



AHS Research Challenge
Qualitative Protocol
Palliative & End of Life Care – Cohort 3

Family physicians' experiences in initiating palliative care conversations with patients who have life-limiting, non-cancer illnesses

Authors: Vanessa Slobogian (MN CNS)^{1, 3}, Lisa Shirt (MN CNS)^{1, 3}, Chandra Vig (MEd RN)^{1, 3}, Margot Sondermann (MEd BScPT)^{1, 3}, Chelsey Shuman (MN RN)^{1,3}, Monique Vanderveen, (RN, BN)^{1,3}, Shelley Raffin Bouchal (PhD)^{2, 4}

Program:

1. Palliative and End of Life Care
2. Faculty of Nursing

Institutions:

3. Alberta Health Services
4. University of Calgary

Corresponding Author: Vanessa Slobogian – Masters of Nursing; Bachelors of Nursing
Palliative and End of Life Care
10301 Southport Lane
Calgary, AB
403-826-3889
Vanessa.slobogian@ahs.ca

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1 BACKGROUND & RATIONALE

Increasing numbers of Canadians living with complex life-limiting conditions demand delivery of high-quality palliative care outside of acute care or specialist practice (Mitchell, Loew, Catherine Millington-Sanders, & Dale, 2016). Family physicians (FPs) are often responsible for discussing and providing palliative care, a topic that remains challenging for most health professionals. Little empirical evidence exists about how FPs identify whether and/or when it is appropriate to engage in these conversations with their patients (Claessen, Francke, Engels, & Deliens, 2013). However, delays in these conversations may impede the ability of the patient to participate in decision-making at all stages of their illness experience (Belanger et al., 2014). The purpose of this study is to explore the experiences of FPs regarding the decision and process of introducing palliative care to patients with life-limiting (non-cancer) diagnoses.

Purpose

Timely access to palliative care can help to reduce stress, improve quality of life, and provide relief for patients with life-limiting illnesses and their families (Canadian Institute for Health Information, 2018). When initial introduction of palliative care occurs late (within the last weeks or short months of an individual's life) there are poorer patient outcomes and greater costs to the health system (Cheung et al., 2015; Temel, Greer & Muzikansky, 2010). As FPs are often the primary providers of palliative care, their proficiency and comfort are essential components of this role. The introduction and provision of quality palliative care is particularly important for individuals with chronic illnesses whose health statuses are likely to fluctuate, characterized by a steady decline and difficult-to-predict crises, ultimately resulting in death. Information gathered by FPs when discussing palliative care can be used to guide decision-making, anticipate future needs, and ensure treatment decisions are aligned with the patient's values and expressed wishes (Temel et al., 2010).

Significance

FPs are in a unique position to introduce palliative care to patients before a medical crisis occurs. Early introduction of palliative care is essential in these populations as an adverse event may leave them incapable of adequately communicating their wishes and place undue burden on family (Rasmussen, 2016). Despite this, it is not uncommon for the initial introduction of palliative care to occur in an acute care setting in the days or weeks before an individual's death (Hawley, 2017). However, if presented with adequate information about palliative care, these individuals may not have wanted treatment in acute care to begin with. Pursuing interventions that are not aligned with what a patient may want can be costly to the health care system (Zimmerman et al., 2014) and likely to impair that individual's quality of life (Cheung et al., 2015). It is evident that timely provision of palliative care is important and that FPs are poised to be front-line and most responsible providers.

Despite this, it has been our experience as palliative care consultants that many patients with life-limiting illnesses have not engaged in conversations about palliative care with their FPs. Individuals who are followed by a disease-related specialist (i.e. oncologist, cardiologist, pulmonologist, etc.) may be more likely to have some awareness of palliative care but this is less likely to come from the FP (Otte et al., 2014; Thoosen et al., 2012). This is especially concerning given the

often long-standing relationship a FP may have with a patient (with chronic illness) and the likelihood that the FP may become the primary provider in the later stages of an individual's disease trajectory if active treatment is no longer pursued. Further to this, the literature, as well as our professional experience, suggest that these conversations are most likely to occur if there is a cancer diagnosis. As such, we have elected to focus on the non-cancer population for our study purposes. Given the dearth of literature available exploring how and if FPs engage in palliative conversations with individuals who have a life-limiting, non-cancer diagnosis, it is clear that further investigation is warranted.

Research Question

The value of FPs providing palliative care has been established, however little research has been done to understand their experience in undertaking such a complex and emotionally challenging aspect of care. This project will seek to investigate the experiences of FPs if and when they introduce palliative care to patients with life-limiting, non-cancer diagnoses. Our primary research question is: "What is the experience and understanding of family physicians in having palliative conversations?". We aim to provide insight into the decision-making processes of FPs, as well as the complexities they face when providing this care. It is our belief that insight gained will help identify ways to assist FPs in introducing and providing palliative care in the future.

Literature Review

A comprehensive literature review was conducted using pre-determined search strategies discussed between a librarian and members of the Palliative and End of Life Care Research Challenge Team. The objective of conducting this literature review was to deepen our understanding of the current state of evidence related to the introduction of palliative care by FPs to non-cancer patients with a life-limiting illness and to identify common themes related to our question of how this occurs in practice. Knowledge obtained from this review serves as the basis for our research study and informed the formulation of our research question.

The databases searched included MEDLINE (Ovid), EBM Reviews (Cochrane Database of Systematic Reviews, ACP Journal Club, Database of Abstracts of Reviews of Effects, Cochrane Central Register of Controlled Trials, Cochrane Methodology Register, Health Technology Assessment, NHS Economic Evaluation Database), PsycINFO, PubMed, CINAHL, and MEDLINE (Ebsco). In addition, five grey literature resources were searched, including AHS Insite, Google, Google Scholar, OAISter (<https://oaister.worldcat.org>), and GreyHub (<https://greyhub.org/grey/desktop/en/search.html>), (<http://oaister.worldcat.org>). A publication date limit of 2009 – present was applied, and the search included studies pertaining to adults, written in English, and from all countries. 819 potential articles were identified following a search of the databases, along with 20 additional records following a search of grey literature resources. After removal of duplicates, the titles and abstracts of 216 documents were screened for relevance, yielding 196 articles for full text review, of which 11 were selected as relevant to the goals of this paper.

Our review identified themes which we further grouped into either facilitators or barriers to FPs engaging in palliative care conversations.

Barriers: One commonly cited obstacle was related to the discrepancy of whose role it is to initiate these conversations: the FP or the patient. Additional findings of our review were the barriers of time and experience (Beernaert et al., 2014; Johnson et al., 2018; Scholten et al., 2018; Sharp et al., 2018;

Vleminck et al., 2013; Wichmann et al., 2018). Both patients and practitioners cited the length of time palliative care conversations require and the perceived busyness of the FP as barriers to initiation (Glaudemans et al., 2019; Scholten et al., 2018). Further, FPs in both the Netherlands and North America report that there is a lack of financial compensation for time spent in ‘conversation’, which impairs their engagement in these discussions (Johnson et al., 2018; Scholten et al., 2018; Vleminck et al., 2013). Wichmann et al. (2018) conducted qualitative interviews with Dutch FPs (n=17) to explore these conversations through the eyes of the physician: they identified a perceived lack of training and experience as further hurdles.

Facilitators: Facilitators to palliative care conversations were also identified in the literature reviewed and not surprisingly, the facilitators were largely contrary to the identified barriers. Having proactive patients, the FP’s experience in palliative care, and effective communication all led to these conversations happening (Johnson et al., 2018; Vleminck et al., 2013; Wichmann et al., 2018).

A common recommendation within the literature was establishing criteria or systems to identify patients who should be introduced to the concept of palliative care. There is general consensus that patients clearly in their last weeks of life, with a diagnosis of advanced cancer or suffering from significant disease-associated symptom burden should be engaged, however, FPs expressed the need for criteria to help target other groups (Otte et al., 2014; Thoosen et al., 2012). “Another important finding is that identification by the family physician of palliative care needs seems to be more problematic in the earlier stages than the terminal phase. Family physicians themselves indicated that it was easier to discuss and identify palliative care needs in the last weeks of life when prognosis is clearer” (Beernaert et al., 2014, p.488). Clear parallels can be drawn between the barriers to initiating conversations and the difficulty identifying patients who would be appropriate for the introduction of palliative care.

Proposal

The proposed study will help build understanding regarding the current experience and practice of FPs introducing palliative care to their patients with chronic life-limiting illnesses such as heart failure, COPD, chronic renal failure, and dementia. We will interview FPs practicing in the Calgary Zone of Alberta Health Services regarding their lived experience within their own practice. In addition to the experience we are seeking to gain understanding of the facilitators and barriers to these conversations within a local context in order to learn better ways to help support FPs with this important work.

2 THEORETICAL FRAMEWORK

We propose the use of the interpretive description methodology to guide investigation of this research question. Interpretive description stems from a core value of clinical experience that may not be adequately captured in other qualitative methodologies. This methodology was initially developed as an approach to qualitative research that aptly addresses complex clinical experiences and as such is often used in research by applied health disciplines, such as nursing (Thorne, 2008). Interpretive description seeks to inform clinical understanding by exploring clinical problems with the goal of guiding future practice (Teodoro et al, 2018; Thorne, 2008; Thorne, 2016). As described by Teodora et al. (2018, n.p.), this methodology was born “to lead the elaboration of research questions focused on practical aspects of these areas of knowledge, as well as, entry into the field in a logical, systematic and justified manner, and the creation of a data analysis so that the researcher's engagement with the data makes possible an interpretation of the studied context beyond the obvious”.

Interpretive description begins with systematic analysis of existing clinical knowledge and theoretical frameworks with pragmatic consideration of context and the diversity of human experience. Knowledge translation remains at the forefront of this methodology and it is seen that the knowledge obtained should be applicable to practice. Given our clinical experience, our research team has acknowledged that the lived experience of participants (FPs) is essential to understanding the complexities of introducing palliative care. These experiences cannot be separated from the context or systems from within which they occur; rather the context informs the experience and subsequently the outcomes.

In keeping with interpretive description our research question does not seek to explain or predict but instead to approach our study with openness. Our team is composed of clinicians working in Palliative Care and as such we enter the **role** of researchers with experience and bias. When we are engaged in initial consultations with patients who have lived with chronic illness for years they have rarely had any discussion about palliative care. We often find the patients are surprised when we venture into a conversation about end of life wishes and goals, as this seems to have not occurred to them. Despite obvious changes in the patients' health leading to the request for a palliative care consultation, palliative care and end of life issues have often not been discussed with their primary care providers. When we first meet the patient, we tend to assume that these conversations have not taken place with their FPs in most cases. We noticed as a group that this is most common amongst patients with chronic illness than those experiencing cancer and are being followed by specialists. This methodology allows us to bring and acknowledge these assumptions inherent to our experience. The pragmatism of interpretive description continues through its approach to data analysis, which relies on pattern recognition, common sense and skill (S. Raffin Bouchal, personal communication, October 30, 2019). As our objective is to determine ways to support current FP practice, this methodology is well aligned.

3 RESEARCH QUESTION/AIMS

This study aims to interview FPs practicing in the Calgary Zone regarding the experience of entering into palliative conversations with patients who have a life-limiting, non-cancer diagnosis. Additionally, we seek to understand the barriers and facilitators experienced by the FPs when engaging in these conversations.

Objective

The objective of this study is to develop understanding of the lived experience of FPs regarding the initiation of conversations about and incorporation of palliative care into their practice with patients who have a life-limiting, non-cancer diagnosis. Input from Calgary Zone FPs will be sought in order to explore (a) if they engage in palliative conversations as part of their practice when caring for individuals with life-threatening illnesses, (b) if yes, which elements of palliative care (Advanced Care Planning, Care Coordination, Illness Comprehension & Coping, and Symptoms & Functional Status (University of Calgary, 2019) are included in palliative conversations, and (c) barriers and facilitators to engaging in palliative conversations as part of FP practice.

Outcome

The intended outcome of this study is to build understanding of the current state of FP practice when engaging in palliative conversations. We anticipate that this knowledge will allow for the development of evidence-informed resources and support for FPs in the provision of palliative care.

4 STUDY DESIGN, METHODS OF DATA COLLECTION & ANALYSIS

As described, this qualitative study will use interpretive description methodology, which will allow us to incorporate both a systematic approach to inquiry, as well as the acknowledgment and incorporation of clinical expertise and bias. Interpretive description in the design of a rigorous systematic study process often borrows from traditional qualitative methodologies (Thorne, 2008). We will employ an iterative process for data collection and analysis, as well as constant comparative analysis, as used in Charmazian Grounded Theory (Charmaz, 2016). An interpretive description methodology uncovers the nuances of FP practice and diverse personal and professional experience. FPs will share their lived experience and perspective of entering into palliative conversations with this patient population and within the context of their own practice.

Participants

The population to be studied are Calgary Zone FPs who are currently working in a private practice or as part of a Primary Care Network. Participants will be purposively sampled, reflecting an awareness of expected and emerging variations within the phenomenon under study (Maxwell, 2013). We will target a sample size of 10-12 physicians, which literature, as well as consultation with an expert researcher in the field, indicate should be sufficient to reach saturation of the data (Thorne, 2008). The inclusion criteria will be English-speaking, FPs, currently practicing within the Calgary Zone who care for patients with chronic non-cancer illnesses including, but not limited to, lung, heart, kidney, liver and neurological disease. Our exclusion criteria will include non-English-speaking FPs, FPs who have sub-specialized practices, FPs outside of the Calgary Zone, those who are not currently practicing, and/or those who do not care for individuals with life-limiting, non-cancer diagnoses.

We are specifically seeking to capture a sample of FPs with a variety of experiences and levels of comfort in engaging this patient population in palliative conversations. As we hope to identify both barriers and facilitators to these discussions, we are looking to recruit FPs with different levels of skill, expertise and comfort in this area of practice.

Recruitment and Consent Procedures

Purposive sampling will be used to identify participants who can offer insight into the experience of engaging in palliative conversations as part of FP practice. Potential participants will be recruited from a variety of locations including private practices and Primary Care Networks (PCNs). We will enlist the help PCN Executive Directors in the Calgary Zone to share information about the study to potential participants.

Executive Directors of the PCNs will ask FPs who meet the inclusion criteria if a member of the research team can contact the FP to provide information about participation. Consenting FPs will complete a 'consent to contact form' (Appendix A), allowing a member of the research team to contact them by phone or email. Alternatively, FPs will be given the option to call the research team directly, if they do not wish to sign the consent to contact form.

Data Collection Procedures

The method to collect data will be semi-structured interviews using an interview guide (Appendix B). Open ended questions will be used to provide the means for the participants to respond in detail about their personal experience; allowing the data to reflect on a range of responses. Interviews will take place by phone or at a quiet location that is mutually acceptable and accessible for both the researcher and participant. Interviews are anticipated to last between 30-45 minutes. Interviews will be audio recorded on a secure device. The open-ended questions can also be modified in an iterative process as each interview is analysed, if any unanticipated themes emerge from the initial interviews. Audio recordings of interviews will be transcribed verbatim and compared against transcripts to ensure accuracy.

Data Analysis

In following with the methodology, an interpretive descriptive data analysis technique will be utilized (Thorne, 2008). As data is collected, the research team will employ constant comparative analysis, as per Charmaz's (2016) constructivist grounded theory. It will not be expected that the research team enter into analysis free from bias or clinical experience as interpretive description calls upon these to guide careful consideration of the data (Thorne, 2008). Coding will be used to begin sorting data with the lens that constant reconsideration will be required. Through this process we can begin to define the phenomena and analyse data gathered. As per interpretive descriptive methodology, our analysis will seek to find meaning in the coded data versus applying pre-determined categories or meaning (Charmaz, 2016).

There are at least two phases of coding: the initial phase, which involves naming each line or segment of data; and the focused phase, which involves using the most significant or frequent initial codes to organize and synthesize large amounts of data. Throughout each phase, constant comparative methods will be used between interview transcripts to determine analytic distinctions and help us to move towards abstract themes.

All members of the research team will independently code each transcript, coding for action words rather than applying previously existing theories to the data. We will each code the first 3 transcripts independently and then come together as a research team to discuss the codes that have emerged. Each team member will write memos to compare the initial codes that emerge. We will continue the initial coding throughout our remaining transcripts, constantly comparing these codes across transcripts looking for similarities and differences.

Focused coding follows initial coding, however the process is not entirely linear. New understanding that emerges through data analysis may prompt the researchers to go back and re-explore earlier data and follow up on new leads as they arise which is all a part of the constant comparative analysis. The researchers will engage in focused coding to advance the theoretical direction of their work by concentrating on the most significant or frequent codes to synthesize, analyse and conceptualize larger data segments. Constant comparing of the focused codes will allow for exploring similarities and differences in the data. Throughout this process, the researchers will continue memo writing to develop some of these focused codes into larger themes and conceptual categories. This is the place in the analysis where we will question whether we need to interview more individuals to clarify the emerging themes or consider if we have reached data saturation, where we agree that our theoretical/focused categories are robust, meaning no new focused codes are emerging from the data, and our established themes/categories are explaining the patterns in the data.

Data Confidentiality, Storage and Retention

Interviews

All electronic data (e.g. digital audio files, de-identified transcripts) will be uploaded and stored within a secure drive on an Alberta Health Services encrypted and password-protected computer. Transcripts derived from the audio recordings of interviews will undergo the process of de-identification to ensure anonymity. Interview participants will be assigned a pseudonym. Only this pseudonym will be associated with all the research data collected and analysed during the course of this study, so that the participant's identity will be kept confidential. A master subject identification list will be created to link study participant information with assigned pseudonym. This list will only be available to the Principal Investigator (PI) and study team with possible access to data by the ethics board. The master subject identification list and consent forms will be kept separate from the study data and will be kept in a locked cabinet in a locked office at the Foothills Medical Centre.

Retention

Participant consent forms, audio files, interview transcripts, interview notes, and the master subject identification list will be kept for 5 years from the completion of the project to comply with federal regulations and to accommodate data validation queries. All files will be deleted using document shredding and deletion of any electronic files from the secure drives.

Consent

Interviews may take place in-person or by phone. For phone interviews, the consent form (Appendix C) will be sent to participants in advance by e-mail or mail. A member of the research team will review the consent form over the telephone. This will include review of the nature and objectives of the study, risks and benefits of participation and provide an opportunity to ask questions, as well as confirm if the participant wishes to participate in the study. Oral consent will be obtained and recorded. For in-person interviews, written informed consent will be obtained from participants prior to beginning the interview, following the same process.

5 ETHICAL AND REGULATORY CONSIDERATIONS

Assessment and management of risk

Risks:

There are no physical, economic or legal risks to the study participants. There is risk of minimal emotional discomfort given the nature of discussing palliative care and the subsequent reflection on each participant's own practice and experiences.

The potential risk will be alleviated by different features of the study design. First, all participants will be informed that they can withdraw from the study at any time. Prior to initiating discussions, participants will be informed that should they experience discomfort at any point, they can take a break and postpone the discussion to a later date or withdraw their consent to participate. Participants may also choose not to answer certain questions. Second, all interview questions will be pre-scripted to maintain consistent structure. As well, all researchers will have participated in education regarding ethical conduct of studies involving human subjects.

Benefits:

Potential benefits for the participants include providing FPs the opportunity to share their experiences about initiating palliative conversations with patients facing life-limiting, non-cancer diagnoses. The results may help to identify barriers and facilitators to palliative conversations as well as build competency for FPs and potentially improve the quality and quantity of palliative discussions they have with patients experiencing life-limiting, non-cancer illnesses.

6 APPENDICES

Appendix A - Consent to Contact Form

CONSENT TO CONTACT FOR RESEARCH PURPOSES

TITLE: Family physicians' experience in initiating palliative care conversations with patients who have life-limiting, non-cancer illnesses

SPONSOR: Alberta Health Services

INVESTIGATORS: Vanessa Slobogian (MN CNS), Lisa Shirt (MN CNS), Chandra Vig (MEd RN), Margot Sondermann (MEd BScPT), Chelsey Shuman (MN RN), Monique Vanderveen, (RN, BN), Shelley Raffin Bouchal (PhD)

You are being invited to give consent for Vanessa Slobogian, or a qualified member of her study team to contact you at some time in the future to invite you to participate in a research study.

Are you willing to learn more about **Family physicians' experience in initiating palliative care conversations with patients who have life-limiting, non-cancer illnesses** study? (Circle one)

YES

NO

If yes, you will be contacted at a later date. Please include your contact information below and check preferred contact method.

Name: _____

Telephone: _____

E-mail: _____

*You authorize your Primary Care Network Executive Director or representative to disclose your name, telephone number and/or email to the research team for the purpose of being contacted to learn more about the research study, **Family physicians' experience in initiating palliative care conversations with patients who have life-limiting, non-cancer illnesses**.*

Every effort will be made to safeguard your contact information. Although access to this information will be limited, there is a small chance that this information could be inadvertently disclosed or inappropriately accessed.

You have been made aware of the reasons why the contact information is needed and the risks and benefits of consenting or refusing to consent.

This consent is effective immediately. Your consent to be contacted can be revoked by you at any time.

Date: _____

Family Physician's Name: _____

Signature: _____

Appendix B - Interview Guide

Semi-Structured Interview Guide

- Obtain demographic information including:
 - Number of years in practice
 - Areas of practice i.e. city, quadrant, community
 - Private practice or primary care network (PCN)
- Tell me about your experience caring for non-cancer, palliative patients in your practice
 - What does palliative care mean to you?
- Considering these experiences, what is your understanding of the elements of early palliative care?
 - Advanced care planning
 - Care Coordination
 - Illness comprehension and coping
 - Symptoms and functional status
- What other elements of palliative care have you utilized in your conversations?
 - What are they?
 - Why do you believe them to be valuable?
- What do you feel are the benefits, if any, to early introduction of palliative care conversations?
- When do you feel is the best time to initiate palliative conversations?
- What strategies have helped you to facilitate these conversations?
- If you struggle to have palliative conversations, what are some of the barriers for you?
- Are you interested in advancing your practice in initiating early palliative care conversations?

Appendix C - Consent Form

PARTICIPANT CONSENT FORM

Title of Study: Family physicians' experiences in initiating palliative care conversations with patients who have life-limiting, non-cancer illnesses

Principal Investigator: Vanessa Slobogian, (403) 826-3889

Why am I being asked to take part in this research study?

You are being asked to be in this study because you are a family physician working in the Calgary zone of Alberta Health Services, caring for non-cancer patients with a chronic, life-limiting illness. This study aims to build an understanding of whether or not family physicians are having palliative conversations with their chronically ill, non-cancer patients. If these conversations are happening, which elements of palliative care (advanced care planning, care coordination, illness comprehension and coping, and symptoms and functional status) are being included? Additionally, what barriers and facilitators are experienced when engaging in palliative conversations?

Before you make a decision, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be clarified. You will be given a copy of this form for your records.

What is the reason for doing the study?

Little is known about how family doctors decide if and when they should start conversations with non-cancer patients about palliative care (Claessen, Francke, Engels, & Deliens, 2013). Palliative care improves the quality of life of patients and their families with life-limiting illnesses (World Health Organization, n.d.). The purpose of this study is to understand if family doctors are having palliative discussions and if so, how and when are they starting these conversations with non-cancer, chronically ill patients.

What will I be asked to do?

If you choose to participate in this study, you will have a 1:1 interview with a member of the research team. You will be asked to speak about your opinions, thoughts and experiences about palliative discussions that you have had with patients under your care.

Interview

Interviews will take place with a member of the research team and can be done in person or over the telephone. Interviews are estimated to take approximately 30-45 minutes and if done in person, will occur at a location that is mutually acceptable and accessible for both you and the researcher. The interview will be audio recorded and transcribed for analysis.

What are the risks and discomforts?

Open discussions about palliative care can be emotionally uncomfortable. If you experience distress, you are free to end the interview at any time. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

You may gain additional insight into how and when to introduce palliative care to patients with life-limiting, non-cancer diagnoses. Alternatively, you may not get any direct benefit from participating in this study. However, your participation may help other family physicians to gain insight into how and when to introduce palliative care to their patients.

Do I have to take part in the study?

Participation in this research study is completely optional. You are free to exit the study at any time should you change your mind. Additionally, you do not have to answer any questions that you are not comfortable with. If you choose to withdraw from the research study, note that your interview data can only be removed if analysis of the data has not begun.

Concerns can be discussed with any member of the research team.

Will I be paid to be in the research?

You will not be paid for taking part in this study, however, a \$50 gift card will be offered for your participation.

Will my information be kept private?

During the study we will be collecting data from you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

What if I have questions?

If you have any questions about the research now or later, please contact Vanessa Slobogian at (403) 826-3889.

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Family physicians' experience in initiating palliative care conversations with patients who have life-limiting, non-cancer illnesses

Principal Investigator: Vanessa Slobogian MN CNS

Phone Number: 403-826-3889

	Yes	No
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to leave the study at any time? (without having to give a reason and without penalty)	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Future Contact		
Do you agree to be contacted for follow-up or to facilitate future research?	<input type="checkbox"/>	<input type="checkbox"/>
Use of my research information beyond this study		
Do you agree for your information to be securely stored at [data repository name] to facilitate future reuse?	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		

I agree to take part in this study:

Signature of Research Participant _____

(Printed Name) _____

Date: _____

Signature of Investigator or Designee _____

Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix D - Recruitment Materials

**Palliative and End of Life Care
Alberta Health Services
&
Faculty of Nursing
University of Calgary**

**FAMILY PHYSICIANS NEEDED FOR
RESEARCH REGARDING EXPERIENCES OF ENGAGING IN PALLIATIVE
CONVERSATIONS WITH NON-CANCER PATIENTS**

We are looking for volunteers to take part in a study of family physicians' experiences in initiating palliative care conversations with patients who have life-limiting, non-cancer illness.

As a participant in this study, you would be asked to participate in a one on one interview with a member of the research team.

Your participation would involve one session, scheduled at a time and location convenient for you, lasting approximately 30-45 minutes.

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

PI: Vanessa Slobogian, MN CNS
Palliative Care Consult Service, Alberta Health Services
at
403-826-3889
Email: *Vanessa.Slobogian@ahs.ca*

**This study has been reviewed by, and received ethics clearance
through XXXXXXXXXX.**

Appendix E – Budget

AHS Research Challenge Draft Budget

Description	Rationale	Cost	Vendor (if applicable)
Audio Recorder		\$160-\$200	
Transcription Services		\$960 - \$1152 (assumes \$24/hour for transcribing 40-48 hours)	
Participant Gift Cards		\$500-600 (\$50/card x 10-12 cards)	
Mileage	Driving to physician offices for interviews	\$150 - \$180 (average 30 km round trip to physician's office x 10 – 12 trips)	
Total		\$1770 - \$2132	

Appendix F – Work Plan

Cohort 3 Research Challenge Work Plan - PEOLC Team

Task	Subtask	2019										2020										
		Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Literature Review	literature search			X																		
	review abstracts			X																		
	request papers			X	X																	
	article summaries				X																	
	selection of appropriate articles				X																	
	draft literature review				X																	
	final literature review						X															
Protocol Development	review requirements					X																
	assign tasks to team members						X															
	identify methodology							X														
	consult with mentor								X													
	team members draft components								X													
	creation of appendices									X												
	compile draft protocol									X												
Ethics Applications	complete final draft of protocol								X													
	obtain CCID								X													
	complete ethics modules								X													
	fill in ethics application								X													
Operational Approval	submit application								X													
	contact director to advise of study and pending approval request									X	X											
Data Collection	submission of Operational Approval request										X	X										
	contact stakeholders re: recruitment									X	X											
	recruitment of participants										X	X	X	X	X							
	data collection - participant interviews											X	X	X	X	X						
Expense tracking	coding of data										X	X	X	X	X	X						
	budget creation								X													
	tracking of expenses by team lead										X	X	X	X	X	X	X	X	X	X	X	
	submission via iExpense										X	X	X	X	X	X	X	X	X	X	X	
	deadline for expense claim submission (March 2021)										X	X	X	X	X	X	X	X	X	X	X	
Key:	Evaluation																					
	Change Management																					
	Reporting/Structure Changes																					

Appendix G – Knowledge Translation Plan

Knowledge Translation Plan

Project: Family Physicians' experience in initiating palliative care conversations with patients who have life-limiting, non-cancer illnesses

Description: The value of Family Physicians (FPs) providing palliative care has been established, however little research has been done to understand their experience in undertaking such a complex and emotionally challenging aspect of care. This project will seek to understand the experiences of FPs if and when they introduce palliative care to patients with life-limiting, non-cancer diagnoses. Our primary research question is: "What is the experience and understanding of family physicians in having palliative conversations?" We aim to provide insight into the decision-making processes of FPs, as well as the complexities of their lived experience when providing this care. It is our belief that insight gained will help identify ways to assist FPs in introducing and providing palliative care in the future.

Background: Increasing numbers of Canadians living with complex life-limiting conditions demand delivery of high-quality palliative care outside of acute care or specialist practice (Mitchell, Loew, Catherine Millington-Sanders, & Dale, 2016). FPs are often responsible for discussing and providing palliative care, a topic that remains challenging for most health professionals. Little empirical evidence exists about how FPs identify whether and/or when it is appropriate to engage in these conversations with their patients (Claessen, Francke, Engels, & Deliens, 2013). However, delays in these conversations may impede the ability of the patient to participate in decision-making at all stages of their illness experience (Belanger et al., 2014). The purpose of this study is to explore the experiences of FPs regarding the decision and process of introducing palliative care to patients with life-limiting (non-cancer) diagnoses.

Objectives: The objective of this study is to develop understanding of the lived experience of FPs regarding the initiation of conversations about and incorporation of palliative care into their practice with patients who have a life-limiting, non-cancer diagnosis. Input from Calgary Zone FPs will be sought in order to explore (a) if they engage in palliative conversations as part of their practice when caring for individuals with life-threatening illnesses, (b) if yes, which elements of palliative care (Advanced Care Planning, Care Coordination, Illness Comprehension & Coping, and Symptoms & Functional Status (University of Calgary, 2019) are included in palliative conversations, and (c) barriers and facilitators to engaging in palliative conversations as part of FP practice.

Methods:

This qualitative study will use interpretive description methodology, which will allow us to incorporate both a systematic approach to inquiry, as well as the acknowledgment and incorporation of clinical expertise and bias. Interpretive description in the design of a rigorous systematic study process often borrows from traditional qualitative methodologies (Thorne, 2008). We will employ an iterative process for data collection and analysis, as well as constant comparative analysis, as used in Charmazian Grounded Theory (Charmaz, 2016). An interpretive description methodology uncovers the nuances of FP practice and diverse personal and professional experience. FPs will share their lived experience and perspective of entering into palliative conversations with this patient population and within the context of their own practice. 10 - 12 Calgary Zone Family Practitioners will be interviewed. The interviewer will follow an interview guide to obtain their personal experience in detail. Each interview will be transcribed and coded. The research team will employ constant comparative analysis, as per Charmaz's (2016) constructivist grounded theory. As per interpretive descriptive methodology, our analysis will seek to find meaning in the coded data versus applying pre-determined categories or meaning (Charmaz, 2016).

Results: This section will be written once the study has been completed.

Discussion: This section will be written once the study has been completed.

Conclusion: This section will be written once the study has been completed.

Knowledge Translation: The primary purpose of KT is to address the gap between what is known from research and knowledge synthesis and implementation of this knowledge by key stakeholders with the intention of improving health outcomes and efficiencies of the health care system” (Graham et al, 2006). The knowledge gained from our study of the experiences of local FPs having palliative care conversations with patients who have life-limiting, non-cancer illnesses will provide insight to understand the barriers and facilitators to having palliative discussions. The study outcomes will be shared with FPs, nurses and allied health practitioners. With this knowledge, FPs have the opportunity to reflect on when and if they participate in palliative conversations and the content of these discussions. Our eventual goal is to develop appropriate resources for FPs to address the barriers identified in the study.

Factors considered in developing the plan:

Since this study is to investigate the lived experiences of FPs if and when they introduce palliative care to patients with life-limiting, non-cancer diagnoses, the Knowledge Translation Plan is to apprise them of the results. Our study uses interpretive descriptive methodology which allows us to develop practical recommendations and resources to address the study’s outcomes. The hope is for FPs to understand their own practice with respect to palliative care conversations and use some of the solution/suggestions we develop to enhance their practice.

Target Audiences:

Family Physicians
Palliative Physicians
Nurses
Allied Health Practitioners
PCN leadership

Messages to be disseminated:

1. There is a growing need for FPs to engage their patients with non-cancer, life-limiting illnesses in palliative care discussions. Audience: Physicians, nurses, allied health
2. Palliative care discussions initiated by Family Practitioners can include Advanced Care Planning, care coordination, illness comprehension and coping, and symptom and functional status. Audience: Physicians, nurses, allied health
3. Family Practitioners can initiate palliative care discussions earlier in their patients’ disease trajectories. Audience: Physicians, nurses, allied health

Goals and Objectives of the Knowledge Translation Plan:

Primary goal:

To develop and distribute practical recommendations and/or resources to assist FPs to have more thorough, effective and timely conversations about palliative care with their patients who have life-limiting, non-cancer diagnoses. This is the logical and necessary outcome to follow our study examining the lived experience of FPs regarding the initiation of conversations about and incorporation of palliative care into their practices.

Specific objectives:

1. Development of recommendations and/or resources to address barriers
2. Distribute recommendations and/or encourage uptake of resources amongst FPs, nurses and allied health providers.

Implementation Strategies and Products:

- Interactive presentations at conferences (local, national, and international), grand rounds, meetings, etc.
- Poster presentation at conferences
- Provincial End of Life Care (PEOLC) newsletter
- Distribution of summary/report/academic article amongst Alberta FPs and palliative care practitioners through email, meetings, and inservices
- Webinars

Project- Phase/Audience-Based Implementation Strategies & Products

Objective	Audience	Strategies
Development of recommendations and/or resources to address barriers	Family physicians, palliative physicians, nurses, allied health practitioners, executives	<ul style="list-style-type: none"> • Our research team to derive recommendations or resources from the results of our study • Utilize assistance of a KT specialist in developing a distribution plan • Find FP champions who have influence with FPs and would help promote practice change • Determine FPs preferred ways to receive practice change recommendations (e.g. conferences, local inservices, emails, bulletins, etc.)
Distribute recommendations and encourage uptake of resources amongst FPs	Family physicians, palliative physicians, nurses, allied health practitioners, executives	<ul style="list-style-type: none"> • Interactive presentations at local, provincial, national and international palliative or family medicine conferences • Presentations/inervices to PCNs and Family practices • Family Practice rounds • FP newsletters, PEOLC newsletter, bulletins • Poster presentations at conferences • Webinars • Palliative Grand Rounds • Find FP champion who has influence with FP and would help with practice change

Facilitators and Barriers:**Facilitators:**

- Local FP champion well-regarded by fellow FPs will engage FPs to adopt and implement our recommendations and resources (Possibly Dr. Amy Tan)
- Palliative physicians with FP background will provide support to FPs who are willing to adopt and implement our recommendations (e.g. Palliative physicians from the Calgary Zone Palliative Care Consult Service)
- Directors of Primary Care Networks (PCN) will likely assist with uptake strategies and suggestions for implementation
- Palliative and End of Life Care, Calgary Zone will provide organizational support
- Faculty of Nursing, University of Calgary, will assist with research advancement support (Dr. Shelley Raffin)
- Executive of the College of Physicians and Surgeons of Alberta may provide assistance and support with best methods for roll-out of recommendations to Alberta FPs
- Research Challenge, AHS will likely provide advice and support with knowledge translation roll-out
- Federal support (Health Canada, 2019) and provincial support “(Improving Public Healthcare”, n.d.) for palliative care have been made priorities and this will give some weight to encourage the uptake of our recommendations by FPs.

Barriers:

- FPs’ current practice priorities may reduce their buy-in to learning and implementing a new skill such as having palliative care conversations.
- FPs are unlikely to receive any monetary compensation for attending inservices, webinars, meetings, etc. as part of our roll-out of recommendations and thus may be less likely to attend.
- FPs who are not part of a PCN may be less likely to adopt recommendations, possibly due to working in isolation

Resources:

- Conference fees (e.g. CHPCA Presenter fee is approximately \$500)
- Printing fees for inservices or meetings
- Fees for presenting webinars
- Time spent by our research challenge team in:
 - developing recommendations
 - creating resources
 - engaging with FPs, PCNs, palliative physicians and other health care practitioners
 - presenting study findings and assisting with recommendation implementation and evaluation of implementation

Assumptions:

- FPs will identify palliative care as a priority in their practices
- PCN directors will identify palliative care as a priority
- FPs will have the capacity (time, willingness) to implement or introduce our recommendations and/or resources into their practices

Evaluation:

We will seek to get feedback from FPs, PCNs, and our FP Champion(s) about the methods and strategies we will employ to disseminate our recommendations and/or resources both early and at the

end of our roll-out. Information will be collected via survey, interview or focus group (exact method yet to be determined). We will ask the following questions early in our roll-out to determine the effectiveness of our KT plan: Has our KT plan been perceived as appropriate and acceptable by these groups and are there any parts of our plan which are not acceptable? We will also find out if our recommendations and resources are effective and relevant, and if FPs find our recommendations can be feasibly integrated into their practices. Based on this feedback, we will amend our KT plan as needed and continue to disseminate our recommendations and/or resources to our target groups (Mental Health Commission of Canada, 2012).

Following the completion of our KT plan, we will utilize the RE-AIM framework to determine how successful our KT plan has been at helping FPs to have timely, thorough, and meaningful palliative care conversations with their patients, and that this change in their practice is maintained over time (Mental Health Commission of Canada, 2012). The exact questions we will ask are yet to be determined, but we envision using surveys, interviews or focus groups to collect the information we seek.

Conclusion:

Our Knowledge Translation plan includes presenting our recommendations and resources to FPs, nurses, allied health practitioners, and others through meetings, inservices, emails, newsletters, presentations, conferences (via presentations and posters), and, ultimately, an academic article. We perceive these methods to be among the most effective ways of encouraging a practice change in FPs to have timely, thorough, and meaningful palliative care conversations with their patients who have non-cancer, life-limiting illnesses. We envision a 6-month roll-out (though it might be as long as a year) and will take advantage of opportunities to disseminate our information as they arise (e.g. just in time learning, unanticipated invitations to present at meetings or education days, etc.). We will utilize a FP champion to assist us in choosing the most effective strategies. After initially implementing our KT plan, we will get feedback to ensure our roll-out is relevant, acceptable and feasible. Following completion of our KT plan, we will engage in a more formal evaluation.

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