relationship and patient autonomy, in reality, there is in fact little research that exists regarding the cost, effectiveness and scope of a shared decision-making model. According to the United States Preventive Services Task Force (USPSTF), shared-decision making involves “understanding the risks or seriousness of the disease or condition to be prevented, the understanding of the preventive services, including the risk, benefit, alternatives, and uncertainties, weighing his or her values regarding the potential benefits and harms associated with the service and engaging in decision-making at a level at which he or she desires and feels comfortable” (Kaplan 81) The role of the health care professional is quite pronounced in this type of patient-provider dynamic to help facilitate the exchange of information and knowledge. A shared decision-making approach however is only a single style a relationship that can exist between a patient and their health care provider. In fact, Emanuel and Emanuel describe four models of provider-patient relationship styles and describe related issues such as informed

consent, patient control, power imbalance, autonomy, roles and responsibilities. The four models include the paternalistic model, the informative model, the interpretive model and the deliberative model.

In the paternalistic model, restoring patient's health and relieving any pain or symptoms prevails over patient choice. The health care professional selects treatment options for the patient while considering their best interest and medical prognosis. The previously selected options are presented to the patient with an understanding that the options selected are most suitable and therefore should be accepted to ensure their health and well-being. This model is also referred to as the parental model or priestly model and resembles the paternalistic model closely insofar as patient autonomy is limited and it is the health care professional who recommends the best course of action (Emanuel and Emanuel 163).

The informative model is also known as the Scientific, Engineering or Consumer model (Emanuel and Emanuel 163). The informative model asserts that the sole purpose of the health care professional is to objectively present all of the information pertaining to medical condition, prognosis, treatment, risks and benefits, to the patient with the goal to simply facilitate the decision-making. The patient will choose a treatment independently and the health care professional will assist the patient in carrying out their selected treatment goals. Obviously patient autonomy and control are central in this model. The informative model resembles a patient-centered care model. By reflecting on their own value system and evaluating the information provided, the patient has the freedom to select and fulfill whatever health care goal they wish to pursue. The Informative model however does not relieve the health care professional of their obligation to be truthful, trained and objective in the transfer of knowledge and information (Emanuel and Emanuel 164).

Alternatively, the interpretive model is different than the previous two in that it places great emphasis on the patient's value system and the responsibility of the physician to interpret it and fully embody it within the care plan. According to the Emanuel and Emanuel, the patient may not fully understand or realize the values they possess and so the goal of the health care professional is to consider the over patient characteristics and to help shape them into goals that are both understandable and achievable. Subsequently, the professional will translate the goals into actionable clinical priorities. Although patient autonomy has great significance in this model, the health care professional has the responsibility to assist the patient to better understand what is important or valuable to them so that their medical decision-making is based on a solid moral foundation and reflects their identity (Emanuel and Emanuel 165).

Finally there is the deliberative model. In this model, the health care professional plays an active role in shaping the values related to the patient's medical trajectory. Essentially the health care professional helps bridge the gap between the patient's personal value system and their health care journey. Patient autonomy evolves over time in this model. There is recognition in the deliberative model that the judgment of certain values does not pertain to the physician-patient relationship but can be leveraged to empower the patient to discover medical preferences not yet explored or considered because of one's personal value system (Emanuel and Emanuel 166).

Although the different styles are unlike each other in many ways, all four models recognize respect for patient autonomy in some manner. The difference is the weight patient autonomy carries in the clinical context. Despite the prescriptive differences, utilizing a different model depending on the circumstances of a situation may be warranted. However, according to the authors, it is the deliberative model that is most symbolic of a patient-health care provider

relationship most effective as it relates to patient autonomy. The rationale for this is for six reasons: “1. the deliberative model more embodies our ideal of patient autonomy, 2. Society’s ideal physician is a caring physician who integrates the information and relevant values to make a recommendation, and though discussion, attempts to persuade the patient to accept this recommendation as it best promotes his or her overall well-being, 3. The deliberative model is not a disguised form of paternalism but rather attempts to persuade the patient of the worthiness of certain values, not to impose those values paternalistically, 4. Physician values are relevant to patients and do inform their choice of a physician, 5. It is believed that physicians should not only help fit therapies to the patient’s elucidated values, but should also promote health-related values, and finally, 6. The deliberative model promotes implementation of changes in medical care and education to encourage a more caring, open and honest approach and recognizes legal, professional and financial implications” (Emanuel and Emanuel 175). Patient autonomy plays a central role in the deliberative model but not simply by means of a patient selecting treatment care completely independent from the medical professional and without constraints on patient autonomy. The deliberative model requires that an individual deliberate and actively assess and uphold personal values and goals to inform the actions required to achieve their objectives because only “freedom and control over medical decisions does not constitute patient autonomy” (Emanuel and Emanuel 175).

The process in which treatment decisions are rendered in patient-centered health care is crucial and is believed to predict the success of the care trajectory. The recognition that patients are partners in their care rather than simply recipients has changed the way in which decisions are made and how compliance to treatment plans is viewed. Traditionally, patients were seen as compliant (or not) with a respective treatment plan which would flag for a health care provider

that either there are changes to the patient's health status, new barriers have emerged or the patient is simply not committed. In fact, compliance is said to occur when "the extent to which a person's behaviour coincides with medical or health advice" (Sandman, Granger and Ekman 115).

Opponents of a compliance-based framework argue that the problem with non-compliance is not the patient themselves but rather the fact that the patient is likely uninformed and unengaged in the treatment development phase (Sandman, Granger and Ekman 117). The term compliance implies that the patient is "conforming" to a proposed treatment plan (Sandman, Granger and Ekman 116) and because patient engagement and involvement in selecting a treatment plan is vital, the term and philosophy of "adherence" has been adopted which instead alludes to a person "willingly following" a treatment plan (Sandman, Granger and Ekman 116).

The adherence framework recognizes that patients' goals and views may change over time and therefore when a patient's behaviour begins to change in ways that conflict with the treatment plan, the health care professional and patient take the opportunity to revisit the treatment care plan, assess the patient's goals and interests and make changes to the treatment plan accordingly (Sandman, Granger and Ekman 117).

The benefits and the essence of an adherence-based perspective are similar to the patient-centered framework care insofar as patients are engaged in the decision making process and are encouraged to select treatments that are most reflective of their treatment goals and interests. Proponents of the adherence-based framework acknowledge that by promoting a treatment plan that is based on a patient's personal goals and interests, the patient's best-interest may not be a principal consideration; the importance is placed instead on the patient exercising their autonomy in order to help ensure adherence to the final plan (Sandman, Granger and Ekman 118). With

regards to the issue of a patient's best-interest, proponents of the framework associate deviations from a treatment plan as an indication for an adjustment from the patient's assessment of what is considered to be in his best interest (Sandman, Granger and Ekman 118). Although patient autonomy is a central focus in an adherence-based framework, the basis of the framework places considerable emphasis on the collaborative relationship and ongoing discussions between a patient and the provider ultimately requiring that openness and collaboration in the decision-making process. This is an important view that does not appear central in the current framework.

Nursing and patient advocacy

The manner in which care plans are developed is critical but ultimately, the nurse-patient relationship is arguably one of the most vital pieces to a successful health care journey for the patient, their family, and the health care team. Given the role-specific duties to assess, facilitate and engage, the importance of the nurse-patient relationship stresses the nurse's role in patient advocacy. The literature regarding advocacy in nursing is varied and includes various definitions. Henderson (1961) states that advocacy is said to occur by "nurses helping people do what they would ordinarily do for themselves to maintain health, recover from illness, or die a peaceful death when persons lack the strength, will, or knowledge to care for themselves", or as stated by Gadow (1980) advocacy as a nurse is "helping individuals to clarify their values when making decisions and to reach decisions that uphold their reaffirmed values". According to Kohnke (1982), nursing advocacy involves "informing and supporting a patient in decision-making" and some definitions like by authors Curtin (1979) refer to *human* advocacy which "ensures the welfare of other human being" (Zomorodi and Foley 1747).

While the difficulty with establishing a standard definition persists, the literature classifies advocacy in three ways which is “1. advocacy motivated by a patient’s right to information and self-determination, 2. advocacy as a right to personal safety, and 3. advocacy as a philosophical principle in nursing” (Zomorodi and Foley 1748).

But for authors like Curtin (1980), issues arise not because patients are not expressing their wishes openly or nurses are doing poorly at advocating for the person, but rather it is because nurses are not *able* to advocate for the protection of patients’ rights because of their relationship with the patient, physician, institution and profession. Curtin argues that “ethical problems arise from the usurpation of the legitimate authority of the nurse over *nursing* decisions regarding care. The major ethical dilemma in nursing is that nurses are not free to practice nursing” (Yarling and McElmurry 64).

Similarly, authors Roland Yarling and Beverly McElmurry (1986) also contend that there are other underlying conditions that contribute to the dilemmas that nurses confront. The conditions include “established standards of nursing care as determined by the profession; consequent commitment of the nurse to the autonomy and well-being of the patient; responsibility of the hospital for all patients who receive care under its auspices; nurses’ knowledge of actual or potential harm to the patient; divergence of the interest of the hospital or one of its power structures; employee status of the nurse in relation to the hospital; nurse’s sub-collegial relation to the physician; vulnerability of the nurse to harmful action by the hospital as the employer” (Yarling and McElmurry 64). The authors go on to contend that a nurse’s commitment to the patient and their autonomy, safety, health and well-being conflicts with their own personal and professional autonomy, safety, health and well-being. As a result of how the system is set up, dilemmas arise and nurses are found in the predicament of being *unable* to

fulfill their duty to protect the rights of the patients (Bernal 182). This is important to note given that the “autonomy of the patient is contingent upon the autonomy of the nurse” (Bernal 182).

Although a variety of definitions relating to advocacy exist, the majority of the concepts should resonate with nurses given professional standards, code of ethics and the foundation of the profession. Notably, almost all of the definitions of advocacy include some form of helping a patient carry out their wishes or goals. Granted, it is imperative that a nurse fully understand and appreciate the patient’s values and wishes but the difficulty is that the nurse “must decide whether to support the patient when the nurse feels that the patient has made the *right* decision (advocacy) and must refrain from rescuing the patient when the nurse considers that the patient has not made the correct decision (paternalism)” (Zomorodi and Foley 1748). Distinguishing the conceptual limits of supporting or rescuing a patient warrants further discussion.

Professional Nursing Standards

Traditionally, it was believed that a nurse’s sole duty was to assist in facilitating the medical orders prescribed by the physician. Based on the manner in which the CNO defines nursing and the inherent features of a health care environment, the degree of involvement from the nurses expands much farther than simply facilitating medical orders. The viewpoint may be especially true in home care.

The role of a nurse in the community working with a chronically ill patient can involve a range of responsibilities such as gathering and assessing patient information, gathering input, evidence and indicators for care planning, assisting the health care team and patient in selecting and developing care plan goals, problem-solving and mitigation of various barriers to care (Wagner, Austin and Davis 68). Simply following the “doctor’s orders” is no longer the nursing

boundary as it once was. The relationship between a nurse and a patient is transforming and the scope of the nursing role is evolving as well to the extent that nurses have greater responsibility and decisional-power to actively assess, treat, prevent and support patients and their families.

Like all regulated health professionals, nurses in the community are governed by various requirements such as legislation, professional and deontological code of conducts and organizational requirements. Best-practice standards are an example of a tool used to establish predictability, consistency and accountability for both the patient and the provider. Best-practice standards are guiding practices for health care professionals to determine a treatment plan most appropriate for a patient with individual clinical characteristics or symptoms with the goal of rendering the best possible outcomes based on empirical evidence. There is an assumption that the best-practice standards are appropriate given that they are evidence-based, reliable and empirically validated. From the health care professional's perspective, if best-practice standards did not exist or are not followed, outcomes of care could potentially be impacted and time, effort and resources required for treatment could be misused or exhausted.

For this reason, the College of Nurses of Ontario (CNO) has developed an overarching framework to support practicing nurses and help guide their decision-making and responsibilities in the provision of therapeutic and clinical care. The guidelines are intended to provide support and guidance to nurses in identifying and resolving issues relating to nursing and patient care.

The framework includes seven categories of professional standards and provides nurses with a description of the legal and professional expectations as well as the associated roles and responsibilities for each standard. The seven professional standards enumerated are accountability, continuing competence, ethics, knowledge, knowledge application, leadership and relationships (College of Nurses of Ontario). According to the CNO, there is an expected

level of skill set, knowledge and clinical judgment required to practice appropriately as a nurse with respect to each standard. The standards are also based on the presupposition that all nurses are accountable for their own professional development and competency and that each nurse will be held accountable for their actions and decisions. This does not go without the acknowledgement that patients play a central role in the health care team and decision-making process, and that the ultimate goal is to maximize benefit for the patient while mitigating any unnecessary risk or harm (College of Nurses of Ontario).

An important note for consideration given the care delivery expectations within the parameters of respect for patient autonomy is the definition of ‘nursing’ and ‘therapeutic relationship’ offered by the CNO. The College defines nursing as “the therapeutic relationship that enables the client to attain, maintain or regain optimal function by promoting the client’s health through assessing, providing care for and treating the client’s health conditions. This is achieved by supportive, preventative, therapeutic, palliative and rehabilitative means. The relationship with an individual patient may be a direct practice role or it may be indirect, by means of management, education or research roles” (College of Nurses of Ontario).

Alternatively, the CNO defines therapeutic relationship as “a relationship that is established and maintained by the nurse through the nurse’s use of professional nursing knowledge, skill, and caring attitudes and behaviours to provide nursing services that contribute to the client’s health and well-being. The relationship is based on trust, respect and intimacy and requires the appropriate use of the power inherent in the care provider’s role” (College of Nurses of Ontario).

Evidently, the chief governing body for nurses in Ontario believes that by virtue of the nursing profession and role-specific characteristics, respect and truthfulness as it relates to a patient’s well-being, health and function are fundamental to the nursing profession. For this

reason, the professional should have the means and support to carry out this established philosophy in any regulated health care institution.

Chapter Three: Current Realities of the Home Care Sector

Increased Demands on Chronic Care Providers

There continues to be a rapid increase in the percentage of older persons in the population. Because of the sophisticated advances in medical technology and medicine, the aging population is also living much longer than in the past which increases the possibilities for co-morbidities and the number of frail adults. In 2011, it was estimated that over 1, 8 million people in Ontario were over the age of 65 years, accounting for approximately 14% of the Ontario population (Sinha 1). Although the longevity of human life is something to cherish, it can also present serious challenges and uncertainties for the individual, their family, the health care systems and the government sustaining the system.

As a result of the increased longevity of lives, the medical community has begun to place focus on the issue of chronic illness and the capacity to sustain high quality care for patients with such needs. Chronic illness, which is also referred to as chronic disease or chronic condition is said to be the primary cause for issues relating to reduced quality of life, decreased functioning, pain and death. A chronic disease is defined as “lasting for more than one year, limits activities of daily living, require ongoing care and are typically progressive” and common examples include respiratory and heart disease and diabetes management. (Cooper and McCarter 37). Furthermore, chronic disease often accounts as the primary reason why people visit their family doctor or local emergency rooms (Cooper and McCarter 36). Unfortunately, the chronically ill patient often goes poorly treated in these situations due to the often psychological, physical and social struggles that are associated to chronic illness (Wagner, Austin and Davis 65). As a result

of patients' needs becoming increasingly more chronic, an acute care model as a framework for the delivery of health services is no longer adequate.

Chronic Care

Given the unique characteristics of chronic illness and associated challenges as noted above, special attention has been placed on how the measure for quality and effectiveness of care may differ than in acute care. The gap in the care required for the management of chronic illness has fortunately been bridged by researchers who recognize that acute care practices would not be entirely adequate. For example, the Chronic Disease Self-Management Program (CDSMP) developed by Dr. Kate Lorig and Colleagues at the Stanford University Patient Education Research Center is a program built on the fundamentals believed to be critical in the management of chronic illness, namely self-management and peer-teaching. Participants enrolled in the CDSMP are provided a 6-week workshop with focus on acquiring skills and techniques necessary for pain and fatigue management, breathing, emotion regulation, relaxation, health and exercise, medication management and communication with health care providers (Cooper and McCarter 38) all of which are crucial in the long-term management of their chronic illness. The CDSMP is used throughout the United States and has been shown to have tremendous results for the participants involved and financially for the greater health care system (Cooper and McCarter 38).

The research team of Dr. Edward Wagner has also been successful in developing a program for the care of chronically ill patients. Wagner built the Chronic Care Model with the recognition that chronic care was managed often unsuccessfully through poor communication, the misuse of best-practice standards, inconsistent follow-up, inadequate training and

coordination of care (Cooper and McCarter 37). By identifying the inadequacies, Wagner proposed changes to practice, standards and outcome measures to ensure proactive, timely, consistent and adequate care for chronic illness.

Based on a literature review by Wagner et al. (2001) common elements of chronic care management were identified and subsequently incorporated into the Chronic Care Model as markers for quality and effective care. Five common elements were identified in the review and include: “1. the use of explicit plans and protocols, 2. the reorganization of the practice to meet the needs of patients who require more time, a broad array of resources and closer follow-up, 3. systematic attention to the information and behavioral change needs of patients, 4. ready access to necessary expertise and finally, 5. supportive information systems” (Wagner, Austin and Von Korff, *Organizing Care for Patients with Chronic Illness* 518). Central in the Chronic Care Model are proactive, informed and productive encounters between a patient and their health care provider.

To foster a better understanding of how complex the care for a patient with a chronic illness can be, Wagner et al. (2001) described the experience “like flying a small plane. If it is flown well, one gets where one wants to go with the exhilaration of mastering a complicated set of challenges. If it is flown badly, one either crashes or lands shakily in the wrong airport, reluctant to ever leave the ground again. The patient must be the pilot, because the other possible pilot, the health care professional, is only the plane a few hours every day, and this plane rarely touches ground” (Wagner, Austin and Davis 66). The way in which the experience described above is very clear when placed in the context of delivery of health care. The description emphasizes the key role the patient plays in navigating his or her care trajectory however it also highlights the role the health care team plays. Like air traffic control, the health care team is

responsible to ensure that the plan and all of its parts are strong and safe and that the patient is equipped and skilled to ensure a smooth trip. Like every successful team, effective communication is imperative to actively plan, deliver and assess for successful outcomes (Wagner, Austin and Davis 68).

Home Care in Ontario

Because this paper focuses primarily on health care provided in the home care sector, it is important to understand the sector separate from the other systems that exist in Ontario. The fiscal and resource constraints that exist today in the health care system are no secret nor can they be denied. The demand for both the resources necessary for provision of care as well as trained nurses to provide the care is increasing. By 2006, approximately 1,000,000 people were employed in the health care profession in Canada and the number continues to grow. This number represents a 6% proportion of the Canadian labour force (Health Canada).

In order to help manage the many fiscal constraints that hospitals are experiencing, the delivery of care in the community is an effective alternative both from a cost and quality care perspective. It was estimated that in 2007, 900,000 Canadians were receiving home care services which was a 51% increase from 1997 (Blais, Sears and Doran 2). The home care sector presents itself as an opportunity to bridge the gap and assist in building access to primary care, improved waitlist management, health awareness and management of chronic conditions as seen in the aging population (Champlain Community Care Access Centre 16). An integral factor in the success of the home care sector however is a very strong partnership with external acute care and community care partners as well as sound ethical and governance frameworks. Hospital admissions and discharges, placement into Retirement Residences or Long-Term Care Facilities

and provision of rehabilitation services such as physiotherapy and nutrition would not be possible without integration and collaboration across systems.

As the population continues to grow in age and the capacity for hospitals to care for patients becomes limited, care in the home becomes an integral component in the delivery of care and the sustainability of Ontario's health care system. According to Health Canada, the home care sector (also known as community care) falls under the category of Secondary Services (Health Canada). Access to home care is simple in that referrals can be made from various sources such as a physician, community agency, a family member or patient themselves as a self-referral. This referral process ensures a timely transition from hospital to home or as needs begin to increase and independent living is at risk (Kitts, Beaton and Cook 22).

The Government of Ontario has acknowledged the importance of the imperative to help seniors remain safely in their homes longer and promote quality of life. In 2012, the Government of Ontario introduced the Ontario's Action Plan for Health Care which builds upon principles of fairness, quality, choice and access to health care for people when they most need it in the place they need it most (Sinha 2). Included in the Action Plan is choice. Choice was defined as receiving the health care a person requires, and in the location most preferred by the person. Interestingly, choice was included in the list of principles suggesting that patient choice and autonomy is a pillar in a sustainable, effective and ethical health care system.

Under the Home and Community Services Act, a person eligible for professional services (i.e. nursing) from a Community Care Access Centre (CCAC) is someone who is insured under the Health Insurance Act, resides in a location that has the necessary environmental features to facilitate service provision, and minimizes the level of risk that a nurse may be exposed to during service provision to a level that can be mitigated by the employer (Government of Ontario 5).

As stated in the Bill of Rights of the Home Care and Community Services Act, a service provider shall ensure that the following rights of persons receiving community services from the service provider are fully respected and promoted:

1. “A person receiving a community service has the right to be dealt with by the service provider in a courteous and respectful manner and to be free from mental, physical and financial abuse by the service provider.
2. A person receiving a community service has the right to be dealt with by the service provider in a manner that respects the person’s dignity and privacy and that promotes the person’s autonomy.
3. A person receiving a community service has the right to be dealt with by the service provider in a manner that recognizes the person’s individuality and that is sensitive to and responds to the person’s needs and preferences, including preferences based on ethnic, spiritual, linguistic, familial and cultural factors.
4. A person receiving a community service has the right to information about the community services provided to him or her and to be told who will be providing the community services.
5. A person applying for a community service has the right to participate in the service provider’s assessment of his or her requirements and a person who is determined under this Act to be eligible for a community service has the right to participate in the service provider’s development of the person’s plan of service, the service provider’s review of the person’s requirements and the service provider’s evaluation and revision of the person’s plan of service.

6. A person has the right to give or refuse consent to the provision of any community service.
7. A person receiving a community service has the right to raise concerns or recommend changes in connection with the community service provided to him or her and in connection with policies and decisions that affect his or her interests, to the service provider, government officials or any other person, without fear of interference, coercion, discrimination or reprisal.
8. A person receiving a community service has the right to be informed of the laws, rules and policies affecting the operation of the service provider and to be informed in writing of the procedures for initiating complaints about the service provider.”

To help set the stage for effective and collaborative provision of care, the Bill of Rights and Responsibilities was developed and included in the Home Care and Community Services legislation. Interestingly, although risk is described in the Act as an element essentially inherent in home care nursing, neither the Act nor the Bill of Rights provides minimal guidance regarding what the standard level of acceptable risk is and how risk mitigation is enforced.

Home Care

Home care, as defined by the Canadian Home Care Association, involves providing “an array of services for people of all ages, provided in the home, and community setting, that encompasses health promotion, teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration and support for the informal (family) caregiver (Kitts, Beaton and Cook 4). Home care involves the caregivers such as family members, neighbours or friends, assisting and contributing in the provision of care. According to

a report by the Health Council of Canada of 2012, home care is intended to be a supplement to care already provided by an informal caregiver rather than a substitute (Kitts, Beaton and Cook 26).

According to the Ontario Association for Community Care Access Centres (OACCAC), delivering care to patients in their home costs approximately \$45 which is minor in comparison to the expense of care in a hospital (\$450 per day) or a Long-Term Care facility (\$135 per day) (Ontario Association for Community Care Access Centres). Given the demographics of the most frequent users of health care services and the increasing constraints on the health care system due to issues such as the management of chronic, longer-term illness, the integration of home care services has become critical to ensure timely, affordable, adequate and supportive health care.

An example of how valuable home care can be is demonstrated through services such as palliative care. Undoubtedly, end-of-life care can be overwhelming and emotional for both patients and their families. Despite the potential challenges, reports by the OACCAC indicated that “70 to 80% of people would prefer to die at home if supports were available, yet 66% of Ontarians die in hospitals” (Ontario Association for Community Care Access Centres). Home Care services allow health care providers to deliver care that is crucial for the patient’s well-being but in a manner that allows for the patient to continue to live with dignity and in comfort in their homes.

The shift in location and type of service provision has been a change for all partners involved including the health care providers, organizations, patients and their families. Historically, provision of care involved a targeted short term or crisis curative approach, often involving a passive patient role with little focus on rehabilitation, self-management or the long term trajectory often within an acute care setting (Wagner, Austin and Davis 65). By helping

people stay safely in their homes and promote access to community services, the system can ideally see a reduction in unnecessary visits to the emergency room and hospital admissions and ultimately an improvement of one's quality of life (Champlain Community Care Access Centre 14).

Chapter Four: Challenges of the Home Care Sector

“My home-my rules”

In most health care institutions such as hospitals or clinics, care is provided in a controlled environment or facility where certain rules exist and can be easily enforced. In hospitals, for example, it would be quite the challenge for patients to engage in any kind of overt criminal activity or inappropriate behaviour. Even when these types of events occur in places like hospitals, security officers are almost always readily available to provide assistance and expertise in handling and mitigating the situation. This is unlike the environment of someone's private home.

In the community, most clients will likely feel more comfortable engaging in certain behaviours or advocating to a certain degree relating to their home care services than they would in a public facility like a hospital, by virtue of it being their own personal home. This is a crucial point for this paper. This phenomenon can present real challenges to organizations in the home care sector, especially when there is an expectation to respect a patient's autonomy, because the client's home is also the workplace for staff. The way in which people choose to spend their free time in the privacy of their own home is not usually a matter concerning the public. However, in the context of home care, because the client's private home is also the workplace, a home care service provider like any employer, has the responsibility to ensure staff safety and monitor quality of care while upholding standards of care expected in any care environment.

Similar to the Bill of Rights and Responsibilities which is intended to protect the rights of a patient, a governing body of legislation that helps guide employers in Canada about their responsibilities in ensuring a safe work environment and informs employees about their rights is

the Occupational Health and Safety Act. The Act is very clear in the types of parameters that employers need to set to ensure safety for their staff. As stated in the legislation, with respect to a potential risk of violence, an employer's duty applies only when it is reasonable to expect that the employee would make contact with the potentially violent person in the course of his or her work and secondly, when there is a possibility of risk to a serious enough degree that could cause bodily harm or physical injury (Ministry of Labour).

In reality, the ability to differentiate responsibility and simply due diligence can be complicated. The amount of the information that the employer is responsible for disclosing about risk is ultimately up to their own discretion however, the Act recommends that an employer restrict the amount of information that is shared to what is reasonably necessary in order to avoid injury (Ministry of Labour). With respect to disclosing information about a person's history, for example, it is expected that an employer will share enough information to protect staff from potential harm yet deliver the care that is required in an appropriate and equitable fashion. The difficulty however lies in attempting to establish an objective threshold to determine what amount of information is 'reasonably necessary' to disclose. Although being aware of possible risks may enable someone to take the necessary precautions to stay safe or deter the inappropriate behaviour altogether, the argument can also be made that if there is more information disclosed about a person, the greater the likelihood the person will be treated differently. From an ethics perspective, this is troublesome, especially in relation to respect for patient autonomy. There is strong correlation in literature regarding the disclosure of personal information with individual autonomy and studies demonstrate that a common theme is that for an individual to have the ability to act autonomously they must be free from intrusion which would require privacy (Doyle and Bagaric 17).

When handling information regarding a patient's history and whether it is reasonably necessary to disclose it, the regulations within the Act proposes that an employer considers whether the violence was associated with the workplace or work, and if it was, to determine if the violence was directed towards a staff member or staff in general, the time that has passed since the most recent incidence of violence and what measures and procedures are in place in the existing workplace violence program (Ministry of Labour). Depending on the outcome of the deliberation, the employer is encouraged to resist disclosing information if it is unlikely that the employee will encounter the person in his or her work and or if it unlikely that the staff would be exposed or at risk for bodily harm (Ministry of Labour). Without clear guidelines regarding group and individual safety, the handling of such issues can be difficult to see carry out for employers of home care nurses, especially considering particular hazardous possibilities home care nurses are exposed to in a person's private home. And the issue of respect for patient autonomy and the view that a patient is to be unrestricted only complicates the issue further.

Patient Satisfaction

As human beings, we have the right to be respected as persons. For some, the respect is believed to extend to the respect of life, dignity, cultural differences, ideas, privacy etc. (Beach, Duggan and Cassel 692). Generally speaking, respect for persons involves "universal obligation that people have towards other people in general" and this differs in a clinical context in which "duty" is emphasized "because physicians have a special kind of relationship with their patients that the nature of this obligation to respect them has special features" (Beach, Duggan and Cassel 692). This special duty could encompasses responsibilities such as keeping a patient's personal health information confidential, ensuring informed consent is obtained prior to administering a

treatment or ensuring respect of dignity during medical procedures. The principle of respect for persons is often used as a barometer for health care professionals and it is a primary indicator of “good bedside manner”; a good physician will uphold respect for persons (Beach, Duggan and Cassel 692).

Authors Mary Beach et al. (2007), have analyzed the issue of respect for persons and differentiate between the global sense of respect for persons and how this respect for persons differ in a clinical context. The authors call attention to the fact that although the principle of respect for persons is taken with high regard in health care environments, it can be unclear as to what constitutes ‘respect’ and which type of respect prevails even in a clinical context. For example, is it the duty of the health care professional to respect a patient’s autonomy or their dignity? Conversely is the goal to respect the patient’s cultural differences the most important or is the respect for a patient’s privacy greater? The expectations of health care professional with regards to respect for persons can be ambiguous and often a moving target, especially in the context of patient autonomy where each patient will appeal to different forms of behaviours, requests and beliefs, expectations etc.

The respect for persons is an important consideration as it relates to patient satisfaction. The need for health care organizations to promote and enhance patient satisfaction is a primary driver from a reputational, financial and legal perspective and has shaped the patient role. Understanding and appreciating the nuances of patient preference and expectation with relation to service standards is an integral component to the delivery of high quality care and is matter is at the forefront in health. The Excellent Care for All Act for instance, is legislation that requires health care organizations to assume accountability for delivering high standards of quality care to all patients. A key requirement of the Excellent Care for All Act is a survey that is administered

to patients and their caregivers drawing on various indicators related to patient experience, quality of care and patient satisfaction. The purpose of the survey is to inform health care organizations of areas in which require quality improvement (Detsky and Shaul 1199).

More specifically, the Act is based on the following principles: “Care is organized around the person to support their health; quality and its continuous improvement is a critical goal across the health care system; quality of care is supported by the best evidence and standards of care and payment; policy and planning support quality and efficient use of resources” (Ministry of Health and Long Term Care). When the Act was enacted in 2010, a regulatory requirement was for health care organizations to ensure and continuously improve outcomes and patient satisfaction. According to research that will be discussed, this initiative could be difficult to measure and ambiguous to interpret.

Patient satisfaction is commonly defined as “a health care recipient’s reaction to salient aspects of the context, process, and result of their service experience” (Leiter, Harvie and Frizzell 1611). Measuring a person’s opinion following a service encounter is not unique to the health care sector and is a practice in many other industries. In health care, the ability to fulfill the expectations of patients and maximize their satisfaction has been shown in research to vary depending on age, income, anxiety, education and comorbidity which leads to ambiguous results that are difficult to interpret and correlate (Detsky and Shaul 1199). The accuracy of the survey responses can also be influenced by the time between discharge of service, time of most recent visit, the time the survey is administered, the ability of the person completing the survey to understand the survey questions, the tool that is being used and the process and the survey administrator (Detsky and Shaul 1200).

Surveying a patient's perspective of the context, process and outcome of their health care experience, as stated in the definition above, will also depend on how positive or negative they considered each aspect to be, by drawing on their emotional reaction to each aspect. Every area whether negative or positive, has been shown to be equally as important to assess yet little research has been done to understand which element impacts global satisfaction the most. (Leiter, Harvie and Frizzell 1611).

An area of knowledge that has been established is the understanding that despite the type of response a patient may have provided, a patient's level of satisfaction is often unrelated to the technical aspects of the service provided or of the service provider, but correlated instead with meeting expectations in areas of communication, responsiveness and reliability (Leiter, Harvie and Frizzell 1611). These findings are similar to other studies that demonstrated little to no correlation between patient satisfaction and the technical aspects of care. For example, Chang et al. (2006) examined the relationship between global patient satisfaction ratings with technical expertise. The authors adopted the quality of care scale used in the Assessing Care of Vulnerable Elders (ACOVE) project which listed 236 quality indicators and conducted phone interviews and chart audits of approximately 235 elderly patients living in a care facility. The results indicated that a positive global patient satisfaction rating correlated strongest with measures of interpersonal styles and communication. A patient's health status was also shown to correlate strongly with high global patient satisfaction surveys.

In summary, the results of the Chang et al., survey are twofold. The fact that global patient satisfaction shows weak correlation with the technical aspects of care, suggests that a low global rating of patient satisfaction may not imply poor *quality* of nursing care and therefore may warrant further and separate analysis. Secondly, the focus on strategies to improve patient

safety may require a separate analysis as well. One would assume that patient satisfaction would correlate with patient safety (i.e. the safer a patient feels the more satisfied they are) however the evidence suggests that this is not perhaps completely accurate. Our understanding of patient safety may differ than that of the patient's and based on the literature, it may not directly concern *how* or *what* care is provided but instead the interpersonal relationship or rapport that matters most.

The research results support the emphasis that the patient-centered care framework places on communication and so organizations within this framework would likely render positive results on their patient satisfaction surveys. This enhanced attention to patient satisfaction however may create weaknesses in other areas such as quality of care or risk mitigation especially in cases where obligated beneficence or limited patient choice would be warranted.

The relationship between the quality of care and patient satisfaction is complicated. Satisfaction ratings from patients are based both on their cognitive and emotional reactions. The responses obtained from patients are critical in the delivery of high quality care but according to Donabedian (1980), there are many facets to measuring quality care. Donabedian suggests in his framework that quality of care has three fundamental aspects which are technical quality, interpersonal quality and amenities. Technical quality of care is "the extent to which the use of health care services meets predefined standards of acceptable or adequate care relative to need" and interpersonal quality is defined as "the characteristics of interactions between the provider and the patient" (Chang, Hays and Skehelle 665).

The emphasis on patient satisfaction has led to organizations adopting a consumer driven-like framework. In this model, "patients are perceived in a sense as paying customers rather than simply recipients of health services" and this has resulted in systematically targeting areas that

are most relevant to patients as demonstrated in the results of the patient satisfaction surveys (Leiter, Harvie and Frizzell 1611).

The role of the nurse providing the care will inevitably have tremendous influence on a patient's satisfaction rating and success of service delivery goals. Nurses are at the frontline delivering the care that is carefully evaluated and rated by each patient. Providers are also evaluated against other targets such as achieving a maximum of a five-day wait time for the first nursing and personal support visits for complex patients, reducing the number hospital readmissions or return visits to the Emergency Room, and facilitating death in a preferred location for palliative patients requiring ongoing and diligent follow up from nursing staff (Ontario Association for Community Care Access Centres).

Understandably, the nurse role is critical in the health care team. A survey by Clarey and Sibert (1993) included responses from approximately 17, 000 participant and results demonstrated that 45% of the care patients rated most closely with regards to quality was delivered by nurses and only 2% by physicians (Leiter, Harvie and Frizzell 1612). According to the literature, nurses are no less qualified than physicians to ensure ethical decision-making and quality care (Zomorodi and Foley 1747); a nurse is pivotal in the process of ensuring patient satisfaction and autonomy but also in assessing their safety and recovery.

Duty to treat

The debate regarding a health care professional's duty to treat is a contentious issue and relates to the focus of this paper for several reasons, especially considering the potential reach of a patient's autonomous behaviour. Although there many varying perspectives regarding the degree of responsibility and obligation of a health care professional, the legal system has

validated that a health care professional does in fact have a responsibility to treat in “limited emergency situations and once a consensual doctor-patient relationship is established” (Annas 1).

Briefly, the duty to treat a patient in an emergency situation stems from a person’s legal right to be treated in a medical emergency regardless of socio-economical class, religion, race etc. Because the duty to treat in medical emergencies does not usually extend beyond the hospital emergency room, we will instead focus on the duty to *continue* treatment once the relationship has been established.

Once a patient voluntarily enters a consensual medical relationship with a physician, the physician is obligated to continue treating the patient until one of the following conditions occur: “1. the relationship is terminated by mutual consent, 2. The relationship is terminated by the patient, 3. The physician’s services are no longer needed or, 4. The physician withdraws after reasonable notice to the patient” (Annas 2). Bound by the moral and professional duty to continue treating, in the event that a physician or any regulated health professional removes themselves from the relationship without meeting one of the four criteria above, the professional would be said to have breached a fundamental duty which would have legal and medical licensing repercussions, especially in the event the patient is harmed following the physician’s withdrawal.

It is important to understand the facets of the duty to treat in order to apply the obligations to various scenarios. Let’s first consider the health care professional’s obligation to enter the medical relationship and treat a patient. Outside of emergency situations, there is a presupposition that health care professionals have an unwavering responsibility to accept to treat any and all patients provided that they have the necessary skill set, knowledge and expertise to do so. The severe acute, respiratory syndrome (SARS) pandemic of 2003 and emerging

concerns of the spread of Ebola are examples of how the limits of duty to treat and whether the duty is so far reaching that that it requires the health care professional to provide care in all situations regardless of potential risk of harm to the themselves or others. While providing care to the patients is critical, it can come at a potentially huge cost for the health care professional. For instance, reports reveal that health care professionals accounted for 30% of the reported cases of SARS and over half of the cases reported, two of which resulted in death, were of health care professionals from Toronto, Ontario, two of which resulted in death (Malm, May and Francis 5). The duty to care during a pandemic is only one example of the potentially hazardous situations health care professionals encounter and expected to overcome. In situations like this, the scope of the health care provider's role and role-related risks is expanded.

Health care professionals are bound by their moral and professional oath and codes of practice and thus the duty to care is rarely questioned and implied consent is almost always suggested. Establishing the threshold for acceptable risk impacting duty to care and the understanding of what constitutes "outside of normal scope of practice" continues to be a challenge. Although the foundation of the oaths and codes are often vaguely understood but frequently asserted, when issues arise and the scope of practice is challenged, the professional is vulnerable to the criticism that they are not fulfilling their duties as a health care professional (Malm, May and Francis 4). In reality, the professional may be exercising their right to a safe work environment.

The respect of a person's choice to live at risk presents unique challenges for the home care sector. The unsecured and unregulated setting of a person's private home presents an entirely unfamiliar context that like in a hospital. Issues of unsecured pets, weapons or drug

paraphernalia, clutter and hoarding issues, and infestations are only a few examples of the complexity of the duty to treat and its relationship with risk and the home care sector.

The duty to help others in need is not unique to only those who choose to pursue a career in health care. As human beings, each of us shares the moral duty to assist others who are in serious need provided that the risk to ourselves is not great. The duty that commands us to “help a lost child, administer CPR to an unconscious person or to call 911 in the event that there is an emergency” is a general positive duty and entails the agent *doing* something (Malm, May and Francis 6). Conversely, a general negative duty would entail someone *not* doing something that would harm others. Although considered general in nature, what some ought to do in order to assist or protect others is symbolic in society and establishes predictability, reliability and effectiveness amongst its citizens.

Although general negative and positive duties still apply to health care professionals, the duty to care for a patient is considered a *special* duty given the relationships (Malm, May and Francis 6). The special duty renders someone responsible because of the role they accept, similar to a police officer, parent or lifeguard and often occurs once the person explicitly accepts the role, like taking an oath or signing an employment contract. Unlike general duties, the special duties requires a person to accept greater risk to themselves than they would usually outside of the role-related context (Malm, May and Francis 7).

The assumption that a health care worker implicitly accepts all risks by virtue of accepting a role in health care can be troublesome as demonstrated by authors Malm et al. (2008). Malm and colleagues assert that the presupposition of implied consent is both vague and inaccurate for four reasons. Firstly, the argument is too vague to the extent that simply because

someone chooses to accept the role in health care which by nature has inherent risks does not imply that the person is also consenting to accept the all risks that are field-related.

Secondly, the assessment of risks should demonstrate that the risks are truly inherent to the role and not simply due to current contextual circumstance. For example, caring for those who are ill is undeniably an integral component to the role of a health care professional however some risks “are not obvious in or central to some fields in the way that risk of fighting fires is obvious in and central to the field of firefighting” (Malm, May and Francis 8). This analogy could arguably be used in the situations of pandemic, violence in the workplace by patient and exposure to other potentially harmful risks to staff like an infestation in a home or an aggressive unsecured pet.

Thirdly, it should not be assumed that a person has provided consent simply by the fact that they have not overtly refused. According to the authors, the absence of a person’s overt verbal refusal (i.e. silence) can be considered a sign of consent if “1. The person knew of the proposal and the opportunity to dissent, 2. The means of signaling dissent were both known and reasonably performable, 3. The time frame for expressing the dissent was reasonable and known”. Regardless of the markers for consent, based on the understanding of duty to care, the opportunity for a health care professional to refuse or dissent appears ambiguous.

Finally, despite whether the risks in question are inherent to the profession or not, it is questionable whether the health care professional in fact has the knowledge or ability to actually understand what the risks are and strategies for mitigation thus truly provide consent. Furthermore, the issue of consenting to the *continued* exposure to risks highlights the importance of sound policy and practice to protect workers should they continue, or feel obligated, to continue providing services.

Moral Distress

A traditional and primary goal for nurses is to ensure the health and well-being of patients and to accomplish this by delivering quality care at all times in an ethical and respectful manner. The rapidly changing landscape of the health care system including the development of new technologies, the expansion of treatment options, the change in care setting and dynamics of service provision has shaped our understanding of moral norms in health care and has expanded the boundaries of a professional's moral duties. The moral aspects of nursing are instrumental and as Jameton (1984) describes "nursing is morally worthy work: caring for and treating the sick, comforting and protecting the suffering, are basic benefits of human culture. Traditionally, people express altruism and idealism by attending to the sick" (Jameton 1).

Attending to the sick is certainly less demanding when there are adequate resources, agreement amongst team members and a shared perspective about goals, roles and responsibilities. In reality though, nurses are confronted with complex and ambiguous dilemmas that require their rapid and efficient use of moral reasoning. The literature indicates that the complex situations that nurses encounter overtime is taking a toll on their health, well-being and employment satisfaction.

Besides their patients, nurses also have a commitment to their employer, their professional association and their colleagues. Although the numerous connections are tremendously complex and fluid, there are instances as discussed throughout this paper that the nurse is not able to fulfill or carry out the moral duties of their respective role which often results in a phenomenon called moral distress (Wilkinson 17). Moral distress is defined as "the suffering experienced as a result of situations in which individuals feel morally responsible and have determined the ethically right action to take, yet owing to constraints (real or perceived) cannot

carry out this action, thus believing that they are committing a moral offence” (Mitton, Peacock and Storch 101).

In addition to the seriousness of moral distress, a phenomenon called “moral residue” emphasizes the significance of the ongoing experience of nurses dealing with moral distress. Moral residue is described as “that of which each of us carries with us from those times in our lives when in the face of moral distress we have seriously compromised ourselves or allowed ourselves to be compromised” (Epstein and Delgado, *Understanding and Addressing Moral Distress* 4). The level of moral residue that nurses are said to experience correlates strongly with the frequency of moral distress. Although sources of moral distress may be resolved, the feelings of powerlessness and distress creates residue that increases overtime and across exposure. This phenomenon is defined as the Crescendo Effect (Epstein and Delgado, *Understanding and Addressing Moral Distress* 4). According to Epstein and Hamric (2009), low level distress that a nurse experiences overtime can result in three consequences: “the provider may become morally numbed to ethically challenging situations, the provider may engage in different ways of conscientiously objecting to the trajectory of the situation and the provider may burnout” (Epstein and Delgado, *Understanding and Addressing Moral Distress* 5).

The influence of moral distress and subsequently moral residue has been validated in research and demands further investigation. According to a study by Wilkinson (1987), the situations and the impact of moral distress are pervasive. Wilkinson surveyed 24 registered nurses from a variety of hospital units with the goal of better understanding the facets of moral distress which were presumed to be influenced most by thoughts and perceptions, situational factors, feelings and behaviours. Based on the results gathered, the researcher was able to categorize the areas pertaining to moral distress by the kinds of cases, frequency of occurrences,

contextual constraints, feelings, effects of moral distress on the nurses' wholeness, effects of moral distress on patient care and coping behaviours.

With regards to the cases that emerged, almost always the case related to patient care. The themes most prevalent were related to the prolonging life, performing unnecessary tests and treatments, dishonesty with patients and incompetent or inadequate treatment by a physician. The underlying moral dilemma in almost all cases was the inadequate care to the patients, potentially exposing the patient to harm and diminishing respect for patient dignity. The frequency of cases was fairly consistent across the 24 participants insofar that morally distressing cases were said to occur frequently in their practice. Of course, not all cases are going to produce feelings of moral distress. As highlighted by Wilkinson, moral distress is a result of a nurse's *perception* of a moral dilemma and a conflict with one's personal and or professional moral framework and value system with that of the institution and health care team.

According to the responses from the participants, the perception of barrier exists was just as detrimental as an actual barrier itself (Wilkinson 21). External barriers that were reported most frequently by the participants were physicians, the law and or threat of litigation, nursing administration, hospital administration and policies.

The feelings associated to moral distress as described by the participants were powerful, mostly negative and were often expressed through anger, frustration and guilt. The effects of moral distress were also significant and according to the participants, often includes loss of self-worth, effects on personal relationship, various psychological effects, behavioural manifestations and physical symptoms.

Interestingly, the effects of moral distress on patient care, was divided across participants. According to the authors, the perception that quality of patient care was unaffected by moral

distress is said to be due to how the nurses define and measure quality of care and may encompass only the technical aspect rather than a more comprehensive view of patient care.

The results rendered regarding coping mechanisms were primarily avoidance of both the patient and or the job. Obviously this type of coping behaviour is unhealthy for the professional and unsatisfactory for the patient. Participants also described their coping behaviours in terms of denying involvement in the moral issue and also expressed that identifying the control they did have over patient care helped with coping.

It is clear that the dilemmas nurses are encountering are both complex and difficult to cope with both in their profession and in their personal lives. The impact can be pervasive and truly influence the health and well-being of nurses and their patients. A reform in practice and policy is necessary to shape a culture of open, honest and respectful communication and collegiality between all members of the health care team, including the physician, nurses, patients and their families (Erlen 78). The moral norms and associated duties need to be addressed head on.

As the moral dilemmas become greater and potentially more frequent, the way in which the individual and their professional life are impacted can be significant. As demonstrated in a follow-up study by author Brigid Kelly (1998) which assessed the moral integrity of nursing students, it is a challenge for nurses, especially new nurses entering into the field of health care, to preserve their “moral integrity” as a result of the dilemmas and situations that arise in practice. The results of Kelly’s study demonstrated that 22 of the original 23 original participants that there are six psychosocial stages that nurses transition through following graduation and entry into the nursing profession. The six stages are “vulnerability, getting through the day, coping with moral distress, alienation from self, coping with lost ideals, and integration of new

professional self-concept” (Kelly 1137). The stages demonstrate that the moral agency of new graduates is gradually diminished as a result of the moral issues and distress. Throughout the stages, there is a culmination of feelings and emotions of uncertainty, alienation, self-doubt and confusion primarily stemming from issues of lack of resources, staff and greater conflict in priority and role which can naturally lead to feelings of moral distress. According to the author, the highest degree of moral distress was experienced when there was a realization by the nurses that they were not going to deliver the kind of care they once believed to be possible prior to entering the field of health care (Kelly 1141).

Part II:

Method

Studies assessing the professional and moral integrity of nurses in relation to changes in the profession, such as studies by Wilkinson (1987) and Kelly (1998), investigate primarily the experience of acute care nurses. Nevertheless, it is hypothesized that similar results would likely be rendered if the practice of home care nurses was examined. Building further on this concept, a secondary purpose of this study was to develop and administer a case study and questionnaire to nurses working in the home care sector in order to validate a hypothesized correlation between ambiguous standards and diminished moral and professional integrity. More specifically, the goal of the study was to assess the interplay between duties related to patient autonomy and other principle nursing duties such as beneficence and non-maleficence in the context of home care nursing.

Registered nurses with experience in nursing in the community either through direct care or care coordination were recruited to participate in the study. A "first-come/first-served" method was used to select participants. Each recruited participant was asked to review a hypothetical case study and complete an electronic questionnaire of six questions relating to the case study. The questionnaire explored the participants' understanding of moral and professional obligations within a patient-centered care model, the complexity of patient autonomy and its implications for nursing ethics and moral distress. The study took place over the course of three months and participants were asked to submit their responses within 30 days of receiving the questionnaire.

The case study used in the questionnaire is the following: "Rudy is a capable 63 year old man with numerous medical conditions and is alone in a one-bedroom apartment. His wife

passed away 4 years ago and his only daughter lives a few hours away in Toronto. The nurses in the home have been reporting recently that Rudy is refusing care and is demanding a treatment plan that he found on the internet and is adamant that this is a right he has as a patient. The nurses have reviewed the treatment option Rudy is requesting and indicate that it is contrary to best-practice guidelines and is not within the scope of what the agency typically provides. Because Rudy has no family doctor, the Physician from the hospital who made the original medical order was consulted and does agree that it is a sub-optimal treatment plan and believes the original treatment plan is best. Various attempts have been made to offer alternative services and options and counseling and education has also been provided about the benefits of continuing with the original treatment plan and possible consequences of refusing care. Nurses are experiencing moral distress because Rudy will not consent to any other treatment and will be at risk if he does not receive any treatment at all. Although the treatment plan Rudy is requesting is not best-practice, staff are not certain that it would contraindicate with the care that is required but because of lack of empirical evidence, there is uncertainty about what results the treatment would produce and therefore could diminish chances for cure”.

The questionnaire began with asking each participant the length of time in which they had been working in the home care sector. Subsequently, they were asked to respond to the following six questions:

1. What does patient-centered care mean to you?;
2. In the case of patient Rudy, would accepting the requested treatment be an example of patient-centered care?;
3. If accepted, would you feel pressure to assist Rudy in carrying out his preferred treatment plan despite feeling that the decision is not ideal or in Rudy’s best-interest?;

4. Do you feel it is your duty as a nurse to respect patient preferences and independent decision-making?;

5. Although there are best-practice guidelines and Rudy is deciding himself to refuse care unless his request is accepted, would you find it difficult to accept this knowing Rudy would be at risk without care?; and finally,

6. Would you feel prepared to handle the conflict between Rudy's request and best-practice or your agency policy and procedure? How would you handle it? A complete account of the responses received from all of the participants is available (appendix A) and the following is a summary of key points and considerations.

The participant was given space to respond to each question in a written format. There was no maximum number of characters in the response field and was anticipated to take approximately 30 minutes to complete. Given the nature of the case study and associated questions, participants were made aware that they may experience feelings of stress and anxiety during the course of filling out the questionnaire depending on their personal experience with the topic and participants were provided resources should this have occurred.

The data obtained from the questionnaire was analyzed through content analysis. The content was organized and coded in order to categorize the text into groups of similar themes and concepts. This allowed for analysis of the relationship among the concepts and testing against the initial research question so that it can be refined. A total of 16 nurses responded to the questionnaire. The following is a summary and analysis of the responses. The entire set of responses can be found in Appendix A.

Analysis of Results

The first question participants were asked was to describe their understanding of patient-centered care. The response from the participants was fairly consistent. There were two main themes that emerged. Much of the emphasis in the responses was placed on considering the patient as a whole and the importance of consultation and collaboration between the health care provider and the patient. An example of a response provided was that patient-centered care involved “working with the patient to determine what the client’s wishes are and developing a plan of care in consultation with the patient to try and meet the patient’s wishes. This is a consultative process where there is discussion between the nurse and the patient that looks at the pros and cons of all choices”. A secondary theme that emerged included the understanding that the patient *directs* care nearly independently from the health care team. For example: “patient-centered care is allowing the client to direct his own care” while alternatively, other responses referred to a patient “accepting or refusing care based on the options presented” and another participant explained that “patient-centered care means that each care plan is tailored to the specific needs of the client”. The latter suggests that treatments options selected for the patient are pre-determined but that the patient makes the final decision regarding which options to accept or refuse. As suggested by a participant, it becomes especially important in this view that “the patient’s participation, compliance, culture and beliefs towards a treatment plan are some facts that much be respectfully considered and accepted when providing patient-centered care”. This would naturally inform what treatment plan would be acceptable to the client. Another participant noted that “health care professionals must listen, hear and be open to the patient’s point of view and realize people do life differently and what is an appropriate choice for one person may not be the appropriate choice for another. Health care professionals must have an open mind in this regard”.

As previously stated, only the client is taken to be the most suitable to determine the measures for quality of life as this potentially differs between members of the health care team. The understanding that quality of life is best defined by the patient is not unfamiliar to nurses. Participants described that by means of patient-centered care, “the client is supported in making decision and the team does everything they can do to respect the client’s wishes. The focus of patient-centered care is on quality of life of the client”. This understanding was emphasized as an important aspect since “it is the patient who has to live with the outcomes of that decision and while the health care provider may perceive one outcome to be the most important one driving the decision, the patient may decide another outcome has greater impact on his/her life or quality of life”.

The second question asked participants to associate patient-centered care to the case study. Twelve of the sixteen participants indicated that “yes”, indicating that they believe accepting Rudy’s sub-optimal and clinically risky choice is an example of patient-centered care. Granted, the caveat for several of the participants included the requirement for a physician’s order, no contra-indications with treatment goals, and the need for the patient to be capable to make an informed decision about possible risks of the decision. This traditional view is potentially now expanding given the multi-faceted concept of patient-centered care and respect for patient autonomy.

The active involvement of the health care team was also a theme that emerged through the responses to the second question. One of the participant responded by saying “accepting his decision would be to an extent patient-centered care however this may not always be care that could be followed up on by the involved medical professionals”. And another participant

responded with “it is imperative that this client remain in contact with the health care system and if client receiving sub-optimal care is the way that this happens, then so be it”.

One view obtained from the questionnaire proposed that “the nurse is there to guide and teach the client about health and wellness but in the end, it is always the patient’s ultimate decision when it comes to care”, furthermore, the same participant stated “the nurse could also facilitate and liaise with other health care professionals, in order to find another provider that will meet the needs of the client”.

In relation to the third question, a little more than half of the participants answered “yes” to feeling pressured to having to help carry out Rudy’s goals. Number of years did not appear to have any relevance to whether a nurse felt pressured to deliver the care. Almost all respondents state that the treatment plan would need to be within RN scope and or accompanied by a physician order and of course require the patient be capable in making the informed decision.

The issue of separating personal views from professional views and its impact on the provision of care was explained by one participant who said “regardless of my personal beliefs, I think the feeling of pressure comes from when you want to help people and they choose to help themselves in a different way”. Another participant noted that “it may go against my philosophy of providing care which will optimize the wellbeing of the patient but again my perception of wellbeing may be different from the patient which I would hopefully accept”.

Although nurses may feel pressured to accept less than ideal patient choices, all participants nevertheless responded unanimously to the fourth question expressing that it was the responsibility of a nurse to respect a patient’s preferences and independent decision making. The difficulty is in defining the scope of respect. The following response summarizes well the primary response of participants in the context of independent decision making by the patient

and the nursing role: “I feel it is my duty as a nurse to respect the patient’s preferences and independent decision-making. However, only after establishing that the patient has been given all possible information and education available so that an informed decision can be made, would I feel secure in respecting the patient’s preference. A point of view or belief on a specific treatment plan should not be imposed or forced on a patient. This, I am sure, happens too often as the patient seeks guidance and answers from health professionals”.

The responses from the fifth question revealed that although all of the participants believe it is their duty as a nurse to respect patient preferences and independent decision making, more than half of participants felt it would be difficult to accept a patient’s choice to refuse services knowing they would be at risk without care. A total of nine nurses responded they would have difficulty and seven responded that they would not.

As stated in previous responses, nurses feel strongly about identifying patient preferences and ensuring they remain at the center of the decision-making process. The caveat in the majority of the responses is that conditions are necessary and should include a physician’s medical order, clear boundaries within professional standards, assessed patient capacity and the ongoing dialogue with other health care professionals as a support system and a means for referral and information sharing in order to carry this goal out successfully. According to the participants, these are crucial features required to successfully support the respect for patient autonomy.

The responses received from the final question show that the almost every participant would feel prepared to deal with a case like Rudy’s. Conversely, participants also referred to need for support such as consultation with the physician and health care team, organizational risk assessment, consultation from an Ethics teams, or a signed consent form or contract from the patient. One participant noted “I would hope that I would take the time to explore his treatment

suggestions further, either independently through review of research and grey literature review or reaching out to other team members”.

A final perspective that was interesting was obtained from a participant who believes that “we need to move from evidence-based practice to evidence-informed practice, with evidence and clinical expertise being integral decision factors but a greater emphasis placed on patient preference. We sometimes base decisions on evidence which is of low quality yet can have profound impact on either patient outcomes or quality of life outcomes”.

Discussion

In the landmark study by the Picker Institute, *Through the Patient’s Eyes: Understanding and Promoting Patient-Centered Care* (Gertais, Edgman-Levitan and Daley) the fundamental elements of patient-centered care were stated to include: 1. respect for patients’ values, preferences and expressed needs, 2. coordination and integration of care, 3. information, communication and education, 4. physical comfort, 5. emotional support and alleviation of fear and anxiety, 6. involvement of family and friends and 7. transition and continuity of care. (Gertais, Edgman-Levitan and Daley). It is intriguing that none of the participants referenced the elements relating to physical, emotional and or stress relief in their description of patient-centered care and equated the approach only with autonomy instead. This suggests that the idea of patient-centered care might be limited to autonomy-centered care rather than *patient*-centered care which indicates that a greater understanding is required about the concept, limits and facets of a patient-centered care framework both at the organizational and employee level.

The fact that the majority of the participants shared a similar view in the second question in that a signed agreement was required to carry out Rudy’s care plan reflects that the way in

which “goals of care” are viewed is perhaps changing. Traditionally the goal of care was for a nurse to intervene and take the necessary precautions to prevent or heal the patient of their condition using best-practice guidelines and clinical expertise. This approach usually implied a clear set of roles and responsibilities. Although overall, the majority of the participants responded to the first question regarding the definition of patient-centered care in ways that reflected collaboration and mutually agreeable care across the patient and the health care team, the responses from the second question suggest that the theory of patient-centered care may be different than it is in practice, especially as it relates to roles and responsibilities. The main response from participants relating to accepting Rudy’s requested treatment plan, despite clinical concerns and possible contra-indications as a form of patient-centered care seems to be a burden for a nurse with possible high risks; hence the required signed agreement in attempt for the nurse to relinquish liability for what should be a primary purpose of her intended role (i.e. nursing). This view of patient-centered care now involves much less shared decision-making and a diminished sense of collaboration because it is so focused on patient autonomy.

From a clinical perspective, highlighting the need for the medical team to have ongoing contact with the client, however minimal seems to suggest that regardless of the patient’s decision, nurses believe that continuity of care is still critical. Given the strong link between the care that is provided and the outcome for the patient, the concepts of obligated beneficence and limited patient choice become more pertinent. Although respect for patient autonomy is a central focus in modern day medical decision-making, the prospect of truly respecting a patient’s choice, for instance to live at risk, appears difficult to achieve. Health care professionals are responsible for the care they deliver. Simply acquiescing to a patient’s wishes in the name of patient-centered care without the skills or capacity to follow up on it is risky.

The option discussed by participants in the second question regarding a referral to an alternative medical team should the requested treatment plan be outside of the professional's scope of practice, is definitely noteworthy. This would provide a logical solution to the provision of services independent from best-practice guidelines or contraindicative of organizational and professional standards of care. The challenge is that health care in Canada is a publicly funded service and is usually at no cost to the patient and if alternative medicine is requested and alternate health care team is identified, it often involves a financial cost to the patient. A naturopath for example and other forms of alternative medicine are examples that require a patient incur a cost for the services. Although this is a viable approach to delivery of alternative medicine, the respect for patient autonomy sets the precedence that the patient is entitled to *any* care and so a referral to a specialist at a cost will likely not be accepted. The higher level of agreement to the second question suggests that the respect for patient autonomy is potentially putting nurses at risk of having to accept all types of care irrespective of the possible outcome. But as a participant noted, "it also depends on how far out of scope of what the agency provides the proposed treatment is. Rudy has a right to choose, however because agencies serve a large population of people there would need to be something in place to protect the agency as well. I believe that with Rudy's right to refuse treatment there must be a reciprocal understanding on his part that the agency may have a right to refuse to participate in his proposed treatment".

An important note in relation to the second question is that the three participants who did not agree that accepting Rudy's choice was an example of patient-centered care were three of the four most senior nurses who participated in the study (i.e. nursing for over 25 years). Although emphasis on an active patient role has been increasingly more prevalent since the 1970's (Keating, McDermott and Montgomery 13), the view of the senior nurses suggests that perhaps

targeted education may be necessary to ensure consistent practice across all levels and nursing experience.

While well over half of the participants believe accepting Rudy's wishes is an example of patient-centered care, according to the responses from the third question, many of them feel *pressured* in believing this and subsequently, pressured to carry out Rudy's wishes. Although disagreements regarding care plan goals are inevitably going to occur with active, engaged, informed and independent patients, it is important to recognize that accepting the nursing role as a nurse does not imply an unwavering agreement to treat in any way; the nurse is not passive. In fact, the CNO's has developed a process for resolving conflicts in implementing care plans and it is as follows: "should the nurse have concerns with implementing the care plan, he or she should consult with colleagues, experts etc., to verify the concerns and also discuss with involved health care provider. Should the concerns remain unresolved, the nurse should then discuss concerns with her manager to gain support or clarify concerns, then follow agency policy to discuss disagreement with the plan with identified higher authority and inform the health care provider of decision not to implement the plan and to document concerns and the steps taken to resolve the issue" (College of Nurses of Ontario). This expectation to address conflicts is primarily grounded in the recognition in the CNO Professional Standards, that a nurse is accountable to provide, facilitate, advocate and promote the best possible care for clients; advocate on behalf of clients; sharing nursing knowledge and expertise with others to meet client needs; ensure practice is consistent with CNO's standards of practice and guidelines as well as legislation; take action in situations in which client safety and well-being are compromised; maintain competence and refrain from performing activities that she/he is not competent in; and take responsibility for

errors when they occur and taking appropriate action to maintain client safety (College of Nurses of Ontario).

As noted by one participant “the nurse by offering support with the treatment plan is not agreeing with the treatment but simply allowing Rudy to choose his path”, nurses are nevertheless accountable for the care they provide. This responsibility can create tensions. Although a nurse ought to respect a person’s choice to live at risk or make a less than ideal choice for treatment, there is an element for responsibility when the nurse actively participates in carrying out or participating in the risky behaviour. If evidence-based practice is preferred in a clinical context, it is not a perfect model. The recommendation from a participant to move to an “evidence-*informed*” model is especially noteworthy as it relates to patient-centered care given the transformation of the dynamics of a patient-provider relationship and care framework. Nevertheless, whether it is evidence-based or evidence-informed, it is important the threshold for acceptable risk in relation to the duty to care in relation to less than ideal patient choices is established so that nurses avoid blindly accepting patient wishes in the name of patient autonomy and inadvertently dismissing their professional duties; hence the focus on obligated beneficence and acceptable paternalism.

The relationship and mutual connection between a patient and the health care provider was acknowledged as a fundamental component in the process of decision-making; however, the result is not that patients necessarily view this information as valuable or feels he is bound by it. Again, the most senior participants (i.e. over 25 years of nursing) each responded that they would *not* find this difficult by recognizing that patients essentially have a right to live at risk provided they are capable and able to understand appreciate the possible consequences for their choices. Even though the senior nurses define patient-centered care differently than the more

inexperienced nurses as seen in the first question, they still believe patient autonomy to be important.

For many participants, the conclusion or the resolution to the scenario is one where it is preferred that that Rudy receive support and care no matter what form it takes rather than be without care”. This warrants further discussion in relation to patient-centered care and the respect for patient autonomy. If we are going to truly adopt a patient-centered care philosophy and uphold the integrity of respect for patient autonomy, it is essential health care professionals are prepared and equipped with tools, resources and supportive policy to assist in carrying out his objectives within the framework. Moreover, it is also crucial that patients are informed and agree to the conditions in place in order to set the stage for a successful care journey with an understanding of the limits of patient autonomy and the potential consequences of their choices. Like in the case of Rudy, health care services were at risk of being terminated, and according to the CNO, this is an acceptable next step. According to the CNO, conflicts in care plan goals should be addressed and only when a health care professional accepts an assignment and discontinues care without “getting the client’s permission, arranging a suitable alternative or replacement, or allowing a reasonable opportunity for alternative or replacement services to be provided” would they be guilty of abandonment and ultimately professional negligence (College of Nurses of Ontario).

The impression that “some care is better than no care” may be accurate from a health care professional’s perspective but in reality and within the parameters of respect for patient autonomy, the patient going without care could be the outcome of an autonomous choice. In the case of Rudy, it is not the health care professional refusing to provide care; it is instead the patient making an independent, informed and intentional choice to decline the care the provider

is *able* to provide. This view will be especially important to emphasize if respect for patient autonomy is going to be the ultimate goal.

The right to live at risk should not imply a plan that by extension puts the health care provider at risk. Although as one participant in the study noted, “the notion of living at risk is real and people should be able to make decisions for their own care as long as they are aware and understand the risks”, it is also important to remember the occupational health and safety requirements and professional standards, as the patient’s choice to live at risk could ultimately impact the ability to provide care. The two possible outcomes in the case study of Rudy is either for Rudy to be at risk of not receiving services based on *his own* decision to refuse an acceptable care plan or Rudy being at risk of an uncertain clinical outcome, potentially reduced health and well-being and the reduced levels of quality care.

The requirement of a signed consent form was noted in almost half of the responses of the final question. Although a signed agreement provides a direction of care and perhaps absolves nurses from moral distress, it also suggests to a certain extent that a signed understanding from the patient negates the nurse’s responsibility to provide the best possible care within professional standards. This notion places nurses and patients in an awkward dynamic and touches again on a narrow view of liability.

The perspective that patient-centered care and respect for patient autonomy would require independent research about interventions outside of best-practice guidelines or standards is interesting. Considering that the basis for nursing guidelines are primarily evidence-based, clinically support practices, patient-centered care, particularly respect for patient autonomy could inform health care professionals and the health care system in general about new and alternative medicine thus expanding the breath of possible best-practice guidelines. This view warrants

further discussion, especially as the resources of the health care system become more constrained and pressure to meet the demand of complex care needs increases.

The information gathered through this study assist in identifying improvements and clarifications that are necessary (E.g. to policy, procedures, frameworks etc.) in order to strengthen the understanding of the extent and limits of the patient-centered care model, specifically the respect for patient autonomy. The responses provided are key in identifying strategies required to improve communication, tools and resources to address dilemmas that may arise while working within the model. By acknowledging the possible gaps in the framework and thus working to improve certain areas of practice, ethical decision-making can be enhanced and the integrity of the nursing profession is respected which will benefit the participants both in the short and long-term. A limitation of the study is that the participant may have been influenced by the case study and responded to the questions in relation to it rather than more generally speaking. Nevertheless, through this study, participants were provided with the opportunity to share their knowledge, experience, opinions and feelings about a topic that impacts them directly. Their participation and insight participants provided has potentially significant value add for the organization in which they are employed with and the greater system.

Concluding Remarks

Despite the evolution of the health care system over time, the Canadian health care system is built on a foundation of ethical principles of fairness, equality and accountability. The complexity, nature and interpretation of health care in Ontario are changing rapidly. Evidence of this is the shift of focus from acute care to the provision of health care in a community and home care setting. The orientation in home care is focused on function and long term, chronic rehabilitation rather than cure oriented like in an acute care setting. As a result of this paradigm, therapeutic interventions and care plan goals in the community are developed over time and are based on fluctuating levels of needs. As a result, there is greater flexibility but with little prediction about care that may be required in the future.

A reform in structure and practice is also a change in culture. In order for the system to sustain itself, there is an inescapable need to share the scarce resources whenever possible and or necessary and to change and improve the structure, policy, practices and procedures in order to keep in up with ever changing landscape (Health Canada). Although the principles of patient-centered care, specifically patient autonomy, are logical, and symbolic as a right to self-determination in health care, it is important that we understand its full breadth as well as its potential consequence so we can put in place ways to respond to new challenges.

As Beauchamp and Childress assert “in a properly structured theory, respect for autonomy is not an excessively individualistic, absolutistic, or overriding notion that emphasized individual rights to the neglect or exclusion of social responsibilities” (Beauchamp and Childress). The bias that patient autonomy should also prevail over other biomedical ethical

principles is dangerous but is likely set out by powerful mission and vision statement, emphasis on patient satisfaction and the conflicting views regarding quality of life and well-being.

Moral agency derives from a development of values and morals and is influenced by society, community, family, religion etc. Ethical decision-making is about deciding what someone should do, how they should do it and why they should do it. Although there are varying views about moral norms and associated duties, the Principlism framework used in this study recognizes that carrying out the expectations is not as straightforward as simply abiding by one's moral duties and can be dynamic across situations, settings and people. This study demonstrates that the interplay of the duties is morally and practically complicated, especially when setting one principle, such as the respect for patient autonomy over. Although there is a level of independent decision-making and critical-thinking that is required, a framework should guide these activities and should be applicable to the realities of the environment in which it is intended to be applied. Nevertheless, as Beauchamp and Childress would contend, "it is usually a mistake in bioethics to frame the issues as giving an overriding status to one principle over another, as if we must prioritize principles or choose one principle over another"(2).

This is not to dispute that patient autonomy and respect for individual preferences does not have significance in health care. The challenge is the applicability of the principles in view of other fundamental ethical principles and duties that one acquires when he or she enters the medical profession.

Provision of health care can present complex situations with varying degrees of predictability, transparency and responsibility. On the surface, the simple rule of "respect and accept patient wishes" seems reasonable however, as this paper demonstrates, following only this rule or allowing it to carry greater weight than the other principles can create conflicts between

nurses and their patients, organizations and profession. Failing to prioritize the principle of patient autonomy should not be considered a failure of morals; there are instances as this paper demonstrated where constraining autonomy would be warranted for valid reasons. Furthermore, Beauchamp and Childress defended, patient autonomy is among other equally valuable principles worthy of equal power in a decision-making process and delivery of health care services. The definition of nursing by the CNO emphasizes key terms such as “assess and maintain”, “treat” and “ensure optimal functioning”. These are considered core duties of a nurse and should be acknowledged.

Nurses have embraced the multiple dimensions of nursing and are a vital component to its success. Progress will always be necessary in health care but the success of this is hugely contingent on a clear vision and a solid support system. As stated by a participant in the study, “the case of a client requesting a sub-optimal treatment is a very difficult decision as we have traditionally expected patients to follow the recommended treatment plan after weighing risks and benefits but as there becomes a heightened awareness of patient preference, we need to respect this. The challenging part though is to put in place risk mitigation strategies to protect ourselves from delivery of a treatment plan which contravenes with best practice. We absolutely need more guidance at a policy or regulatory level to guide clinicians in transitioning to this new way of thinking”. This is a crucial perspective as it attests to the moral complexities of providing nursing care and to the moral harm that can happen if the issues are not attended to adequately. Issues relating to the limits of professional and organizational standards in the home care sector are far more worked out in institutions where frameworks are much more established and controlled.

Considering the information discussed in the previous chapters, my point is that the goal of respect for patient autonomy as the priority principle establishes a moral norm that would place both patients and health care providers, namely the nurses, at risk for delivering poor quality care and create increased levels of moral distress and consequently, moral residue. If we are going to use terms such as “autonomy” and encourage clients to exercise this right, it is important that the guidelines and moral frameworks that nurses have support in this initiative so that patients do not take advantage of their health care team by using patient autonomy as a means to carry out poor decisions that are potentially costly to both themselves and the team involved.

The gap between nurses and the integrity of the profession and patient autonomy needs to be bridged. Nurses are accountable and expected recognize their accountability in all of their decisions and follow through. For this reason, clear boundaries need to be set with patients to recognize that while their autonomy will not usually be threatened or constrained, there may come a point that limits will be placed in order to protect the nurses (and other health care professionals), the limited resources and ultimately the patient. Instead, patients should be provided with the freedom to accept or refuse a service and if they choose to decline the service and the associated basic conditions, then the patient could choose to render the services elsewhere. This would permit certain requests or preferences that a patient expresses, for instance, regarding a preference for particular profile of provider they would prefer to receive service from (for example, only Caucasian nurses), a preference of which is not a request that can be accepted by a publicly funded organization given discrimination laws. The challenge is that access to health care services for most Canadians is considered a right insofar as they are entitled to it because it is a universal service provided to citizens. Patient autonomy and the right

to health care suggest that that such preference would be accepted. This stresses the importance of explicitly setting the expectations and possible limits at the onset, so that the patient can make a choice then rather than once the health care provider and patient relationship has been established and is bound to the professional duty to care.

In health care, a physician or health care professional and the patient exist in a relationship together. In order to succeed, the relationship should be dynamic and collegial and the communication as a two-way interaction. Although the patient-centered care framework asserts that patient autonomy is a fundamental standard to uphold, the expectation that the role of the health care professional refrain from potentially influencing the patient could be troublesome for the concept of patient autonomy emphasis the decision making *process* (i.e. expressing and exercising autonomy) rather than the significance of the choice itself. A final serious point of consideration is that patient autonomy ultimately requires that an individual and their family members make complex, medically grounded and powerful decisions during a time in their lives that they are potentially at their weakest, most vulnerable and overwhelmed. By re-emphasizing duties for beneficence and non-maleficence and empowering patients to trust in their nurse-patient relationship,

It is crucial that the level of risk health care organizations are willing to accept is explicitly stated to patients. As a participant stated in the survey, “patient-centered care does no guarantee that the patient will be without harm”. It may be naïve to assume that provision of *any* health care related service would guarantee this however by placing such emphasis on patient autonomy and minimizing the role of the health care professional, we may be inadvertently placing patients and their health care provider at risk without setting clear guidelines, boundaries

or mitigation strategies. Granted, it may be a rare occurrence that conflicts in patient care arise though the potential precedence they would set could have serious repercussions.

In summary, a critical appraisal of the patient-centered care framework is required. This implies assessing the complicated relationship with patient autonomy and the nursing role is required. By having such a strong focus on the benefits of patient autonomy, we overlook the possible harms to providers and consequently the means to deal with them. This can result in issues such as moral distress and residue, staff burnout, and professionals who are pressured to reject their professional and moral standards. The principle of respect for patient autonomy needs to be revisited in the greater context of provision of health care in the home care sector. This will foster a reform that will enable access to greater resources, education and supports for nurses. Furthermore and more importantly, with an improved understanding and restructure of the patient-centered approach, education to patients about their rights and responsibilities as a partner in the delivery of their health care services as well as the limitations of their rights will be possible. This will help ensure a morally justifiable and sustainable system in which we can embed principles of accountability, responsiveness and transparency.

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Appendix A

Participant 1

Yrs	-
Q1	The patient is the center of all decision making within the interprofessional team. The client is supported in making decision and the team does everything they can to respect the client's wishes. The focus of patient-centered care is on quality of life of the client.
Q2	I think that the client should be informed about all treatment options available to him and then letting him make the final decision. Yes, accepting the requested treatment would be an example of patient-centered care.
Q3	Yes, I would feel pressure to assist Ruby in carrying out his treatment wishes especially if I know that they are not in his best-interest. I do believe thought that client's have a right to live at risk and make decisions that we don't necessarily agree with if they are informed of all risks/consequences.
Q4	Yes, I think as an RN we need to respect patient preferences and independent decision making.
Q5	Yes, it would be difficult for me to accept that Rudy is refusing care knowing that Rudy would be at risk without care.
Q6	I'm not sure if I would feel prepared to handle this conflict. I would have to make sure that I documented clearly that all options have been presented and that it is the client's choice to review the recommended treatment. I would then need to review our policy and procedures to make sure what he is asking for is something that is possible from my agency. I would call a case conference with my manager to review his decision and outline how we can support him.

Participant 2

Yrs	32
Q1	Always keeping the wishes of the client at the centre of all decisions made around client care. Giving the client the ability to participate in the development and the evaluation of the plan of care including any multiple options available to the client.
Q2	No, it would show lack of provision of best practices. Pt. Centred care must provide best practice or best available practice which is vetted and validated
Q3	Without feeling pressured, I would be able to support Rudy if he wished to proceed with his treatment plan. The nurse by offering support is not agreeing with treatment, but simply allowing Chris to choose his path and as long as he is aware of the risks he should be allowed to proceed with support to symptoms.
Q4	Yes, I believe that a patient should be allowed to live at risk as long as the patient is aware and able to process and critically think through the consequences to the actions.
Q5	No, the notion of living at risk is real and people should be able to make decisions for their own care as long as they are aware and understand the risks.
Q6	Absolutely. Firstly a case conference with the stakeholders should take place to discuss and ensure that Rudy is completely aware of the risks. Would insist that CCAC and any other agency attend. Would ask that CCAC provide the client a summary of the conference clearly underlining the client wishes and the risks that were discussed. Would also want to write that the client can change his mind at any time and without prejudice, care plan would be modified to reflect best practice that the agency could offer and again a letter should go to the client and all agencies to keep everyone informed of client wishes.

Participant 3

Yrs	3 months
Q1	Needs that are “individualised”.
Q2	Not sure, I wouldn’t accept without a physician’s order.
Q3	Not if I had a medical order to follow that was centered on patient’s immediate needs, regardless of my personal beliefs. I think the “feeling of pressure” comes when you WANT to help people and they choose to help themselves in a different way. It is sometimes hard to let people live with their choices if you feel that “in your opinion” they are making the wrong choice in getting healthy. In the end, it is their health and they are entitled to choosing the best option in THEIR opinion.
Q4	Yes, it’s part of our values. We often serve as “patient advocate”.
Q5	It is always hard to let someone live “at risk”. However, if he is deemed “competent”, you cannot “make” a patient accept care.
Q6	I could always make a call to my agency to see if there is anything we can do. Sometimes situations are “special circumstances” and I would at least ask on behalf of my patient to see if we could accommodate any of the patient’s needs.

Participant 4

Yrs	11 years
Q1	That the patient is the centre of care and should be allowed to direct his care.
Q2	Yes, patient directed.
Q3	Yes, he is reportedly capable and should have should be able to direct care received.
Q4	Yes
Q5	No as I feel he should have say in his care plan and he is capable. He should be made aware of possible outcome of his decision and if still wanting it his way then it is the health cares obligation to support his decisions in the safest way possible.
Q6	Yes, I would advocate for Rudy and help others understand his rights. Regardless of views of others if Rudy understands his decision and consequences then that is his right.

Participant 5

Yrs	-
Q1	Delivery of care based on patient preference and clinical condition in consideration of available research, resources and clinical expertise. I do strongly believe we need to move from evidence-based practice to evidence-informed practice, with evidence and clinical expertise being integral decision factors but a greater emphasis placed on patient preference. Also concerned that we sometimes base decisions on “evidence” which is of low quality yet can have a profound impact on either patient outcomes or quality of life. We need to be more mindful of the patient’s choice as he/she has to live with the outcomes of that decision and while the healthcare provider may perceive one outcome to be the most important one driving the decision, the patient may decide another outcome has a greater impact on his/her life or quality of life.
Q2	Yes, as long as there are no contraindicators- that the treatment will not result in harm to the patient and there is perceived benefit to the treatment.
Q3	If I have internal conflicts with the patient choice due to availability of a more optimal treatment option, I would certainly feel pressure and a sense of burden at providing what I may perceive to be a sub-optimal treatment but ultimately would need to respect the patient’s decision. Absolutely this would weigh on my conscience if I felt that the selected treatment plan delayed the wellness trajectory. This may go against my philosophy of providing care which will optimize the wellbeing of the patient but again my perception of wellbeing may be different from the patient which I would hopefully accept.
Q4	Again, a very difficult decision as we have traditionally expected patients to follow the recommended treatment plan after weighing risks and benefits but as there becomes a heightened awareness of patient preference yes we do need to respect this. The challenging part though is to put in place risk mitigation strategies to protect ourselves from delivery of a treatment plan which contravenes “best practice.” We absolutely need more guidance at a policy or regulatory level to guide clinicians in transitioning to this new way of thinking.
Q5	If I have interpreted the question appropriately, it would weigh upon me if he received no care at all because it wasn’t based on best practice, yet might provide some positive outcomes. We really need to look closer at how much weight “best practice” should have in determining care. A patient should be able to accept risk as long as he has been

	<p>informed of the risks. I would hope that I would fight for the patient for his treatment plan to be considered, or a version of it, than no treatment at all.</p>
Q6	<p>I would try to explain the benefits of the best practice/policy recommendation and the rationale, providing evidence directed at the patient's learning level, using a multi-media approach (i.e., information sheets, handouts from the web, internet-based videos if appropriate). I might try to put him in touch with resources such as support groups or consumer associations (i.e., alzheimers/diabetes societies...) to ensure he truly understands why the team was proposing alternate solutions. Perhaps engage his family/friends to discuss this through a family meeting.</p> <p>I would hope that I would take the time to explore his treatment suggestions further, either independently through review of research and grey literature review or reaching out to other team members. If I felt there was merit (and yes this is where I am making a judgment for the patient), I would try to advocate for the patient with the decision makers and help give him the tools he needs to change the decision to support his choice.</p> <p>I would also speak with my team, if we decided to respect his choice, to determine how we can mitigate our risk in going against best practice (i.e., through documentation of the informed decision making process and any literature found that supports his choice; waivers; enhanced monitoring; consultation with quality/risk team).</p>

Participant 6

Yrs	9 years
Q1	Patient-centered care to me refers to having the patient involved (if possible) in his plan of care, making the final decision re treatment/service etc.
Q2	Accepting his decision would be to the extent patient-centered care however this may not always be care that could be followed up on by the involved medical professionals
Q3	I would accept his decision however would advise him of my professional responsibility to abide by my nursing standards. I would teach him and explain to him that as a nurse I could not legally follow a treatment plan he found on the internet which may not be safe or proven
Q4	Yes I feel it is my duty to respect a patient preferences and decision-making along with explaining my role and legal responsibilities to work within my professional practice
Q5	I would find it difficult to observe a patient not receiving any care however would provide what care I could within my practice. I would reinforce to the patient what we would receive or not receive from his chosen care plan
Q6	Yes I would by ensuring that as a nurse I would provide as expected some minimal care to ensure client is safe and well. I would continue to teach client about his choices and the potential outcomes.

Participant 7

Yrs	16 years
Q1	To me, patient-centered care means that the patient is front and center in all aspects of his/her care. The patient's participation, compliance, culture and beliefs toward a treatment plan are some factors that must be respectfully considered and accepted when providing patient-centered care.
Q2	Yes, accepting Rudy's request for an alternate medical treatment would be an example of patient-centered care. The case study does specify that Rudy is capable of sound decision-making. Therefore his ability to make an educated and informed decision should be accepted. My nursing care towards Rudy should be "tailored" to his wishes.
Q3	If Rudy's requested treatment plan would be accepted and ordered by his physician, as a nurse I would feel obligated to assist Rudy in carrying out his preferred treatment plan. Even though knowing that this would not be in Rudy's best-interest, I would respect and accept his decision.
Q4	Yes, I feel it is my duty as a nurse to respect the patient's preferences and independent decision-making. However, only after establishing that the patient has been given all possible information and education available so that an informed decision can be made, would I feel secure in respecting the patient's preferences. A point of view or belief on a specific treatment plan should not be imposed or forced on a patient. This, I am sure, happens too often as the patient seeks guidance and answers from a health professional.
Q5	Yes, I would be struggling with the knowledge that the patient would be putting himself at risk and increasing the likelihood of complications and potentially non-healing. I would hope to have a choice as a nurse in removing myself from Rudy's care if the distress would be too conflicting with my beliefs.
Q6	I think it would be taxing and distressing in handling this kind of conflict. I would have to consult with other supportive departments within my agency. Discussions with colleagues, supervisors, managers, the risk management department and the ethic department would be necessary for me to feel comfortable with my nursing care to Rudy.

Participant 8

Yrs	-
Q1	A client is able to direct his/her care (accepting or refusing care) based on options presented and informed consent.
Q2	Yes, however, for nursing to accept, a physician's order would be required (I'm assuming) and the treatment has to be within the nursing's' scope of practice. In the above stated example, some care sounds like it is better than no care. And it is imperative that this client remains in contact with the healthcare system and if client receiving sub-optimal care is the way that this happens, then so be it. A client has the right to live at risk and the treatment is not detrimental.
Q3	No, see above explanation.
Q4	Yes.
Q5	No.
Q6	According to the scenario, it is not according to "best practice guidelines" but these are "guidelines", not necessarily black and white directions. It is hard to explain and not be more specific when you don't have the actual "treatment" that you are referring to. I would use my best nursing judgment and provide the care as close to best practice as possible. As for policy and procedure for the nursing agency, I would look to management to create a legal document for the client to sign that would cover the nurse and the agency should the client or their family look to sue for improper care. Before even beginning treatment I would look into finding a physician to cover this client if orders were required and would contact the CNO regarding the legalities around treatment. I'm assuming that all has already been done around determining this client's competency.

Participant 9

Yrs	1.5 years
Q1	Patient-centered care means that each care plan is tailored to the specific needs of the client. The client is empowered to make his own decisions and is involved every step of the way throughout the care process.
Q2	Yes, I do believe accepting the requested treatment would be an example of patient-centered care. It is not the nurse's responsibility to make decisions for patients. The nurse is there to guide and teach the client about health and wellness. But in the end it is always the patient's ultimate decision when it comes to care. Also, the client is capable of making his own decisions. The nurse could provide all advantages/disadvantages when choosing a certain care regimen. The nurse could also facilitate and liaise with other health care professionals, in order to find another provider that will meet the needs of the client.
Q3	If accepted, and the care is within an RN's scope of practice, then yes I believe it is the RN's duty to carry out the care. A nurse should be non-judgmental when providing care. It is important for the nurse to support the client's decision even if the decision conflicts with the nurse's own personal value/belief system. However, if it is not within a nurse's scope of practice to initiate such care, then I think the nurse has the duty to refer the client to another health care professional who is more suited to the client's care needs.
Q4	Yes, a nurse should always respect patient preferences and decisions. The nurse may inform and educate the client to ensure the client is making an informed decision, but in the end, the patient makes the final decision in his/her care.
Q5	Yes, I would definitely find it difficult to care for a client, who I believe is not receiving optimal care. However, I would not allow my views affect the way I cared for the patient.
Q6	I think it depends on the situation, but I don't think I would feel fully prepared. I find that there are not a lot of resources for when a client decides to sway from the norm when it comes to health care. I think it would be difficult to locate supports for Rudy as well as maintain professionalism when responding to his request. It is difficult to remain credible if you do not have the supports and evidence to back you up.

Participant 10

Yrs	5.5 years
Q1	Patient centered care means that the patient is to be informed of their condition, treatment, tests, prognosis in an honest, understandable manner. The patient then has the right to accept or decline the treatment, testing offered. Healthcare professionals are obligated to outline the consequences of the patient's choice but it is ultimately the patient's choice. Communication is vital to this process. Healthcare professionals must listen, hear and be open to the patient's point of view and realize people do life differently and what is an appropriate choice for one person may not be the appropriate choice for another. Healthcare professionals must have an open mind in this regard.
Q2	I believe it would. BUT I would stress that Rudy must be capable of making decisions. As well, the treatment that he is requesting cannot be a treatment that would cause him any harm or put healthcare professionals in a position of causing harm. It also depends on how far "out of the scope" of what the agency provides the proposed treatment is. Rudy has a right to choose, however because agencies serve a large population of people there would need to be something in place to protect the agency as well. I believe that with Rudy's right to refuse treatment there must be a reciprocal understanding on his part that the agency may have a right to refuse to participate in his proposed treatment. The agency would have to show a very clear rationale however and ensure any refusal to provide a different treatment is not based on judgement, power, reluctance to change/open-mindedness on their part. For example....if the treatment he was proposing meant there needed to be 2 extra staff on in order to carry out the treatment, I feel the agency could refuse as this is not realistic or sustainable.
Q3	As long as I knew that all of Rudy's options had been explained to him and that he had a clear understanding of the consequences I would not have an issue with helping him as I feel he has a right to choose. As a nurse I feel my role is to advocate for the patient and their choices. I would also want to ensure that my practice would not be in jeopardy by assisting Rudy.
Q4	Absolutely 100%, always ensuring that the patient has an understanding of options and consequences.
Q5	I might personally wish his choice was different. But this is his choice not mine and as a nurse I must respect that and support him.
Q6	I would be prepared to handle the conflict if I believed that Rudy's choices were made

	after all options and consequences were explained to him. I believe his right to choose to over rides best practice guidelines. I would speak to managers, educators etc. at my agency and advocate on Rudy's behalf. I would support his choices up to the point of knowing that my employment/registration would not be harmed by providing him with the treatment he chooses. But I would advocate for him up until that point.
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Participant 11

Yrs	23 years
Q1	Patient centered care to me means looking at the client as a whole and trying my best to take in consideration what he or she feels they want whether or not it may be not what I would feel is best but taking into account religious beliefs as well as nationality.
Q2	No because it is not Nurses best practice and medical advice from Dr who ordered initial RX also feels his original plan is best as well the Rx he is requesting could diminish chances for cure
Q3	No I would not feel pressured to carry out his preferred RX but would continue to look for other options.
Q4	Yes I feel when at all possible to respect their preferences and independent decision-making whether it is their choice to continue having bath without assistance when not safe and aware of what could happen or continuing to live in home which is not kept well or in home which is no longer suitable as isolated and difficulty with stairs .As long as I explain the risk that are involved I don't feel responsible for some poor decisions they make and document well they are aware.
Q5	No I feel I would be able to respect his wishes and still would not feel I could give something that may diminish his chances for a cure if did give.
Q6	I feel I would be able to handle this conflict between Ruby and agency policy as well as best practice and would not give up on trying to get him to agree to original Dr's orders but may agree to get back to him if there is more evidence comes up with what he is requesting. May also ask if he would agree to this Rx until we can find more evidence re his request. Would also explain we always try to have pt centered care whenever possible providing we are not contributing to adverse in their health.

Participant 12

Yrs	3 years
Q1	To me, it means considering all the elements of a client's needs- social, emotional, physical, cultural, spiritual, medical, psychological, economical etc. Any factor that can affect a person's life, care decisions and choices, should be taken into consideration when providing care.
Q2	Yes, this would be an example of patient centered care. If the patient is aware of the pros and cons of one treatment option compared to another, and they are deemed of sound mind, then it becomes a matter of individual choice. The Nurse involved should be aware of why the patient is making that informed choice- is it motivated by spiritual, emotional, social reasons...etc. And clearly document all the counselling that was given to the client.
Q3	I would gladly assist Rudy is carrying out his preferred treatment plan as long as it was clearly outlined re: concerns and empirical evidence contradictory and I was satisfied that the patient was informed and capable. I would optimally require an informed consent document detailing the decision and the contradictory evidence, signed by the client, before I administered the treatment.
Q4	Yes- as long as they are capable and well informed and the choice they are making will not be doing harm to another party.
Q5	I would prefer that Rudy receive support and care- no matter what form it takes rather than be without care. I would advocate for his choices.
Q6	I would clearly document the results of my counsel with this client and the decision that was made after the counsel. I would require a signed consent detailing all the information given to the client and the contradictory evidence for the requested treatment - and then proceed with the treatment.

Participant 13

Yrs	35 years
Q1	Working with the patient to determine what the client's wishes are and developing a plan of care in consultation with the patient to try and meet the patient's wishes. This is a consultative process where there is discussion between the nurse and the patient that looks at the pros and cons of all choices.
Q2	Yes but there would have had to be discussion of the pros and cons of this patient decision. If the patient is mentally competent and fully understands the risks involved in accepting this treatment, and the treatment does not explicitly put the patient at risk then the nurse should do as the patient wishes.
Q3	If the patient is mentally competent to make the decision to accept this treatment and understands pros and cons and that the nurse and MD think this is not ideal, but this is the decision the patient makes, then the nurse should carry out the treatment.
Q4	Yes if the patient is competent to make decisions as long as there is no harm to the patient or nurse.
Q5	If Rudy is mentally competent and makes this decision then it is his decision and I would have to accept that.
Q6	If the patient's request is not following best practice or agency policy, this would have to be discussed with management to determine the course of action. There would have to be a discussion with the MD and determine if this is the patient's wishes whether or not we could agree to it. There may have to be an ethics review where all relevant parties could discuss the case.

Participant 14

Yrs	27 years
Q1	It is the opportunity for client to participate actively in all self-care decisions within the parameters of services available.
Q2	No
Q3	Yes would be pressured because I disagree note: as a more experienced nurse I would not hesitate to refuse
Q4	Yes within limits since we must practice within our College's scope – so not all preferences are feasible/legal. This is the constant balancing act that nurses experience throughout their practice.
Q5	No
Q6	<p>Yes I would be prepared to handle to conflict as I would review CNO Standards such as 1- Decisions about Procedures and Authority Revised 2014 “Authority” Nurses ensure that the have the appropriate authority before performing procedures. The nurse meets the Standard by: - Initiating the performance to controlled act procedures within the boundaries of legislation, competence and agency policy.” “Managing Outcomes” Prior to performing procedures, nurses ensure that they are able to identify the potential outcome of procedures, have the authority and competence to manage outcomes, or have the resources available to manage those outcomes”</p> <p>2- Complementary Therapies 2014 is designed to help nurses determine when and whether it is appropriate to incorporate complementary therapies into their nursing practices. I would confer with colleagues, agency management and refocus the scenario on the capable client's refusal of a well-informed, evidence based original treatment. There are two conflicting issues in this scenario: client's right to choose versus the scope of practice of regulated health professionals. Capable clients can choose whether treatments they want however not to the detriment of scope of practice that regulated health professionals must adhere as per their respective Colleges. When treatment requests become unregulated and as cited in text: “is not best-practice, staff are not certain that it would contraindicate with the care that is required but because of lack of empirical evidence there is uncertainty about what results the treatment would produce” I see no issues in pulling out of care (well-documented, client aware and alternate services</p>

	have been offered to assure nurses do not fall in the abandonment of client scenario).
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Participant 15

Yrs	11 years
Q1	Respecting client choices
Q2	For him it would be
Q3	Yes, as far as it did not breach my licence
Q4	Yes as long as they have all the facts
Q5	It really is his decision as long as he is competent
Q6	First I would research which, if any parts we could support Rudy with inside our P&P. I would advocate for change to P&P IF that seemed prudent

Participant 16

Yrs	11 years
Q1	To me, patient-centered care means care that involves the client or substitute decision maker (SDM) in the decision-making process at key points of the overall client care experience and spectrum, it also constitutes an application of client specifics and unique attributes
Q2	I believe that the client/SDM directs or prompts at which points of care decisions/changes many need to be made and this part of patient-centered care
Q3	I would not feel pressured as it is within my professional standard to separate my personal views and bias and also to identify if the therapeutic relationship is put at risk. That being said, I would have to ensure that the treatment provided fell under my scope of practice, as well as ensuring that I have the appropriate skill, knowledge and practice level. If so, Rudy as long as Rudy is fully capable, he is within his right to refuse treatment and live at risk. That being said, a case conference with the client, hospital MD, the daughter, CCAC and home care agency should be set up to ensure everyone is on the same plate. There should also be a focus on getting Rudy a family MD. The agency and CCAC should work close together to develop a plan to ensure that nurses have adequate training and support.
Q4	Yes, I do feel strongly about respecting patient preference and independence as long as it is within the confines of the law, my practice and professional standards, as well as my employers, professional practice and best practice guidelines.
Q5	As Rudy is fully capable and as long as all the risks were clearly discussed and understood, although it would be difficult to accept this, his decision would have to be respected. That being said, the circle of care should continue to connect with Rudy regularly and keep the lines of communication open.
Q6	I would feel prepared to handle this conflict as this would not be a decision that I would have to make on my own. If I encountered this similar conflict, I would try to get the client's perspective and priorities/values firsts, then take this to the circle of care. I would also facilitate and communicate as decisions are made, changes happen as needed, I would also request that a Ethical Tool Kit be initiated to allow nurses the opportunity to discuss and debrief as needed.