

CONVERSATIONS THAT MATTER:
PATIENT PERSPECTIVES ON CONVERSATIONS AT
END-OF-LIFE

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ABSTRACT

The introduction of new legislation in 2016 that allows for medical assistance in dying (MAID) has created a need for patient-centred research that seeks to understand patient needs at end-of-life. More specifically, how do patients want conversations about end-of-life care or options at end-of-life to go? This research employed the Interpretive Phenomenological Analysis methodology to gain a deep understanding of the lived experience and gain insight that will help medical professionals and policymakers develop procedures that maintain a patient focus. Through five in-depth semi-structured interviews, it became apparent that patients prefer conversations with physicians that are truthful, maintain a sense of familiarity, are rooted in humanity, and that provide comfort. When it comes to talking about MAID, patients prefer conversations that are “straight up” and take place at a time prior to any suffering or loss of dignity. Perhaps most importantly, this research was able to highlight that while non-terminally ill people may fear death, dying people only fear what they could consider to be a “bad death.” This study provides insight into patient need so that future training or learning resources are developed in a way to address and highlight what patients want. This study also demonstrates how marketing and consumer researchers can play an important role in healthcare and health policy research.

Key Words: End-of-life care; palliative care; Interpretive Phenomenological Analysis; health communication; health policy

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Often the person that's in front of you isn't the person that they were. And I think in order to sort of understand the humanity and the dignity, you need to know something about the person from before.

-- Grant, study participant.

1. INTRODUCTION & BACKGROUND

Death is inescapable – it is a natural part of life. Death is a central focus for many of the world's religions and has been captivating poets, songwriters and artists for generations. Dramatic and tearful or bloody and mysterious iterations of death have been the focus of primetime plotlines since television was invented. Yet, despite the role death has in society, it is something most people avoid talking about. Death is awkward, uncomfortable, incredibly sensitive and inherently personal. Death is also something marketing and communication researchers have failed to explore in any depth, likely because of its sensitive nature and the potential for emotional conversation, despite the size of the industry and its impact on consumer behaviour. But regulation, first introduced in Canada in 2016, surrounding end-of-life care and medical assistance in dying (MAID) is starting to bring death back into daily conversation and potentially back into the realm of everyday life. Death is an incredibly personal experience, but marketing and communications researchers need to learn to be comfortable with it because they have the skills, methodologies and knowledge that can provide necessary support and insight to healthcare teams and death care workers. As more people begin to plan for their death, encounter more choices at end-of-life and begin conversations about their own deaths, there is a need to ensure their rights are being protected, their needs are being met, and their voices are being heard.

The goal of this research is to answer the following question: how do terminally ill patients want medical professionals to talk to them about end-of-life care and options for end-of-life care? Using an interpretive phenomenological approach, I will seek to obtain a deep understanding of the lived experience from palliative or terminally ill individuals to help inform policy and practice as the province of Saskatchewan works to implement MAID.

Before an in-depth description of the current literature can take place, a definition of death needs to first be established. This next section aims to provide a definition and some general background information about why death is an important area for marketers to examine. The goal here would be to establish a baseline for the underlying ideas that guide the specific research studies within.

1.1 DEFINING DEATH: MORE THAN JUST THE END OF PHYSICAL LIFE

Death, or at least the concept of death, can be a tricky thing to apply a common definition to. From a clinical perspective, death is defined as the cessation of a heartbeat or, more recently, as irreversible damage to the brain, also known as brain stem death (Haddow 2005). But in nearly every other aspect, from familial to cultural, death means much more than simply a body that no longer functions. Often, how we think about death is shaped by our beliefs — beliefs that are constructed from both our social influences and reference groups, including our culture (Haddow 2005). For the purpose of this research, the definition of death needs to include elements of the lived-experience of dying, death and bereavement. In many aspects, death can be considered as a separation from material items, loved ones and the body (Bonsu and Belk 2003). The reason why death cannot necessarily be solely defined in terms of the body is that the dying and/or the bereaved still make decisions and change behaviours with their own death or the death of another person in mind (Bonsu and Belk 2003). In other words, the dying or the bereaved will make consumer decisions based on, respectively, what they think ‘survivors’ will want or what they think the dead

would prefer. Thus, to ensure the dying or the bereaved are able to make choices that are most appropriate to them, health and medical professionals need to have a deep understanding of the perspectives, wants and needs of individuals facing death of any kind. The information gained from qualitative research can prove to influence policy development for end-of-life care and the creation of marketing and communication standards for the death care industry that focuses on the individual, rather than politics or organizational values.

The way death impacts consumer behaviour is not limited to periods of grief or end-of-life — even the idea of dying and death will have ripple effects on the consumer decisions we make. Research shows that when our own mortality is made salient, either by what we see in pop culture or by experiencing the death of a loved one, it is natural to feel extreme fear or terror, which ultimately “challenges the public and private identities of the living,” (Bonsu and Belk 2003, 42). This terror is often mitigated by subconscious choices to make grandiose purchases of items we cannot afford that demonstrate affluence, go on extravagant vacations or change our consumption habits to ‘keep death at bay’ by joining a gym, changing diets and buying cosmetics (Kasser et al. 2000; Radford and Bloch 2012; Robinson 2014; Trémolière, Neys, and Bonnefon 2012). This relationship between dying, death and consumer habits forces a need to foster a deeper understanding of the way people make choices at end-of-life if only to influence ethical policy making for end-of-life care and develop appropriate marketing standards for the death care industry. Yet, there is a very small amount of marketing research that explores the death care industry and even less that examines how patients interact with the healthcare system at end-of-life.

When defining death, a simultaneous narrative is taking place about including concepts regarding the quality of death into how we define death. Professionals and academics alike refer to

the idea of a ‘good death,’ which can be difficult to define universally because of its subjective nature (McNeil 2000). A common definition is that a ‘good death’ takes place during sleep, is quick and painless, is free of suffering for patients, their families and caregivers and is in accordance with the patient’s wishes (Considine and Miller 2010; Trice and Prigerson 2009). But in defining a ‘good death,’ there is the inherent implication that there is also a ‘bad death.’ While a ‘bad death’ can also have a variety of different meanings depending on context, poor communication between a patient and a medical professional will only compound problems (Larson and Tobin 2000).

The following section presents a brief outline of the history of MAID in Canada, including some of the concerns raised by healthcare professionals and the valuable role consumer researchers can play in addressing these concerns.

1.2 MEDICAL ASSISTANCE IN DYING IN CANADA

In February 2015, the Supreme Court of Canada ruled that a “prohibition on physician-assisted death infringes on the right to life, liberty, and security of the person in a manner that is not in accordance with the principles of fundamental justice,”(Chochinov 2016, 253). Rooted in a belief that a person’s response to a diagnosis of a “grievous and irremediable medical condition” is a matter of dignity and autonomy (Health Canada 2018a), the Supreme Court ruling meant that blocking physician-assisted death (PAD) at a legal level had become significantly more difficult to do (Browne and Russell 2016). Prohibiting it would have to be done on the basis of religion or moral grounds, both of which are areas the legal profession tends to avoid and can lead to very long or go-nowhere court cases (Browne and Russell 2016).

What also emerged after the Supreme Court ruling was a shift in the entire debate across the country. From what was presented in formal news reports to casual conversations at local drinking

establishments, the conversation was no longer about whether it was right or wrong but focused more on the right and wrong ways of permitting physician-assisted death (Attaran 2015). The original court case that led to the Supreme Court ruling, *Carter v. Canada*, added a new perspective on PAD as it pertains to disabled individuals (Browne and Russell 2016). Essentially prohibiting PAD “discriminated against the disabled in that it treats those who are not physically able to end their lives by doing what able-bodied people legally can” (Browne and Russell 2016, 380). But perhaps the most compelling aspect of the renewed debate surrounding PAD is the concept of having a life that is ‘worth living’ and that by prohibiting PAD to preserve life could, in fact, jeopardize one’s ability to live it (Browne and Russell 2016). Ultimately, the federal government passed Bill C-14, Medical Assistance in Dying, in June 2016, leaving the provinces and territories to determine how to incorporate appropriate policies and procedures that would allow medical practitioners to administer MAID (Chochinov 2016).

As provinces and territories operationalize the federal legislation and health laws are being drafted, now is the time to incorporate a multidisciplinary approach to ensure patient perspectives are kept at the centre of all decisions. They are, in some respects, the consumers of MAID. And between enactment and December 2017, Health Canada reports that 3714 patients have accessed the service (2018). In an effort to understand who and how people are choosing MAID over other medical care options at end-of-life, Health Canada, in partnership with the provinces and territories, has collected and released data every six months since the MAID legislation was enacted. The most recent report, released in June of 2018, shows that between July 1 to December 31, 2017, 1086 patients, with an average age of 73, received MAID (Health Canada 2018b). These biannual reports provide a significant amount of data that comes together to tell the story of MAID in Canada. When looking closely at the numbers over time, researchers learn that number of people choosing MAID is increasing over time (an increase of 29.3 per cent between the second and third reports) and that

more people are starting the assessment process sooner (Health Canada 2018b). Considering that this medical service is relatively new in Canada and is still very controversial, these increasing numbers would indicate that despite its controversial nature, people who are facing end-of-life options would consider MAID as a viable option for their particular situation.

To ensure medical professionals and care providers meet this increase in patient need and demand, researchers and policymakers need to approach lines of academic inquiry delicately and cannot simply disregard the medical context in which MAID takes place (Karsoho et al. 2016). While the current conversations regarding MAID imply that medical systems have not been able to address suffering very well (Karsoho et al. 2016), statistics show that more than 40 per cent of medically assisted deaths in Canada take place in a hospital setting. This highlights a need to examine concepts and concerns from both the patient and medical perspectives to ensure policy is accurately informed to help meet patient needs and address gaps in care. In the months that followed the ruling an increasing concern among professionals regarding the implementation of MAID was that it would be inconsistent across provincial and territorial boundaries, similar to what happened in 1988 when the federal government decriminalized abortion (Browne and Russell 2016). To address this concern, the federal government is continuing to organize reporting standards from each province and territory to better understand how Canadians access the service and ensure that the “system” is consistent between national borders.

In conducting research and information gathering for the development of Bill C-14, a panel of experts found that from the patient perspective, PAD is not a medical decision but a deeply personal one (Chochinov 2016). Therefore, a solution to the concerns about implementing MAID across Canada would be in determining how the patient prefers conversations about MAID and their options regarding MAID. Understanding this particular patient perspective is essential to effective

implementation of MAID, if only because it is, at its most basic level, a service provided to them to fit their individual needs — something marketing science is well equipped to understand. Patient-orientated research that relies on the methodologies established by marketing researchers and is informed by marketing and communications theory can help define vague terms in a way that the patient wants them to be defined. A marketing scientist can also provide theory and perspectives on how information should be shared not only with patients but across provincial/territorial boundaries.

So then, why can't marketers easily talk about death? The next section seeks to explore this idea to some length, relying on literature from a number of areas of academic knowledge to problematize the situation so that potential solutions, over and above what I present here, can be discovered for future research and exploration into an underdeveloped area of marketing research.

1.3 DEATH BECOMES THE MARKETER

The brevity of marketing research into end-of-life care and the death care industry is surprising, especially considering that funerals are big business in North America. Statistics Canada reports that in 2010 the total operating revenue for all funeral service providers in Canada was more than \$1.6 billion (Statistics Canada 2012). In the US, the average cost of a funeral is over \$8,500 while funeral and burial costs combine can easily climb above \$10,000 (Kopp and Kemp 2007). The industry itself includes funeral services, crematories, cemeteries, pre-need sales of funeral plans and some crossover with other industries, such as insurance (Kopp and Kemp 2007). Furthermore, there is a growing number of third-party companies that specialize in goods and products related to death — both human and pet — to consumers to provide either a kind of symbolic immortality, either for the dying or for the mourning (Bonsu and Belk 2003). So, for example, one can choose

to have the ashes of a loved one pressed into a vinyl album that is functional and will carry a recorded message or song from the deceased (Walsh 2017).

However, as previously mentioned, marketing any death related service or good can and will be a tricky process. On the one hand, the death care industry is one of a very few marketing scenarios where the consumer has little to no control over the situation (Schwartz, Jolson, and Lee 1986). On the other hand, consumers turn to the death care industry for specific services and products when they are typically in a highly emotional state (Kopp and Kemp 2007). As a patient making end-of-life choices or as the bereaved plan a funeral, time can create great pressure and a lack of reference information regarding processes, prices, or quality of services from which decisions can be made can increase stress (Schwartz et al. 1986). Similar concerns about how to appropriately respond to the needs of patients at end-of-life are starting to be raised in other industries as well. The tourism industry is currently trying to determine how to work with and provide the appropriate services to those who are choosing to travel to foreign destinations for end-of-life care as it relates to MAID (Miller and Gonzalez 2013). What they are doing as an industry is trying to determine how to commodify “a solution to suffering and human misery fashioned together by the tourism industry in such ways that make it appeal to the individual seeking to travel abroad for the expressed purpose of seeking death,” that meets social, ethical and legal requirements (Miller and Gonzalez 2013). Yet, in Canada, the death care industry is relatively under-regulated, with the provinces and territories being responsible for any legislation that guides how the industry trains new employees, competes with one another and shares information with consumers (Northcott and Wilson 2017). This is where the marketing lens can be most appropriate because it is marketing research that has a long history of collecting consumer perspectives and developing theory that is rooted in their needs rather than the needs of the industry.

A marketing perspective can also help normalize an industry that society has largely characterized as ‘pariah capitalists’ who have very little regard for ethics (Han 2016). In Canada, the argument has been made that the bureaucracy of the death industry fails to take Indigenous beliefs and practices into account (Northcott and Wilson 2017). Conversely, it has been documented that funeral workers are often subject to stigmatization, simply because of their connection to such a taboo object – the dead (Carden 2017). Applying strategic and ethical marketing practices, informed by marketing research, can help to reduce stigmatization while simultaneously protecting the consumer’s needs and rights (Carden 2017).

Applying a marketing lens to how we, as a society, interact with death and the dying also proves to be beneficial as provincial and territorial governments and health authorities across the country enhance and implement medical assistance in dying (MAID) policies. Just as a marketer will not be asked to perform a medical procedure, healthcare experts should not be expected to know how to appropriately engage in conversation with patients facing end-of-life decisions and options without informed advice. Moreover, marketing research has determined the appropriate methodologies to obtain a clear and useful assessment of patient needs and wants, interpret them and apply appropriate theory to provide medical care teams with the insights required for successful communication strategies.

1.4 TALKING ABOUT DEATH IS IMPORTANT

Until roughly the second half of the twentieth century, high death rates and typically large families meant that dying and death was a common experience for many Canadians, who also often shouldered the burden of caring for the dying family members and dealing with the dead (Northcott and Wilson 2017). But, over time, advancements in healthcare and improved technologies drastically changed the way we care for the dead and the dying (Kopp and Kemp 2007). As more

Canadians are expected to live a long life, death has been removed from the public eye and placed within healthcare systems and in the death care industry (Northcott and Wilson 2017). The result is a society where knowledge and skills regarding death and dying are scarce, reserved only for medical and death care professionals, forcing death to become a topic too taboo for “civilized” conversation (Northcott and Wilson 2017).

Talking about death is important for a variety of reasons, especially when it comes to advanced care planning. Defined as a public health issue, advanced care planning is the overall process of thinking about and communicating values, wishes and preferences for healthcare in the case of a life-threatening illness (Venne et al. 2015). While research shows that personal experiences in dealing with death increases people’s readiness to engage in advance care planning, statistics show that just over 50 per cent of Canadians have not talked to family or healthcare providers about their wishes for end-of-life (Venne et al. 2015). Moreover, it appears that many Canadians who would like to talk about advance care planning would be most comfortable if the necessary information about advance care planning came from a health- care provider. The underlying reasons for any reluctance to talk about advance care planning are that talking about death is more than just taboo but can also come with unnecessary emotional difficulty (Venne et al. 2015).

With a growing number of Canadians reaching retirement age and entering into their more senior years, there is an increasing need to encourage and support individuals who want to have a conversation about advanced care planning their options for end-of-life and, more specifically their thoughts and ideas on MAID. As such, there is a growing group of healthcare providers and professionals who are hoping to develop strategies for conversation so that talking about death and advance care planning becomes a normal part of healthy living. As Venne et al., 2015, highlight, there is an increasing number of peer-to-peer education and support groups, such as death cafés

and death dinners popping up across the country. Providing safe spaces to talk about death and dying can help normalize taboo topics, and can encourage people to begin conversations about their wishes at death, including their thoughts and preferences as it relates to MAID.

The taboo qualities of death prove to be problematic for the marketer because strong taboo themes in ads lead to a strong negative effect on consumers' attitudes towards brands and purchase intentions (Sabri and Obermiller 2012). This notion creates an awkward paradox when one is trying to market death related goods and services: how do you create an ad when what you are trying to market is inherently taboo? This paradoxical situation has no easy solution, but it can be argued that despite the difficulty of the task ahead, marketing researchers are indeed the best equipped to begin exploring questions about information sharing, patient need and consumer behaviour at end-of-life.

The taboo nature of death also means that those in charge of caring for the dying or providing services after death are required to be medical professionals, industry experts and communication specialists all at once. This inevitably leads to inconsistencies in communication and marketing practices that are either ineffective, inappropriate or both. The gap in the available literature proves there is a natural aspect of life which marketing knowledge and insight can be used to inform and improve circumstances and situations for everyone involved. This should be a job marketing researchers approach with honour rather than fear.

The next section explores the current thought in health communications and communication at end-of-life to help provide a context of understanding where this research fits within the body of knowledge.

2. COMMUNICATION IN HEALTHCARE

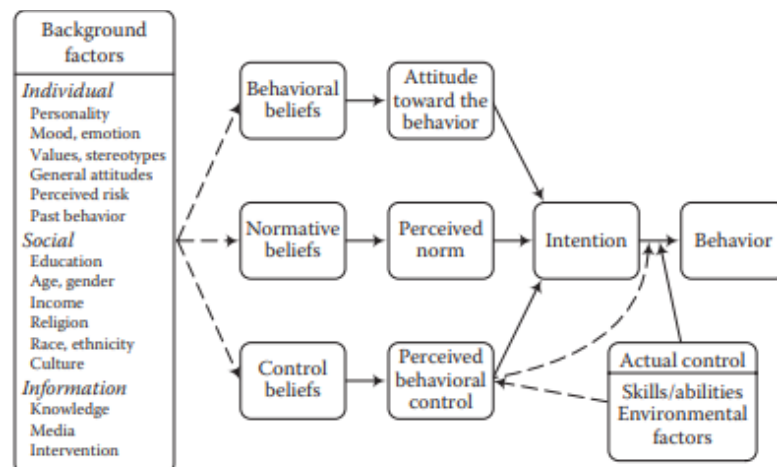
Healthcare providers and researchers use specific messaging and targeted marketing campaigns to convince people to make healthy choices and adopt behaviours that will help stop the spread of disease, minimize health risks and improve a person's overall health. But persuading people to change their behaviour, especially as it relates to health can be tricky (Daniel, Bernhardt, and Eroğlu 2009). Adding to these barriers to change can be social determinants such as social status, level of education, and geographical location, which will also impact a person's ability to change behaviours (The Canadian Council on the Social Determinants of Health 2013). It becomes especially difficult when evidence shows that Canadians are not aware of the way the world around them impacts their health and that health is largely impacted by individual decisions (Moore 2010; The Canadian Council on the Social Determinants of Health 2013). Thus, understanding how to communicate health issues needs to follow frameworks that can influence a large portion of the public audience.

Communication in a healthcare context in Canada is often shaped by two “deep metaphors” — a system metaphor and a journey metaphor — that form the way people understand and make sense of the world around them (The Canadian Council on the Social Determinants of Health 2013, 3). A system metaphor connects different elements into a single unit of interdependent parts in which poor health is the result of a complex interrelated system of social, cultural, economic and behavioural factors (Robert Wood Johnson Foundation 2010). A journey metaphor takes the perspective that the way to good health is by way of a journey (The Canadian Council on the Social Determinants of Health 2013). As journey stories appear in fiction, a journey can be full of challenges to overcome but the traveller can have a map that guides the individual to the treasure (The Canadian Council on the Social Determinants of Health 2013). From this perspective, poor

health is then recognized as a lack of a clear map to guide the journey and, simultaneously, individuals are recognized as able to choose their own path (Robert Wood Johnson Foundation 2010).

Health communicators turn to a number of behavioural change models and theories (ex: Transtheoretical Model, Social Cognitive Theory) to help develop campaigns that focus on encouraging and influencing changes in individual behaviour (Parvanta, Nelson, and Harner 2018). The theory of planned behaviour, first presented in 1985, has a long-standing history in health communication practices because it states attitude towards a behaviour, subjective norms and perceived control over a behaviour help to shape someone’s intent to engage in a particular behaviour. However, as previously mentioned, there are a number of social factors that will impact our health and how we interact with the healthcare system. Therefore an updated theory, known as

FIGURE 2.1 THE REASONED ACTION APPROACH (FISHBEIN AND AJZEN, 2010)



The Reasoned Action Approach, shown in figure 3.1, is an integrative model extending the Theory of Planned Behaviour and has been applied to health communication practices in the recent past (Parvanta et al. 2018). It suggests that the best predictor of behaviour is the intention to perform the behaviour “but that it is also important to take skills and abilities as well as environmental factors (i.e., behavioural control) into account,” (Fishbein and Ajzen 2010, 21). The model itself

highlights the predictors of a person's intention to perform (or not perform) a behaviour and offers some insight into possible steps to follow when developing health communication plans (Fishbein and Ajzen 2010). This approach to communication can sometimes be tricky because of its close relationship to the Theory of Planned Behaviour. According to Fishbein and Ajzen (2010) the theoretical framework they propose does not assume rationality and “encompasses both deliberative and spontaneous decisions making,” and seeks to account for the power a set of beliefs can have over a decision, even if they are irrational, biased and inaccurate (Fishbein and Ajzen 2010, 24).

Health communicators often rely on risk learning models, which have their roots in consumer behaviour research, such as protection motivation theory and health belief model (Pechmann 2009). These approaches highlight severity of disease consequences, individual vulnerability to disease contraction and efficacy of advocated behaviour (Pechmann 2009). However, there is a growing amount of interest in using priming effects of stereotypes that make social constructs more salient in memory to enhance information processing (Pechmann 2009).

When it comes to specific messaging methods, health communicators will use gain-framed appeals or loss-framed appeals (Parvanta et al. 2018). Messaging from a risk learning model perspective focuses on the negative health consequences of not behaving as advocated, often framed as dire and likely to happen to the consumer personally (Pechmann 2009). The stereotype priming model suggests using messaging that makes “salient positive stereotypes about people who behave as advocated or negative stereotypes about people who fail to do so,” (Pechmann 2009, 194–95).

This next section explores current research on how doctors talk to patients about end-of-life and how the communication process is perceived by patients. As you will see, research has

identified that this is one area many patients feel could be improved upon. However, there has been nearly no research into communication at end-of-life or post-death conducted by marketing or communications professionals. The only resources available are ones that have been developed by health professionals..

2.1 COMMUNICATION AT END-OF-LIFE

It has been said many times before — there is no good time for bad news. Communicating bad or sad news is never an easy process and is fraught with emotion for both the giver and receiver. It is also something medical professionals have to do on a regular basis despite having a perceived reputation of not being very good at it (Abdul-Razzak et al. 2014; Fallowfield and Jenkins 2004; Larson and Tobin 2000; Rafferty, Cramer, and Priddis 2016). However, for many individuals facing end-of-life decisions, communication is one element of what they consider to be effective care (Wenrich et al. 2001). A review of the available literature reveals a few significant insights; however, there is little research into the efficacy of various guidelines or workshops that have been developed as a result of the insights collected (Fallowfield and Jenkins 2004; Pagano 2016). The most troublesome revelation drawn from the literature that explores communication at end-of-life is that little of the extant research has been conducted by consumer scientists.

There are four major themes that come out of the literature about communication at the end of life: delivering information clearly, humanizing the patient, straight-talk and comfort with the topic (Abdul-Razzak et al. 2016; Hagerty et al. 2005; Rafferty et al. 2016; Wenrich et al. 2001). The research also highlights that a conversation about end-of-life care is not limited to the patient and medical professional and often happens at home between spouses as a “preventative health behaviour” (Rafferty et al. 2016). Applying Problematic Integration Theory, which addresses issues involving an individual’s expectations and desires that influence the management of

uncertainty, researchers were able to discover that “messages emphasizing the value of having [end-of-life] conversations as well as the value of avoiding the conversations may illuminate, correspondingly, what a good death and bad death might look like,” (Rafferty et al. 2016, 74). In other words, meaningful and effective communication that does not discourage a need for hope while providing clear, easily understood information provides the patient with the resources for defining what is considered to be a ‘good death’ (Rafferty et al. 2016). These kinds of conversations, however, are delicately nuanced and require an appropriate perspective to decipher, especially when the quality of language and clarity of message are also vital components of effective communication at end-of-life.

Effective communication can prove to have benefits for all parties involved. Some research highlights that ineffective communication between medical professional and patient signals to the patient that the doctor has given up on providing care, rather than redefining what care could mean at end-of-life (Wenrich et al. 2001). As Wenrich et al., 2001, highlight, “Information should be laid out in an organized, straightforward manner using language that is understood. Listening with interest, especially by asking open-ended questions, is perceived as a strong basic skill that symbolizes the physician’s concern for the patient,” (873). However, this needs to be “tempered by a physician’s ability to assess patient readiness to engage” and to balance the amount of information based on the patient’s level of readiness (Abdul-Razzak et al. 2016, 891) — a skill that is not easily taught in medical school (Brighton and Bristowe 2016). It has been suggested that barriers to effective communication at end-of-life include the patient’s own fears and emotions; physician’s personal fears; and, the structure of the medical system (Larson and Tobin 2000). If patients want their medical care team to initiate conversations about end-of-life, especially regarding advance care planning as mentioned earlier, there are a number of identified issues that need to be addressed. Research has found that physicians have difficulty with conversations at end-

of-life because of uncertainty regarding prognosis or disease trajectory and worry about causing distress (Brighton and Bristowe 2016). Other barriers can include fear of causing pain, lack of knowledge regarding laws, viewing death as an enemy in need of defeat, anticipated disagreement and medical-legal concerns (Amati and Hannawa 2015). Abdul-Razzak et al., 2016, suggest that many patients acknowledge that having such conversations would be difficult for the physician and that doctors should simply ask the patient if they are ready to have a conversation about end-of-life care. Another potential solution to the barriers mentioned above can be found through collaborative research that includes the expertise of a consumer researcher, medical professionals and support care workers, to develop specific tools that address barriers and enhance conversations between patients and healthcare staff at end-of-life.

FIGURE 2.2 MINDFUL COMMUNICATION PRACTICES IN HEALTH

Know your audience	<ul style="list-style-type: none"> • It is a new experience for each patient, even if the doctor has acclimatized to death and dying • Patients shoulder a large amount of uncertainty • Try putting yourself into the patient’s shoes
Ask questions. Listen. Repeat	<ul style="list-style-type: none"> • Ask questions and remain engaged while they answer them. • Make attempts to be your authentic self. • Pay attention to how patients answer questions and mimic that style.
Discard scripts	<ul style="list-style-type: none"> • Especially if anxious about the conversation, a memorized narrative will not work. • They likely don’t fit the situation properly.
Recognize your role	<ul style="list-style-type: none"> • Blends other three practices • The clinician is a main character in the story of someone’s death.

(Source: Omilion-Hodges and Swords, 2016)

When exploring the literature on ideal and effective communication at end-of-life, it becomes apparent that the idea of storytelling can be a way to develop connections between patients and healthcare providers (Omilion-Hodges and Swords 2017). In this sense metaphors and intentional language can be used in communication at end-of-life to help all those involved look at

the larger picture – the story of the patient, their life and their death (Omilion-Hodges and Swords 2017). The care providers working in palliative care services must be “experienced in addressing the physical and physiological needs but also must demonstrate compassion through their words and actions,” (Omilion-Hodges and Swords 2016, 328). It has been suggested that mindful communication practices, outlined in Figure 3.2, can help improve communication in palliative care centres, not only between doctor and patient but also inter-professional, which can help care teams share the burden of the emotional work involved in palliative care (Omilion-Hodges and Swords 2016).

Considering that administering MAID is relatively new, with relatively new policies, assessing the state of communication about MAID between healthcare teams and the patient could be considered to be premature. However, as a starting point, it is prudent to seek to understand how patients would prefer to be engaged in such conversations – is it up to the patients to ask about it as an option? Do they see it as the doctor’s responsibility to offer it as an option? Research suggests that patients would prefer the decisions to be made jointly, through an open and honest conversation between the patient, doctor and, where appropriate, patient family members (Wenrich et al. 2001). One researcher found that parents of children who have died would have made different decisions if they had better access to clear information and by improving the two-way nature of communication between patient and doctor, everyone involved feels more confident in the final decision made (Xafis, Watkins, and Wilkinson 2016).

While marketing and communications experts are not often listed as faculty in medical schools, there is the untapped potential to create an interdisciplinary approach to helping care providers learn about effective ‘real-world’ communication strategies that will enhance the quality of care they provide. In an attempt to lay some groundwork that will open the doors for further

research in this area by marketing and communications researchers, and hopefully influence the development of strong collaborations that include traditionally non-medical perspectives, this literature review has summarized the current state of research in regard to the death care industry in Canada and Saskatchewan, MAID in Canada and communication at end-of-life.

3. METHODOLOGY

A large portion of the methodology for this project was determined in accordance with the parameters of patient-orientated research provided by the Saskatchewan Centre for Patient-Oriented Research (SCPOR). The funding body encourages a multidisciplinary approach to research that includes both patients and policymakers throughout the research process. Therefore, research began with the development of a research team comprised of a representative from the Saskatchewan Medical Association, members from Saskatchewan Health and patient family advocates for palliative care. This team was consulted at a number of critical points during the research process to ensure research development, data collection and reporting would have meaning for all stakeholder groups.

This next section explores the reasoning and thinking behind a patient-centred approach to research and forms a foundation for a research process that is rooted in a need to engage the patient, or healthcare consumer, in deep, meaningful conversation that provides insight into the lived experience.

3.1 CONSUMER-FOCUSED RESEARCH MEETS PATIENT-CENTRED RESEARCH

Anyone who accesses the healthcare system — in other words, a patient — is a consumer of that system. Marketing and consumer researchers have spent decades refining a consumer-centred approach to research, which places consumer needs and wants at the center of academic inquiry. With this logic in mind, it stands to reason that marketing and consumer researchers are well equipped to step into the realm of patient-orientated research. This increasingly popular approach to research “focuses on the care of patients in the healthcare system as opposed to research focused on whole populations,” (Canadian Institutes of Health Research 2011) and

“encompasses both clinical research and health services research, the synthesis, dissemination and integration of this new knowledge into the healthcare system and into clinical practice,” (Canadian Institutes of Health Research 2011).

When it comes to end-of-life care, there is a notable gap in the available literature conducted by consumer researchers — much of it examines perspectives from physicians and care providers, (Considine and Miller 2010; Omilion-Hodges and Swords 2016, 2017; Wittenberg, Goldsmith, and Neiman 2015) but not those of the patient. The few pieces of research that aim to understand patient perspectives typically opt to use a survey-based methodology rather than one in which the researcher collects data through direct interaction with the patient (e.g. Sparks et al. 2007). Patient perspective research that focuses on qualitative methodologies are largely conducted by healthcare providers, such as psychologists or nurses (Brighton and Bristowe 2016; Larson and Tobin 2000; e.g. Voorhees et al. 2014). While entirely valuable in their contributions to a growing amount of knowledge, complete patient centred care and patient-oriented research needs to be interdisciplinary in nature. Marketers may not be healthcare providers, but they are experts in understanding consumer needs, and if patients are consumers of the healthcare system, then a consumer-focused approach to research can be a useful fit within an interdisciplinary approach to care.

This research uses the qualitative method of Interpretive Phenomenological Analysis (IPA), which allows the researcher to gain a deep understanding of the lived experience. From a consumer research perspective, IPA is rooted in narrative theory, which asserts that every individual thinks and talks about their lives in a series of stories (Shankar and Goulding 2001). The goal of IPA is for researchers to investigate “how individuals make sense of their experiences,” (Pietkiewicz and Smith 2012, 362), which means the researcher reflects on shared personal narratives as central

pieces of data. Data analysis in IPA is detailed, time-consuming and designed to lead to an idiographic logic (Smith 2004). As such, sample size is typically small with sample sizes typically ranging from one to 15 to provide the researcher with an opportunity to examine “the very detail of the individual” so that we can highlight “significant aspects of a shared humanity,” (Smith 2004, 43). This kind of data collection and analysis becomes the heart of patient orientated research because it seeks to ask questions about how individuals think and feel about their interactions with the healthcare system.

3.2 THE RESEARCHER’S EXPERIENCE

IPA is a qualitative methodology that provides space for and acknowledges the researcher’s own experience with the topic and assumes that the researcher’s own experience and expertise are “valuable guides to inquiry and, in fact, make the inquiry a meaningful undertaking,” (Lopez and Willis 2004). It would be inappropriate to not acknowledge my own experience with death and dying, both in my personal life and my academic journey in undergraduate and post-graduate programs. However, perhaps most importantly is my own experience of conversations with physicians about end-of-life during my father’s final years in the late 2000s. This particular experience provides me a sense of familiarity with how patients interact with “the system” and how conversations at end-of-life can go and will inherently influence the interview process. This influence, however, should not be ignored because it can become a useful tool in establishing rapport through a shared sense of understanding and inform the interview process to ensure the conversation produces meaningful data. As such, IPA becomes the ideal methodology to approach this particular research question if only *because* of my own experience.

3.3 PARTICIPANT RECRUITMENT AND DEMOGRAPHICS

Five participants were interviewed for the purposes of this research. The goal was to interview at least six terminally-ill patients, who are at least over the age of 18 and have had at least one conversation with a medical professional about end-of-life care and options for end-of-life care. However, because of the sensitive nature of the topic and the still on-going debate regarding MAID, participant recruitment proved to have some significant challenges. For the purposes of this research the term ‘terminally ill’ is broadly defined to include participants that are diagnosed with a specific condition or disease that will eventually lead to their death but may have longer life expectancies than individuals with other diseases or ailments.

The research project received ethics approval from the University of Saskatchewan’s Behavioural Research Ethics Board (delegated review) in the fall of 2017. To ensure the research process remains as ethical as possible, each participant was asked to give written consent prior to beginning the interview. Participants were informed about the benefits and perceived potential risks in participating and their right to end the interview at any time without consequence. In exchange for their participation, participants received \$50 (CAD) from the interviewer at the end of the interview.

FIGURE 3.1: PARTICIPANT DEMOGRAPHICS AT A GLANCE

Pseudonym	Age	Gender	Diagnosis
Chris	37	Male	Cerebral Palsy
Mable	92	Female	Cancer
Suzie	83	Female	Cancer
Grant	57	Male	HIV/AIDS
Joyce	90	Female	Cancer

The majority of participants were recruited in partnership with a long-term care facility in Western Canada. Data collection was conducted through semi-structured, in-depth interviews in a space in which participants felt most comfortable. Given the exploratory level of this research, participants were not recruited on the basis of gender, ethnicity or by any particular diagnosis, leaving room for future research that may want to explore different facets of the topic at hand. Three of the five participants interviewed are seniors, with one being over the age of 80 and two over the age of 90 – they are all female. Two males, one over 35 and the other over 55, were also interviewed. Three of the five participants were diagnosed with cancer; one has a diagnosis of HIV/AIDS and another with Cerebral Palsy. Three participants also reported secondary illnesses such as heart failure.

Participant recruitment proved to be difficult as terminally-ill patients are not readily accessible within a standard research recruitment process. One primary solution to this is to work on building relationships with organizations that support those who are terminally ill or provide regular care to them. While there were a few organizations approached who were willing to work with me throughout the recruitment process, there were quite a few more that demonstrated some hesitation. The general sense was that I would be causing unnecessary distress and therefore was not allowed to recruit participants from their facilities. The fallacy in this assumption is that participants, once they were recruited, were eager to talk and share their stories. Not only were they able to chat, they had clearly thought about the topic prior to the interview as the majority of interviews took less than 30 minutes to complete (originally thought to take an hour or more). This difference between organizational assumptions and patient reality is quite significant and showcases an opportunity for further research to determine how to bridge this gap in communication and understanding between administration, care providers and patients.

The difference between organizations is not just between patients and administrative staff. Throughout the research process there were many conversations with medical professionals, senior leadership at community-based organizations and other influential decision-makers, who each demonstrated an appetite for information about patient perspectives on conversations at end-of-life. Yet, some cultural or religious-based organizations have made anti-MAID decisions at an organizational level, thus potentially inhibiting the quality of care such organizations can provide. This would indicate there is a philosophical gap between medical practitioners, care teams, and organizational administration — medical professionals and healthcare policymakers are working to adapt their practice to meet legislative direction while some organizations still feel pressure to take a stance on the moral debate surrounding MAID. While frustrating from a participant recruitment perspective, it does highlight a need for future research that seeks to understand how, if at all, these kinds of philosophical gaps impacts service delivery and patient care in Canada.

The organizations that did agree to help with participant recruitment are research partners and provided valuable insights to inform both participant recruitment and data collection. Their industry expertise also provided secondary insights not found in the literature review that are based on their own lived experiences, which proved to be beneficial during the interview process itself.

In an effort to ensure confidentiality, all participants were asked to choose a pseudonym. If they declined, a pseudonym was chosen for them at random. Figure 4.1 provides a brief profile of each participant. Each interview was recorded digitally, transcribed by a contractor in another province and then reviewed by the primary researcher. Data was analyzed following an interpretive phenomenological analysis (IPA) approach. IPA provides an opportunity to understand the lived experience that gives meaning to how individuals respond to a particular phenomenon, thus creating a foundation from which they can construct their own reality (Penner and McClament

2012). Thus, the participant's lived experience and views about the experience is the only required source of data (Hays and Singh 2012). Data validation occurred by engaging the research team — more specifically, the patient family advisor — who also read the transcripts looking for repeated phrasing, words and other data points. The two analyses were then compared and any differences were discussed between the primary researcher and the patient family advisor until a consensus was reached.

4. FINDINGS

Four major themes, which will be explored in depth below, arise from the data: Truthfulness, familiarity, humanness, and comfort. These findings are similar to themes outlined in the literature review, but because these are teased from the lived experience of patients the meanings of each theme are more robust and refined. Ultimately, as Larson and Tobin (2000) highlight, the patient wants their care team (not necessarily a singular professional) to focus on their unique experience of the disease and decision-making process regarding end-of-life care. As outlined in the mindful communication practices, it is important for healthcare providers to remember that each patient believes they are going through an experience that is unique to them, even if they have been through it in the past with loved ones (Omilion-Hodges and Swords 2016). What may be ‘every day’ for the care team is an obstruction of the every day for the patient.

4.1 TRUTHFULNESS DOESN’T MEAN JUST THE FACTS

Four out of five participants mentioned words related to truth (such as truthful, honest or truthfulness) multiple times throughout the interview. However, in doing so, they were often able to draw a line of distinction between concepts of truth and just the facts. When Mabel spoke about her experience, she articulated that when she talks to her doctor about her palliative care options she wants the “truth more than the facts,” indicating that there is a perceived difference between a truthful (or honest) conversation and merely presenting the facts. As Mable states:

Mabel: [I want it] straight. I don't say, really, 'blunt.' I don't think anybody should be hurt.

This phrase, while short, packs a lot of meaning. The idea that being blunt can be hurtful, but “straight talk” does not, articulates the nuanced difference between truth and fact: truth is inherently subjective and is often influenced by context. This means that a single truth can, therefore, be a combination of truths, half-truths and untruths (Lee 2011). In the context of learning about one’s own terminal diagnosis, a truthful conversation — that is, one where you might combine truth with an untruth — is something participants indicated they would prefer when having potentially emotionally charged conversations with a medical professional. For example, Joyce had a conversation with her doctor in which he referred to her as his grandmother (which is untrue), saying “if you were my grandmother,” to demonstrate the fact his sincerity when advising against treatment due to the nature of her disease. This ultimately helped create a scenario in which Joyce is accepting of her palliative status.

Joyce: So I know when I went back to him one day – I don’t know when it was. And I said, “Uh-huh.” I said, “I know.” I said, “I’m on palliative care. I’ve only got, you know, so long.” ...I said, “That’s okay, doctor. I’m okay with that.” You know and I think it made him feel good, you know, not to worry. That I am okay with it. And that’s exactly how I am.

The ability to have a truthful conversation is not a solitary endeavour and requires that the patient believes what the healthcare provider is saying to them. Abdul-Razzak et al., 2014, refers to this as “candid information sharing” from which patients can make informed healthcare decisions. Conversation does not have to be strictly factual but should remain informative. Chris, who has had the same doctor for his entire adult life, talks about how he believes his doctor keeps him informed about possible treatments and potential challenges. This kind of information sharing

allows Chris to trust in his doctor's ability to choose the right time to escalate the conversation from treatment to end-of-life decisions.

Chris: I think [my doctor] would be at a point where he would probably say, "You know, your ailments have to get to a certain point before we can have a frank conversation about it...He's very frank with me...there's not a lot of wishy-washy with us.

Just as patients perceive a care provider's truthfulness through their ability to hold a conversation that consists of "straight talk," a lack of such candid information sharing can create a sense of untruthfulness. Suzie, who has a number of healthcare providers to help manage multiple issues, outlines an expectation that certain kinds of information should come from the doctor looking after a particular issue. She describes how learning about her prognosis from a pulmonary specialist and not from her oncologist was upsetting and made her feel "a little bit sad."

Suzie: My doctor – my cancer doctor doesn't say nothing. He's tight-lipped...I wish they'd be more open.

Interviewer: What do you mean by open?

Suzie: Like telling you the truth. Instead of sitting there...himming and hawing about this and that.

Suzie mentions that it is the pulmonary specialists who originally informed her that her cancer has spread, but because of a lack of familiarity of her cancer history and previous conversations

with other medical staff the pulmonary specialist was not able to provide much more information, leaving Suzie to feel as though a large portion of her care team was untruthful. This sense of familiarity is often mentioned among participants and can impact how patients feel about the conversations they have with their care providers. Chris at one point simply adds that “I think [my doctor] understands me, so I trust him with what he says about me.” This indicates a strong relationship between truthfulness and familiarity, which is the next theme to be explored.

4.2 FAMILIARITY ON ALL SIDES

One of the recurring themes throughout the data is the idea of familiarity and each participant reflected on familiarity or concepts similar to familiarity in one way or another. Some of the familiarity mentioned by participants stems from previous experience with end-of-life care and conversations at end-of-life because spouses or other close family members have already passed away. The ideals of familiarity mentioned by participants, however, is not reserved for conversations at end-of-life. There is a desired sense of familiarity with the individual, familiarity between patient and medical doctor/care provider, and the amount of time spent with the patient during appointments. Even familiarity with the disease and how it relates to everyday life is important. This can manifest as offering advice and/or appropriate paperwork to obtain the necessary disability papers to get time off work or clarifying insurance issues and other administrative tasks that come with facing one’s own death.

Grant: It was just, you know, there was the beginning of the AZT and DDI and all that kind of stuff. But it was more like, you know making sure these things are in order. Do you need papers signed for disability? Do you need stuff off of work? Like, all of those practical things that were actually very

much more helpful than the medical stuff. Because the medical stuff was kind of, we kind of knew what was going to happen...But, as a good doctor, he was trying to make sure that the things that could be dealt with were on the table, so that...I mean, we had a very highly-evolved group of doctors by that stage, because they really understood and there was enough of a community there to get doctors to think about what end-of-life care was going to look like.

While the adage suggests that familiarity may breed contempt, it appears that for patients facing end-of-life decisions, familiarity can actually breed comfort. The notion of familiarity is an idea that focuses on understanding the patient as a person and understanding that they were someone different before they were given a terminal diagnosis. Grant articulates this in the quote at the beginning of the paper – there is the person before the diagnosis and the person after the diagnosis – and both need to be acknowledged. This reflects a larger idea brought up by a number of participants: relationship building.

Joyce: I didn't like the doctor I had. And so she wasn't there and so I had to go in and see a doctor and he was the one that I seen. He checked me out and that and everything was good and I asked him, I said "Are you taking any..." – because he was a new doctor – "Are you taking patients?" He said "yes." I said, "I would like to be yours." [Joyce has been with her doctor for 15 years].

While Mabel refers to her doctor as a “friend,” she has had twelve years to develop the relationship. Some people who need to access the healthcare system may not have the opportunity to build a

relationship with a general practitioner or specialist over time, but that does not imply that a sense of familiarity cannot exist. Mabel describes how she has been through a lot in her life, including having to help her spouse through the end-of-life care process, and that, from her perspective she's been through "a lot worse than this."

Mabel: I'm very comfortable with the fact that I don't have much time to live, because I know neither does anybody else.

4.3 HUMAN TO HUMAN

While humanizing the patient will enhance the quality of conversations about end-of-life care between patient and healthcare provider (Abdul-Razzak et al. 2014), it becomes apparent that the medical professional must also be willing to demonstrate their own humanity. Nearly all of the participants mentioned they preferred it if their doctor had a sense of humour and/or a positive approach to conversations that followed the initial delivery of the terminal diagnosis.

Joyce (about after having blood drawn): ...and then he had to put a little Band-Aid on there. And I thought "What is he doing? He's taking a long time." Puts the Band-Aid on. When I got home, it's a happy face! He'd written on it...put on that Band-Aid.

Patients are looking for their medical care team to demonstrate some kind of personality and, it would seem, would prefer light-hearted and candid conversation. Chris spoke quite extensively about how care decisions are made together – both he and his doctor are engaged in the conversation – and that after more than two decades of seeing the same physician, they have a well-established rapport, which Chris calls a "bond of understanding."

Chris: With the way my body tolerates pain, like usually I don't complain about something until it's significant. So he knows that if I'm complaining about it then it must be a significant issue...he teases me that I don't pharma more than I have to...he makes fun of me all the time.

Interviewer: What do you mean he makes fun of you all the time?

Chris: Well, he just says "oh you're...you're a medical student's dream," ...I mean, I don't think he's used this word, but I get this sense that I'm a puzzle to him...and I make him think. So he always makes fun of that.

Interviewer: Yeah. How does that make you feel?

Chris: It's the truth, so it's like, whatever.

This underlying idea presented by patients in this study is that a physician who is willing to demonstrate his/her own emotions, be it positive or negative, is authentic. This sense of authenticity leads to a sense of trust and familiarity from the patient towards the medical care personnel. That is to say, that if telling a joke or drawing a happy face on a Band-Aid is something you might do with someone who is closer to you than a patient, then you should be willing to be that person – be your authentic self.

The fear that some physicians face is that these types of authentic human interactions can fall flat if they are directed towards the wrong audience (Amati and Hannawa 2015). While reading one's audience is not necessarily an inherent skill — it often needs to be developed or taught — it

is a skill that needs to be addressed while physicians are still in training and readdressed throughout their career journey because it would appear that some of the most seemingly minor actions have the largest impact. As Grant discusses, when the medical professional is willing to show his/her humanness, it immediately establishes an equal field – both patient and doctor are humans working through a truly human experience.

Grant: Some people come to [it] naturally and I don't think that shouldn't be suppressed. In other words, if your natural response is to...is to try to understand the imminent tragedy in terms of the human condition and how absurd and how funny that can be, and that's a natural inclination, then that always fits to me...It's not like the 'lighten-up' thing, its like your understanding of this doesn't [have] to include the other parts of your spirit...With my own situation, the humour has always been there, has always been something that I kind of expect. It's a communication tool, because it can actually, from my perspective, let the caregiver know that it's, that this is okay.

4.4 COMFORT, COMFORTING AND COMFORTABLE

Learning that you are dying is uncomfortable, no matter how accepting you are of it. What this research shows, however, is that the previously mentioned themes of truthfulness, familiarity and humanness, can come together to provide a natural sense of comfort or comforting conversation. More than half of the participants are users of an in-home palliative care service provided by the provincial government and all mention that the nurses who visit provide a sense of comfort because of their honesty and familiarity.

Suzie: Every time they send me a different nurse, she's...she's just...I don't know. She got everything. She's more of a doctor than she is a nurse. She knows her things, she knows what to say, and she knows how I feel.

For Mabel, the conversations about her end-of-life care are, in her words, “just like as if I had a cold,” because she has a strong relationship with her doctor, she believes him and they share human moments together through humor and wit – all of which come together to give Mabel a sense of comfort. She was also the only participant who directly mentioned a concern about causing other people discomfort. She continues to discuss how the comfort she has her with care team helps alleviate the distress of worrying about the impact of her illness on her loved ones. The comfort she receives from her doctor brings her confidence in being able to talk about the hard stuff with her family. While it may not be a recurring theme in the data, it is worth mentioning how effective and meaningful conversation with care teams at end-of-life can have a greater impact than what is immediately observed.

4.5 TALKING ABOUT MAID

All respondents said they want to have a conversation with their physicians about options at end-of-life, but most participants admitted that they have not actually had the conversation. This lack of conversation about MAID may not be due to an omission or oversight on behalf of the care team, but because patients feel as though, or assume, that an established rapport with their physician means their care team will inherently know what they want or will be able to intuit their needs without conversation. For example, Mabel said she has not had the conversation with her physician because she believes he already knows her preference. Joyce said she brings it up as a joke saying that she will “head for Oregon for some purple juice,” —Oregon has had physician-assisted death

(PAD) for nearly 20 years (Blanke et al. 2017) — but that she has not had a direct conversation about it with her physician.

When asked about why they would want to have a conversation about MAID with their care team, participants primarily said, indirectly or directly, that the conversation would be to address any worry about anticipated suffering and dignity.

Grant: The primary thing was to make sure that you weren't going to end up with a lot of suffering and with no dignity. And that was the biggest challenge...I guess that's palliative care in a nutshell, but to make sure that people are not suffering and that they are able to live with whatever they have in a certain amount of dignity.

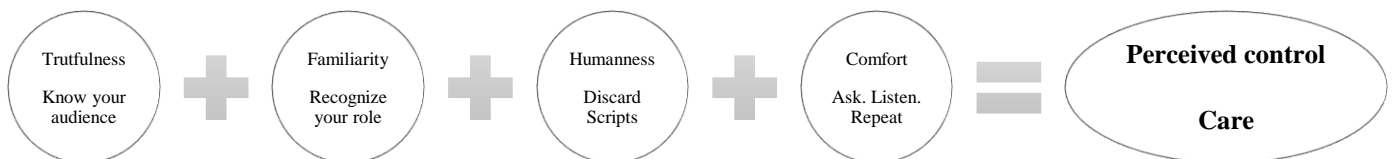
This falls in line with what researchers in Oregon have found when exploring trends in PAD over time. Some statistics report that nearly one-third of terminally ill patients do not take the medical-aid-in-dying medication but find comfort in having the prescription (Coombs Lee and Grube 2017). This data suggests that patients want to remain in control of their own death and are more likely afraid of having a “bad” death rather than death itself (Coombs Lee and Grube 2017). The concept of control comes into play when participants spoke about worries or concerns about how their illness will affect their ability to enjoy their life, even if they are aware there is not much life left. Chris often talks about how the quality of life is important to him. Already confined to a wheelchair, Chris works hard at remaining social and getting out of the house and maintains what he feels is a good quality of life. The loss of that independence is a bigger deal to him than his eventual death.

Chris: I'm always conscious of the quality of life quotient...I don't think I would want to live a life where I couldn't leave my house, or I couldn't at least travel to see some friends...

I would want to live a shorter life with a higher quality than a longer life with limited quality.

What these quotes highlight is that the conversation about MAID is not about whether patients want to die, but rather it's about their idea of being able to have a sense of control over their death and any perceived suffering that could come with it. Ultimately, this comes down to patients wanting to feel as though they are cared about — that a lack of suffering and their dignity

FIGURE 4.1 A FRAMEWORK FOR CONVERSATIONS AT END-OF-LIFE



matters to someone who is a medical professional. They want to feel as though they can trust their doctor, that they are more than just a number on a file, that their doctor is not a robot and feel a sense of comfort along the way. Patients want to feel as though they are still important and that they matter right until the very end.

To achieve this sense of being cared about and control over their situation, and to have a meaningful conversation about MAID, all four themes are required. Primarily interrelated, though not necessarily interdependent, the themes come together to function like interchangeable building blocks that can create a strong foundation of steps toward meaningful conversation. When

compared to the mindful communication practices in health as presented by Omillion-Hodges and Swords (2016) (Figure 3.2) it is clear that the themes presented in this research are a more emotive representation of what happens when mindful communication is practiced. Each theme is related to a mindful communication element in a way that can help care providers understand the impact mindful communication can have on the overall care experience at end-of-life. These building blocks come together to increase patient perceptions of control over their care at end-of-life because the sense of care allows the patient to feel as though they are emotionally supported, as well as medically supported, which leads to feeling of unity and the belief that the patient and care team are “in it together.” It should be noted that there is no evidence that there is a “right” or “wrong” order in which these building blocks should take place and because of the inherently personal aspects of end-of-life issues, it is crucial they remain fluid in order to promote meaningful conversation between patients and care providers. By incorporating these building blocks into care practices, health care professionals can help their patients at end-of-life achieve a feeling of care, in the truest sense of the word, and mutual control over their eventual death.

5. DISCUSSION

Talking about death is hard for many people, but when death becomes a reality for the individual, it appears that talking about death gets to be a little bit easier. This became apparent during the data collection phase, where interviews were roughly 20 minutes in length even though the original estimate for each interview would be at least an hour in length. The shorter time frame can be attributed to the fact that participants had clearly spent some time thinking about the topic and had already formed opinions prior to the interview. Similarly, it appeared that male participants were typically more conversational and verbally expressive than the female participants, who were often more succinct in their word choice and descriptions of feelings. This actually bucks a trend in observed grieving styles, where women are often considered to be “intuitive grievers,” meaning they express the emotions of grief with greater ease and will often adjust to their perceived losses (Martin and Wang 2006). Conversely, men are often referred to as “instrumental grievers” and are known to experience loss intellectually where the crisis is more of a challenge than a threat (Martin and Wang 2006). However, the men and women in this study were flipped in their approach to the conversation about conversations about care at end-of-life, where the women expressed more logical insight and the men were somewhat more emotive. This could be due to a number of factors, ranging from age to sociocultural background, and seems to indicate that grieving styles might not be as gender-specific as researchers believe.

Despite the differences in responses from participants, there was one very distinct feature that was similar in each interview: the conversations patients are looking for at end-of-life are not about death, but instead about talking about *how* death will happen. They are concerned about the experience of death. Will it be painful? Will there be suffering? Will I be a burden to my family? While some physicians worry that delivering bad news will add to patient suffering, there is evidence that delivering bad news well can enhance a patient’s care experience in a positive way

(Sparks et al. 2007). Fostering an environment where open and honest communication can happen between patient and medical professional can provide an opportunity for personal growth at end-of-life, which is something patients and their families value (Larson and Tobin 2000). This qualitative research project found that a patient's experience with conversations at end-of-life can be positive when medical professionals are truthful, express familiarity, are willing to express their own humanity and cultivate a comfortable environment.

The stories told by participants in this study relate to the “deep metaphors” of a system and a journey as described by the Canadian Council on the Social Determinants of Health (2013). The system metaphor can be heard in Suzie's stories of how the system broke down for her, ultimately making her wary of trusting said system. Similarly, Chris describes his ongoing struggles with cerebral palsy and his desire to live every day as best as possible as though he is on a journey, and it is his close, trusting relationship with his doctor that provides the necessary map.

It should also be noted that many participants wanted to continue the visit once the interview was over, and continue sharing narratives. The majority of participants did not return to the topic of their death or their perceptions of their care at end-of-life, but rather wanted to talk about “every day” things such as the weather and local politics. This is likely largely due to participants' age and access to a captive audience – sharing stories of one's life is part of the metaphorical journey towards death.

Much of the discussion surrounding communication at end-of-life has focused on intent; that is, whether or not an individual intends to seek medical assistance in dying. This is perhaps due to the influence of models such as the Theory of Reasoned Action and the Theory of Planned Behavior in the field of health communication. Much less attention has been paid to the perceived control an individual feels over their death, something this research found was a very important concept to people facing a terminal diagnosis. While intent is a major component of the reasoned action

approach, so to is perceived control. Given the findings, it might be more fruitful to examine the importance of perceived control and human agency to understand how best to communicate about MAID. As explained by Bandura (2006, p.170) “Unless people believe they can produce desired effects by their actions, they have little incentive to act, or to persevere in the face of difficulties.”

This relationship is manifested in the belief that one’s own capabilities will ultimately influence events that affect their lives, or in this case, their death. Considering that there is an observed need for terminally ill patients to maintain some element of control over their own death (Blanke et al. 2017) focusing on an individual’s perceptions of control and agency may be a better foundation for conversations with patients at end-of-life, especially in regards to MAID, where the conversation isn’t about choice, but helping patients gain the capability to influence their life and their death. That is not to say that a focus on intentions should be totally abandoned. It does serve an overall purpose when it comes to positive communication experiences between care provider and patient, which, as previously mentioned, is part of effective care in general.

It is important for medical professionals to remember that while they may live through death experiences often, it will be the first time the patient is facing his or her death — from the patient’s perspective it is a unique experience (Considine and Miller 2010). The quality and quantity of end-of-life conversations between a doctor and a patient can be improved by teaching communication skills to professionals working in end-of-life care (Larson and Tobin 2000). Medical schools in the United States rely on a number of communication training modules to enhance the learning experience for students, but these are not necessarily focused on end-of-life (Larson and Tobin 2000). Similarly, these modules are likely not a good fit within a Canadian context where talking about end-of-life should include a component that addresses MAID. Perhaps more to the point, having a conversation with a patient without knowing their moral stance on something as controversial as MAID would require a large amount of empathy, which is difficult to teach.

However, the mindful communication practices outlined in figure 3.2 may prove to be the tangible resource that can be added to medical education curricula or developed into a workshop for medical professionals. Marketing and consumer researchers can help identify where training enhancements can be made and, relying on current research, build effective resources that will help medical professionals develop the skills required to engage in conversations at end-of-life that meet patient need.

6. RESEARCH LIMITATIONS AND FUTURE OPPORTUNITIES

Because death is still latently taboo, it has proven to be difficult to recruit participants because of hidden worries of causing distress or perceived potential problems from medical administration. Similarly, some organizations are volunteer-run and coordinating between volunteers, staff and clients can be complicated and time-consuming. While a few organizations were welcoming and supportive, a great number either declined or were altogether unresponsive. While this will invariably cause problems for future research exploring cultural or population-specific patient perspectives on conversations at end-of-life, it may also prove to be an opportunity for future research that seeks to understand how organizational perspectives can shape the patient experience in regard to end-of-life care and MAID.

The difficult recruitment process also meant that the majority of data collected came from seniors over the age of 80, which will have impact perspectives because the lived experience changes greatly over time — many of the more senior participants have had a fair bit of previous experience with end-of-life care. It also impacts data because the more senior participants felt that they had led a good life and were not afraid of dying. A similar argument can be made on the basis of diagnosis. Some terminally illnesses are slow progressing while others are aggressive and quick. This can often change someone's perspective on MAID and end-of-life. As such, future research should make sure to take this into account.

It should also be reiterated that many participants indicated that they assume that their physician or care provider knows what their individual wishes are regarding MAID, but have not actually have a conversation. This introduces some problematic insight that should be farther explored. Working with health care providers to understand their perspectives can highlight if this assumption between doctor and patient has any merit. By definition, a conversation is never simply

one-way and to work to improve the quality of conversations at end-of-life, gaining a deep understanding of the lived experience from doctors is extremely necessary.

6.1 PUTTING RESULTS INTO AN APPLIED CONTEXT

Part of the requirements laid out by SCPOR is that all research must also include an applied element, which will serve to inform future practice and policy. This means the results of this research will be developed into something that can enhance physician/ healthcare training for students learning about effective communication with patients. Resources will be created as online learning modules and curriculum adaptations.

There may be an opportunity to host a seminar or workshop with medical students currently studying at the University of Saskatchewan. This research can also enhance tools currently in development by health authorities to address recognized patient concerns about the quality of their healthcare. For policymakers, resources can be developed that outline patient needs and wants for conversations about end-of-life care. The findings in this research highlight that when it comes to death and dying, patients want to be able to have some control over the experience and say in how they die. This kind of information has the potential to inform policy adaptations to ensure that patients are allowed more freedom when it comes to making their own choices at end-of-life.

The key findings mentioned would be the primary focus of resources; however, they should also include strategies on how to achieve specific communication goals such as fostering a sense of truthfulness. There is also an opportunity to collaborate with the Saskatchewan Health Quality Council in developing training programs and further assessment tools that seek to address communication issues at end-of-life care and assess ongoing patient perspectives regarding end-of-life care and MAID.

7. CONCLUSIONS

Death is a fact of life. And for a long time, death was something “civilized” people did not talk about, especially in public — it was taboo (Northcott and Wilson 2017). However, when the Supreme Court, and eventually the Federal Government, began discussing medical assistance in dying (MAID) in the public sphere, the topic of death became more common in everyday conversation. Now the conversation is shifting again and thought leaders are starting to talk about what it means to have a ‘good death’ (McNeil 2000; Considine and Miller 2010; Trice and Prigerson 2009). This research contributes to that conversation and to the growing health communication literature on conversations between patients and healthcare providers at end-of-life by asking the patients themselves what they want and how they feel about the conversations they have already had. This research also provides a foundation from which more research can grow, keeping patient needs and desires at the centre of future policy and care delivery methodologies.

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APPENDIX A – ETHICS APPROVAL



Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR
Marjorie Delbaere

DEPARTMENT
Edwards School of Business

BEH#
17-320

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED
City of Saskatoon

STUDENT RESEARCHER(S)
Jane Caulfield

FUNDER(S)
UNIVERSITY OF SASKATCHEWAN

TITLE
Conversations That Matter: Patient Perspectives on Communication About End-Of-Life Care

ORIGINAL REVIEW DATE	APPROVAL ON	APPROVAL OF:	EXPIRY DATE
05-Sep-2017	21-Sep-2017	Application for Behavioural Research Ethics Review Recruitment Poster Research Information Letter for Recruitment Participant Consent Form Interview Questions	20-Sep-2018

Full Board Meeting Delegated Review

CERTIFICATION: The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2014). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS: In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: <http://research.usask.ca/for-researchers/ethics/index.php>



Please send all correspondence to:

Research Services and Ethics Office
University of Saskatchewan
Room 223 Thorvaldson Building
110 Science Place
Saskatoon, SK Canada S7N 5C9

APPENDIX B – INTERVIEW GUIDE

Interpretive phenomenology is a qualitative methodology aimed at collecting, analyzing and understanding the lived experience of an individual.

The interview process is not meant to be structured and should merely be a reference to help establish real dialogue between the researcher and the patient (Passos et al. 2016). The conversation should be allowed to go where the patient wants to take it and the research is obliged to engage in careful listening without interference from previously established ideas or notions (Passos et al. 2016).

General introduction/consent:

Hi, thanks for agreeing to chat with me today. Have you had enough time to read the consent form? Before we begin, I want to make it clear that you are welcome to stop this interview at any time by simply asking for it. I will be asking some demographic information about yourself, but your actual name will not appear in the final study; instead, I will use a pseudonym rather than your real name. All data will be stored on a secure server at the university. Do you consent to this interview?

I will be asking you some questions that might be hard to answer, please do not feel like you have to answer them or feel pressured to answer them quickly. Please let me know when you are ready to begin.

Questions

Ice breakers/getting to know the participant a bit

1. Tell me a bit about yourself
 - a. What did you do for a living?
 - b. Where are you from?

Demographics

1. What is your age?
2. How do you self-identify your ethnicity?
3. What is your official diagnosis?

Questions about EOL care

1. Tell me about your experience learning about your terminal diagnosis?
 - a. Tell me about the conversation you had with the doctor/care team/ medical professional when you received your diagnosis
 - b. How did that make you feel?
 - c. Can you tell me more about that?
 - d. Was there anything positive [negative] about this experience?
 - e. Do you or your family need more support?
 - f. What would have made it different?

2. What kind of communication you would like to have about your end-of-life care?
 - a. Why do you think you feel that way?
 - b. Can you tell me more about that?
 - c. What would help you the most?
 - d. Does your experience match what you would like?

3. How would you like to discuss the options for your end-of-life care?
 - a. Who would you like to have this conversation with?
 - b. Why do you feel that way?
 - c. Can you tell me more about that?
 - d. How would that make you feel?
 - e. Does your experience match what you would like?
 - f. Do you or your family need more information?
 - g. What is important to you and your family?

APPENDIX C – RECRUITMENT MATERIALS

EDWARDS SCHOOL OF BUSINESS UNIVERSITY OF SASKATCHEWAN



PARTICIPANTS NEEDED FOR RESEARCH IN COMMUNICATION AT END-OF-LIFE

You are invited to participate in a study that seeks to understand patient perspectives of communication about end-of-life care.

Participants must:

- Be over 18 years old
- Have a terminal diagnosis
- Have had at least one conversation about care at end-of-life with a medical professional
 - Are of sound mind.

As a participant in this study, you would be asked to participate in a recorded conversational interview with a researcher.

Your participation would involve at least one interview, approximately one hour in length. You can also choose to have multiple interviews over shorter amounts of time.

In appreciation for your time, you will receive an honorarium of \$50.

For more information about this study, or to volunteer for this study, please contact:

Jane Caulfield
Graduate Student
Edwards School of Business, Marketing
306-203-6131 or
Email: jlc289@mail.usask.ca

This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.

To health care professionals and care workers at [ORGANIZATION]:

We will be recruiting participants at your centre to partake in a research study titled “**Conversations that matter: Patient perspectives on communication about end-of-life care.**” This study has been discussed with [MANAGER’S NAME], who has given us permission to work with your centre. The data collected during this study will form the basis for a graduate thesis.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975. The researchers involved in this study are:

Researcher(s):

Jane Caulfield, Graduate student
Edwards School of Business, Marketing
University of Saskatchewan
jlc289@mail.usask.ca
306-203-6131

Supervisor:

Dr. Marjorie Delbaere
Associate Professor
Edwards School of Business
University of Saskatchewan
delbaere@edwards.usask.ca
306-966-5916

Purpose of the Research:

This research aims to gain an in-depth understanding of patient perspectives on communication regarding end-of-life care and options for end-of-life care. As the Saskatchewan government works to develop policy surrounding the medical assistance in dying (MAID) legislation passed by the federal government in 2016, there is an opportunity to ensure any policy is well informed by the patient. The goal of this research is to serve as the bridge between policymakers and palliative or terminally ill patients to ensure the future of end-of-life care in Saskatchewan meets the needs of the patient above anything else.

Procedures:

Participation will include an in-person interview with Ms. Caulfield that will last approximately one hour in total. This could be one longer session, or multiple shorter sessions, depending on patient preference. The number of interviews and the length of each interview will be determined based on patient comfort levels.

The interview will be similar to a conversation, in which Ms. Caulfield will ask one or two questions to begin and additional questions should the conversation call for it. Even though it is a conversation, patients may still refuse to answer any individual questions. The conversation will be audio recorded for data collection purposes and the recorded conversation will be transcribed verbatim.

Patients will be asked a few questions about themselves, including an official diagnosis; however, responses to these questions will only be used to describe characteristics of the sample of participants in this study. Should patients decide to end the conversation and resume at a later time and date, they are welcome to do so at any time.

Potential Risks:

Because patients are being asked to talk about something that is likely very difficult to discuss, there is the risk that these conversations can cause some psychological distress. The [ORGANIZATION NAME], of which you are a part of, has access to social workers and counselors who are available to help patients

through any difficulty that may arise. If patients would like to know how to contact these individuals, they can ask the researcher at any time.

Potential Benefits:

This research will help ensure policy about end-of-life care and communication of end-of-life care options are communicated to patients in a way they would prefer and a way they are requesting. By participating in this research patients have an active role in the shaping the future of our health care system.

Compensation:

Participants in this study will receive an honorarium of \$50.

Confidentiality:

Patient identity will be protected at every step along the way. While the researcher will know his/her original name, any identifying information will not appear in the final report. Instead patients will be referred to by a pseudonym.

Any master list that includes names and contact information will be stored on a secured server at the university until it is no longer needed for data collection purposes. At that time, this information will be destroyed.

All audio recordings will be immediately uploaded to a secure server at the university and subsequently deleted from the recording device. All materials, including recordings, will be securely stored at the university for no less than seven (7) years.

Right to Withdraw:

Participation is voluntary and participants can answer only those questions that they are comfortable with. They may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.

Should a participant wish to withdraw, any reference to partial or potential participation will be destroyed. Any recordings will also be destroyed. Patients' right to withdraw data from the study will apply until May 01, 2018. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw their data

Follow up:

Participants are more than welcome to review the results of the research, either through an in-person meeting or through receiving a copy of the final written report, or a combination thereof. You may also consider the option to have the researcher share the results with family members. If the participant should choose this option, they are to inform the researcher at the time of the interview.

Questions or Concerns:

Any questions or concerns can be directed to Ms. Caulfield or Dr. Delbaere using the information provided above.

APPENDIX D – CONSENT FORM



PARTICIPANT CONSENT FORM

You are invited to participate in a research study entitled:

Conversations that matter: Patient perspectives on communication about end-of-life care

Researcher(s):

Jane Caulfield, Graduate student
Edwards School of Business, Marketing
University of Saskatchewan
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306-203-6131

Supervisor:

Dr. Marjorie Delbaere
Associate Professor
Edwards School of Business, Management and
Marketing
University of Saskatchewan
delbaere@edwards.usask.ca
306-966-5916

Purpose of the Research:

This research aims to gain an in-depth understanding of patient perspectives on communication regarding end-of-life care and options for end-of-life care. As the Saskatchewan government works to develop policy surrounding the medical assistance in dying (MAID) legislation passed by the federal government in 2016, there is an opportunity to ensure any policy is well informed by the patient. The goal of this research is to serve as the bridge between policymakers and palliative or terminally ill patients to ensure the future of end-of-life care in Saskatchewan meets the needs of the patient above anything else.

Procedures:

Participation will include an in-person interview with Ms. Caulfield that will last approximately one hour in total. This could be one longer session, or multiple shorter sessions, depending on your preference. The number of times you meet and the length of each interview will be determined based on your comfort level. Should you decide to break things up into smaller amounts of time over multiple meetings that is entirely up to you.

The interview will be similar to a conversation, in which Ms. Caulfield will ask you one or two questions to begin and additional questions should the conversation call for it. Even though it is a conversation, you may still refuse to answer any individual questions. The conversation will be audio recorded for data collection purposes and the recorded conversation will be transcribed verbatim.

You will be asked a few questions about yourself, including your official diagnosis; however, your responses to these questions will not be part of the official results and will only be used to describe characteristics of the sample of participants in this study.

Should you decide to end the conversation and resume at a later time and date, you are welcome to do so at any time.

Funded by:

The Saskatchewan Centre for Patient Oriented Research and Edwards School of Business.

Potential Risks:

Because you are being asked to talk about something that is likely very difficult to discuss, there is the risk that these conversations can cause some psychological distress. The [ORGANIZATION NAME], of which you are a part of, has access to social workers and counselors who are available to help you through any difficulty should arise. If you would like to know how to contact these individuals, please ask the researcher at any time.

Potential Benefits:

This research will help ensure policy about end-of-life care and communication of end-of-life care options are communicated to patients in a way they would prefer and a way they are requesting. By participating in this research you will have an active role in the shaping the future of our health care system.

Compensation:

Participants in this study will receive an honorarium of \$50.

Confidentiality:

Your identity will be protected at every step along the way. While the researcher will know your original name, any identifying information will not appear in the final report. Instead you will be referred to by a pseudonym.

Any master list that includes your name and contact information will be stored on a secured server at the university until it is no longer needed for data collection purposes. At that time, this information will be destroyed.

All audio recordings will be immediately uploaded to a secure server at the university and subsequently deleted from the recording device. All materials, including recordings, will be securely stored at the university for no less than seven (7) years.

Right to Withdraw:

Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.

Whether you choose to participate or not will have no effect on your health care, access to care or how you will be treated.

Should you wish to withdraw, any reference to your partial or potential participation will be destroyed. Any recordings will also be destroyed. Any information you have provided up until you choose to withdraw will not be part of the final report. Your right to withdraw data from the study will apply until May 01, 2018. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data

Follow up:

You are more than welcome to review the results of the research, either through an in-person meeting or through receiving a copy of the final written report, or a combination thereof. You may also consider the option to have the researcher share the results with your family members. If you choose this option, please inform the researcher at the time of the interview.

Questions or Concerns:

If you have any questions or concerns, please do not hesitate to contact Ms. Caulfield or Dr. Delbaere using the information provided above.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Oral Consent:

I read and explained this Consent Form to the participant before receiving the participant's consent, and the participant had knowledge of its contents and appeared to understand it.

Researcher's Signature *Date*

APPENDIX E –TRANSCRIPT: CHRIS

CHRIS: Chris.

JANE CAULFIELD: Chris? It's a good name.

CHRIS: Why not?

JC: Yeah. It's a good name.

CHRIS: That was weird.

JC: Where can I put this where it's gonna work best?

CHRIS: You want to use ... would the floor work, or what?

JC: I'll just ...

CHRIS: Or what about a footstool?

JC: Yeah, let's do that.

CHRIS: I can park over here a little bit.

JC: Okay, I just knocked something off. I'll just drag this out.

JC: So ...

CHRIS: So?

JC: My first few questions are, I guess, relatively easy. Tell me ... tell me a little bit about yourself.

CHRIS: Well I'm 37.

JC: 37? Do you identify as anything other than Caucasian?

CHRIS: No.

JC: No?

CHRIS: I'm born and bred British but was born in Canada.

[00:01:03.01]

JC: Yeah. And your ... your diagnosis is cerebral palsy?

CHRIS: Palsy.

JC: Oh, that was a bad one.

CHRIS: Caused by prematurity. So it's spastic diplegia.

JC: Spastic diplegia?

CHRIS: Yeah. But I'm kind of an anomaly because I was born early enough -- ten weeks' early -- that mentally, for the most part I was good. But physically I'm quite severe on the CP spectrum. Like CP can be anywhere from minor physical ailments to significant ones, and I guess I'm not ... not fully ... I guess I would identify as, like, semi-quad, because I have use of all four limbs to some extent.

[00:02:02.16]

JC: Yeah.

CHRIS: So I have feeling everywhere, but I have a lot of, like ... I can't think of the word. Referred pain, and sort of ... my feeling's a little weird. So if I bash my ankle, sometimes my arm will hurt.

JC: Yeah.

CHRIS: Things like that. So I'm a little bit ...

JC: Your nerves are a little ...

CHRIS: A little bit messed up.

JC: Yeah.

CHRIS: Yeah. So, it's kind of ... you know? And my sense of direction is really, really poor, so ... so I guess but that's typical male for the most part. But ...

JC: And you don't ask for help in the stores and all those other typical male stuff?

CHRIS: Yeah. But I ... I can direction a little bit by landmarking, but ... but I'm pretty much one, two blocks out of my house and if you take me any further, you know, so ... even if I've known somebody for, like, 20 years or something, I can't find their house.

[00:03:08.14]

JC: Yeah.

CHRIS: Unless they're like my neighbour or live in my building.

JC: Yeah.

CHRIS: And even that sometimes I take the wrong hallway, so ...

JC: Yeah.

CHRIS: I've got a really good friend in the building, and sometimes I even get lost finding their apartment, so ...

JC: Yeah.

CHRIS: Or for example, if I ... if at work, somebody's office moves I'm like, messed up for ...

JC: Yeah. A little while. Well, I've gotten lost in these hallways, so don't feel bad about that one. They all look exactly the same.

CHRIS: Well that is true.

JC: So then, when it comes to end-of-life care, the medical ... the care teams that you work with have talked to you about the possibility that you -- because of all of these ailments that you have, or -- I don't know if 'ailments' is the right word that you would choose to use.

[00:04:03.05]

CHRIS: Well yeah, I guess it would be that. I mean, I don't have an end-of-life date, but we've talked about, you know, if ... if I ended up with a severe, you know, a terminal illness or something whether ... because I live in chronic pain already, so ...

JC: Yeah.

CHRIS: Whether that would be an option to me and sort of living wills and that kind of ... those kind of questions.

JC: Yeah.

CHRIS: So nothing formal per se, but just sort of like discussions and that kind of thing.

JC: So then how ... how have those conversations gone?

CHRIS: Well, just more of like, you know, you deal with enough shit day-to-day anyways, so if you ... you want ... you need to think about those things, then those are fairly normal. I mean, I would imagine if I ... I don't know. I mean, I don't ... you know, you don't ... if you have cancer or something, people don't respond to those treatments very well, well I'm not sure. Because of my ... because of, you know, the issues that I have, like responding to drugs. I can either handle a lot of drugs or very little, depending on the drug. And, you know, and those sort of things. And I have an incredibly high pain threshold that amazes my doctor sometimes, so I mean I can deal with a lot, but I would assume like if I got cancer or, you know, a terminal illness or an illness that could be terminal, then ... then those conversations would have to intensify.

[00:05:44.24]

JC: Yeah.

CHRIS: You know, what do you really want to do? And I'm always conscious of the quality of life quotient. I mean, I'm not somebody ... you know, I've always been conscious of ... I don't think I would want to live a life where I couldn't leave my house or I couldn't at least travel to see some friends or ... I mean, those kinds of things.

[00:06:10.00]

JC: Yeah.

CHRIS: I would want to live a shorter life with a higher quality than a longer life with limited quality.

JC: Yeah.

CHRIS: So ... and there's very little written on aging with CP because, well to be brutally honest, like, kids that were born that premature didn't usually survive. And ... and now it's ... it's much, much easier for kids to survive and live, you know ... be ... quote-unquote 'live normal lives.'

JC: Yeah.

CHRIS: But I don't know. Like, I feel that I'm somewhat closer to the cusp of, you know, maintaining my independence is fairly important.

[00:07:00.25]

JC: That's a big deal.

CHRIS: If that ... if that, you know, like I always say, "I don't know, I mean as much ..." is I don't know if I had a, you know, my transfers or whatever.

JC: Yeah.

CHRIS: If I had a bad fall or something and I ... you know, limbs were broken. I don't know, you know, I'm not somebody who wants to really live a ... well I guess I live a somewhat restricted existence anyway, but I don't to not be able to leave my house and have, you know ... I mean, my heart breaks for these seniors that ... that don't see anybody and don't ... don't sort of leave the house and stuff. So those kind of discussions have taken place. It's like, I don't think I could individually end my life at all, but I mean if ... if my quality of life was severely affected by either my ailments getting worse, or something else occurring which affected my ailments ...

[00:08:05.09]

JC: Then ...

CHRIS: Then, you know ... then [inaudible] before we chatted, I suppose I ... I mentioned to my family members that when I was in my late teens, like other surgeries were suggested ...

JC: Yeah.

CHRIS: And my family said no, because they didn't want me to go through any more.

JC: Yeah.

CHRIS: So I suppose if like, you know, umpteen major surgeries were required and ... and that kind of thing, I think I would really start thinking about, "Well ..."

JC: Other options.

CHRIS: "Do I have a number ... a short time of good quality of life? Or a longer term of very restricted life." And I ... I think I would pick the shorter.

JC: Yeah. Yeah. So when you talk to your doctor about this, how does that conversation go with your doctor? How does ...?

[00:09:00.00]

CHRIS: Well I've been quite lucky. I mean, I've had the same, you know, family doctor for over 20 years, and he knows me really well. So like ... and he's very open to sort of new treatments and ... and those kind of things. So I mean, I think if we got more intensified then he would probably be fairly open to that. I think he would be at a point where he would probably say, "You know, your ailments have to get to a certain point before we can have a frank discussion about it." But, I mean I know that, in myself I really don't want to end up in a very intensive institution.

JC: Yeah.

CHRIS: I mean at some point I know I'm going to have to end up in one later in life. But I almost think that I would want ... I would want ... I wouldn't want to end up in a very intensive one where ...

JC: Yeah.

CHRIS: So, those kind of things. But at this point, those aren't reasons to ... to go down that end-of-life discussion.

[00:10:03.11]

JC: Yeah.

CHRIS: I believe you must have a, you know, a terminal date to be eligible, so ... but I think more people are ... are more open to those kind of discussions, especially because ... I mean, my ailments are not going to be cured by medical science, really. Like, the brain is damaged, so unless they give me a new brain or something, then I'm not ... I'm not gonna be better. And I mean, the other thing is I mean, you can repair spinal cords but repairing brains is not ...

JC: It's not even a thing.

CHRIS: It's not really plausible.

JC: Yeah.

CHRIS: So as medical science improves and those individuals who have accidents and those kind of things ... a lot of the birth disabilities ... I mean, they'll improve treatments and stuff, but I don't think they'll quote-unquote 'cure people.'

JC: Yeah.

CHRIS: You know, because ... maybe I'm wrong, but I don't ...

[00:11:03.00]

JC: Yeah, yeah. It might happen but like, whenever Star Trek happens.

CHRIS: And I ... yeah, of course. And this is probably ... isn't a discussion for this interview, but you also have to think about, like, for individuals that have become injured, like they ... they've seen a different life, whereas I haven't. So ... so I think even ... even if medicine improved enough, that would be a really hard decision for me because I haven't really seen ... seen any other life. But if my life deteriorated where I was ... you know, I'm already reliant on caregivers and those kind of things to a great extent. But if I became completely reliant or lost my ability to communicate or ... write. I can't write, so I know that at some point my doctor's like, "Well, if you lost your ability to communicate and you couldn't ..." I lost the ability to make decisions and make choices ...

[00:12:04.27]

JC: Yeah.

CHRIS: ... with my physical ailments, then I think I'd have to have a frank discussion.

JC: Yeah. You've used the word 'frank' a couple of times. Is that important to you when you have these types of conversations?

CHRIS: Well I ... I have a relationship where ... with my doctor where I can ... he's very frank with me and he's like, "Yeah, that's no good." So there's not a lot of wishy-washy with us, right? So ... so you know it's been very good and I feel very lucky that I've had that relationship. But it's also because ... because you know, I know I'm not the prototypical patient, right? Like, he tells me that all the time. So ... so it's good that, you know, he has that kind of history with me, because I ... I think if you don't, then it's a real ... real little problem.

JC: Yeah. Yeah. So I just want to explore that a little bit further: when you say 'frank' what do you mean by 'frank?' Is that being blunt, or ...?

[00:13:05.19]

CHRIS: Well honest, basically. Like he'll ... I mean last year I had an issue where my pain was increasing and ... and then, you know, so we went through this whole, you know, we tried this one, tried this one, but ... but one thing that with pharma things for sure, the side effects have almost a greater impact on me because of all my different ailments than the actually the drugs do. So ... and I'm not a big proponent of taking a pile of drugs either. So I think -- I mean, this is different -- but if I became reliant on, you know, 15-16 pills a day or some of the people that ... that, you know, I hear about in my charity work that are on 12-13 pills a day and they can't ... they can't function or they can't ...

JC: Yeah.

CHRIS: And it affects their functionality. I think that would be a point also where I would have to have a discussion and say, you know, "Something's gotta be killing me if I'm on this many pills."

[00:14:08.26]

JC: Yeah. Yeah.

CHRIS: I'm currently ... I'm not on that many. You know, I'm experimenting with a new one right now which seems to be having some impact. But you don't know the impact it's having on other things, too.

JC: Yeah.

CHRIS: As you increase doses and stuff. So, you know ...

JC: So you ... you have a lot of conversations about care with your doctor, and they ...

CHRIS: Yeah, yeah. We talk regularly.

JC: Yeah.

CHRIS: Probably more regularly than the prototypical patient, for sure.

JC: Well, and you ... so in our conversations before today you've kind of hinted and skirted around the issue of having conversations with your doctor about MAID and medical assistance in dying. And it ... can you describe that for me? Like, have they been ...? It sounds like you have a good relationship with your doctor, but have they been ...?

CHRIS: I don't think we've had the ... the formal medical assistance dying discussion. But I think we've had discussions about my fears of losing what independence I have and my fears of losing decision-making.

[00:15:14.08]

JC: Yeah.

CHRIS: You know, I lived ... I lived in a very structured setting in my younger days and for a time period I liked it, and then it became that I was losing the ability to make my own decisions and live my own life and, you know, I wasn't getting treated very well. I mean, it was never proven but, you know, well I believe there was lots of abuse and mistreatment and those kind of things. And those ... those were the times when I first thought about, you know ...

JC: Yeah.

CHRIS: Later in life if I ended up back there, then I would have to start seriously considering ...

[00:16:10.05]

JC: Options.

CHRIS: Options to ... but at that time and at this time that's not an option, right? You must have a diagnosis of a ... I think that's what I understand anyway. Yeah, so ... so I wouldn't qualify.

JC: Yeah.

CHRIS: But I know that, you know, I wouldn't want, you know that ... I mean, those kind of discussions came up when my father passed as well -- after his massive heart attack -- was that ... that, you know, he wouldn't want the kind of life that I may have later. I'm gonna want to delay it as much as possible.

JC: Yeah.

CHRIS: But ... but I mean it's a tangible thing that might occur to me. So ... so I don't think we've had formal like, "How would you go about it," or that kind of thing. But more of like the importance of maintaining freedom of life that I have now. But I'm sure I'm quite different than a lot of the other people that you've probably spoken to because, you know ... but I can relate to them in that if I ... if I contracted another illness that would put my life in danger, I would seriously have to think about those options because of the other ailments I already have.

[00:17:42.01]

JC: Yeah.

CHRIS: So I guess I'm ... I might be unique in your other study subjects.

JC: That's more than fine. Everybody is super unique in their own way.

CHRIS: Can we have a break so I can use the bathroom?

JC: Yeah.

[break in tape]

[00:18:01.00]

JC: I think ... I actually suspect my father-in-law will be there today fixing them on his own.

CHRIS: Well, Shane's dad isn't around too much, so probably if you can help with that, it would probably go over well.

JC: I'm just going to dive right back in. Is that okay?

CHRIS: Yeah, yeah.

JC: So one of the things I want to know about is, what kind of language does your doctor use? Because you've ... you've said that you have good conversations, you're happy with the way they go, pretty much. In a nutshell you've described that. But what makes them good conversations for you, when you're talking about end-of-life care, or talking about having those conversations in the future?

CHRIS: Well, I think it's just, you know, that ... that there isn't much beating around the bush, right?

JC: Yeah.

CHRIS: Like, it's pretty, you know, the thing I enjoy about him is that he doesn't ... he involves me in the discussion. Like he doesn't ... he doesn't just say, "Well, I think this is best." He's more of like, "Well, what do you need, this certain aspect?"

[00:19:17.03]

JC: Yeah.

CHRIS: "To do for you?"

JC: Yeah.

CHRIS: Like even if it's not end-of-life, but like, you know, what do you want out of life and how, you know, it's more ... I feel like it's more of a team.

JC: Yeah.

CHRIS: Then just sort of like, "You need to do this." And like, I'm sure if I got a, you know, something significant, like a [inaudible] or something, he would be like, "You can't ... you can't do this, you can't do this, you gotta do this." But it's more of like, "Okay, how do we balance what you want out of life versus what you need to do for your body." And my body reacts weird to things.

JC: Yeah.

CHRIS: So it's like ... so a lot of times he'll be like, "Well, we'll try this, and then you need to tell me like, you know, how you're feeling with it and then I'll work around that." Like it's not ... and it's more of like, there's regular engagement.

[00:20:11.03]

JC: Yeah.

CHRIS: I think -- I don't know if I should admit this, but I think I get more ... it's more of a follow-up and a holistic approach more than, you know, "Here's a bunch of antibiotics. Take them and come ..." you know.

JC: So ongoing ...?

CHRIS: Yeah, but I mean he always says, "Well with that." And I always think, "Well, I'm a difficult patient." And he's like, "You're not really a difficult patient because you ... you come to me ... first of all, you come to me usually when something is ... needs to be dealt with. You're not somebody that just comes to me with everything." And you know, I'm having issues right now with, you know, getting accommodated at work and those kind of things. And so there's more interaction now, so it's ironic that you're doing the

interview now. But ... but I mean with the way my body tolerates pain, like usually I don't complain about something until it's significant. So he knows that if I'm complaining about it then it must be a significant issue, because I'm ... he teases me that I don't pharma more than I have to, right?

[00:21:33.19]

JC: Yeah.

CHRIS: So those kind of things. So more that it ... more that it's more of a holistic approach, and that there's ... that there's ... oh God these are terrible.

JC: Do you want me to clean them for you?

CHRIS: Well, I wouldn't normally ask, but ...

JC: Do you have cleaner?

CHRIS: Well usually just water and just down by the sink, but I literally ... I'm struggling to see you.

[00:22:02.03]

JC: Yeah. I'll do it. Well you just put your thumb on them, so ...

CHRIS: Well there was a fingerprint there before.

JC: You just use water and a towel?

CHRIS: Yeah, just use water. And there's Dawn there that sometimes they rinse them in. But you gotta ... you gotta rinse it well.

JC: Yeah.

CHRIS: That's the blue stuff.

JC: The green? This is green.

CHRIS: Yeah, that stuff. Is your tape recorder still going?

JC: Yeah, but I can edit this part out.

CHRIS: Okay.

[00:23:12.04]

CHRIS: I was literally having to peer at you.

JC: You were what?

CHRIS: Literally having to peer at you. I could not see at all.

JC: How's that?

CHRIS: I'm sure it will be better. Oh yeah.

JC: Better?

CHRIS: Oh yeah. Thank you.

JC: No problem. When you have talked about making sure that you want your quality of life to remain at a good level, do you feel as though your doctor understands what you're asking for?

[00:24:06.20]

CHRIS: Yeah. I think ... yeah. Because, you know, he knows that I went through the group home experience, and knows that ... I mean, he's been very supportive of documentation on my care plan, caregivers and that kind of thing. And he's very aware of the fact that I have caregivers and that I need a level of care and what I need and stuff like that. So yeah, I would say he's ... he's aware. I mean, we haven't talked about what point those things would be ... you know, what the triggers would be.

JC: Yeah.

CHRIS: But I feel that the ... that the groundwork for the discussion has been had and there would be a level of understanding of what ... at what point ... when those discussions would be ... would have to be had.

[00:25:04.06]

JC: Yeah.

CHRIS: Obviously those ... those things and obviously the issues with my immune system related to CP, then those discussions may not be needed because I may naturally be finished off. But ...

JC: That's a nice, blunt way of putting it.

CHRIS: Well, I mean you know, I've seen people that have had chronic conditions.

JC: Yeah.

CHRIS: I mean, you know, I'm always aware of, like, taking precautions and trying not to be exposed to too many things.

JC: Yeah.

CHRIS: Because you know, even the common cold takes me, you know, longer, much longer to get over and those sort of things. So you're aware of those things and you ... you talk about your own mortality and you're aware of your own mortality. But nothing's guaranteed in life at the best of times.

[00:26:04.17]

JC: Yeah, yeah.

CHRIS: But I think that I'm more philosophical about it than most, probably.

JC: That's okay.

CHRIS: Judging by the bluntness you said I just used. But, you know ... and I don't really have a fear of death per se. I mean I ... I don't want to die, and have no intention of dying. But I don't really fear it because I really shouldn't be here, so I've always looked at it as a bonus. But I've always ... I've always wanted to sort of overachieve and prove people wrong. So there's that part, too.

JC: Well that's ... I mean that's something that I know about you: that you were kind of told a few times, "Oh, you're not gonna make it to 30, you're not gonna make it to 40. You're not gonna ..."

CHRIS: Well, I mean you know, I mean the fact that I survived very early infancy. I mean, I probably wasn't supposed to. And then my ... my poor parents, they said, "Oh he'll be fine." You know, "He'll be the normal distribution and won't be any issues." And then age two I couldn't walk and they started to think, "Oh, shit. There's something wrong." So you know, and I ... I know that, given my ailments I have overachieved and I have, you know, sort of broken out of the box.

[00:27:31.24]

JC: Mm-hmm.

CHRIS: So I ... I don't really know what the future holds. Which is ... I suppose nobody does, but medically I don't ... I don't, you know ...

JC: Yeah.

CHRIS: Prototypical aging things.

JC: Yeah.

CHRIS: You know, I mean I don't want to talk about other people, but I have this ... this friend that his CP started a lot less severe than mine. Like, he ... he began walking with a cane and then it was crutches.

[00:28:07.01]

JC: Yeah.

CHRIS: Now he's in a chair most of the time. And he can stand a little bit. And he's, what, early-60s.

JC: Yeah.

CHRIS: So ... and the CP and aging is ... is really starting to catch up with him. But we are more equally physically now than we would have been when he was 20.

JC: Yeah.

CHRIS: So ... and he's 65 and at this point.

JC: Yeah.

CHRIS: So you kind of look at him and go, "Well, you know, am I going to make 65?"

JC: Yeah.

CHRIS: You know, he can drive, so his ... he's not ...

JC: He's got more use of his ...

CHRIS: ...as affected there, right? So there's that. And you know, some people compare us and it's not ... not really a fair comparison.

[00:29:05.18]

JC: Yeah.

CHRIS: But I'm physically ... I'm sort of closer to him now at 37, 38, and he's 60-something.

JC: Yeah. Yeah.

CHRIS: But then he started a lot lower on ...

JC: On the scale.

CHRIS: ... than I did. And then you have kids that have severe, severe CP that have a life expectancy of maybe teenagers, right? So there's not a lot of research on aging with it. So medically, you know, it's hard to really peg where I'm going to end up, so the fact that there's openness about those discussions is probably good, but we really don't know.

JC: Yeah.

CHRIS: And part of the issue is kids didn't survive ... that premature. So ... so there's nobody to research, right?

JC: Yeah. Yeah. Well you can start a trend if you want.

[00:30:01.13]

CHRIS: Maybe.

JC: So do you ... like, you've pretty clear on the things that you ... the conversations that you have had with your care team, with your doctor. Have you ever ... like, have you talked to him about a living will or any of those types of things?

CHRIS: Yeah, I probably should have one.

JC: But you haven't ... you haven't had ... it just hasn't come up?

CHRIS: I haven't written it, but there's talk of ... but it's like, I've always had a difficult time ... like, I love life and I love the people in my life, so it's like, "Well, do you say no desperate measures, do you say some?" Like, those aren't really ... I mean I'd have to think about it. I mean, you know ... so I don't really know where I would stand on that.

[00:31:03.19]

JC: Yeah.

CHRIS: I mean, I would ... and let's be honest, friends and loved ones can override those things anyway. I've seen it. So, I mean ...

JC: It's not supposed to happen.

CHRIS: It does on the regular, though.

JC: Yeah, I know.

CHRIS: So I mean it's ...

JC: So then is that a conversation you would want to have with your doctor?

CHRIS: Yeah, I mean we've talked about probably I need one. And, you know, it's probably sensible. But I don't know to what extent I would go and ... I mean, and there's talk of like ... we've talked about, like, a medical trust.

JC: Yeah.

CHRIS: And that people should make decisions and, you know, where I end up. But it's very ... I suppose a living will is important now that I think about it, because I want to be able to make the decisions, so ...

JC: So your voice will be there, yeah.

[00:32:00.14]

CHRIS: I guess it's needed and I ... but I need to do more research into what you can put in there and how, and those kind of things. But it's definitely been brought up by ... by the doctor, so ...

JC: And ... so if you were to have that conversation with the doctor, how would you want that conversation to go?

CHRIS: Well, I mean to me that's my decision, so I mean, I think with that he would just tell me how to write it, advise me on, you know, the options that I had, and those kind of things. I don't think he would ... I mean ...

JC: So you kind of just want the facts from the doctor.

CHRIS: Yeah, I don't think he would want to influence that at all. I mean, he would probably ... I mean, like, that's a really, really tough question because it's like, well ... you know, I suppose I would want to weigh up chances of recovery and ...

JC: Yeah.

CHRIS: But I would kind of want ... I mean, I suppose a living will would be good, but I would kind of ... I've always been a percentages guy.

[00:33:03.13]

JC: Mm-hmm.

CHRIS: So there was a surgery that I could have had when I was younger, and it was like, the percentages I was given was 50 percent would stay the same, 30 percent you'll get better, and 20 percent you'll get worse.

JC: Whoa.

CHRIS: Or it might have been slightly different, but it was like a percentage where you'd stay the same, a percentage where you'd get ... maybe it was 50 you'd get better, 30 you'd stay the same, and 20 you'd get worse.

JC: Yeah.

CHRIS: And it was a year-and-a-half recovery.

JC: Whoa!

CHRIS: And I was like, "Nah."

JC: Nah.

CHRIS: And now I ... now I deal with pain as a result of not having the surgery.

JC: Yeah.

CHRIS: But I didn't lose a year-and-a-half of my life, and I'm fairly certain now, because the same surgery people that I know are having to have it redone.

[00:34:03.01]

JC: Mm-hmm.

CHRIS: Like, it worked, but they're now discovering that you have to have it about every five to seven years to sort of reset bones and stuff.

JC: Yeah.

CHRIS: So ... and the fact I haven't had it is probably going to cause me problems later in life, but my life wasn't adversely affected by having it. So, to me that was a good decision.

JC: Yeah.

CHRIS: But, you know, so I suppose it would be like, well if what happened to me, there's a very good ... there's a solid chance that I'll get back to the life I had ...

JC: Yeah.

CHRIS: Or a small chance I'll be better, and kind of a lesser chance that I'd be worse, then I would want to give myself a shot.

JC: Yeah.

CHRIS: But if was like 70 percent he's gonna be worse, 10 percent he might be better, 20 percent he's gonna be as he is now following the incident, then I would probably say, "Well ..."

[00:35:05.06]

JC: Screw it.

CHRIS: Screw it. But those ... those ones are always ... always tough. And I'm 38, so you know, you should do living wills when you're old. But I probably need one, so it's probably a discussion I need to have.

JC: So I have one last question.

CHRIS: That's it? One? Oh, okay.

JC: I might, depending on your answer ... I might go higher. But ... so you've mentioned frankness, a sense of relationship. Is there anything else, like humour or ...?

CHRIS: Well he makes fun of me all the time. So you know ...

JC: What do you mean he makes fun of you all the time?

CHRIS: Well he just says, "Oh you're ... you're a medical student's dream." You know, "You're the jackpot for medical student," right?

JC: Yeah.

CHRIS: You know, because he works in a teaching hospital.

JC: Yeah.

CHRIS: So, you know and he says, "Oh," like, "You're not the prototypical ..."

[00:36:05.06]

JC: Mm-hmm.

CHRIS: I mean, I don't think he's used this word, but I get this sense that I'm a puzzle to him.

JC: Mm-hmm.

CHRIS: So like, and I make him think. So he always makes fun of that.

JC: Yeah. How does that make you feel?

CHRIS: It's the truth, so it's like, whatever.

JC: Yeah.

CHRIS: I don't ... I don't like being ... I'm not a fan of, like ... the one thing I don't like is when, like, I guess I'm very particular in this case. Like, I don't like seeing members of his medical team. I don't like seeing residents of his team. Like, residents and medical students can be with him, but I'm always very like, "Nah." You know, so I suppose ... probably don't print this, but I suppose it's like a bond of understanding, I guess. Is that I think ... I think he understands me, so I trust him with what he says to me.

[00:37:05.00]

JC: So there is ...

CHRIS: Which is ... which is, I mean ... and I wouldn't say we're ... we're not friends in any way. Like I don't ... I don't ...

JC: Hang out with him?

CHRIS: Hang out with him or anything, because you know you're not allowed to do that. But I feel like there's this ... I don't ... medically, I don't trust a lot of people.

JC: Yeah.

CHRIS: So ... and the fact ... and others make ... make fun of it like, "Oh, he's only a GP."

JC: Mm-hmm.

CHRIS: Right? He's only ... you know, the problems with work, they always say, "Oh, he's only a family doctor, he's not a specialist."

JC: Yeah.

CHRIS: But the fact is he knows me better than most specialists, right?

JC: Yeah. And you've ... you've had to deal with specialists.

CHRIS: Oh yeah. And I mean they change like the sky of any particular day, and they change more than the weather a lot of times, particularly in this province because they shuffle you around more than ... than, you know, like you're pieces of meat. So I guess it's ... it's a bond of understanding and trust, really. Like, if he tells me something, you've got ... of all the doctors I have, if he tells me something like, "You gotta quit doing this," I'm more likely to quit doing it.

[00:38:20.16]

JC: Mm-hmm.

CHRIS: Right? Because I feel like he understands me. Because I'm not gonna respond to things in the normal bell curve. And he knows that, so he'll take my input on board, whereas a lot of doctors, because I have a chronic condition will just dismiss me a lot of times. Or talk around me, or not at me, right?

JC: Yeah.

CHRIS: So ... that's why I had so much trouble with the contractor. You can take that out, but ... he spent the whole time talking to Shane.

JC: Yeah.

CHRIS: But yeah, it's ... I mean, I feel that he ... I'm valued in the discussion.

JC: Yeah.

CHRIS: And that there's a bond of trust there. So he's not gonna bullshit me.

[00:39:06.21]

JC: Yeah.

CHRIS: Right?

JC: Yeah.

CHRIS: And I'm more likely to take his advice than anybody else's.

JC: Yeah. So if it came down to, "Alright Chris, you've got pneumonia. This is it for you, you're not going to bounce back from this." You would want him to ... to talk to you about what?

CHRIS: Well to talk to me about, like you know, if I've got days or weeks or am I ... is there any chance I can fight it off?

JC: Yeah.

CHRIS: Because he doesn't write me off either, right? I've ... I've surprised him a whole bunch of times.

JC: Mm-hmm.

CHRIS: It's like, "Oh fuck. You weren't supposed to recover from this as well as you have. Boy, you should have recovered more than this, quicker than this." Or, "Man, you're recovering from this slower, not healing." So yeah, I mean he would be the one doctor ... well, I'll give an example: when, a number of years ago -- I think it was '07 -- I was having major stomach pain.

[00:40:06.10]

JC: Mm-hmm.

CHRIS: And I went to emergency and I had a whole bunch of gallstones in my gall bladder. Like, the doctor's like, "You know, the amount of stones would have like ... other people would be on the floor, writhing in pain, begging for their mother to hug them. You came in and you were like, 'I'm a little sore. Something's going on, but I'm going out of the country in four or five days, so if it can be delayed then let me know.'"

JC: Yeah.

CHRIS: And he was like, "You have, like, 16 stones," or something. I can't remember the number but it was pretty big. So they took me in and I was like, "Well I'm still going on my vacation. So whatever." So ... and I told the doctor, "You know, you don't get to do the surgery unless I get to go." So ... and I told the doctor that ... the surgeon that I was going, and then he made ... they made me a deal that if I could urinate within a certain amount of time I could go. So ... and I managed to do it with, like, 30 minutes to spare. And I was gonna ... you know, my mom was like, "Nah, you shouldn't go," and I'm like, "Fuck it. I'm going."

[00:41:16.17]

JC: Yeah.

CHRIS: So ...

JC: I'm gonna squeeze it out, every last drop.

CHRIS: So it was basically that ... that I -- even though the doctor was like, "There's no way you're going," I was like ... I was like, "Yes I am." And I didn't ... probably if he would (have) told me, like ... if my regular doctor had said to me like, "This is stupid," you know, things like that. But like he'll ... he'll take into account, like he ... he always tell me, like being out of my regular life and in a more relaxed environment, when I do go away, he says it's beneficial to my health.

[00:42:00.17]

JC: Yeah

CHRIS: Which other doctors have been like, "Well, why do you ... why do you put yourself through the travel because you're gonna end up in more pain and stuff." But he can look at things as kind of equations a lot of times. So ... so that those kind of discussions are probably ... so if he told me that, you know, "You got a couple years and then it's gonna be hell," or whatever, then I would be like, "Well, okay. Well then we'll make plans that ... I'll do everything I want to do in the next few years and then ... then we'll have a frank discussion about how ..."

JC: Options.

CHRIS: Options. And I can't imagine being somebody with a terminal ... terminal date at this point. But I would think it has to be an equation between quality of life, desires, and you know, there's a lot of things you gotta balance. But for me, it would probably be the quality of life quotient.

JC: Over everything.

[00:43:02.03]

CHRIS: Would be the thing that ... you know.

JC: Yeah, well you said that a few times: quality over length kind of would be your ...

CHRIS: Yeah, I would think so. I mean ... and I suppose age, right?

JC: Mm-hmm.

CHRIS: I mean it's ... you know, I mean I wasn't really supposed to live. So it's kind of like well, you know if I get to ... if I get to 50 and then it's like, yeah your quality of life quotient's going down, then I would think discussions have to be had and those kind of things.

JC: Yeah.

CHRIS: So I suppose I'm unique in that way in that I can ... I can foresee that and be honest with myself with that.

JC: Yeah. So when it would come down to having a conversation about MAID specifically, it depends on that equation. Is that ...?

CHRIS: Probably. And his ... I mean probably by that time he'll be retired, but I would think he'll ... I don't know. I would ... I would like to think to some degree he would be involved, I would think.

[00:44:02.24]

JC: Mm-hmm.

CHRIS: I don't know. I don't even know if that's possible or whatever. But ... but yeah, it's weird now. I can't really, really picture going to another doctor, even though it would have to ... it's a reality, right?

JC: Mm-hmm.

CHRIS: But yeah, it would be ... it would be a tough, tough ...

JC: Tough go?

CHRIS: Tough ... well, a tough thing to sort of have. And I ... I don't know, I would think with the amount the guy teaches other doctors he'll be around, so ...

JC: Yeah. And I also think -- and I could be wrong -- but because an MD is a professional degree, he can retire but still practice. Like, he could come here.

CHRIS: Yeah, I mean I don't know. I would ... I would think, you know ... because even other medical practitioners he works with says that he ... he understands you the best. Like if you see other doctors, it's gonna ...

JC: Yeah. Yeah. Alright.

CHRIS: So that's it?

JC: That's it.

APPENDIX F –TRANSCRIPT: MABEL

JANE CAULFIELD: So we'll start the recorder. And again I want to stress that you can stop the conversation at any point in time. You don't have to answer right away. You don't have to answer questions you don't want to. You ... you get to steer the ship.

Mabel: Okay.

JC: And so my first questions are going to be really easy ones.

M: Are they? Maybe not ... if I've got to remember they might not be so easy.

JC: Well can you tell me your age?

M: Yes. Do you want my date of birth or my age?

JC: Just your age is good.

M: I'm 92.

JC: 92: You don't look a day over 75.

M: (laughs)

JC: It's true. You're looking pretty good for 92.

M: Thank you!

JC: And what would you identify as your ethnicity? So, Indigenous, Caucasian ... ?

M: I've always ... like, our background leads to Scottish.

[00:01:03.22]

JC: Okay.

M: But for Christmas I got a ancestry thing?

JC: Oh!

M: One of my kids sent it to me for Christmas. So I sent it off just not so long ago. I've got to do some ... they sent some work back on the iPad and I guess it would be, I don't know, a page or two. So I have a friend there, Wanda, and she's like a companion to me.

JC: Yeah.

M: She's my son's wife ... my son's friend's wife.

JC: Yeah.

M: And she's really, really good. She's an ex-ambulance ...

JC: Oh, a paramedic?

M: A paramedic with the extra medicine thing on it. So she's wonderful.

[00:02:01.11]

JC: That's good, that's good.

M: And so -- what was I saying? Oh, so she's going to help me with that.

JC: With the other work that you have?

M: I have trouble retaining, like ... my memory is not good. But if I'm reading something, very often I have to go back and read the sentence again.

JC: Mm-hmmm.

M: So if she ...

JC: I have to do that sometimes, too.

M: If she takes it to do it, well she just does it, you know?

JC: Yeah.

M: Asks me the questions and I answer them.

JC: Yeah, yeah. That's good. That's good.

M: So I'm very fortunate with her. Oh yes, she's a wonderful friend.

JC: Yeah. That's good. I'm glad, it seems you have quite a few friends.

M: Oh yes. I'm very ... I'm a lucky girl. And I'm in such a good place.

JC: Mm-hmmm.

M: But [WORKER's NAME] is ... and the rest of the staff are just as good as she is.

[00:03:03.21]

JC: Yeah.

M: They're just so good.

JC: Yeah.

M: And it's such a nice place to live. I'm just whoever I am. If I wake up at 7:30 and bring in my paper and am sleepy I go back to bed and go to sleep.

JC: Mm-hmmm.

M: You know, it's a really good place to live. And the food is good.

JC: That's good. That's a bonus.

M: Wonderful, wonderful food. And, you know, everybody ... there's just nice people in here.

JC: Mm-hmmm. That's good.

M: Oh, I couldn't be in a better place.

JC: Well that's good to know. Because my mother's starting to look for a place, so I'll have to tell her ...

M: The best place you can be, because it's independent.

JC: Yeah.

M: There's no nursing staff or medical help, but as long as you can look after yourself, you can stay in ...

JC: In this one. In the towers, yeah. So one of my next easy questions is: what your official diagnosis is? So you had mentioned that you had palliative come in yesterday.

[00:04:11.04]

M: Yes. I have stage four breast cancer.

JC: Oh!

M: But, I had a double mastectomy 12 years ago.

JC: Okay.

M: So it's in my lungs.

JC: Oh, okay. So it's moved.

M: But it is ... it's not lung cancer, it's breast cancer.

JC: Yeah.

M: And I guess that's what's doing the dementia on me.

JC: Yeah, yeah.

M: Because it ...

JC: Yeah.

M: That's what it does.

JC: Yeah, and 12 years ago, when you had your double mastectomy, was it stage four then as well?

M: No, it was stage two.

JC: Stage two? Yeah.

M: And I had 30 rounds of radiation, which is too much.

[00:05:04.03]

JC: Mm-hmmm.

M: And I couldn't take the chemotherapy because I only have one kidney.

JC: Oh, okay.

M: And it wouldn't ... couldn't [unintelligible]. So I took, oh I forget the name of the ... it was a chemotherapy for a long time.

JC: Mm-hmmm.

M: It must have been five years.

JC: Yeah. That must've been really hard on your system and on your ... ?

M: Well I think it has to be hard on your system, but I don't know, I'm doing pretty good.

JC: Yeah.

M: Can't argue with that.

JC: That's good. That's, well half the battle is a positive attitude I hear. So, yeah. My mother is a breast cancer survivor, actually, so she's 20 years cancer-free now.

M: Oh, good for her!

JC: Yeah, yeah she's pretty proud of that.

M: Yeah.

JC: Yeah. Alright, so these are the real questions.

[00:06:02.12]

M: The real questions. Okay.

JC: So tell me about your experience when you learned about your terminal diagnosis. How did that ... tell me about your experience when the doctor told you about the diagnosis.

M: Well I knew it before he did, so ...

JC: Yeah.

M: I told him at Christmas, a year ago Christmas. I said, "I've got some daisies growing in here," and he started to laugh.

JC: Yeah.

M: So it wasn't any shock to me.

JC: Yeah.

M: But that's a little different than some. And I've had diagnoses handed to me before.

JC: Yeah, it sounds like it.

M: And my husband died with it, so ...

JC: Yeah. Yeah. So when you had that conversation, you ... you steered the conversation, then?

M: You what?

JC: You steered the conversation? You took charge? Or ... ?

M: Sure. Whatever. My doctor's my friend, so ...

JC: Yeah. That's good, that's good.

[00:07:00.10]

M: He's a great doctor.

JC: So when you have conversations about options at end-of-life and palliative care, how did that conversation go?

M: Oh, just like I'm talking to you now.

JC: Yeah?

M: Just like as if I had a cold.

JC: Yeah, yeah.

M: It's very, very easy to talk with someone.

JC: Yeah. What ... ?

M: And, you know, I'm 92. Something's going to break pretty quick anyway.

JC: I don't know. You seem pretty tough to me. So when you have those conversations are they straightforward? Or ... ?

M: Always.

JC: Always?

M: Oh, yes. I have a good doctor.

JC: Yeah. And you prefer the straightforward conversation?

M: Oh, yes.

JC: Why is that?

M: Well I've had to be quite independent in my lifetime. And I need facts.

JC: Yeah.

M: Just the facts, ma'am.

JC: Just the facts, yeah. And when you ... so then when you have those conversations, does it make you ... how does it make you feel when you have the straightforward conversations?

[00:08:01.05]

M: No different than if it was through my toe.

JC: Mm-hmmm. Mm-hmmm.

M: I have no trouble handling the facts. You know, I know that you're going to go someday, too.

JC: Yeah.

M: I just ... I just said it to Sharon. I said, "Sharon, you might die before I do." (laughs) Who knows?

JC: Who knows?

M: I don't know. I make no bones about it. I don't make people ... I hope I don't make people uncomfortable.

JC: Yeah.

M: Talking. Because you know that's always kind of ... a hard swap. But it ... I just said, well he gave me ... he said ... it was actually Wanda that asked, and I said ... she was going to ask him in the hall, and I said, "No. I want to hear what you're going to say." And he said, "Between four to six months."

[00:09:03.10]

JC: Yeah. And that was last Christmas?

M: No. This Christmas.

JC: This Christmas. So just recently.

M: Just a little while ago. When I went ... see, I had to go back to the cancer clinic again.

JC: Mm-hmmm.

M: I don't go to the cancer clinic. I'm ... because I'm not taking anything or doing anything with them.

JC: Yeah.

M: But through the clinic, you see, I'm in palliative care.

JC: Mm-hmmm.

M: And that's what I needed.

JC: Yeah, yeah. So what type of conversation did you have with your doctor about palliative care? How did you ... what did he talk to you about that?

M: Well, how was it ... oh, I said to him that I wanted to get into that loop.

JC: Mm-hmmm.

M: And I knew about it because I ... Bill had had ...

JC: Yeah.

M: And the nurse is the director now, was one of Bill's nurses, his favourite. In fact, in his obituary she's acknowledged.

[00:10:09.04]

JC: Oh! That doesn't always happen with nurses.

M: (laughs). Isn't that something? She said [unintelligible]. I thought she looked familiar, but you know. That's a while ago. And she said she was doing the same thing, you know. Oh, I met this woman.

JC: So she's the director of the palliative care now?

M: Or something to do ...

JC: Oh, with the home care part of it?

M: Palliative care.

JC: Yeah, yeah. So then -- just looking at my questions here -- so you've ... you've mentioned that you like the straightforward and just the facts.

M: Mm-hmmm.

JC: When it comes to options, when you think about ... there's the new Medical Assistance in Dying legislation that's come out?

[00:11:01.02]

M: Mm-hmmm.

JC: Did you have any of those conversations with your physician, or ... ?

M: No, well I haven't met ... I often say to him when I'm not feeling good, "Maybe I'll head for Oregon for some purple juice." (laughs) He says, "Don't say that!" But we've never had the euthanasia conversation.

JC: Mm-hmmm.

M: Per se.

JC: Yeah.

M: But he knows where I stand if I ...

JC: Yeah. But he's never engaged in the conversation with you?

M: Not that I ... Doug's home this time. He'll go with me and Doug is interested in what ... we've never got to that point yet.

JC: Yeah. Yeah.

M: But he ... he'll be easy to talk to. He is so easy. He is such a good doctor.

JC: What makes it easy to talk to him?

M: He's just easy to talk to.

[00:12:00.21]

JC: Mm-hmmm.

M: I can ... I can reply. It doesn't ...

JC: Yeah. He doesn't use big words, or ...

M: Oh, not a bit of it. And he's got a good sense of humour.

JC: Yeah.

M: I say that's what saves my soul: is that I can laugh at things.

JC: Yeah.

M: And that's just what Sharon said. "Yeah, you go smiling, I know." It beats crying all to heck.

JC: Yeah. So having a sense of humour is important in those conversations?

M: Oh, I couldn't live without laughing.

JC: Yeah, yeah. And he laughs with you?

M: Oh, yeah.

JC: That's good, that's good.

M: He knows. I've had him for quite awhile.

JC: Yeah? For how long?

M: Well it was after Ed died because I didn't like the way the doctor looked after Bill and he ... you know, she didn't take any interest in him at once. He was diagnosed, he went to the cancer clinic, and never heard from her again.

[00:13:04.15]

JC: Mm-hmmm.

M: And he's not like that at all.

JC: Yeah. That's good, that's good.

M: And that's when I got ... changed doctors. It's been about 12 years.

JC: Yeah, yeah. And he's straightforward, which is good. I know I always prefer straightforward doctors.

M: Mm-hmmm.

JC: So then when it comes to talking about the ... going to Oregon and drinking the purple juice as you called it ...

M: Yeah. (laughs)

JC: How would you want that conversation to go?

M: What do you mean?

JC: Would you want to start it with the doctor? Would you want the doctor to have that conversation with you?

M: Oh yeah, I want everybody to have a conversation with me about this. I mean, that's ... would be ... it would be not a hard topic. And I probably wouldn't use it if I have to in the end.

JC: Yeah. Yeah. So then would you ... would you feel uncomfortable or awkward having a conversation, or ... ?

[00:14:07.14]

M: No.

JC: Why not?

M: It's life.

JC: What was that?

M: It's life.

JC: It is life, yeah.

M: I've had a lot of things happen to me in my lifetime.

JC: Yeah.

M: And, I mean, a lot worse than this. So ...

JC: Yeah. So this is ...

M: So what. Doug says, "My mom's a tough old girl."

JC: (laughs)

M: I'm not tough, I've just been there and done that.

JC: Yeah. Yeah. So when it ... when it comes to talking about the end of your own life, you're pretty ... you seem pretty ...

M: Oh, it's easy.

JC: Yeah.

M: It's easy. I know I could go tonight, or ...

JC: Yeah.

M: And the doctor said that ... the cancer doctor when I answered ... he was good, too. He had a good sense of humour, too.

[00:15:04.26]

JC: Yeah.

M: And you know, he said to me, "Well, you've got a three-way." My heart is not good, I don't have ... my kidneys -- or kidney -- is not good. And the cancer, so ...

JC: Yeah.

M: There you go. Take your choice.

JC: Take your choice. And what were the choices that he gave you?

M: Pardon me?

JC: You said 'take your choice.' So ...

M: No, he ... I said 'take your choice.'

JC: Oh, ah. Yeah.

M: So, there's a few options.

JC: Yeah. Yeah. So then ... I don't know, you've answered all my questions so quickly. You're just ... you've got all the answers.

M: Well, no, I don't have all the answers.

JC: (laughs)

[00:16:00.19]

M: I tell you, I ... when I accepted to do that I said, "Well, I'll tell her what I know, but I don't know very much."

JC: Well it's ... it's about how you feel. So it ... but it sounds like you feel like you've had good conversations with your physicians and ...

M: I'm very comfortable with the fact that I don't have much time to live, because I know neither does anybody else.

JC: Yeah, yeah. That's a really good approach to life. I think more people would enjoy life if they thought that way.

M: And I don't count days.

JC: Yeah, yeah. That's good. That's good. And you ... and it sounds like ... just to, if I can recap and you can tell me if I'm wrong, but it sounds like you are really happy with blunt, just-the-facts conversation?

M: Yeah. Straight. I don't say, really, 'blunt.' I don't think anybody should be hurt.

JC: Mm-hmmm.

M: I don't want ... I could be hurt.

JC: Yeah.

M: But I want ... well, it's the truth more than the facts.

[00:17:02.18]

JC: The truth, yeah, more than the facts. Yeah. And it's ... so but when the doctor gave you the truth and the facts, he was nice about it?

M: I was expecting it. Oh, of course he's ...

JC: Yeah. Yeah. And what is the way that makes him nice?

M: Him nice?

JC: Yeah.

M: Well it's just ... he's just a nice person. He's a fun ... fun guy. He can laugh. He is ... he pays attention to me.

JC: That's good.

M: And, you know, we all need a little bit of attention.

JC: Yeah.

M: And that's what's so good around here. I get a lot of attention. (laughs) I've had a cough most of my life. Just kind of a dry cough. I've had a bad one since I've had this. But ... and the kids used to say that, when I coughed, "Oh, mom needs attention, she's coughing!"

[00:18:10.27]

JC: She's coughing, she needs attention.

M: Yeah.

JC: So do you just stand out in the hallway and cough then?

M: Yeah. Well, no. My children live ... the youngest one lives in Mississauga.

JC: Mm-hmmm.

M: Doug, the one that's coming up on Sunday, he lives in Palm Springs, California. And Brian, the oldest one -- my pride and joy -- lives in between Sacramento and Stockton in California. Just out of ... just out of San Francisco.

JC: Oh, wow.

M: So they're all away.

JC: Yeah.

M: But I have a wonderful ... I have three sons only. I lost my little girl with leukemia.

JC: Oh, no.

M: (laughs)

JC: Oh, are you okay? What's going on there? Pins and needles?

[00:19:03.18]

M: No. It's a kink in my arm. I guess I had it in one place too long.

JC: Oh, oh. Oh, oh. The feeling coming back?

M: Yeah, yeah.

JC: Oh, that's good.

M: It's okay now.

JC: I get that sometimes when I sit too long on my butt.

M: That happens, yeah.

JC: And then I get a kink in my butt.

M: It's circulation.

JC: Yeah, yeah. Well is there anything else that you want to tell me about the conversations you've had with your physicians about your end of life or the palliative care team? Is there ... ?

M: No.

JC: It's all been a pretty positive experience?

M: Yes it has. It hasn't been, you know, upsetting. It didn't upset me at all.

JC: Yeah, yeah.

M: I just move on.

JC: Yeah, yeah.

M: It's all I can do. On my hands.

JC: You've got some good life lessons to share with people, that's for sure.

M: I said, "I don't know why they drag me along like this." And that's what Doug said to me, "Mom, you've got more to teach."

JC: Yeah, yeah. Well if there isn't anything else that ...

M: That's it?

JC: That's it!

APPENDIX G – TRANSCRIPT: JOYCE

JANE CAULFIELD: There we go. So I'm just going to ask you some demographic questions first.

Joyce: Okay. Like, you may have to repeat because of my hearing aids.

JC: Yeah, that's fine. So how old are you?

Joyce: I am 90 years old.

JC: Holy moley!

Joyce: I had a birthday in November.

JC: Oh!

Joyce: Yeah. And I'm looking, hopefully, I'm going to make 91. I don't know.

JC: Yeah, yeah. So then what's the ... what's your diagnosis?

Joyce: I have lung cancer.

JC: Mm-hmmm.

Joyce: And lung cancer, you know is ...

JC: Spreads.

Joyce: Yeah. That ... I have lung cancer. I also have heart problems.

JC: Mm-hmmm.

Joyce: And Lord knows what else.

JC: Yeah.

Joyce: But those are the two main ...

JC: Yeah. Well it seems like you've got lots of life in you.

Joyce: Well hey, you have to. You know, if I were to sit here and mope and groan. What good am I going to be for anyone, hey?

JC: Yeah, yeah.

Joyce: So, no. I get out and I enjoy myself. I like to bug people.

JC: Mm-hmmm.

Joyce: And ... and I do whatever I can. And each day, I'm happy, hey?

[00:01:05.22]

JC: Yeah.

Joyce: Like, no. Like I can't really complain.

JC: Yeah.

Joyce: Like, you know. I know I'm going to have some bad, bad days. But hey, while I've got good ones I'm having a ... I'm going to enjoy every day.

JC: That's good.

Joyce: And that's how I go with life.

JC: Yeah, yeah. So what I'm interested in is the conversations you've been having with your doctors.

Joyce: Okay.

JC: So when your doctor first gave you your diagnosis, how did that conversation go?

Joyce: Well the first ... you see, I had a spot in my lungs oh, before I moved in here for some time. And then that spot grew so then that's cancer, hey?

JC: Mm-hmmm.

Joyce: And it didn't bother me. And I didn't ... I decided not to go and let them do any biopsies or anything, hey?

[00:02:00.29]

JC: Yeah.

Joyce: And that was fine with my family. And so then, oh I guess -- I don't know -- oh, not even a year ago, it wasn't too many months ago that I got pains in my side here.

JC: Yeah.

Joyce: So I went to the doctor and right away he x-rayed, hey?

JC: Yeah.

Joyce: Because this ... this lung was clear, hey?

JC: Mm-hmmm.

Joyce: It was cancer, hey?

JC: Yeah.

Joyce: And so I seen the thing, like, and my daughter was with me and the doctor. And I just went over to his ear and I said, "Hey." I said, "How long do I have?" (laughs) And my daughter says, "Mom!" I said, "Well, he was so truth ... the doctor was so truthful with me with my husband because he only had two years." I thought, you know ...

JC: Yeah.

Joyce: Because I had gone in and then I had ... I was really sick at that time also. And I guess it ... they more or less took it as I only had just a few weeks to live, hey?

[00:03:09.11]

JC: Wow!

Joyce: And that was, I'm thinking August, September. August.

JC: More than a few weeks ago.

Joyce: Yeah. You know, like I think that's about when it was, eh? And so I thought, well you know, the kids and the grandkids they came and they were coming and coming. And I knew, well jeepers, they think I don't have long. Well, I said, "Don't worry." I said, "I'm enjoying every day I've got you guys."

JC: Mm-hmmm.

Joyce: I said, "Don't worry about me. When my time comes, it's my time."

JC: Yeah.

Joyce: I said, "You know, I'm not worried." And so I was feeling good, and so I felt really good and got over what it was, feeling good and then had to go see the doctor for him to check me out. It floored him. He said, "Oh," he said, "you're looking so good!" he said. So he gave ... right away he gave me a booster shot for pneumonia.

[00:04:11.01]

JC: Okay, yeah.

Joyce: Because if I catch that, you know?

JC: Yeah, yeah.

Joyce: Yeah. And I think that's what I had before all of this. And so ... and then he had to put a little band-aid on there, hey? And I thought, "What's he doing? He's taking a long time." Puts this band-aid on. When I got home, it's a happy face! He'd written on it ... put on that band-aid.

JC: Yeah.

Joyce: So he was really happy with me.

JC: Yeah.

Joyce: So I just have to take it as it comes.

JC: Yeah.

Joyce: Like, you know? You know, I've got the strong stuff for ... to take if I need it, like right away, hey? So right away when that happened he put me on palliative care.

JC: Yeah, yeah.

Joyce: So I know when I went back to him one day -- I don't know when it was. And I said, "Uh-huh." I said, "I know." I said, "I'm on palliative care. I've only got, you know, so long."

[00:05:07.21]

JC: Yeah.

Joyce: You know? I said, "That's okay, doctor. I'm okay with that." You know, and I think it made him feel good, you know, that ... you know, not to worry. That I'm okay with it. And that's exactly how I am.

JC: Yeah. And when he talks to you about it, how does that conversation go for you? Are there things that he does that make you feel better or things that don't make you feel better?

Joyce: No, like ... no, I just feel ... I feel fine. It does not ... I can honestly say it doesn't bother me.

JC: Mm-hmmm.

Joyce: I might think of it once in a while, but you know, I let it go.

JC: Yeah, yeah.

Joyce: I think ... I think my son worries more about me, and my daughter also. The three kids worry about me, hey? And as far as I'm concerned, I'm fine.

JC: Yeah.

Joyce: You know? Like I just let it do what it has to do.

[00:06:03.06]

JC: Mm-hmmm.

Joyce: I mean there's nothing I can do. Sure, I could have ... they could have gone down and done something. The same as the heart: they could have went down and put stints or whatever.

JC: Or something, eh? Yeah. But did they ... and did they ask you if you wanted that?

Joyce: Yeah. No ... and I said no.

JC: Yeah, yeah.

Joyce: At that time ... at that time with the stints I think I was 87, 88, hey?

JC: Yeah.

Joyce: Yeah.

JC: Yeah.

Joyce: And, like the doctor? It was okay with him.

JC: Yeah.

Joyce: He said, "Well, you know," he said, "You can have a heart attack or a stroke with or without that."

JC: Yeah, yeah.

Joyce: So ... and why ruin my ... ? Lord knows what they're going to find other than that, hey? And I'm happy the way I am.

JC: Yeah.

Joyce: So just let me be.

JC: Yeah.

Joyce: That's exactly ...

JC: So, and you had said that he put you on palliative care?

Joyce: Right away, yeah. I'm on palliative care, so a nurse comes and sees me.

[00:07:01.17]

JC: Yeah.

Joyce: And checks me out and then ... like, I wasn't feeling good a while back, so she faxed him and then I go and see him, like, next week. So ...

JC: Yeah. And so when he put you on palliative care, did he talk about your options for palliative care? Or ...

Joyce: No. Just came ...

JC: He just did it without talking to you?

Joyce: Hey?

JC: He just put you on palliative care ... ?

Joyce: He just put me right as soon as I got that cancer thing.

JC: Yeah.

Joyce: And I asked how long. And that he put me right on palliative care right away.

JC: Yeah. And you're okay with that? You felt okay?

Joyce: I'm okay with it, sure.

JC: Yeah.

Joyce: Well sure! Why not, like, you know? She comes and sees me and ... and there might be a week that I don't need her, I'll say, "No, I'm fine."

JC: Yeah.

Joyce: Like, you know? So, you know, it's hard to explain. I think a lot of people don't realize, because I go downstairs and everyone says, "Well how are you today?" I'm fine, don't worry, you know? Because that's how I am.

[00:08:09.05]

JC: Yeah, yeah.

Joyce: You know, I said there's ... you know, in time, maybe. No, but right now I'm good.

JC: Yeah, yeah. And so the conversations you've been having with the doctor, what -- has he been using big words or little words or straight talk?

Joyce: Well my daughter comes with me. If he's using big words she understands because she's a ... she was a pharmacist, hey?

JC: Yeah.

Joyce: So, like ... and with my hearing aids I don't hear that well.

JC: Yeah.

Joyce: And so she's there. And she just explains in the easiest way.

JC: Yeah.

Joyce: But, you know, that's ...

JC: Yeah, so it's helpful to have a translator of sorts?

Joyce: Yeah, like you know, right? Yeah, no, so she comes with me.

JC: Yeah.

Joyce: And if she's not able to, my son will come with me. So I've got someone always that comes with me to any of my doctor's appointments.

JC: Yeah. That's good, that's good. You had mentioned that he did the smiley face on your band-aid. It sounds like your doctor has a bit of a sense of humour?

[00:09:10.27]

Joyce: He is. Like, and he's always ... he's always glad to see us -- the two of us, like, my daughter and I. And he'll sit there and I always feel, "Oh, we're taking your time, eh?" But he's so good, he'll ... he'll sit and ...

JC: And chat.

Joyce: And talk. And talk, like, you know?

JC: Yeah. And when he talks to you, what's the tone like?

Joyce: Hey?

JC: What's his tone like? What's his presence like when he has those conversations?

Joyce: He seems okay, like, you know? He knows ... he knows me.

JC: Yeah.

Joyce: Because he was the ... he was my husband's doctor, hey? And he knows what I went through with my husband.

JC: Yeah.

Joyce: So he knows that I can take quite a bit and that I will be honest with him.

JC: Yeah.

Joyce: Like, you know?

JC: Yeah.

[00:10:00.29]

Joyce: And I want him to be honest with me.

JC: Yeah, yeah.

Joyce: Because it was one ... one of the things that he had said -- I don't know whether it was the heart one or the lung one. And I said, "What do you think I should do, doctor?" He looked at me and he said, "Well, if you were my grandmother." I said, "I'm your grandmother!" "I would tell her 'no.'"

JC: Yeah.

Joyce: Yeah. And I thought he is great because I wasn't going to have it done anyhow hey?

JC: Yeah.

Joyce: And he was honest enough for me.

JC: Honest. That's good, that's good.

Joyce: Yeah, he's an honest, honest one.

JC: Yeah. Has he spent any time talking to you about options at end-of-life care? So, as things progress, what happens then? Has he had any of those conversations with you?

Joyce: Like, as I progress and I'm going to pass on?

JC: Yeah.

Joyce: Like, okay. That's where palliative care comes in, okay?

JC: Yeah, yeah.

[00:11:01.25]

Joyce: And yes. Palliative care have talked to me.

JC: Yeah.

Joyce: Like, I know that when I'm really down and I'm right near the end, they will ... I will go to St. Paul's Hospital.

JC: Yeah.

Joyce: I think it's about 12 days before or something?

JC: Yeah.

Joyce: Yeah. And that's where I will be with the palliative care.

JC: Yeah.

Joyce: Yeah, no that I know. Like, the head palliative care maybe nurse came and was speaking to me when we first came.

JC: Yeah.

Joyce: So we learned all that.

JC: Yeah. And how did that conversation go?

Joyce: Good.

JC: Yeah?

Joyce: Like, you know? Like I say, I haven't had tears or anything over any of this. No I haven't.

JC: Yeah.

Joyce: Like, you know? And I'm one that tear up very easy.

JC: Yeah.

Joyce: But I know what's happening to me?

JC: Yeah, yeah.

Joyce: You know? And that's the main thing.

JC: Yeah, yeah. And it sounds like you've had people talk to you about it all along the way.

Joyce: Yeah. Like, you know? So, yeah, and I've gone to different doctors and that ... and if I don't want them to do it that's it, hey?

[00:12:07.01]

JC: Yeah.

Joyce: And, like, it's all unspoke. The daughter and the two boys, they always agree to what I have to say.

JC: Yeah.

Joyce: Like, you know? They always say, "Yeah, that would be the best."

JC: That's good. Yeah. That doesn't happen all the time. That's really good.

Joyce: No. Well you have to be, you know? It's just like, I'm hoping everyone has a willing ... a living will, you know? But I guess I was fortunate in a way you might say, because when my husband only had two years to live we were able to get the funeral things -- both of ours. Then at the same time, everything was done.

JC: Yeah.

Joyce: Right now I have nothing.

JC: You could just live it up.

Joyce: Everything is done for the funeral and the kids don't have to worry.

[00:13:02.17]

JC: Yeah.

Joyce: They know that it's all done.

JC: Yeah, yeah.

Joyce: And I wish people could ... I wish other people could think that way.

JC: Yeah.

Joyce: You know? Especially ... even when you're getting old, hey? And you're feeling good. At least get a living will thing. At least have a will done, you know? Have a will also. You know, I just don't know ...

JC: Yeah, yeah. Well, and so you learned about all of that when you were going through it with your husband.

Joyce: Yeah, exactly. Like, but I have to tell you -- and this is really cute -- like, when we were doing up this, my son and his wife were there and we were at the table and Bob says, "Huh." We were wondering what funeral home to use, eh? And Chris was telling him different ones. And then the one on -- I forget, downtown? Oh, there's one ...

[00:14:05.09]

JC: Oh, the one on Third?

Joyce: Yeah, probably.

JC: Morning Glory, I think that is?

Joyce: Not Morning Glory. It's the other one. Anyhow, when you have the lunch you have to walk across the street somewhere.

JC: Oh yes, yeah. Yeah.

Joyce: And I always get those ... and maybe I've got that blocked.

JC: Well and it changes so fast.

Joyce: Yeah. Anyhow, Chris had told him about this funeral home, hey? And he said you have to walk across to ... for lunch. And he said, "Well you guys, don't forget, I can't walk that far!" Well, we all just laughed. Said, "Dad, you won't be walking!" It was just out of the blue and I guess he wasn't thinking. "Well I can't walk that far!"

JC: Yeah.

[00:15:00.14]

Joyce: You know, I've told so many people this and they get such a bang and I can still see him doing this.

JC: Yeah, and laughing about it.

Joyce: And having a laugh over it, yeah.

JC: That is a good story. That sounds like, when it comes to end of life you've ... you have got a fairly good perspective.

Joyce: Exactly, exactly. I feel that when it's my time it's my time and he'll say, "Hey, you're ready to go." And I'll be going.

JC: Yeah, yeah. Is there anything else that you want to talk about in terms of the conversations you've had with care providers about ... ?

Joyce: Well, the only care providers are, like, the palliative care that I get, hey? And they're all so great that I've got nothing, you know. They ask me what's wrong and do whatever they have to do. And if I'm not good then they will fax and let the doctor know.

JC: Yeah, yeah.

Joyce: Oh yeah, and then you see I had a blood clot in my leg here, oh a month ago maybe?

[00:16:05.13]

JC: Yeah.

Joyce: And the [UNINTELLIGIBLE] I never thought anything so showed her my ankles and they were swollen and they were bruised up. And she didn't like the looks of that, and I said, "Well, my ankles always swell every once in a while." But yeah, and so she said, "Oh, no. No." So she got ahold of the doctor right away when she was sitting here, so she was able to get ... she had to wait awhile until he finished with a patient, and she told him right away what was happening. And the doctor got ahold of us near the end of the day and told us to get to the ... I guess it was a -- what do you call those scans?

JC: Oh, a CT scan or something like that?

Joyce: One of the scans where you have to go. And so we went the next day and, yeah, it was a blood clot.

JC: Yeah.

Joyce: So you see, she caught that. Because I wouldn't have even bothered.

[00:17:02.08]

JC: Yeah.

Joyce: Like, you know? Yeah, so they watch for things like that and then they tell him. But other than that, I can't tell you anything else. I really don't know ...

JC: No, I'm just interested in your experience and how it's gone for you, so ...

Joyce: Yeah, no, my doctor is just so great.

JC: That's good.

Joyce: He'll be ... yeah. He's there for me.

JC: Yeah, yeah. Can I ask how long you've had him as a doctor?

Joyce: Oh my gosh. Oh, I don't know, it's got to be 15 years or more.

JC: Wow.

Joyce: I have no idea.

JC: Yeah.

Joyce: Like he was just sort of new, hey?

JC: Yeah.

Joyce: And I didn't like the doctor I had. And so she wasn't there and so I had to go in and see a doctor and he was the one that I seen. He checked me out and that and everything was good and I asked him, I said, "Are you taking any ..." -- because he was a new doctor -- "Are you taking patients?" He said, "Yes." I said, "I would like to be yours."

[00:18:11.23]

JC: Yeah.

Joyce: So then he was good enough, he sent me, I don't know, to every place to get examined and, you know, a thorough examination which I had never, ever had.

JC: Yeah.

Joyce: He really did the works.

JC: Yeah.

Joyce: And so he knows me from head to toe, like you know?

JC: Well then ... and it sounds like he knows you as a person too.

Joyce: Yeah, as a person, too. Because he knew me when I could hear. Because I had to ... you know, I would go with my husband and that. And now he knows that I can't hear very good. He's one that will ... talks a little bit fast. And he tries to slow down. And I know that if I had to, like, if my daughter wasn't able to come I know that I would be able to understand.

[00:19:01.11]

JC: Yeah.

Joyce: And he would ... because I sort of try to look at him.

JC: Yeah.

Joyce: And I don't know whether I'm reading lips or not, but I like to look at the person I'm speaking to, hey? And so I'm sure I would make it out okay with him.

JC: Yeah, yeah. That's good. Have you had to deal with any other doctors, like an oncologist or any other specialists?

Joyce: Oh when you say ... see, I'm not good with all ...

JC: An oncologist would be a cancer doctor.

Joyce: No I have not. I've never, no, not seen a ... because he knows I'm not doing anything for it.

JC: So there's no point, yeah.

Joyce: Nothing for it. You know, I'm just going ... when my time comes, that's it, hey?

JC: Yeah.

Joyce: Yeah. So, no, so far so good. So ... other than that, no. No, I've been really fortunate because I was born at home, I had my tonsils out at home. Three years old, at the kitchen table, okay? I'm two or three, hey? And the first time I was ever in the hospital was with my first ... my son, hey?

[00:20:16.08]

JC: Mm-hmmm.

Joyce: You know, so I've been lucky. I've been fortunate.

JC: Yeah.

Joyce: Yeah. I've been healthy, and so ...

JC: That's good.

Joyce: Up until now.

JC: Well at 90 you don't look a day over 80.

Joyce: Yeah, I get that a lot, you know. And I do not dye my hair.

JC: Get out!

Joyce: No, you can see the grey is in there now.

JC: I've got the same amount of grey that you do, though.

Joyce: Yeah, no. I've never dyed it, hey? And so anyone that I tell them, hey, you know they can't believe this, but even here when I came here, hey?

JC: Yeah.

Joyce: They just looked at me and they were all grey-haired. Took a while for them to, you know? And now, my gosh, they're all my friends.

[00:21:05.10]

JC: Yeah, excellent.

Joyce: I said, "Will you take a look? It's my own darned hair." Because they even asked the lady that does ... the hairdresser, hey?

JC: Yeah.

Joyce: If that woman that just moved in, does she dye her hair? So even now, after I've been here over two years, I guess.

JC: Yeah.

Joyce: Just about two-and-a-half. There's still some that don't believe that I ...

JC: That you have your own hair?

Joyce: Yeah.

JC: Yeah. Well you look good.

Joyce: Oh, thank you.

JC: I'm going to turn this off.

APPENDIX H – TRANSCRIPT: SUZIE

JANE CAULFIELD: Hit record. I'm going to put this here, is that okay?

SUZIE: Sure.

JC: Not in the way?

S: No.

JC: I'll put that on top of there. So Suzie, how are you feeling today?

S: Today I'm feeling not too bad.

JC: Not too bad?

S: I had a very bad day on Monday.

JC: Oh no!

S: Yes. I have cancer.

JC: Yeah.

S: And Monday I was in terrific pain.

JC: Yeah?

S: So the nurse came this morning and assured me that I'm okay.

JC: Yeah? That's good. So you're feeling a bit better today?

S: Yes I am.

JC: Yeah, yeah. And then ... do you mind if I ask what kind of cancer?

S: I have cancer of the ...

DAUGHTER: It started off with breast cancer. Would you rather her answer and me not get into it?

S: It don't matter.

JC: It doesn't matter.

D: Oh, okay. She had breast cancer, it's where it started.

[00:01:01.07]

JC: Yeah. Then it's moved around?

D: It's moved around now to her liver, her bones, her lungs.

JC: Oh, yeah. Yeah. And how old are you?

S: 83.

JC: 83. You don't look a day over 70.

S: Thank you.

JC: So do you mind if I ask how that conversation went when you were given the diagnosis? How did that conversation go with your doctor?

S: What diagnosis?

JC: When you were given a terminal diagnosis. When they told you it wasn't ... the signs don't look good.

S: Actually, I said to doctor, I said ... he said, "How much do you want to know?" I said, "Everything." And he said, "Okay, here goes." So he told me everything.

JC: Yeah. And what kind of ... what kind of language did he use? Did you understand what he was saying?

S: I understood everything. He is Chinese and he understands that people need to know the ...

[00:02:02.18]

JC: Need to know, yeah. Why did you ... do you mind if I ask why you wanted to know everything?

S: Because I'm to the point where I'm ready for dying.

JC: Yeah, yeah.

S: I'm not ready to hang around here and suffer and all that sort of thing.

JC: Yeah, yeah.

S: So I asked for all the ... everything to know where I was. My doctor -- my cancer doctor doesn't say nothing. He's tight-lipped.

D: He's tight-lipped about it. We learned all the information from her.

B: Cancer doctor. Or I mean from the lung doctor.

D: The lung doctor, yeah.

JC: So the oncologist doesn't say much, hey?

S: He doesn't say much.

JC: No. Do you talk to him at all, or ...?

S: Yes. And sort of, I should say. But other than that, no.

[00:03:03.19]

JC: No. So it sort of is just idle chit chat, nothing really ...

S: Yeah.

JC: Yeah. So then when you talk to your lung doctor, how do those conversations go? Do you feel ...?

S: Went good. Because my son was there with me and he felt quite open about everything, too. He felt good about it, like, you know? We know where we're at, sort of.

JC: Yeah, yeah. So then, how does that make you feel to know that you have some doctors that are willing to ...?

S: I wish they'd be more open.

JC: What do you mean by open?

S: Like telling you the truth. Instead of sitting there ...

D: Himming and hawing.

S: Himming and hawing about this and that and ...

JC: Yeah. What do you mean by 'himming and hawing'? Can you give me an example of what they do?

S: Well they don't ... they don't tell you. They just say ... I said to him, "Should I make arrangements for a ... you know ..."

[00:04:09.09]

D: Make arrangements for the ... the funeral home, you mean? Or ...

B: Yeah, the other home.

D: The ... oh yes, the nursing home.

B: Nursing home.

D: You know, like, when her final stages come here.

B: And he said, "No."

D: "No." He never really would give us a straight answer, it seemed like.

JC: Yeah, yeah. And you really were looking for a straight answer.

D: Well I mean we wanted to know how long she had. Because my brother and I were there with her and, "Oh, it varies from people to people." And I said, "Well, does she have a year?" He says, "Yeah, a year."

JC: Oh.

D: So I don't really know. Just the way he said it, like, we don't know if it's true or not, you know?

JC: Yeah, yeah.

D: If it's less than that or more than that, you know?

JC: Yeah, yeah. Yeah, and nobody's been kind of ... even the lung doctor hasn't been that up front? Or has ...

S: Oh yes, he's up front, eh?

[00:05:01.13]

JC: Yeah.

S: He told me, and he said, "You go ahead and do this and you ... your cancer has spread." He didn't tell me how long I had, because he doesn't know.

JC: Yeah.

D: Well, because they don't really all know/

JC: Yeah.

S: He just said, "Your cancer has spread to the ..."

D: Lungs. The bones.

S: All the places.

D: And see, the other cancer doctor wouldn't tell us that.

JC: Yeah. Yeah. So how does that make you feel when the doctors don't tell you those things?

S: Well it makes me feel a little bit sad.

JC: Yeah?

S: Yes.

JC: What do you ... a little bit sad, how so? Can you elaborate on that?

S: Because I'd like to know. I want to know everything.

JC: Yeah.

S: Snoopy.

JC: Snoopy's good sometimes. Yeah. But ... so do you feel like you eventually got the information you needed? No?

S: Well, yes. From the ...

JC: From the lung doctor?

S: From the lung doctor I got the information, but I didn't get it from the one that I should've got it from, you know? Like now she's ... my ...

[00:06:13.02]

D: Family doctor.

S: Family doctor is sending me to ... back down to the cancer doctor, because she wouldn't give me any information on Monday.

JC: Mm-hmmm.

S: So we're going back to the cancer doctor.

JC: Yeah. Yeah.

S: I guess I'm just going to have to come out and say, "Look, tell me everything."

JC: Yeah. Yeah. So when you say 'everything,' that's ... that's about your prognosis, how long you have. What else ... what else is involved in 'everything?'

S: Well just how long is there, what do I got to look forwards to?

JC: Yeah.

S: Am I going to have to suffer?

D: He did say, mom, that ... like in other words, don't worry about it. We're not going to let you be in pain. The cancer doctor. So that was one good thing.

JC: Yeah. But has anybody talked to you about your options at end of life?

[00:07:02.01]

S: Yes, palliative care is just wonderful.

JC: Really? Yeah.

S: You know, those nurses are worth more than what they're getting paid.

JC: Yeah.

S: They're ... they're worth everything. Those ... well, I don't know how many's here now, but they're really, really good.

JC: Yeah. Yeah.

S: They seem to know what they're talking about. They seem to know what they're supposed to be saying. I don't know, they ... they're really good.

JC: Mm-hmmm.

S: The palliative care. And they're so good to me.

JC: Mm-hmmm.

S: You know, they're really looking after me good.

JC: Yeah. And they've ... have they talked to you about options at end-of ... when things start to get worse?

S: Well sort of, but it's not in their ...

D: Not really, though.

S: It's not in their jurisdiction to do so.

JC: Yeah, yeah. Yeah, and so no ... all the other doctors you have, nobody's really talked to you about options?

S: No.

[00:08:02.10]

D: No.

JC: Who ... who was the one who signed you up for the palliative care, do you remember which doctor that was?

S: Dr. Schoen [SP?]

JC: Is that the ...

S: The family doctor.

JC: The family doctor?

D: Was it Dr. Schoen, mom? Or Dr. Tai-on [SP?], the lung doctor?

S: Schoen.

D: Schoen?

JC: Yeah. And did that doctor ask you about signing you up for the home care?

S: Yeah.

JC: Yeah? How did that conversation go?

S: She was asking me if ... well she ... they have a notice up there ... the appointments can't take any more than so many minutes because they're booked all that ... well, you see the sign.

JC: Mm-hmmm.

S: And so I ... I don't remember just how it got started, but anyway I said, "I got to have this looked after." And she said, "Yes." She says, "We'll do it right now." And so she went on the computer and filled it out.

JC: Yeah. Yeah. So along the way it sounds like you've had some conversations that you have okay with, and some that you haven't been okay with. What ... what do you ... in terms of conversations, if somebody in your position in the future was to have a conversation, what would you like ... how would you like those conversations to go?

[00:09:19.03]

S: I would suggest that they be given a little bit more information from their doctor.

JC: Mm-hmmm.

S: To say that ... which way to go and which way not to go. And a lot of people are scared of dying.

JC: Mm-hmmm.

S: And they don't want to hear the truth.

JC: Yeah.

S: But I wanted to hear to the truth.

JC: Yeah.

S: Because I'm not scared of dying.

JC: Mm-hmmm. Mm-hmmm.

S: So you gotta put your mind and tell your doctor, "I'm not scared of dying, I ..." Like I said to him, "I'm not scared of dying. I want to know where I'm at."

[00:10:00.17]

JC: Yeah, yeah. And when you said you want the doctor to talk about where to go and where not to go, what do you mean by 'go?'

S: Like, do I go to a doctor and find out, or where do I go for the information?

JC: For more information. Yeah. Yeah, so if you're not getting it from the doctor, where do you go? So you ... you didn't feel that you were getting that ... even that kind of level of information?

S: From Dr. April [SP?], no. My surgeon ... I mean the cancer doctor.

JC: Cancer doctor. It sounds like you got a lot of doctors.

D: Yeah.

S: Tell me about it.

JC: Can you keep them ... I don't think I could keep them straight.

S: No. Sometimes I ... I don't get them straight either. Sometimes, like, I wonder what ... which way I'm going.

JC: Mm-hmmm. So the conversations that you have had that you do feel good about, what makes them good conversations?

S: Well, the lung surgeon I was very pleased with him. I think that he did an exceptional job. He, as soon as Bruce said, "Yeah, we want to hear ...," -- that's my son, he was with me -- we went to the ... he went right

away to the computer. Now he wasn't the one that sent me for the tests and all that. He broke into somebody else's ...

[00:11:28.11]

D: The files.

JC: Your son did?

S: No.

JC: Oh, the doctor. Oh.

S: The doctor. Oh no, not the son. He wouldn't do that. He broke into the computer and he got the information from the ...

D: The results back from all their tests.

JC: Oh. Because he wasn't the doctor that was supposed to give that information?

D: He wasn't the one that had ordered the tests.

JC: Okay. Okay.

D: Like, it was a bone scan, wasn't it mom? I think it was a bone scan that was ordered, and that's where they could see where all the cancer had gone.

[00:12:02.16]

JC: Mm-hmmm.

S: Oh yes, you're right.

D: And then the one doctor, you told him that you had this bone scan, so he went in there and looked at the ...

S: Yeah, as soon as we told him that, he broke in.

D: Because he's one of her doctors and he could see all the information that other doctors ...

JC: Yeah, had said.

S: Isn't it funny how you forget?

D: He's not really supposed to look at other ...

JC: Look. Yeah.

D: He just decided to look at them, so ...

JC: Yeah, and then he was the one who really talked to you about the ...

D: Told us where the cancer had gone and ... because the cancer doctor didn't tell us.

JC: Yeah. Yeah. So then, how does that make you feel -- to know that the doctor had to break the rules a little bit to give you the information you were looking at?

S: I'm pleased with him.

JC: You're pleased with him?

S: Yeah. I think it was very brave of him to ... to ...

D: Tell us the truth, you know?

S: Tell us the truth. And seeing as how ... like, he said, "Do you want to know ... what do you want to know?"

[00:13:02.13]

JC: Mm-hmmm.

S: And I says, "Everything." Well when somebody says they want to know everything, that means they want to know everything.

JC: Yeah.

S: They don't want to just be brushed off like the cancer doctor did.

JC: Yeah. Yeah. And how did ... how did he have that conversation? Did he sugar-coat things? Did he ...

S: No. He just told me right out.

JC: Straight up.

S: Straight up.

JC: Yeah. Yeah.

S: He didn't tell me how long, he just told me ...

D: We didn't ask, though.

S: We didn't ask.

D: That's one thing that he, like ... I think my brother went down -- back and talked to him about length and that. But he ... but he never ... because we did not ask, I don't think he volunteered it.

JC: Yeah. Yeah.

S: I don't ... we don't know what Bruce went back and talked to him.

JC: Yeah.

S: We left the office, we don't know what he ... what Bruce went to talk to him about. Never asked him. Because I got the information that I was satisfied with.

[00:14:02.16]

JC: Mm-hmmm.

S: And so it was good enough as far as I was concerned.

JC: Mm-hmmm.

D: I think I was more worried about getting him in trouble for ... like, that's why we didn't say, "Well, how long does she have?" Because we wanted to go to the cancer doctor and get him to tell us, because he's the one that should have been telling us.

JC: Yeah. Yeah. That sounds ... that sounds really frustrating to be in that position.

D: Yeah, it was.

JC: Yeah.

D: We didn't say nothing.

JC: Yeah. Well, and you said that the cancer doctor hasn't really talked to you much about anything.

S: Hasn't talked to us at all.

JC: No.

S: None of us. Like, sometimes Linda's with me, sometimes Bruce, my youngest son's with me, and the cancer doctor has never said nothing about ... anything about after or how long it's going to take, or where I go from here, or what.

JC: Yeah. And has anybody ... has anybody talked to you about what happens as you get sicker and pain care? You ... it's already been mentioned that they've just kind of said, "We'll make sure you're pain-free," but has anybody ... ?

[00:15:12.01]

S: Well, Maureen downstairs?

JC: Mm-hmmm?

S: She has come up and filled us in.

JC: Yeah.

S: And palliative care.

JC: Yeah, yeah. And palliative care, they just ... they come on a regular basis? Or when you need them, right?

S: Well, you see I have a tube in my lung?

JC: Mm-hmmm?

S: And they come twice ... well, they come once a week.

JC: Palliative?

S: Yes.

JC: And the home care nurse comes twice.

S: Once a week. Well, there was a big scrap there.

JC: Oh?

S: That we won't mention. But anyways, that went over like a lead balloon, but ...

JC: Yeah. Do you ... do you find that palliative medical care and other medical care don't always mix and match very well?

[00:16:04.15]

S: Well, we've become like this, which we shouldn't with a nurse.

JC: Yeah.

S: And I just ... I've never met her little girl, and she wants to bring her little girl to meet me. And I said no. I have grandchildren of my own, and I says, "It's just going to be confusing for me."

JC: Yeah. Yeah.

S: And I said, "I'll give this little doll to your ..."

JC: Daughter.

S: "For Christmas." But I said, "I don't want to have nothing to do with her."

JC: Yeah.

S: Just, between you and I in here, she's the love of my life.

JC: Yeah.

S: So that is ... the reason the scrap became ... if it hadn't been for the little girl, we wouldn't have gotten into a scrap.

JC: Yeah. Yeah. So, in terms of conversations about care, it sounds like one has been good and then the rest really haven't been all that great.

[00:17:06.20]

S: The ... Janice from the regular nursing is really just good. But, I'm going to say iffy for the rest. And palliative care, every time they send me a different nurse, she's ... she's just ... I don't know, she's just got everything. She's ... she's more of a doctor than she is a nurse.

JC: Yeah. Yeah.

S: She knows her things, she knows what to say, and she knows how I feel.

JC: Yeah. What kinds of things does she say?

S: Well, I can't explain what she says, but she ... she knows how I feel and all that sort of thing.

JC: And that .. that matters, hey?

S: That matters.

JC: Yeah. Yeah.

D: Well she gets to know her, because she's been with mom for, three years now, mom? Janice has been with you?

[00:18:01.23]

S: Yeah, Janice has been with ... well, in August it will have been two years. And so we've kind of ... we're just kind of like this.

JC: Mm-hmmm. That's good, that's good.

S: She's a special nurse to me. Actually, she's not a nurse anymore, she's a friend.

JC: That's good. We all need people like that in our lives. Is there anything else that you want to add in terms of conversations that you've had, or something that's really been on your mind?

S: No, just that the palliative care nurses are the best. They know their thing. They've ... they know exactly what they're going to say, when they're going to say it. They're ... they know the situation.

JC: Mm-hmmm. Mm-hmmm. Do you think ... do you think that's because they are in palliative care and not ... ?

[00:19:03.14]

S: Yes.

JC: Yeah.

S: They're well-trained.

JC: Yeah. And they're having those conversations all the time. Yeah. I have one last question. This is a fun one. Because everything I do, when I write this up is anonymous, so your name won't be associated with this at all. Nothing ... nothing that people can identify you with. And I'm using pseudonyms, fake names. Is there a name that you would like to have? If you could ... ?

[00:19:31.05]

S: Suzie.

JC: Suzie? Perfect. That sounds great. You'll be Suzie, then. And there's nothing else you want to add? No? Yes?

S: No. Not that I can think of right now.

JC: Okay.

S: Something of a thing right now.

JC: That's okay.

S: Other than, I love my nurses.

JC: That's good.

S: Do you know, if it wasn't for the nurses, I wouldn't be living.

JC: Really? They're the ones that are keeping you going?

[00:20:03.15]

S: They've been keeping me alive for the last year. Two years.

JC: That's good. So you've said two years, and you had said a year -- the diagnosis was a year. So have you outlived that?

D: Well, no. That was in November they told us we've got a year.

JC: Okay.

S: You see, I have my lung surgery in August -- it'll be coming up to two years ago.

JC: Oh, okay.

S: And I had my cancer two years ago also.

JC: Yeah. Okay.

S: And my breasts removed. Both of them.

JC: Both ... so you had a full dual mastectomy?

S: Yes.

JC: Yeah. That would have been tough.

D: Oh, has it been two years? I thought it was going to be three since you had breast cancer.

S: No, it's two.

D: No, two? Oh, jeez.

S: That's why ... that paper that I gave you had info in it. I thought it said two years.

D: Oh, I never really looked after you gave it to me. I just put it in the file.

[00:21:01.06]

JC: Well that would've been really tough. My mother had one breast removed 20 years ago and she still ... she talks about ... she lost a piece of her identity when that happened.

S: You do.

JC: Yeah.

S: You feel less important. You feel less a woman.

JC: Yeah.

S: I went into my doctor and I said to her ... she said, "You never listen to me anyways," so she says, "Why am I telling you?" And she says, "I've got two ladies coming in, in the next couple of weeks." She says, "They had their breasts removed a couple of years ago and now they've got to have the other one done." So she says, "Do what you want to do." She said, "Suzie, because you won't listen to me anyways."

D: This was when she was deciding whether she should have just the one breast removed or the two.

JC: Or both, yeah.

D: And mom said right from the very beginning, "I'm having both of them removed."

[00:22:01.25]

JC: Yeah. Yeah.

D: It was probably a good thing, because the way they spread, you know, it'd probably would have been in the other one the next year anyway.

JC: Yeah. Yeah. Well, and then ... you seem like a broad who won't take shit from anybody, pardon my French.

S: Well, I ... in here I'm known as the quiet one that doesn't say much. I don't ... I 'hi,' and that's about it. And I ... I kind of don't talk too much to the ... the ladies. Except when I had my surgery, oh my goodness, the ladies that came to me and said, "I've had the same thing."

JC: Mm-hmmm.

S: It's really surprising how many ladies in here have their second one ...

[00:23:01.22]

JC: Yeah. Yeah. It is quite surprising. I'd agree. Yeah. Alright, well if there's nothing else that you want to add then I'm going to turn this off.

APPENDIX I – TRANSCRIPT: GRANT

[00:00:02.19]

JANE CAULFIELD: And you're okay if I record our conversations?

GRANT: Yeah, that's fine.

JC: Alright. I'm going to put this here. I'm sure we will have cat noises in the background.

G: Yeah. Figure out how to sit on it.

JC: Yeah. That'll be great. Please pause for cat butt. So can I get your age?

G: Yes. I am 57.

JC: And your official diagnosis?

G: Official diagnosis would be HIV-positive. Probably back in '95 or so, I would have been declining rapidly in terms of my immune responses, etc. So I never actually ever got an AIDS diagnosis, but I did have a ... an HIV-positive diagnosis with rapidly declining health in the mid-90s.

[00:01:00.15]

JC: Yeah. So how did that first conversation go?

G: It was kind of weird because in Toronto, I'm not exactly sure ... so the diagnosis was ... was earlier than that. So the problem was, was that my doctor was actually away and I was called by somebody who didn't know me or ... and just said, "Your tests are positive. Hi, sorry to hear that. And if you have any questions your doctor will be back next week." And that was it. I got no counselling, no nothing. It was just a ...

JC: Oh, wow!

G: It was ... I was told over the phone. We were about to go on a retreat with my partner at the time, who was ... who had an AIDS diagnosis, and a couple of other people who were from the same the group of people. And we were going on a retreat that was specifically designed by -- I'm trying to think of all the different groups that we had together at the time, but it would have been one of the AIDS-specific ... it would have been people with AIDS, it would have been ... like, there's the service agents and then there's the ... the activists.

[00:02:25.06]

JC: Yeah.

G: And then there's the consumer group, right?

JC: Yeah.

G: So this was the consumer group. As in, we're a bunch of people who, we want to get some resources together, so they hired a ... luckily, they hired ... they had a counsellor and they had a massage therapist and all these people who were at this retreat that were awesome. Like, that was a terrific thing to have, but my doctor's office was kind of like, "See ya!"

JC: Oh!

G: Yeah, it was really weird. And I kind of was a little bit ... I mean, what happened was I stopped being able to hear. Like, I stopped ... it was just like a ... I was fully expecting it, but it was like ... and my ears just went whoosh with that horrible thing that you get when you have this tremendous anxiety that overcomes you and there was, like, nothing I could do because we had to ... like I basically was, picked up the phone just as we were all going out the door and it was like, "Oh, so guess what?"

[00:03:19.15]

G: It was like, "Come on, come on. Get your bags together, come on, come on, we're going." And like, "Okay." So that was a bit odd. However, it was with the right group of people because they all kind of went, "Yeah, well, no surprise."

JC: Yeah.

G: You know. And here we are, so we're going to do this together. So ... so that was good, because that was a ... a group of people who were in the same boat essentially. All of whom are dead now actually, except me. At least the ones that I remember. I'm sure there might have been a few other survivors, but ... it wasn't because the camping trip was so awful. It was ...

JC: Camping trip and death unrelated.

[00:04:00.19]

G: But it was nice. And so that part of the experience wasn't that great. And at the time, the reason why the test ... why I got the test was because my partner said, "You know, you're behaving really awfully, like you're really becoming a very morbid kind of person. And you're kind of drinking too much and you're kind of having difficulty. So there's things that you need to know about your situation because you need to just sort of smarten up."

JC: Yeah.

G: And ... and so that was the, you know, "Regardless of what the outcome of this is, you need to make a plan of some sort, because I'm going to die. You have to not ... not do this," right?

JC: Yeah.

G: So that part of it -- the actual information of the diagnosis was kind of ... kind of like, "Oh your ... yep, broken arm. You have to come in for some tests."

[00:05:01.15]

JC: Yeah.

G: You know, it was kind of like, "Wow, this is actually important, but apparently for the person who was making the phone call, it was just phone call."

JC: It was just a phone call. And you had said your doctor was away, so when your doctor came back were you able to have a ...?

G: Yes, yeah. And he was fine. That was actually interesting, because he was both my ... my doctor as well as my partner's doctor at the time. So he was just totally apologetic and he was a very ... one of the early pioneers. Because his practice was right in the gay ghetto, like he was right, not on Wellesley Street but close. And so he was totally, "Here's the stuff you need to do, here's what we're going to try." Like, there was no ... there was no treatment really, at the time.

JC: Yeah.

G: It was just, you know ... there was the beginnings of the AZT and DDI and all that kind of stuff. But it was more like, you know, making sure these things are in order. Do you need papers signed for disability? Do you need stuff off of work? Like, all of those practical things that were actually very much more helpful than the medical stuff. Because the medical stuff was kind of, we kind of knew what was going to happen.

[00:06:06.24]

JC: Yeah.

G: But it was more like, "Oh, okay, well do you have an insurance policy? You know, are you going to ... do you need me to sign you out of work for a few weeks to figure out what you're doing?" And that was very helpful, because that was more along the lines of, "How do you construct a life now?" Right? It's not over yet. It will be, but not yet. And some of it will be awful, but it doesn't all have to be awful.

JC: Yeah.

G: So that was sort of the message I got from him. And he was ... he was very good.

JC: How ... and when you say 'good,' can you describe what 'good' means in that context?

G: I think he understood that the most important thing that he could do as a medical professional was to make sure that you were connected to all the things that could give you the best possible options. And ... and, you know, that was more important than offering ... I mean, it's not that there wasn't offering hope, because hope meant something different at that point.

[00:07:12.16]

JC: Mm-hmmm.

G: But ... but as a good doctor, he was trying to make sure that the things that could be dealt with were on the table, so that ... so that you didn't have to feel like ... I mean I didn't have any of the ... the big issues that were around at the time, but it was things like, "Oh, okay." You know, like, because my diagnosis came without any other symptom except just failing general health, which could have been the result of everything else that was going on. And so the type of work that he would do would be, "Okay well, you've got a lesion, so we need to get you to see a dermatologist. So I have a dermatologist coming in." The one dermatologist he had to can because ... so he had a clinical specialist come in and do work and he ... the guy just didn't understand what was required of him and was kind of ... he was kind of creeped out by the types of lesions that people were coming with.

[00:08:10.28]

JC: Yeah.

G: Because nobody had ever seen it before. I didn't have any of that stuff, but I knew that ... people who ... I kind of went, "I'm in an office, and there's, like, you know, a bunch of couples, this guy's got some complete weird outgrowth of fungus on his hand. And, you know, there's all these things that are happening, and it's like, I'm there with, like, a wart or something like that. And ... or my raw elbows, or whatever.

JC: Yeah.

G: And so I kind of went, "Oh. This can get really bad." And it's like, yeah, but that ... that dermatologist didn't last very long. His problem was, I think he was just homophobic.

JC: Oh.

G: I think he just didn't get that you were ... had to touch people, you know, you had to be ... like, you know, a lot of the stuff is intimate because you're ... you're trying to figure out what this is, and it might be on your butt or might be on your scrotum, or it might be ... you know, like, he's kind of like, "Ewww..."

[00:09:02.21]

JC: "I might catch the gay disease!"

G: Yeah. I think he was just squeamish about the whole thing. But that ... most of my ... most of my medical care in Toronto, and most of the direction that I had around how this was going to unfold most likely was very matter-of-fact, and particularly well-informed.

JC: Mm-hmmm.

G: I mean we had a very highly-evolved group of doctors by that stage, because they really understood and there was enough of a community there to get doctors to think about what end-of-life care was going to look like. What ... what were the ... what were the elements of making sure that somebody felt like they were the people that were in control.

JC: Mm-hmmm.

[00:10:00.25]

G: And it was very interesting because they were totally blind, right? At the time, they ... there was palliative care, which was starting to become like a thing, and it was mostly centred around cancer and mostly centred around elderly and ... and all of a sudden you had this completely weird population that was ... you know, that needed these kinds of things. So that was ... that was ... like, all those avenues were opened up fairly quickly, and it was very well understood that there will come a time where you can choose to leave if you ... you can choose to die if you want to. There was no such thing as medically ... medical assisted dying that was official, but really what it was was ... there was a couple of doctors who would do housecalls, and it was just relief. They would just say, "Oh, you need some more morphine? Okay. Oh, you want some more? Sure." Or they would give you control, especially in the hospitals.

[00:11:02.04]

JC: Yeah.

G: They would ... they would say, "Hmmm, we don't really know how much pain you're in, so here's a ... here's a button that you can push whenever you want." And ... and so that was set up as a ... I think it was honest, because I think they ... I think they understood how everything was going on. But it a way of coming to terms with the fact that this was a group of people who were not going to stand for it. Like you know, these were a lot of gay, white men who had been used to having their way, you know? So they kind of weren't about to say, "Diapers? I don't think so."

JC: Yeah. So, like, when it came to those options of end-of-life care, or ... that was something that was discussed in indirect terms or direct terms?

G: With my partner who had ... do you want another one of these?

JC: Sure.

G: With my partner, it was very openly discussed because he was a bit of a ... a bit of an activist in the field, actually. I would say no one really had a -- oh here, have one. No one really had a framework.

[00:12:22.16]

JC: Yeah.

G: So a lot of the activists were ... were ... a lot of the activists and the new counsellors that were ... because I worked at the AIDS Community of Toronto eventually, and a lot of them were trying to develop frameworks for these kinds of discussions. But I personally found them unsatisfactory because they tended to focus on your death as a political event, your death as a community thing. And I think that that may have been okay for some people, and I think that was where the activists ... because it came out of an activist stance, but it wasn't what I was ... wanted to hear. I wanted to hear individual options. How does this work for me? What are the ... what are the things that ... and so that became more my concerns as my disease progressed, which wasn't very far, but it was still kind of like, okay what do I need to do to make sure that I am not part of the politics associated with this? And it wasn't easy.

[00:13:39.27]

JC: Mm-hmmm.

G: Because there was almost an insistence that every death ... every AIDS death be political, right? And that was ... you kind of went, "Okay, well ..." I knew how that worked and I knew where that came from, but it was quite clear that that's not how I wanted to have it dealt with. So I never really did get a framework for my own coming to terms with that. My partner, however, just did everything on his own terms anyway.

[00:14:09.02]

JC: Yeah.

G: So that ... that's how ... I mean, he was in Wellesley Hospital, which doesn't exist anymore, and he had a morphine pump. He had all sorts of other things wrong with him, he had various kinds of cancer and all sorts of things that was partly related to HIV but partly related to the fact that he was a metal plater. And he, you know ... before health and safety rules were in place. And so he ... he made all of those kinds of things known to his medical professionals, was able to just, you know, get out on his own terms. And things like, the night before he died, he had a whole bunch of family over, like nieces and nephews and didn't really say goodbye, just wanted to see them.

[00:15:03.21]

JC: Yeah.

G: And then died that night. And then the ... the after-care for his body was very respectful and very ... it was good to see. You know, it was kind of like, "Oh, okay, well ..."

JC: Good to see for your own peace of mind?

G: Yeah, very much so. Because ... because you're ... it was an intensive care situation and I unfortunately, made myself radically unavailable when he actually died. I was quite drunk. And ... because we were actually going to radically unavailable.

JC: Every time I'm drunk I'm going to say 'radically unavailable.'

G: But it was ... we were planning on bringing him home and saying, "Okay, we'll set this up so that he can die at home." And he ... so he chose not to come home, I guess maybe he was disgusted with me or something, but ... which was perfectly alright.

[00:16:04.19]

G: And perfectly understandable. So I didn't really find out until the morning after. So ... so then it was in intensive ... because they, they said, "Well, you're the power of attorney so, you know, we revived him." And I went, "Oh yeah, okay. Sorry I wasn't available." So they revived him and had him intubated and everything, and we just said, "No. That's fine." We got his brother and sister, who he was quite close to, we all gathered around and said, "Yeah, let's do this." So that was reassuring because, I think one of the big fears that a lot of people have is that when you're ... when everything is mediated by ... by technology, that the humanity disappears. But that's not the case. That's not ... when you have good professionals and you have good people ... so that part of it was like, "Oh, okay. I don't have to worry about ... about that." You know, about being in a state where I am actually requiring machines, I am ... like, so it was kind of presented a new ... a new facet that I'd never really thought of, which is, "Oh, being hooked up to a machine might be acceptable under certain circumstances."

[00:17:13.14]

JC: Yeah.

G: "That might be okay, and that might be ..." So in other words, the line in the sand that when you are reasonably healthy and you're vibrant and you think the world is going to be fine, that might be a hangnail. But then when you have a hangnail then you go, "Well, maybe I'll wait for my toe to fall off." And then you have your ... toe falls off, then you go, "Well, if they amputate me below the knee, then I'll be fine, and I'll still be able to do all this ..." So I think that part of the lesson that I learned was, as you move through watching other people, but also you feel it yourself, you ... you become ... you change. Your perspective on what 'terminal' means changes. And I think that that's an important thing to understand for people who are ... who are providing any kind of service that's related to end-of-life care, is that you're caring for a living person, you know?

[00:18:12.12]

JC: Yeah. They're not dead yet.

G: Yeah. They're not dead yet. And ... and they might choose not to be dead yet. Like, they might ... they might have told you yesterday, but now they're not going to. I don't know quite how we're going to, you know ... how all that stuff fits into ... with people who are no longer able to say ...

JC: Yeah.

G: And I guess you just have to say, "Well, the last time we heard from them was this." And I guess that's ... that's going to be the dilemma. But ... but it was very ... all of those things were reassuring. There were a few people that I had started to pay attention to at the time who were very end-stage, also very public, who talked about things like the nature of hope. And I think a lot of people who are healthy think that hope means, "Oh, you're going to get better." And it's like, "No, that's not what hope means." Hope means, "I'm going to make it through dinner without throwing up" Or, "I'm not going to shit myself in front of my mom." You know like, that ... that's what they mean by 'hope.' It's a different ... it's a different kind of thing. And that's important to remember as well, is that when somebody ... when somebody is asking for hope or looking for hope, it doesn't mean they want to get better because they know that that's probably not going to happen.

[00:19:17.06]

JC: Yeah.

G: You know, and so ... and so that's an important lesson that I learned from watching other people sort of go through gracefully and very publicly what that was like.

JC: Well, and you mentioned that. You mentioned that conversations with the medical care teams were rather matter-of-fact. And then witnessing that humanity isn't gone. So when you're ... when you have those

conversations, are you ... what kinds of things did the physicians or the medical team do that demonstrated that this is matter-of-fact or they still had humanity. What ... was there a certain tone? Or ... and even thinking in terms of more recent conversations, like, is there things that physicians are doing that make ... give you that quote-unquote right kind of hope, versus the wrong kind of hope?

[00:20:14.04]

G: I think we had it good with my ... with my own sort of ... my own situation, which is ... I mean I'm in great health right now. There are a lot of ... like, as a long-term survivor, there's a lot of aspects of my life that really do need to change because they are ... they represent the sort of the habits that you pick up out of despair at the time. So drinking too much, I quit smoking three years ago, that was a huge accomplishment. And ... and so those things were ... were hopeful.

[00:21:04.08]

G: In other words, you ... you've got some choices that you can make now that will actually make whatever you have left be better. And there's still the gnawing sense that ... I mean they're starting to find out now that you've got about ... 15 years gets taken off your life just by inflammation alone.

JC: Yeah.

G: And that's just ... we're not quite sure when we know that, but that's a ... that's an aspect of long-term survival -- for an awful lot of diseases, not just HIV and AIDS. But you know, you've got this thing that's been constantly there, and it's probably aged you a little bit faster than you'd have normally aged. And, as you get older, the amount that amount that you've aged more becomes more obvious. So then you have to start dealing with old man things, and that's all good. But then that means, "Oh, there's stuff I still need to worry about that isn't related to my identity as an HIV-positive person that I now have to deal with." And I'm now in a situation where I can deal with them.

[00:22:13.20]

JC: Yeah.

G: Where before, the primary thing was to make sure that you weren't going to end up with a lot of suffering and with no dignity. And that was the ... that was the biggest challenge. So a lot of the ... a lot of the infrastructure that was put in place in the late '80s and the '90s was about those issues, about ... about ... I guess that's palliative care in a nutshell, but to make sure that people are not suffering and that they are able to live with whatever they have in a certain amount of dignity that they ... that they identify as ... as, might look completely undignified from the outside, but to talk to people about that.

[00:23:08.06]

G: And I think -- well, I know -- that the health-care professionals became very good at that dignity conversation, and that sounded like things like, "Is there anything ... do you want someone else around? Is there anybody else you need to ... to let know about what's going on? Is there any other component, like do we ... is there a thing that you need around you that will make you feel better?" Even if there is no ... even if there's no comfort from it, like no medical comfort from it, is there something around you that ... that you would prefer to have here? Like you know, all the ... and Casey House was like, even though it was a ... it was a, you know, it was a highly-regulated healthcare environment, there were cats there. There were regular visits from dogs. There were snotty-nosed little kids running around with all sorts of different kinds of flus. And like death really, to the people who were there. But that wasn't the point. Like you're not ... it's like, "Oh, so your kid's got the flu. It might kill you." It's like, "Really? Oh well, imagine that. I might die a little sooner." So ... so those kinds of issues around remembering that ... that at that type, at that time, the medical concerns are not primary. Like, the things that we would consider to be basic healthcare no longer ... don't always matter as much.

[00:24:45.09]

JC: Yeah.

G: So things like infection control. It's like, you still have to do it but, if a kid comes in and, you know, and it's like you've got a couple of weeks to live and, you know, that's all there is, you kind of go, "Well, you come back in a couple of weeks when your cold's gone," like, that doesn't make any sense.

[00:25:04.17]

JC: No.

G: And you can't go, "Well, we'll meet on neutral territory where it doesn't matter." So all that kind of stuff has to be dealt with, I think, in ... in the healthcare setting. If these are going to be ... if this is going to be assistance in a medical setting, then some of that has to be dealt with. I don't know how. I mean, Wellesley Hospital did it by just having a ward where it's like, "These doors? Sterile. These doors? Not so much." I mean, it's still clean and still healthy, but there's cats over there and there's ... that's where the visitors come, and there's people over there, like all the friends. A lot of them will also have all sorts of weird diseases as well, right? So ... so that's kind of a ... a way that doctors and nurses and the social workers and the cleaning staff eventually -- they were not on board early on, but eventually -- all got used to just saying, "Okay, you know that's fine. We're just not going to worry about that quite so much."

[00:26:04.07]

JC: Yeah. Yeah.

G: And the ... the part that was kind of the ... the letdown on the medical professional side often was where it always is and that's the emergency ward, you know? You're just not ... I don't know to what extent emergency medicine will play into all of this, but at the time it was ... often that was the first sign that you were going to have something really awful happen. So I was admitted ... I was admitted twice with pneumonia, just garden-variety pneumonia. However, very very rapid onset, very ... and as my mom the mourner said, "Oh yeah, people would have died of that back, you know, before penicillin." It was like, "Thank you, thanks mom!" And ... so that was really when I started to realize that, "Oh, I could die from this. Like, this is actually now ... I might not recover from this infection, and I have to really pay attention."

[00:27:07.12]

G: But the first hint I had of that was I had a job interview that morning, kind of coughing and not feeling that great. I had to help somebody who had a grand mal on the sidewalk and he was banging his head. So I had to push my coat underneath him and I just sort of sat there to wait until the ambulance came by. No cellphones at the time, so somebody had to actually go across the street, make a phone call. So it wasn't like, you know ... so ... So that was that day, and then I ... I did this interview. And got home at night and wasn't feeling very well. And about two hours later, I couldn't breathe. Like I was actually so heavily fevered and my lungs had just completely filled up and I went, "Oh, this isn't very good." So I had to call an ambulance. And so the fire truck came, and off I went to the hospital. And it was just a really ... quite a different experience in emerg. And I'm sure that's just the nature of emergency.

[00:28:03.03]

JC: Yeah. Sorry, you were ... you had been diagnosed at this time?

G: Yeah.

JC: Sorry to interrupt.

G: No, that's fine. And so that ... that was the point at which ... at which I kind of went, "Oh, well you know, this is ... this is kind of a ... this is a different way in." And I think ... I think it's just the medical system isn't

really set up -- we know that already -- I mean, the emergency care system isn't really set up to deal with end-of-life care.

JC: Yeah.

G: And there ... there does not appear to be any doorway between the two.

JC: Yeah.

G: So that's ... when I reflected back on what that experience -- because I recovered and the antibiotics worked and I was fine in six days or so. I had to stay in the hospital for four days and they pumped me up and they did all sorts of weird things, but ... but when I reflected back on it, I thought, "You know, if this had gone the other way, where was the handoff? How ... there was nobody came to talk to me about ... about anything. It was more ... it was that matter-of-fact, but not in a ... not in a helpful way. It was like, you know, the guy's taking your arterial blood and he says, "So ... so how do you think you got AIDS?" And I went, "Oh! I don't know."

JC: Thanks, buddy!

G: Thanks, buddy, yeah. It might even have been worse. I think he might have said, "How'd you get it?" It! Pneumonia? But there's a lot of that. I mean we had ... we had the same problem with ... with ... when my partner slowly became less and less capable of eating, and he got ... there was just a shortage of people who knew what they were doing.

[00:30:05.12]

JC: Mm-hmmm.

G: And so we got a lot of weird, you know, like we'd go to emerg and then they'd say, "Okay, here's a stopgap measure and then we'll book you an appointment with this specialist. And they will be able to see you, but not until tomorrow." So that's fine, so that's terrific, actually. And they would ... but then the specialists would just have no review, no casework, no ability to look at a file. And basically, they were there just to say, "Yeah, looks like you can't eat," you know? So there's no ... there was no assistance there, and so the point of that was kind of missed. It was like, "Well, this is expensive, for one thing." But that happened on a number of occasions with my partner. And happened a number of occasions with my mom too, when we were taking care of her at her end-of-life, where it was basically, "No, she doesn't have pneumonia." And then the next doctor would say, "Yeah, she has pneumonia." But that would be, like, four days later.

[00:31:08.08]

JC: Yeah.

G: And in the meantime she had been declining in health and ... and, you know, then you go, "Well, what do we do?" Like, because if some ... if you're there and someone says, "You don't have a condition for which we're going to do anything about," regardless of whether or not that's because there is nothing that they can do about it or because they've misdiagnosed. Because if that ... I think the AIDS stuff is more like ... at the time it was more like, "Well, we can't do anything for you anyways, so just go home and whatever."

JC: Great.

G: Yeah, try to, you know, eat soup. If you can't eat solid foods then try some liquids. Like, "Oh, thanks for the suggestion. That never occurred to us. Liquid food, never thought about it." You know, meanwhile he's got a jejunal tube and a pump that's pumping in ... you know?

[00:32:00.19]

JC: So then that sounds a lot like having members of the care team -- whether it's the physician or somebody -- know at least something about you, know your history on some level, whether or not they've read a file. That when you're having those conversations that ... it sounds like what you're saying is that ...

G: That would be very helpful because the ... the biggest problem that we had, that I still think we have, is that there's no ... there's no Coles Notes for what your life is. And I don't know how you do that, but ... but if you have somebody who is in ... who has a medical file and the predominant feature of the medical file is that they are at end-of-life, then you don't really know who's going to be involved. And there needs to be a way to communicate fairly directly all of the important things like directives, who's who in this person's life. How does all that get resolved?

[00:33:02.12]

JC: Yeah.

G: So I think those technical matters are highly required, because that's ... that's just the way the law's going to have to work. And also, you know, morally and ethically how do you ... who do you go to? But I think some synopsis of what this person was and is and how they ... because often the person that's in front of you isn't the person that they were. And I think in order to sort of understand the ... sort of the humanity and the dignity, you need to know something about the person from before.

JC: Do you need a break?

G: Yeah, a little bit.

JC: Okay.

[TAPE PAUSED]

JC: So one of the things that some of the other participants have talked about is the importance of having what they call a sense of humour. It's a bit more like wit. It's not college humour, slack jokes. What do you feel about that? Did you experience anything like that? Or have you experienced anything like that, or does it matter? Did it not come up?

[00:34:16.17]

G: I would say that yes, it's always there, and most of the time ... in a lot of the end-of-life situations that I've been in -- not me, personally personally, but that I've witnessed or participated in, some people come naturally to and I think that that shouldn't be suppressed. In other words, if your natural response is to ... is to try to understand the eminent tragedy in terms of the human condition and how absurd and how funny that can be -- and that's a natural inclination, then that always fits to me.

[00:35:00.22]

JC: Yeah.

G: When it ... when the person would normally be like that and they're not allowed to by the circumstance or by the ... or by whatever code of conduct, that is noticed. When it's ... when it's like, it's not like the 'lighten up' thing, it's more like your ... your understanding of this doesn't ... has to include the other parts of your spirit. And some of the spirit is often sardonic or a slightly wistful way of looking at the world that might actually be quite informative, right? Because sometimes you're ... sometimes you're contextualizing a lot when you ... when you present a situation as, not necessarily as a funny situation, but as an absurd or an ironic or a ... or a ... humorous is often the case, because that is what happens sometimes.

[00:36:09.04]

JC: Yeah.

G: And so if it's ... if that's the way the person is naturally, then that shouldn't be suppressed. It also isn't a requirement, because some people don't feel like -- in other words, it's noticed on both ends. If the person is normally that way, and they don't kind of yuck it up a little bit and have a little bit of gallows humour about it, then that gets noticed. If not by the person whose life is ... is in question, but certainly by the people around them.

JC: Yeah.

G: And if it's somebody who isn't inclined to be that way and then makes an off joke, then that also really shows up. That's ... and that's unfortunate when that happens.

JC: Yeah.

G: And sometimes it's people who are caregivers who are trying to be one of the buddies, and sometimes you're not.

[00:37:07.19]

JC: Yeah.

G: You know, sometimes you're not one of the buddies.

JC: Yeah.

G: You know, it's just the way that ... the way that the situation goes. So I would say, "Who are you doing this for?" Often if you're with somebody who's ... who's not interested, then you might be doing it for the survivors. You might be doing it for the people that ... that are there to be part of the support network that's required. And it just becomes a way of ... of dissipating the types of tensions that are always going to be there. But it has to be natural and it has to be ... it has to be present when it's natural.

JC: Yeah.

G: So, yeah. Yeah. But I've never ... I think they do a lot of ... they did a lot of workshops around humour when I was working at the AIDS Committee of Toronto. They did a lot of workshops around that, because it was often a way that was neglected in the ... the literature was very sombre at the time.

[00:38:13.27]

JC: Mm-hmmm.

G: Like, extremely sombre. And the journalism was very sombre. And it was like, well what do we do about that, because that's not who we are. Have you been to a gay club recently? They're not sombre events. So ... so that was the ... I think the purpose of that was to make sure that the people that were affected didn't feel like they had to be somebody other than who they actually were.

JC: Yeah.

G: And then that, as they became less and less themselves, then that extended to their support network and their family. So it became understood that it was just part of the mix when required and appropriate. And ... but it was ...

[00:39:03.01]

G: Yeah, that's ... I think that with my ... with my own situation, the humour has always been there, has always been something that I kind of expect. It's a communication tool, because it can actually ... it can actually, from my perspective, it can let the caregiver know that it's ... that this part is okay. Or ... or I understand that ... that there's other things I need to worry about. So I'm going to ... so that's some of the roles that humour plays is also to let the person understand -- the caregiver understand -- from your perspective (that) this is okay. So that ... that becomes important. And certainly, you know ... just trying to, can't think of any specific examples now from my ... from my partner's demise.

[00:40:06.22]

JC: Yeah.

G: But there was ... lots of times when people were just laughing.

JC: Yeah.

G: And I was like, "Oh, okay. Well, that's better."

JC: They do say laughter is a medical ...

G: Yes. Yeah. And again, it's a ... that's another one of those definitions of hope, right? Is that, "Oh I hope there's laughter today."

JC: Yeah.

G: You know, like, that'd be good!

JC: Yeah. Before we wrap this up, is there something I haven't asked about that you ... because I know you've thought ... put some thought into this, so is there something I haven't brought up that you want to say? Anything about ...?

G: I think so. I think the reason why I was so caught off-guard emotionally was because it hadn't occurred to me before how important it was to know what the person was like.

[00:41:04.19]

JC: Yeah. Yeah. And there's ... well, that's something that has come up in other [UNINTELLIGIBLE], but that is a pretty strong theme. So hopefully this helps point that out to people and helps them figure out the systems.

G: Yeah. The framework. Yeah, the framework for providing care is not ... like, you're not talking about the whole person as they are presented to you at that moment in time. But you're talking about the whole person as they have lived up to that point.

JC: Yeah.

G: Cool.

JC: Thank you!

G: Yeah. No, thank you for helping me come to a realization. It's like, "Oh, yeah!"

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