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Living fully, choosing wisely: Exploring patient-centred approaches to palliative care and MAiD – Part II, the role of the oncology nurse

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ABSTRACT

This paper is Part II of a case study that follows Nancy, an oncology patient, through her diagnosis of advanced cancer, involvement of early palliative care (EPC), and consideration of Medical Assistance in Dying (MAiD), and her oncology nurse, Laura. Highlighted is the importance of open communication, emotional support, and involvement of the patient's family in the process, to the level that is acceptable to the individual seeking or considering MAiD. The paper also addresses the ethical considerations for nurses when personal beliefs conflict with professional responsibilities. Practical insights and suggestions for oncology nurses are offered for promoting a compassionate and respectful approach to end-of-life care.

INTRODUCTION

Supporting patients with advanced cancer poses significant challenges for oncology nurses (Blaževičienė et al., 2017). This paper is Part II of a case study that follows Nancy, an oncology patient, through her diagnosis of advanced cancer, involvement of early palliative care (EPC), and consideration of Medical Assistance in Dying (MAiD). The case study was developed using findings from ongoing and published research and clinical expertise from healthcare providers with established expert practice in palliative care, MAiD, ethics,

and related academics, as a tool to support oncology nurses in their practice. Part I focused on the patient and family experience and Part II highlights the role of the oncology nurse. (Living Fully, Choosing Wisely: Exploring Patient-Centered Approaches to Palliative Care and MAiD PART I can be found in the Canadian Oncology Nursing Journal, Volume 34, Issue 4, Fall 2024).

Part II of this case study highlights the importance of open communication, emotional support, and involvement of the patient's family in the process, to the level that is acceptable to the individual seeking or considering MAiD. It also addresses the ethical considerations for nurses when personal beliefs conflict with professional responsibilities. Additionally, the paper explores the ongoing need for palliative care, even when patients choose MAiD, emphasizing continuous symptom management and psychosocial support. This case provides practical insights and suggestions for oncology nurses, promoting a compassionate and respectful approach to end-of-life care. Through this exploration, the paper offers strategies to enhance communication, support patients and families, and uphold patient dignity and autonomy.

CASE STUDY

Laura recently graduated from nursing school and feels she has found her calling in the field of oncology. She embarked on her career with a desire to make a difference in the lives of those battling cancer. Laura has worked on the infusion unit at the local cancer centre for more than a year. Even as a student, she was drawn to the impact she could have on patients facing the daunting challenge of cancer. She saw an opportunity to provide expert nursing care and offer emotional support and guidance to patients and their families during their most vulnerable moments. For Laura, the best part of her job is the rapport she forms with her patients. She finds personal and professional satisfaction in the opportunity to be a source of comfort and encouragement, helping patients navigate the complexities of their treatment journey with empathy and compassion. Laura loves getting to know her patients as they receive treatment.

One of her toughest challenges as an oncology nurse is grappling with situations where she feels powerless to ease her patients' suffering. Despite her passion, there are moments when she finds herself at a loss, unsure of how to provide the support and guidance her patients need. Recently, Laura encountered a scenario where her long-term patient, Nancy, confided in her about her wish to stop her cancer treatment. Nancy's words, "I don't want to do this anymore," echoed in Laura's mind and it bothered her that despite knowing and

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caring for Nancy for a long time, she did not know what to say or how to help her. Nancy hinted at considering MAiD as a potential option. Laura was surprised and pained at the suffering this statement revealed for Nancy, but also felt a responsibility to acknowledge it. Not having a helpful answer, or even knowing what to say, left Laura feeling unsettled. However, despite her own uncertainty, Laura remained committed to Nancy's care, vowing to ensure that Nancy felt heard, respected, and supported in her decision-making process.

ROLE OF THE ONCOLOGY NURSE

How do I support my patient while they actively explore end of life options?

A lack of knowledge and experience in supporting patients and their families exploring end-of-life options can challenge an oncology nurse's ability to adequately respond to requests for MAiD (Davidson et al., 2022) and palliative care (Banerjee et al., 2016). A starting point for you in supporting patients is to familiarize yourself with the MAiD and palliative care options available to your patients. In your interactions, you can offer compassionate support and unbiased information to patients, and ensure they feel heard and empowered to make decisions that align with their values and goals. Your role is to provide validation, facilitate open discussions, and advocate for your patient's autonomy and dignity throughout their decision-making journey. Consider implementing a standardized process (see Box 1) to ensure a thorough, timely, and compassionate response to end-of-life option requests.

While providing support in a patient-focused manner, it is also important to consider a patient's involvement with their family and their family's needs. Emerging MAiD research underscores the significance of nurses respecting patients' autonomous decisions regarding MAiD, while also providing care that is attentive to the needs of their families (Brown et al., 2020b; Powell, 2023). The National Consensus Project for Quality Palliative Care also emphasizes the importance of identifying family caregivers' needs in planning for supportive interventions (Washington et al., 2021).

Box 1

*Responding to End of Life Option Requests**

1. Clarify the request
2. Assess the patient to understand what elicited the request
3. Evaluate the patient for any unmanaged symptoms
4. Collaborate with the interprofessional team to provide comprehensive care for the patient's quality of life and personal preferences, including timely information and referrals
5. Develop short- and long-term plans with the patient to discuss their needs and the needs of their family members

*adapted from *The Oncology Nursing Society (DeWolf & Cazeau, 2022) endorsed Hospice and Palliative Nursing Association Guidelines (2017)*

What do I do when my patient wants MAiD?

If a patient like Nancy raises questions about MAiD, you, as the nurse, should clarify their wishes. If Nancy says, "I don't want to do this anymore," it would be important to ask more about what she means, rather than assuming or disregarding her statement. If your patient expresses suffering, explore their experience of suffering, how that suffering is perceived, and offer any additional resources that may help to alleviate it, including palliative care.

If your patient has clarified their wishes for MAiD, it is necessary to involve other team members in a timely manner (see Box 2). A nurse's responsibility when a patient requests MAiD will vary based on their practice setting and any institutional and organizational policies. It is important that you review any guiding documents from your regulatory body and identify any relevant employer policies, guidelines, procedures, and/or processes in place that guide the nurse's role in responding to a request for MAiD (Canadian Nurses Protective Society, 2024).

Why do patients continue disease-modifying therapy if planning to have MAiD?

Patients may continue disease-modifying therapy while they are considering MAiD for multiple reasons including quality of life, a hope for cancer remission or improvement, wanting more time to consider their options, or emotional and psychosocial factors.

Quality of Life– Disease-modifying therapies can help manage symptoms and improve quality of life (Harrington & Smith, 2008). Despite considering MAiD as an option, patients may still wish to alleviate their suffering and maintain a certain level of comfort and function for as long as possible.

Hope for Remission or Improvement– Some patients may still hope for remission or improvement in their condition (Harrington & Smith, 2008). They may view continuing treatment as a way to potentially prolong life or enhance health outcomes, even if they are also considering end-of-life options like MAiD. A patient can pause or withdraw from the MAiD process at any time.

Timing– Pursuing MAiD is deeply personal and complex. Patients may require time to fully consider their options, discuss them with loved ones, and come to a decision that aligns with their values and preferences (Kremeike et al., 2018). During this process, they may choose to continue treatment until they have made a final decision about end-of-life care. It also takes time to work through the MAiD process. The time

Box 2

Nursing Practice Collaboration in MAiD Request

1. Check the MAiD policy at your site or institution
2. Determine if your area or jurisdiction has a MAiD coordination service
3. Locate trusted resources (e.g., CAMAP Canada [Canadian Association of MAiD Assessors and Providers], Dying with Dignity Canada)

to work through the eligibility and safeguards for MAiD is patient- and location-dependent, but can take several days to weeks or even months to complete. Continuing treatments may give a patient time to complete all the steps to determine eligibility.

Emotional and Psychosocial Factors— Patients facing serious illness may experience various emotions including fear, uncertainty, and ambivalence about their treatment choices. Continuing therapy may provide a sense of control and structure amidst the uncertainty, allowing patients to navigate their journey with some clarity and peace of mind (Liu et al., 2022).

How do I work with the palliative care and MAiD teams?

The role of the oncology nurse is centred on advocating for patients' comfort, autonomy, and dignity, while fostering collaborative partnerships to optimize the quality of end-of-life care (Childers, 2023). This should include screening and assessments regarding patient needs (Childers, 2023), encouraging open dialogue, and making appropriate referrals (Spine et al., 2022). When a patient is engaged with palliative care providers, the oncology nurse communicates their patient assessments to the team and discusses care plan suggestions with both the palliative care team and the patient (Pornrattanakavee et al., 2022). If a patient has engaged with MAiD providers, the role of the oncology nurse can vary, depending on comfort and competence. This could range from engaging in deeper conversation with the patient and family, declining direct involvement in MAiD-related activities, but providing basic care, or providing oncologic nursing up to the time of MAiD provision. If a patient is receiving MAiD, a nurse may be asked to start intravenous lines, be present during the MAiD provision, and engage in debriefing with the family afterwards (Beuthin et al., 2018). A three-tiered framework for multidisciplinary collaboration within the context of MAiD, implemented by University Health Network in Toronto (see Box 3), is highlighted as an effective example (Fujioka et al., 2018).

How can I support my patients if I am uncomfortable with their decisions?

Your patients may make a variety of decisions that you personally disagree with, including choosing MAiD, or even declining further treatments and investigations in favour of optimizing quality of life with palliative care. However, even when disagreeing, prioritizing compassion and patient autonomy is vital, as is offering non-judgmental support and advocacy for a patient's holistic well-being, maintaining the therapeutic relationship (Canadian Nurses Association [CNA], 2017).

In circumstances where MAiD is part of the journey, ensuring your patient feels heard and empowered to make a decision that aligns with their values, even if they differ from yours, is crucial. A nurse can delegate provision of information about MAiD or how to access local services in a timely manner and with clear documentation, if they are unfamiliar or uncomfortable with elements of the process (Canadian Nurses Protective Society, 2024). Regardless of comfort level, a nurse cannot ignore or minimize a patient's request for health

services. Continuing to support your patient includes providing ongoing non-MAiD-related oncologic nursing care, such as continuing psychosocial support and validating any feelings related to suffering (see Box 4).

The nature of suffering reported for those choosing MAiD is often a loss of ability to engage in meaningful life activities, perform activities of daily living, or control of bodily functions; inadequate pain or symptom control or a concern of inadequate future symptom control; a loss of dignity; or a perceived burden on family, friends, or caregivers (Health Canada, 2023). Providing psychosocial support in validating feelings related to suffering recognizes the validity of feelings and experiences within a specific context and does not equate to endorsement of a patient's considerations or decisions to ease those feelings (Harvey & Ahmann, 2016). When uncomfortable with a patient's informed decision, it can be helpful to consider your role as supporting the patient's right to make an informed decision, as opposed to supporting the decision itself. It may also be helpful to seek out additional healthcare provider supports, such as the Employee Assistance Program.

How do I respond to my patient if I am a conscientious objector to MAiD?

Although a legally acceptable healthcare intervention, in accordance with their freedom of conscience, nurses may morally object to participation in MAiD. This is called conscientious

Box 3

Multidisciplinary Collaboration in MAiD Framework Using Three Decision Teams

1. Clinical team of all healthcare providers involved in the patient's usual care
2. Assessment team of two physicians with expertise in assessing MAiD suitability
3. Implementation team including a physician or nurse practitioner for final evaluation, confirmation of capacity for informed consent, and MAiD provision

Box 4

Practical Strategies for Communicating Validation (Salamon, 2023)

1. Reflection: when you mirror someone's words back to them, it shows you are listening and understanding. For example, "so, what you are saying is...."
2. Clarification: ask questions that show genuine care and empathy, such as, "can you tell me more about that?"
3. Normalizing: it is common and normal to feel (expressed feeling) when facing an advanced cancer (reference), so whether you would feel comfortable with a patient's desire for MAiD or not, it is supportive to validate their feelings. For example, offering the supportive statement, "It makes sense you would want relief from your suffering (or not want to be a burden to your family, etc)."

objection (Shanawani, 2016). However, they must continue to honour their ethical responsibility of duty to provide care, ensuring non-abandonment and access to appropriate healthcare (CNA, 2017), while ensuring an effective referral is made (Schuklenk, 2018). Box 5 provides an example of healthcare provider responsibilities, including conscientious objectors, in response to a request for MAiD. An effective referral is “taking positive action to ensure the patient is connected to a non-objecting, available, and accessible physician, other healthcare professional, or agency” (College of Physicians and Surgeons of Ontario [CPSO], 2023, p. ??). Therefore, if an oncology nurse morally objects to MAiD and a patient such as Nancy enquires about it, the nurse is required to inform the patient that their questions or request will be referred to another healthcare provider, and then do so in a timely manner.

As a nurse, you are expected to continue to provide care, unrelated to MAiD, until an alternative can be arranged (College of Nurses of Ontario, 2021). The Code of Ethics for Registered Nurses (CNA, 2017) provides key guidelines for declaring a conflict with conscience that includes communicating moral objections in advance, wherever possible, to ensure alternative arrangements can be made for the person receiving care. This can help limit individual and team distress and avoid delays in care. These key guidelines also include a responsibility for fair treatment and against discrimination toward nurses declaring a conflict of conscience (CNA, 2017).

Moral concerns and an informed reflective choice, rather than prejudice, fear, or convenience, should be the motivation of a moral objection (CNA, 2017). However, some nurses may choose to limit their involvement in the MAiD process for reasons unrelated to a moral or conscientious objection, such as a lack of familiarity with the process. As an oncology nurse, it is important to reflect on your willingness to be involved in MAiD, ideally ahead of an actual situation, and consider how you might respond to requests so that you honour the choices of all involved. This critical reflection also may enable you to

Box 5

Example of Responsibilities When Someone Requests MAiD From the Saskatchewan Health Authority (SHA) Provincial MAiD Program: A Resource for Facilities and Caregivers (2022)

- All staff, including conscientious objectors, will
- respond to inquiries about MAiD with compassion, respect, and a non-judgmental approach;
 - provide contact information for the MAiD Program;
 - find someone who is willing to speak with the patient if the provider is uncomfortable discussing MAiD;
 - arrange for appropriate supports to enable an individual to contact the MAiD Program when they are unable to do so themselves, due to physical limitations or any condition, medical or otherwise;
 - assist in obtaining a witness for the patient’s “Written Request.”

Note. All patient care in the facility will continue as normal

determine how you might make an effective referral within your area. Additionally, the suggestions made for supporting patients when uncomfortable with their decisions would apply also in the setting of conscientious objection. One nurse choosing conscientious objection to MAiD shared their response, “My approach to nursing care does not change at all. It doesn’t change my ability to listen to that person, my symptom management, or my eliciting of their wishes, goals, and perceptions of what is happening” (Pesut et al., 2020, p.5).

What is my role if I work in a setting where MAiD is provided?

In the days leading up to a MAiD provision, nurses may take on many roles and responsibilities to support the process. Some of these tasks may be practical, such as moving a patient to a private space, gathering and double-checking paperwork, and ensuring that IV sites are patent (Fujioka et al., 2018). This time can be intense for family members and friends, so communication with these individuals about their needs, emotions, and thoughts can be beneficial (Smolej et al., 2023). Early discussions may be helpful and may include logistics for after their loved one has died (e.g., a plan for getting home; Hales et al., 2019). The MAiD provider is responsible for the medication administration for MAiD. As the nurse in the room, you are there to support the patient, the provider, and those in attendance.

Whether you are in the room for a provision, starting IVs, or supporting the family, this experience can lead to a range of emotions and it is important that the focus remains on those in our care. After a provision, there may be an opportunity for you to debrief and create space to process the experience and the death. It is also important to remember that participating in the MAiD process never obligates you to do so again in the future.

Does my patient still need palliative care if they have chosen MAiD?

A patient considering or awaiting a MAiD provision may benefit from palliative care at any point from the time of diagnosis of a life-limiting illness until a MAiD provision. Palliative care aims to improve quality of life by managing symptoms, addressing psychosocial and spiritual needs, and enhancing overall well-being (World Health Organization, 2018). While MAiD provides an option for patients seeking to hasten their death in the context of unbearable suffering, palliative care seeks to provide comprehensive, compassionate support throughout a life-limiting illness for both patients and their families. The goal of palliative care is to alleviate distressing symptoms, offer emotional and existential support, and facilitate informed decision-making from the time of diagnosis until the end of life, regardless of how it may occur. While there are no guidelines or legislation mandating a referral to palliative care in the context of a request for MAiD, palliative care options should be offered (Munro et al., 2020).

How do I support the family through a loved one’s MAiD request?

While the interactions and relationship between family members and the patient are the most impactful, family members’ relationship with healthcare providers also can be

impactful throughout consideration of MAiD to bereavement. Family concerns, which can be specific to the experience of MAiD, include social disapproval creating secrecy, which may isolate them further during a period when additional support is needed (Yan et al., 2023). Relevant to both MAiD (Yan et al., 2023) and palliative care (Coelho et al., 2020) is a family's anticipatory grief. Family may require additional support surrounding the certainty of an impending death and the awareness of finite time to create meaningful memories, sometimes with a distressing element of a countdown to death or a "parade of lasts," knowing each meaningful activity might be the last time it is shared.

Supporting family members is essential when your patient has involved them in their engagement with MAiD. Oncology nurses should seek out family members and offer conversation to assess their coping and supports. It is important to engage with family members individually to respect the autonomy and dignity of both your patient and their family. You may find a wide range of responses: from expressing reservations about MAiD while still showing support for the choice to wanting to ensure that attention and care is not diverted from their loved one (Powell, 2023). Providing support to family members, regardless of their involvement in the MAiD process, can enhance their experience and mitigate potential challenges, particularly after their loved one has died (Brown et al., 2020a; Crumley et al., 2023).

Offering emotional support, accurate information about MAiD or palliative care, and facilitating open communication between the patient, their family, and the healthcare team, may improve a family's overall experience (Beuthin et al., 2018; Crumley et al., 2023; Dees et al., 2013; Denier et al., 2010; Spine et al., 2022). This approach also may reduce the need for secrecy and feelings of isolation noted among family members, both before and after MAiD (Brown et al., 2020a; Dees et al., 2013; Frolic et al., 2020; Goldberg et al., 2021; Variath et al., 2020). Check with the MAiD program in your area to see what resources are available for family members. A social worker or MAiD navigator might be available to assist the family and a referral to psychosocial oncology for emotional support and practical preparation for end-of-life care can be beneficial.

CASE STUDY CONTINUED

On a subsequent shift, Laura heard from a colleague that Nancy had been approved for MAiD and had scheduled her provision for the next weekend. Nancy would be coming into the cancer centre later that week to have a final appointment with her oncologist. While Laura had discussed MAiD with Nancy and they had shared several beneficial and supportive conversations, Laura still felt grieved upon hearing this news and wondered if there was more she could have done to support Nancy. Despite her sadness and conflicted feelings, Laura wanted to provide the best nursing care by focusing on Nancy's well-being and supporting her and her family. She sought out her colleagues and personal support system so she could explore her own uneasiness. In reflecting on

her thoughts, feelings, and personal beliefs, Laura resolved to approach Nancy with sensitivity and compassion, ready to listen without judgment.

Laura was also aware that Nancy's decisions could significantly impact her family. She considered that they were likely grappling with their own emotions and questions. In response, Laura determined she could coordinate the oncology team efforts to ensure that Nancy's family received the support they needed, such as counselling services, community resources, or by simply being present and lending a listening ear.

When Laura saw Nancy that afternoon, she made a point to continue their rapport in its usual friendly manner, treating her with dignity and respect. She offered her support to Nancy and asked if she felt all her questions and needs had been addressed. Nancy shared that she is struggling with pain and shortness of breath, so Laura contacted the palliative care team asking them to follow up with Nancy to ensure the best possible quality of life leading up to her MAiD provision. Nancy was a bit teary when discussing her death, so alongside providing a supportive presence, Laura offered to refer Nancy and her family to the psychosocial oncology team. Nancy declined this for herself, but as she felt her sons had been struggling with her decision, she wanted them to have the opportunity. As their time together ended and Laura said goodbye to Nancy, she was left with feelings of sadness and grief, but also acceptance and gratitude that Nancy's autonomy and wishes were respected, and that she had provided the best care possible.

CONCLUSION

As an oncology nurse, the experience of supporting a patient like Nancy, who is considering MAiD, can be profoundly challenging and deeply impactful. Laura's journey with Nancy highlights the delicate balance of personal uncertainty or suffering around a patient's end-of-life decisions and providing empathetic, patient-focused, family-centred care, respecting the autonomy of your patients. The role of the oncology nurse involves fostering open communication and providing support to patients and their families at all stages of the MAiD process. These actions can significantly enhance the quality of end-of-life care and help alleviate the emotional burden on the patient, their family, friends, and caregivers.

This case study emphasizes the importance of interdisciplinary collaboration and understanding your institutional, organizational, and unit-level MAiD policies. It also underscores that even when patients choose MAiD, comprehensive palliative care remains vital to ensure their quality of life and to address their psychosocial needs.

Laura and Nancy's story offers practical insights and strategies that you can apply in your own practice. By approaching these situations with compassion and respect, you can uphold the dignity and wishes of your patients, ensuring they feel supported during their final days. Through your dedicated care, you can help navigate the complexities of end-of-life decisions and provide meaningful support to patients and their families.

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