**Case Study 1:**

**Applying Evidence-Informed Interventions to End-of-Life Care**

Reem Boudali, Joanne Ta, Abigail Tuason, Nicky John, Sakina Namuro

Faculty of Nursing, University of Windsor

NURS4980: Palliative and End-of-Life Care

Professor Rita Di Biase & Dr. Kathryn Pfaff

March 23, 2023

**Case Study 1:**

**Applying Evidence-Informed Interventions to End-of-Life Care**

Pedro is a 65-year-old retired high school teacher diagnosed with brain cancer (glioblastoma). He has two adult children and four grandchildren. His family immigrated from Mexico 30 years ago and are living in Toronto, Ontario. He and his wife live in a one-bedroom apartment on the ground floor.

When Pedro was diagnosed, the family was informed that it is an aggressive tumor with high recurrence, rapid progression, and poor prognosis. Pedro underwent surgical resection of the tumor, radiation, and chemotherapy. Initial treatment of the tumor was successful with resolution of his symptoms.

Six months later, Pedro visited the ER with complaints of back pain, bilateral leg weakness, and speech impairment. His CT scan revealed return of the tumour with extension into his spinal cord. Pedro was admitted to the neurology floor at the hospital. At a patient and family meeting, the oncologist informed Pedro and his family that there are “no curative treatments available.” The nurse introduced the topic of palliative care and describes the process and benefits. Despite Pedro’s speech impairment, he agreed stating, “I have lived a full life and am blessed to have seen my children grow up, get married, and have children – I am ready to die.” The nurse noted that the family seems to be struggling to accept this new information and Pedro’s reaction. The oncologist leaves the room without discussing code status.

Pedro’s physical and mental status have now begun to decline as he becomes more confused, drowsy, and weak. He fell twice in the last three days while trying to get to the bathroom by himself. Pedro’s family is having differences of opinion about whether to bring him home for his last weeks/months, or to transfer him to a palliative care setting. Pedro’s children question their mom’s ability to meet his needs due to her own physical limitations. Pedro’s wife feels guilty about sending him to a facility instead of taking care of him at their home. “The place for family is at home – here I can cook, and we can have prayers for his healing.” Pedro and his wife practice Catholicism and attend mass several times a week.

The team is pressing Pedro’s wife to change his code status from full code to do not resuscitate. Pedro’s wife feels that she is giving up and abandoning her husband by signing the document.

1. **Noticing**
2. **What case study data are most important/clinically significant and to which palliative care domains do they apply? Add rows where needed. Remember that more than one domain may apply to each datapoint.**

|  |  |  |
| --- | --- | --- |
| **Most Relevant Data** | **Why Important/Significant?** | **Palliative Care Domain(s)** |
| Speech impairment | With speech impairment and possible language barrier, Pedro’s wishes and complaints may not be fully understood. Pedro may also not fully comprehend what the HCPs are saying. This can lead to errors | * Psychological – because of speech impairment and possible language barrier, his mental health may not be addressed properly. He may experience anxiety and fear * Physical – he may not be able to entirely describe the type of pain or other symptoms |
| Change in cognitive functioning | With a change in cognition, Pedro cannot state his wishes to the HCPs and his family. His care becomes more complex for the family, especially if the patient has severe fluctuation in moods. Personally, it will be difficult for his wife and kids to see the change in their loved ones | * Disease management – this is part of the disease progress, and it may be hard for family members to witness * Social – this will influence the roles within the family as the kids will have to step up and care for their dad. This will also affect the normal routine Pedro may have with his wife * Psychological – there will be a change in personality and/or behaviours which will change his self-image (how he sees himself and how his family members will see him) * Practical – ADLs will increase as he may require more assistance and dependency will increase |
| Family is struggling with Pedro’s decision | The family is struggling with the disease progression and Pedro’s reaction. This can lead to family conflict which can affect the patient | * Psychological – if a family conflict arises, this can affect the mental health of the patient and the family members which can lead to depression, guilt, and poor coping response * Social – it can affect the routine of the family, relationships, and roles and responsibilities. If a certain family has a different opinion from the majority, this can lead to isolation and abandonment * EoL/Death management – family is struggling to accept Pedro’s reaction and disease progression, this can affect the closure and any legacy creation |
| Oncologist not discussing code status | Without the guidance from the oncologist, the family member may not make any change in code status, which may prolong the suffering of the patient and their family members. | * Disease management – as part of managing the disease, the plan of care is always changing to adapt to the disease progression. Without the guidance from the oncologist, there may be communication and knowledge gaps which can affect the care and lead to adverse effects. * Physical – if the code status is not being discussed early on, it may become too late when their cognitive ability changes, and this may cause the patient to encounter pain and other symptoms * Psychological – without guidance from the oncologist, the patient and family members may experience fear of the unknown and stress * Social – without addressing the code status, this may become a legal issue if everyone is not on the same page * EoL/Death Management – EOL care is not being done properly if the patient’s wish is not heard and this can affect closure. |
| Caregiver guilt | Pedro’s wife is not physically capable of caring for him due to her own health. This can lead to further harm to Pedro and his wife, because she is not able to physically assist him with his care, which can lead to more falls.  Since she is feeling guilty for sending him to a palliative care setting and for updating the code status to DNR, this can affect her mentally and emotionally. | * Disease management - If his wife is not physically capable of caring for Pedro, this puts him at further risk for falls, which can lead to a secondary diagnosis. With Pedro’s change in cognitive ability, more monitoring is needed to prevent any adverse events, such as taking the wrong medication or taking the medication more than prescribed which can lead to toxicity * Physical -Pedro’s safety is at risk if there is not someone who can help with ambulation. His cognitive ability is declining which will require more complex care. * Psychological – with a change in cognition, his personality and emotions may fluctuate. Along with caregiver guilt and burnout, she is experiencing anxiety, depression, guilt, and fear of abandoning her husband * Social - there is a change in relationship, such as the wife and kids becoming the caregiver to their husband/dad. There may need to be a change in environment despite the wife wanting her husband to stay at home, which is his comfort area, and maintain their routines. * Practical – with the decline in his health, ADLs is becoming more complex and extraneous. |
| Fall history | Can lead to faster disease progression or secondary diagnosis, such as broken bone or head injury | * Disease management - as part of the disease process, Pedro is declining and is more at risk for secondary diagnosis. Especially if he is immunocompromised, he is at risk for infection * Physical - his physical symptoms could worsen with more falls, and he may require more medications which will cause additional side effects. For example, after a fall, he may need pain medications which may cause sedation, and therefore, put him at risk for another fall. * Psychological – after history of falls, Pedro may experience fears and loss of control and dependence which can put him at risk for depression * Social - falls will affect his independence as he will require more assistance. Overall, it can decrease some privacy and cause a change in roles within the family dynamic * Practical – ADLs are affected and will require more assistance |
| Catholicism and attending mass several times a week | Due to disease progression, this may not be possible for the patient which may lead to spiritual distress, question his belief, and feelings of isolation and abandonment | * Physical - spiritual distress can lead to physical distress and worsen his physical symptoms * Psychological – by not attending mass as frequent as before, it can lead to depression and loneliness. He may start questioning religion and God. * Social - by not attending mass, he may feel a sense of isolation and loneliness. There may be some questioning about his values and beliefs. And due the physical limitations, there will be modification to his practices and roles within the family dynamics * Spiritual - it's important to keep his routine with attending mass and keeping in touch with his culture and beliefs for his physical and mental health |
| Rapid progression of the disease | Indicate less time for preparedness and legacy creation. This can also be more stressful for the family, especially if there are special events that may come up, such as a wedding, that he is not able to attend. | * Disease management - with the poor prognosis of his disease and the cancer occurring rapidly, the family is under extreme stress with having to watch their loved one change so drastically. There is an increase in pressure, for the family members, to become caregivers, such as monitoring his medications and for side effects * Physical - physical symptoms could be affecting his quality of life. * Psychological – with the change in his cognitive ability, is it difficult for the family to see a change in his behaviours. There is also a sense of loss of control for the patient * Social - with the diagnosis, his routine is changed, the roles are changed, and relationships are different. It's important that they start figuring out the legal aspects, such as the POA during the early stage of his care * Loss/grief - the patient will experience a sense of loss. Such as a loss in control, independence, normal routine, etc. While the family members are grieving and mourning the diagnosis and the loss in the future. It will be important to plan the bereavement care to ensure closure and healthy coping mechanism * EoL/Death Management - EOL care will be important for the patient, so they feel that their life meant something and that they’ve made a change in the world. While for the family, this will help bring closure and create memories for the future |
| Living with spouse | There is less support for patient and spouse, which may increase risk for caregiver burden | * Physical - this is becoming physically demanding for the spouse, especially if she already has physical limitations. This can put the patient, and the spouse, at risk for injuries * Psychological – the patient may feel a sense of helplessness and a burden while the spouse may feel stress and experience caregiver burnout. * Social - it's important to start planning out the legal aspect such as advanced directives, DNR, etc. Finances may become stressful for the family if the patient requires certain medications that are not covered. * Practical – ADLs will require more assistance than prior. Family may have to consider bringing in PSW to provide support. |

1. **In up to three sentences, summarize what you think is happening in this situation. In another two to three sentences, summarize contextual/other factors that might be influencing your group’s thinking (past clinical experiences, personal experiences, values, beliefs, other?)**

Pedro has accepted his prognosis and is “ready to die”; however, his wife is experiencing caregiver guilt by sending him to a palliative care setting and for updating code status to DNR. She is undertaking more roles to provide care at home which is increasing the risk for caregiver burden.

From past experiences, when the patient is ready to go but the family members are not ready to *let* the patient go, this can lead to more physical and emotional harm for the patient and the caregiver. Such as prolonging the patient’s suffering, tarnishing the last few memories of the patient, and caregiver guilt and poor grieving process. Therefore, it's important to acknowledge the disease and maintain communication between all members to ensure that all needs are met, and it allows time to create closures and create legacy.

1. **Interpreting**
2. **What data are missing but are needed to formulate a comprehensive assessment of the client/patient’s palliative care needs. What tools/instruments might the nurse or other members of the team use to collect this information. Which member of the interprofessional team is most responsible/appropriate for gathering the assessment? *Add rows if needed.***

|  |  |  |  |
| --- | --- | --- | --- |
| **Data Needed** | **Tools/Instruments** | **Team Member** | **Rationale** |
| **Physical mobility** | * Palliative Performance Scale (PPS) * Edmonton Symptom Assessment System Revised (ESAR-r) * Physical Assessment | * Physiotherapist * Nurse * Palliative Care Team (Oncologists, Neurologists, Palliative Physician) | Pedro has fallen twice within the last 3 days. The question here is: does he need assistance (walker, standby) or is he generally weak and unable to ambulate completely?  Through collaboration between the Palliative Care team and a Physiotherapist consult, a focused musculoskeletal capacity of strength and movement assessment can be done to determine what physical movements and activities of daily living (ADLs) can Pedro perform, in which ADLs and iADLs he needs assistance with, and how the team is going to provide him assistance.  Then, education provision to Pedro and his family regarding these assessment outcomes is crucial in planning how he can perform daily living activities that are important to him (especially at his end-of-life stages), which involves physical movements, can be supported by his family and what kind of support does his family need as well (Thiel, Harden, Brazier, Marks, & Smith, 2020).  PPS is a tool that the Palliative Care Team can use to determine Pedro’s ability to function and will then help in determining how to move towards the end-of-life.  The ESAS-r tool will then assess the kind of symptoms he experiences when mobilizing or performing certain physical activities and movements.  A full physical assessment tool by the nurse, and collaboration with the Palliative Care Team regarding assessment outcomes, is also important in this process of determining physical mobility, ADLs and iADLs support (Remawi, Gadoud, Murphy, & Preston, 2021). |
| **In-home assessment** | * ESAS-r * PPS * Patient-reported Outcome Measures (PROMS) * WHO (Five) Well-Being Index * Quality of life at end of life (QUAL-E) | * CCAC (home support workers, home care/community nurses, home care social worker(s)) * Palliative Care Team (Oncologists, Neurologists, Palliative Physician) | Pedro’s family wants him to receive care in his home but are questioning if his needs are being met. Given that, an in-home assessment can be implemented to determine what support is needed if he goes with the decision of receiving palliative care at home, and how often it can be provided. For instance, if he chooses to stay at home, rather than a palliative care home, the palliative care team can connect with community nurses working in the home care setting and home support workers or home care personal support workers (PSWs).  Some tools that can be used in determining the kind of support he will need if he stays at home for his end-of-life includes:  ESAS-r will allow him to self-report the symptoms he experiences and each symptom’s severity.  PPS can help the Palliative Care Team assess his functional condition, and plan supportive and therapeutic interventions that match his wishes and goals (Remawi, Gadoud, Murphy, & Preston, 2021).  PROMS can help capture Pedro’s perception of his own health, which helps the team acquire an insight on further support he needs, patient satisfaction on care plan that is being received, and mental and emotional insights he has towards his care plan, the team, and his end-of-life situation.  The WHO (Five) Well-Being Index is a questionnaire that asks the patient five questions about the intensity of their feelings of cheerfulness, calmness and relaxation, feelings of being active, feelings of being fresh and rested, and how their daily life activities are. This will help assess Pedro’s well-being.  The Quality of life at end of life (QUAL-E) will then assess Pedro’s symptoms, relationship with health care provider(s), preparation for his end-of-life, and communicate other unaddressed mental and emotional feelings regarding his goals/wishes for life completion (Vetter, 2022). |
| **“Last wishes/goals”** | FICA tool | * Nurse * Social Worker * Chaplain/Priest | As Pedro’s disease progresses rapidly, and he states practicing Catholicism, the FICA tool (which focuses on addressing faith, importance of spirituality, community, and how spiritual needs are addressed), will help determine the kind of spiritual support he needs in his end-of-life (Remawi, Gadoud, Murphy, & Preston, 2021).  As Pedro states attending mass several times a week, him and his wife may already have a Priest/Chaplain/religious support role in mind that he can trust regarding communicating his last wishes/goals at end-of-life, or the Palliative Care Team can help connect him with a trusted Chaplain/Priest who he can share his last wishes/goals with (Huang, Tai, Longcoy, & McMillan, 2022).  Another important team member is a Social Worker, can assist Pedro in terms of counselling, psychotherapy, and mental and emotional support as he thinks of and states his last wishes/goals, and advocating on behalf of him to the Palliative Care Team.  In this case, a Social Worker can also play a key role in supporting Pedro’s wife and family in terms of coping with Pedro’s end-of-life. The Social Worker can play a role in providing an insight to the family regarding Pedro’s wishes/goals, if Pedro permits them to. They can also provide the family counselling, psychotherapy, psychosocial education regarding coping skills in terms of palliative care philosophy, crisis intervention, conflict mediation especially as his family members have various opinions regarding Pedro’s care plan, and advice on legal matters such as finances (Taels et al., 2021). |
| **Loss/Grief** | * Bereavement Risk Assessment tool (BRAT) * Caregiver Social Impact Scale (CIS) * Family Impact Interview | * Nurse * Palliative Care Team (Oncologists, Neurologists, Palliative Physician) * Social Worker * Chaplain/Priest (in the case of the patient’s religion) | While Pedro’s wife is experiencing feelings of difficulty and feeling that by allowing the care team to change his code status from a full code to a DNR, it shows that further support and education from the Palliative Care Team is needed to help Pedro’s wife and/or his family make this decision.  As Pedro’s disease progresses and his cognition and mental function is causing him to become confused, weak, and drowsy, which may be causing him to be unable to verbalize his wishes towards his family as his cognition and mental state are not as optimal anymore, the family may also be experiencing some sense of loss and grief already as they are seeing that he is “not how he used to be anymore”, and are finding it emotionally hard to adjust to these changes.  Given these points, BRAT is a tool used by care teams that allows caregiver(s) and family members of a patient to communicate situational, personal and interpersonal factors that may place them at a greater risk of significant negative bereavement experience(s) (Vetter, 2022).  Along the utilization of this tool, the Palliative Care Team can also utilize the Caregiver Social Impact Scale (CIS), which is a 19-item scale that measures the extent to which specific family life aspects are altered, resulting from caregiving for a family members (Remawi, Gadoud, Murphy, & Preston, 2021).  Another tool that can be used to determine the types of Social Work and Palliative Care Team support Pedro’s wife and family members need, especially in making decisions regarding Pedro’s code status is the Family Impact Interview, which is a 10-item interview questionnaire that helps measure the caregiving burden on family members, which includes decision making for a family member whose cognitive and mental functions is deteriorating, as well as the financial impact of caregiving. The responses are recorded verbatim (Taels et al., 2021).  Due to Pedro’s practice of Catholicism, the Palliative Care Team can also assess the spiritual health of his family, this can help determine what factors and domains are affecting his wife’s decisions towards his changing code status, and whether she also needs spiritual health support especially in making this decision (Remawi, Gadoud, Murphy, & Preston, 2021). |
| **Religious practices** | Spiritual Needs Inventory (SNI) | * Nurse * Chaplain/Priest | Pedro practiced Catholicism with his wife and attended mass several times a week. If this could be incorporated into his care plan it would give him a sense of his regular day-to-day activity.  To continuously support Pedro and his wife’s spiritual health, a SNI tool can be used to assess their spiritual care needs and to ensure prevention of spiritual distress. By connecting the patient with a trusted Chaplain/Priest whom they may already know of from their church or who is introduced to them by the Palliative Care Team and whom they trust and is able to communicate their spiritual and belief system to, and whom they can share spiritual needs to especially if they don’t feel comfortable addressing these spiritual needs to their nurse or Social Worker who may have differing spiritual beliefs as them (Huang, Tai, Longcoy, & McMillan, 2022). |
| **Activities of daily living** | * Functional Independence Measure (FIM) * McGill Quality of Life Questionnaire (MQOL) | * Nurse * Palliative Care Team (Oncologists, Neurologists, Palliative Physician) | The more information collected about what Pedro did on his free time, the easier it is for him to be in charge of his care.  Questions to be addressed by the nurse and Palliative Care Team:   * How was Pedro’s ADLs routine like? * What kinds of ADLs can he still perform and how can we support him in performing these ADLs? * How can his family support him at home in terms of ADLs? * What were/are the activities he enjoys doing and how can we support him in performing these activities? * Is he able to perform these activities he enjoys?   By utilizing FIM, we can assess his independence in performing certain ADLs and which ADLs he needs the most support in. This will help us determine the roles of home support workers and home care nurses that will be visiting his home – and in which ADLs they will support him in doing (Remawi, Gadoud, Murphy, & Preston, 2021).  MQOL then helps assess his overall quality of life, including his perception of the support being provided to him - how he perceives his current ability to perform his ADLs and iADLs, and how much his care plan interventions and goals are helping him every day of his life (Remawi, Gadoud, Murphy, & Preston, 2021). |
| **Cultural practices** | Interview & Discussion with Patient, Wife & Family Members – focusing on their culture, language, customs, health literacy, belief systems, morals and values, traditions, personal cultural beliefs and practices, decision-making preferences, and end-of-life practices | * Pedro (as this focuses on his own cultural background and practices) * Pedro’s wife * Family members involved * Palliative Care Team (Oncologists, Neurologists, Palliative Physician) | By performing a full interview and discussion with Pedro regarding his cultural practices, language, customs, traditions and end-of-life practices, the Palliative Care Team can build an insight on how they can better provide patient education to him and be able to “speak in his language”.  This can be done with his wife as well as his family members – preferrable one-by-one to allow for privacy and comfortability in communicating each of their perception and belief systems especially regarding situations as the end-of-life stage of their family member (Thiel, Harden, Brazier, Marks, & Smith, 2020).  This will also help the Palliative Care Team build an insight on what the family wants to know, and what they do not want to know regarding his care plan, as the team incorporates these interview questions into the cultural-focused discussion (Huang, Tai, Longcoy, & McMillan, 2022). |

1. **Develop 3 palliative care-focused diagnostic statements based on the data provided in the case. Formulate as RED (response, etiology, defining characteristics). Identify all relevant palliative care domains and list the diagnostic statements in priority order. Provide rationale for your ranking.**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Diagnostic Statement** | **Palliative Care Domain(s)** | **Rationale for Ranking** |
| 1. | Impaired communication related to speech impairment and cognitive decline as evidence by progressive confusion | Psychological, physical | This is the most important aspect of his care. It places a limitation on his involvement because it is now harder to have him voice what he wants and express himself on how he wants to live his last days. |
| 2. | Compromised family coping related to Pedro’s wife feeling guilt as evidenced by her wanting to have him receive care at home despite her own limitations | Social, psychosocial, End of life/disease management | His family’s support plays a major role in his care. He feels he has achieved a full life in relation to the accomplishments of his children. Rejecting his decision will affect how he copes and may end up feeling guilt himself and conflict with his own further decisions. |
| 3. | Activity intolerance related to weakness as evidenced by cognitive decline and increase in falls while mobilizing independently | Physical, disease management, practical | Pedro still wants to maintain a sense of independence but has shown he is too weak to do so. This may not allow him to complete other goals he may have. |

**C. Responding**

**Select one of the priority diagnoses. Complete a summary of the literature (last five years) to inform palliative care nursing intervention(s) that are clearly related to the diagnostic statement.**

1. **Begin with stating your clinical question. For example, “How can nurses support patients/clients who have received a terminal diagnosis?” or “What assessment tools are reliable and valid for assessing pain among palliative patients/clients with cognitive deficits?”**

P – patients with altered mental status

I – communication methods

C - none

O – understand patient’s wishes and goals-of-care

Final Question: What strategies can healthcare providers use to communicate with patients experiencing an altered mental state and/or their families to still understand their wishes or goals of care?

1. **Document your search strategy in the following table. *Add rows as needed.***

|  |  |  |  |
| --- | --- | --- | --- |
| **Database** | **Search Terms** | **Limits applied** | **Number of articles retrieved** |
| **CINAHL** | ((altered mental status) OR (altered patient behaviour) OR (reduced LOC) OR (reduced level of consciousness)) AND (("goals of care") OR (wish\*)) AND (communicat\*) | Within 5 years, English, Full-Text, Peer-Reviewed | 0 |
| **MEDLINE via Ovid** | ((altered mental status) OR (altered patient behaviour) OR (reduced LOC) OR (reduced level of consciousness)) AND (("goals of care") OR (wish\*)) AND (communicat\*) | Within 5 years, English, Full-Text | 0 |
| **PubMed** | ((altered mental status) OR (altered patient behaviour) OR (reduced LOC) OR (reduced level of consciousness)) AND (("goals of care") OR (wish\*)) AND (communicat\*) | Within 5 years, English, Full-Text | 9 |
| **ProQuest: Nursing & Allied Health Premium** | ((altered mental status) OR (altered patient behaviour) OR (reduced LOC) OR (reduced level of consciousness)) AND (("goals of care")) AND (communicat\*) | Within 5 years, English, Full-Text, Peer-Reviewed, Scholarly Journals | 135 |
| **PsycInfo** | ((altered mental status) OR (altered patient behaviour) OR (reduced LOC) OR (reduced level of consciousness)) AND (("goals of care")) AND (communicat\*) | Within 5 years, English, Full-Text, Peer-Reviewed | 0 |

Additional search with modified search input

|  |  |  |  |
| --- | --- | --- | --- |
| **Database** | **Search Terms** | **Limits applied** | **Number of articles retrieved** |
| **UpToDate** | Goals of care discussion | N/A | **\***3 – UpToDate does not say how many relevant search results were found, but based on the results displayed, only 3 were related to the topic |
| **CINAHL** | Patient communication at end-of-life | Within 5 years, English, Full-Text, Peer-Reviewed | 24 |

1. **Select the top 5 articles that answer your question and inform your nursing interventions. Complete the following table.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Author (last name and year)** | **Type of article (qual, quan, mixed methods, systematic review, other)** | **Aim/Purpose** | **Relevant Results/Findings** | **Quality/Rigor**  **(strengths, limitations, methodological flaws)** | **Rationale for including this article** |
| Ozavci, Bucknall, Woodward‐Kron, Hughes, Jorm, & Manias (2022) | Qualitative - ethnographic design | “Explore how older patients participated in managing their medications across transitions of care through formal and informal modes of communication” | **Patient-created notes**   * Creates autonomy * Patients that demonstrate motivation to learn * Gives patients an agenda of items to bring up in meetings with provider (helps when rounding times are inconsistent) * Helps with memory issues * Acts as a form of mock documentation for previous care received so patients can compare and raise concern about changes to care * Shifts power from doctor to patient * e.g., “remember to ask Dr about potassium dose”   **Prompts**   * Talking points for healthcare provider to address most important points * Elicits patient’s opinion; encourages open conversation * Based on patient’s chart; patient-specific * e.g., “ask if patient is enjoying medication self-management”   **Environment**   * Have full conversation in room with patient (rather than discussing a little with the patient, then conferring with the team in a separate room; involve the patient and give them power in decision-making) * Stand close to allow lip reading and auditory comprehension * Reduce distractions   **Other**   * Vary questions; stop repeating the same one   **Patients with cognitive impairments**   * simplify options * create a quiet environment * ask them to teach-back * decision aids | **Strengths**   * Mixed-age participants within the older age sample. * Focus on transitions of care helps address if there is a mismatch in communication received in different settings or at different times (i.e., consistency). * Involving family members in data collection (focus groups) as they are also involved in the patient’s care. * The ethnographic methodology assesses system-level factors affecting communication, such as power imbalances; this allows providers to be aware of the structural/social factors that may indirectly prevent effective communication.   **Limitations**  The article is specifically talking about communication with medication, but a lot of the information applies to communication in general. Additionally, hospitals were in an urban area; lacking rural perspective.  **Methodological Flaws**  The exclusion criteria included severe cognitive impairment, GCS less than 14, individuals younger than 65. While this may be okay for the purposes of the study, it still leaves the article unable to address how to navigate more difficult situations, specifically with patients who have altered mental status and potentially cannot understand the full depth and complexity of formal communication instances. | This article covered a lot of communication modes such as written, electronic, verbal and nonverbal, as well as formal and nonverbal modes. More communication options allow the healthcare provider to assess the patient’s situation and choose a patient-centered approach (what works for one patient, may not work for another). The authors also gave recommendations to directly involve patients with cognitive impairments. |
| Chandregowda, Stierwalk, & Clark (2021) | Case Report based on author experience and literature review | “Promote conversation among medical speech-language pathologists (SLPs) about their role in facilitating family–patient interaction involving patients who acutely encounter the end-of-life (EOL) phase and have severe communication impairment” | There are no known guidelines on how to communicate with patients who have a severe communication impediment (little to no research on the topic).  Repeat counselling helps reaffirm teaching (e.g., at admission, then after discussing options with the care team). Begin teaching with a smaller group of family members, then gradually expand to a larger group.  Advance directives help communicate desired comfort measures.  Communication is important at EOL to help patients find life meaning/spirituality, express love, mend relationships, and reassure family. The family can take lead in discussing these topics for closure.  **Counselling points**   * Minimize background noise * Observe and interpret body language (e.g., are they calm or in pain?) * If they appear restless/confused, reassure them and attempt to reorient them in a calm manner after notifying the nurse * “Focus on increasing the number of pleasant moments” * If spiritual, play recordings of prayers * If awake and observing the room, show significant objects and talk about memories. * Speak calmy and positively even if it looks like they cannot understand * Consult SLP if needed | **Strengths**   * Focus on palliative/EOL care * Patient/family-centered approach * Well-known/reputable healthcare facility (Mayo Clinic)   **Limitations**  The provided counselling points are not comprehensive, just as a general guide. The points were also not evaluated for effectiveness in the provided case. Likewise. The barriers to such points are not explored. Finally, the issues including capacity for making decisions are not explored; advance directives are only briefly mentioned.  **Methodological flaws**  Only one scenario is explored in which the family benefits from the information (potential bias; opposite case is not shared). The authors also do not come to a concrete conclusion on whether or not the provided counselling points are helpful. | SLPs are the experts at communicating with individuals in non-traditional ways. The patients they see typically have some sort of barrier that the SLPs have to overcome. Nurses and other healthcare professionals can apply some of these techniques to their own practice when normal communication cannot occur. |
| LeBlanc & Tulsky (2022) | Literature Review, mention of a multicenter cluster randomized trial | “Provide a practical approach to discussing goals of care in patients with a serious, life-threatening illness” | Goals of care conversations should be done outside of crisis situations (ideally as early as possible in care) and would continue/evolve with care. Rather than medical-based, they should revolve around life goals. Providers should schedule adequate time and reduce distractions for such conversations.  **REMAP stepwise approach (“talking map”)**  ***Reframe***   * Establish patient’s understanding of illness then reframe to discuss next steps * “Now that you have this news, is it okay if we talk about what the next steps are?”   ***Expect emotion***   * Observe, name, and acknowledge emotional cues (NURSE acronym) * “I’m noticing that you look concerned about then. Can we discuss what this means to you further?”   ***Map out the future***   * Identify goal before giving treatment options * “Are there situations that concern you are you would like to avoid. What’s most important to you”   ***Align with values***   * “What I am hearing is that \_\_\_\_ is most important to you, is that correct?”   ***Plan treatments that match values***   * Provide recommendations if patient consents   Document is great to store patient’s goals, values, and preferences | **Strengths**  High level evidence that is consistently reviewed and updated to the most current literature. Links to similar or expanding topics are integrated within the article.  **Limitations**  Does not discuss communication barriers from the patient’s end (focuses more on the provider’s perspective).  **Methodological Flaws**  Does not rank research (not all information with varying perspectives from the literature is presented, only quality information the authors have deemed applicable) | Provides a tangible framework that providers can use without intensive training; step-by-step process. |
| Quest & Lamba (2023) | Literature Review | "Focuses on the ED implementation of palliative care core concepts, including methods for determining goals of care, communication with patients and loved ones, and appropriate referral” | **Goals of Care Conversations**   * “Road maps for care” * Adverse outcomes to avoid * Open-ended questions * Culturally sensitive * Appropriate language * Avoid negative statements (“there is nothing more that we can do”) * Even with time limits, take some time to clarify patient’s goals/wishes first * REMAP framework   **Surrogate decision-makers**   * When patient loses capacity * Guide individual to limit stress and guilt (reframe it to “doing what the patient would want” rather than “what do you think”) * Give the surrogate time * Keep the patient at the center * Show respect for the patient   Build trust with loved ones | **Strengths**  High level evidence that is consistently reviewed and updated to the most current literature. Links to similar or expanding topics are integrated within the article.  **Limitations**  The article is more acute focus (rapid decline of patient rather than a chronic issue). Not much information on continuity of care or passing communication of the goals of care conversations through the transition phase.  **Methodological Flaws**  Does not rank research (not all information with varying perspectives from the literature is presented, only quality information the authors have deemed applicable) | This article was chosen because it discusses both goals of care conversations and then conversations with a surrogate when direct communication with a patient is not possible. Uniquely, because the article is focused on palliative patients in the emergency department, topics such as rapid decline or time constraints are discussed, which apply in palliative care settings when conversations have not been held early in care and there has been a sudden change in status. |
| Ramos, Hold, & Mahmoud (2020) | Case Report | “In this case report, the end-of-life disease trajectory,  advance care planning, decision-making, and ethical considerations of a person living  with advanced dementia are explored.” | When patients are unable to make decisions due to their mental state, family members need to uphold wishes indicated in an advanced directive.  “During the EOL care, about 45% to 70% of patients are not capable of making informed decisions”  **Advance Care Planning**   * Defining patient’s care preferences and values/wishes and communicating them to family and healthcare providers * May be ambiguous and hard to access quickly which may result in wishes not being honored   **Surrogate/Proxy Decision-Maker**  Difficult if individual is unprepared. When a decision cannot be agreed on, it is often decided to continue treatment  **Recommendations**   * Family conversations over individual conversations * Consider patient’s autonomy, respect, and dignity * Be attentive to their unique needs * Show empathy | **Strengths**  Discusses various forms of decisioning-making or planning including advance care planning and proxy decision-making.  **Limitations**  Specific to dementia (although can loosely be related to general situations involving a decline in mental status)  **Methodological Flaws**  The case report is brief and does not provide enough information to understand the depth of the situation like what Maria’s wishes actually entailed. No mention is made whether the case report is based on a true incident or is simulated. | The article provides the perspective of documentation or more formal interventions made very earlier on before or at diagnosis. While it is tailored to dementia patients, it still views goals of care and patient wishes from a lens where the patient is unable to communicate for themselves anymore. |

1. **In two pages (maximum), briefly synthesize the intervention evidence.**

Overall, most care providers and researchers in the field of communicating wishes, goals, and values agree that these conversations should happen as early as possible to ensure that the patient has time to express or document these statements in a competent state and allows discussion with family members or loved ones so that they understand the extent of these wishes (LeBlanc & Tulsky, 2022; Ramos et al., 2020). When situations are more concrete, such as when a patient receives a poor prognosis, more formal actions, such as advance directives and assigning a substitute decision-maker, can be taken (Chandregowda et al., 2021; Quest & Lamba, 2023; Ramos et al., 2020). Ramos et al. (2020) note that issues do arise when directives are not detailed enough or cover all situations, or when a substitute decision maker feels unprepared because they do not feel confident in upholding the patient’s wishes. This reaffirms the need for early conversations incorporating family at all times.

With any level of cognitive functioning, the patient has some level of capacity and can be included in interactions (Chandregowda et al., 2021). When having conversations or general communication with patients and their families, the literature generally divided recommendations into two categories: techniques for patients and advice for providers. Firstly, patients can create notes for themselves that can guide conversation with their provider (Ozavci et al., 2022). These notes can be of previous care, so that the patient can ensure all treatment they received remains continuous, or notes can be clarification points on aspects of care that have not been explained to them or that arise after discussion. For example, after having a family conversation, the patient may want to ask the physician about options for increasing pain medication dosing, so they can write a note for themself. This increases the patient’s autonomy and also helps if the patient has memory issues or has a change in cognition after writing the note (Ozavci et al., 2022). Family can also engage the patient by communicating with them even when it does not appear that a patient is mentally present (Chandregowda et al., 2021). Chandregowda et al. (2021) recommend reminiscing about memories aloud in a calm and soothing tone, showing pictures, playing audio recordings of prayers, and adapting to the patient’s body language to reorient the patient in times of decreasing mental status.

From the provider's perspective, staff should ensure they are empathetic and recognize that the patient has unique needs (Ramos et al., 2020). Prompts are one tool that can assist with guiding an assessment (Ozavci et al., 2022). The provider should read through the patient’s chart and make notes for clarification. For example, if the pharmacist notices a patient has been taking short-acting morphine for pain, but the chart says that the patient reports pain being well-managed, the pharmacist may prompt a discussion by saying “tell me about your morphine prescription”. The REMAP framework is another great tool. Reframing establishes baseline knowledge then moves towards discussing next steps, emotions should be named and acknowledged, mapping the future identifies the patient’s goals, then ensure treatment aligns with those values, and finally, plan the treatment (LeBlanc & Tulsky, 2022).

Other interventions include altering the environment to decrease background noise, standing close within the patient’s visual and auditory field, and consulting the palliative care team or SLPs (Ozavci et al., 2022; Chandregowda et al., 2021). Ozavci et al. (2022) suggest decreasing power imbalances by keeping the patient at the center of communication by keeping all discussions in the patient’s room. Finally, simplifying options, the use of decision aids, and asking patients to teach back are all interventions that can assist communication with individuals who have cognitive impairments (Ozavci et al., 2022).

**D. Reflecting**

1. **What outcomes do you expect if you implemented the evidence summarized above? List 3 to 5 patient/family-centred outcome statements.**

If the evidence summarized above was implemented into the care of Pedro and his family, general expected outcomes may include a better understanding and acceptance from Pedro’s family regarding his prognosis, an increased sense of trust and respect from Pedro’s family towards the healthcare team, a sense of autonomy for Pedro, a mutual agreement amongst the family about the next steps for Pedro, and a sense of peace amongst Pedro’s wife and the family once hard decisions are made after being adequately informed. More specific patient/family-centered outcomes include:

1. Within the next day, Pedro’s wife will demonstrate adequate understanding of “code status,” including the risks and benefits of changing Pedro’s code status to DNR under his specific circumstances, as evidenced by responses of understanding and planning for the future during the “Reframe,” “Map out future,” and “Align with values” portions of the REMAP framework as well as coming to a decision about his code status.
2. Within the next few days, Pedro’s wife will demonstrate less feelings of guilt towards making EOL decisions regarding her husband through adequate teaching of the roles of the “surrogate decision-maker" and guidance towards “what the patient would want,” as evidenced by an increase in trust towards the care team and coming to decisions regarding Pedro’s living situation.
3. By tomorrow, Pedro will communicate with the healthcare team through a form of communication that works with his altered mental status (like patient-created notes, electronically, etc.) to indicate some of his wishes and promote a sense of autonomy (\*member of the team to determine if Pedro has the mental capacity)
4. In the next few days, Pedro’s family will decide where Pedro will reside after receiving adequate teaching about the pros and cons of the two options, as evidenced by responses of understanding and planning for the future during the “Reframe,” “Map out future,” and “Align with values” portions of the REMAP framework, as well as the family coming to an agreed upon decision about where Pedro will spend his last days.
5. In the next few hours, the team will create a safe and comfortable environment to discuss the next steps for Pedro and his care with Pedro’s family as evidenced by the ability for Pedro’s family to express their thoughts and questions to the team freely, the creation of trust and bonds between the team and the family, and a better understanding of the situation from both ends through teachback methods.
6. **List 3 to 5 potential barriers (patient/client/family, nurse, provider, organization, system, etc.) to implementing the interventions in this case as described above? Briefly describe how they could be addressed.**

Some potential barriers to implementing the interventions described above include:

* **Family/client-** The late start to having the goals of care discussion (LeBlanc & Tulsky, 2022). Unfortunately, code status and advanced care planning/directives were not discussed within Pedro’s family until Pedro started to experience a decline in his health status. This is why Pedro’s family and his wife especially, show disagreement and unacceptance in this situation. Discussing the goals of care at this stage in Pedro’s journey (as we said we would implement) can make Pedro’s family feel rushed and pushed to make decisions, when conversations about goals of care should be a process. Making these decisions too quickly can also cause distress within the family and make families wonder if they made the right decision. This could be addressed by potentially giving the family more time to make their decisions, providing therapeutic communication and ensuring the family is adequately informed about each decision they are making.
* **Nurse/providers**- Expecting an answer too quickly (LeBlanc & Tulsky, 2022). Since Pedro’s health status is declining, the team is expecting Pedro’s wife to make a decision about his code status very quickly. This is a barrier because the team is neglecting to see that conversations regarding goals of care should not be rushed; they are life changing decisions, and it is unfair for the team to expect so much from Pedro’s wife in such a short period of time. In addition to this, Pedro’s family may feel a poor connection between themselves and the healthcare team who is neglecting to show them empathy in the situation. This can be addressed by allowing the family more time to process the situation and make a decision, using empathy and emotional awareness as a healthcare team, and refraining from pressuring the family.
* **Nurse/provider/organization-** Biased conversations (LeBlanc & Tulsky, 2022). The team delivering the bad news about changing Pedro’s code status to “DNR” may be swinging towards pressuring the code status change as opposed to weighing out the pros and the cons with the family regarding each different code status. Similarly, the team could be trying to sway the family into making decisions like putting Pedro in a palliative care setting as opposed to equally discussing the options that they have. This is a barrier because it is unfair, and the family does not have an equal chance to make a decision that they feel is right for Pedro’s and their own values. This can be addressed through better open conversations between the team and the family, ensuring all options with the pros and cons are discussed during conversations, and allowing the family to discuss what is important to them as opposed to the team thinking they know what is most important.

1. **How did you feel about this case? What data did you miss? What did you learn? What will you integrate into your practice?**

Our group collectively thought this case was great in showcasing the many aspects that go into providing quality palliative care to a patient/family. The case was not one note; the family required a lot of focus in this case, all while the patient’s status was actively changing and evolving into a new situation. All of the palliative care domains played a role in this case which made it a bit difficult to focus on a couple of the most important ones (which happened to be the psychological, physical, and social domains). Our group thought that the most difficult part of this case was catering our care towards Pedro as his mental status declined and he became less capable of doing his own thing, as well as coming up with interventions to help a disagreeing family. A couple of us really related to Pedro’s wife’s feelings of guilt and abandonment, as we come from cultures that believe that putting a family member in a care facility is very shameful. Other than that, our group as a whole enjoyed the challenge this case gave us to really think about the main focus of the situation, despite there being multiple conflicts within the case. One point of data that we missed was knowing if Pedro had an advanced care plan ready to go after his first round dealing with cancer. A couple of points which we did not focus on as a main issue included Pedro’s religion of Catholicism, the physical limitations of Pedro’s wife to take care of him at home, and the fact that Pedro stated that he was “ready to die” before his mental status began to decline.

This case study taught all of us that providing palliative care is not a straight line; there are so many different bits and pieces that come together to get the full patient picture. Similarly, as a palliative care nurse, you must consider each one of those pieces because they can play a huge role in the outcomes of the patient and the family. For instance, our intervention surrounding methods of communication Pedro could use as his mental status decline offered him a sense of autonomy, even in his dying days. Providing a patient with a sense of autonomy could make the difference between a peaceful death and an unfulfilled, miserable death. This case study really solidified that idea of the importance of considering every aspect of a person’s life in palliative care. We also learned a lot about different communication strategies to use with patients/families in palliative care. For instance, the REMAP framework, which was kind of similar to the SPIKES framework, highlighted important aspects of communication such as aligning with the values of the patient/family to understand what their goals are for care. These communication bits of knowledge will help to better prepare us for those hard conversations we may need to have in the future. Many of us in the group currently struggle with communication; especially surrounding tough topics like end-of-life, so this was a great case study to actively learn from. Again, communication strategies such as the REMAP framework and patient-created notes will be taken into our practice as nurses in the future because as we know, communication is such a critical part of healthcare. Communication really sets the groundwork for the client-nurse relationship, and without a good, trusting bond between the two, the nurse and the client can equally have horrible experiences. Our group also agreed that we would collectively be taking consideration of the palliative care domains into our practice as well. We felt that these domains really break down each aspect of a person receiving palliative care in a way that is understandable and organized while also considering issues that happen after death, like death management. Knowledge of these domains will allow us to provide holistic care to all patients receiving palliative care and put focus on aspects we may not have considered before, like loss and grief. All in all, this case study was a nice opportunity to collaborate with others to promote the best outcomes for a patient/family in need while changing the way we think about palliative care along the way.

**References**

Chandregowda, A., Stierwalk, J. A. G., & Clark, H. M. (2021). Facilitating end-of-life interaction between patients with severe communication impairment and their families. *Perspectives of the ASHA Special Interest Groups, 6*(3), 649-653. https://doi.org/10.1044/2021\_PERSP-20-00282

Durieux, B. N., Tarbi, E. C., & Lindvall, C. (2022). Opportunities for computational tools in palliative care: Supporting patient needs and lowering burden. *Sage Journals, 36*(8). https://doi.org/10.1177/02692163221122261

Huang., Tai., Longcoy., & McMillan. (2021). The mutual effects of perceived spiritual needs on quality of life in patients with advanced cancer and family caregivers. *Journal of Hospice & Palliative Nursing, 23*(4), 323-330. https://doi.org/10.1097/NJH.0000000000000758

LeBlanc, T. W., & Tulsky, J. (2022). Discussing goals of care. *UpToDate.* https://www-uptodate-com.ledproxy2.uwindsor.ca/contents/discussing-goals-of-care?search=goals%20of%20care%20dicussion&source=search\_result&selectedTitle=1~150&usage\_type=default&display\_rank=1

Ozavci, G., Bucknall, T., Woodward‐Kron, R., Hughes, C., Jorm, C., & Manias, E. (2022). Creating opportunities for patient participation in managing medications across transitions of care through formal and informal modes of communication. *Health Expectations, 25*(4), 1807-1820. doi:10.1111/hex.13524

Quest, T. E., Lamba, S. (2023). Palliative care for adults in the ED: Goals of care, communication, consultation, and patient death. *UpToDate.* https://www-uptodate-com.ledproxy2.uwindsor.ca/contents/palliative-care-for-adults-in-the-ed-goals-of-care-communication-consultation-and-patient-death?search=goals%20of%20care%20dicussion&source=search\_result&selectedTitle=2~150&usage\_type=default&display\_rank=2

Ramos, M. D., Hold, D., & Mahmoud, R. (2020). End-of-life care decisions for patients with dementia. *Journal of Nursing Practice Applications & Reviews of Research, 11*(1). https://doi.org/10.13178/jnparr.2021.11.01.1008

Remawi, B. N., Gadoud, A., Murphy, I. M. J., & Preston, N. (2021). Palliative care needs-assessment and measurement tools used in patients with heart failure: A systematic mixed-studies review with narrative synthesis. *Heart Failure Reviews, 26*(1), 137-155. https:/doi.org/10.1007/s10741-020-10011-7

Saotome, T., Iwase, S., Nojima, M., Hewitt, B., & Chye, R. (2018). Assessment of activities of daily living and quality of life among palliative care inpatients: A preliminary prospective cohort study. *Progress in Palliative Care, 26*(1). https://doi.org/10.1080/09699260.2018.1427677

Taels, B., Hermans, K., Audenhove, C. V., Boesten, N., Cohen, J., Hermans, K., & Declercq, A. (2021). How can social workers be meaningfully involved in palliative care? A scoping review on the prerequisites and how they can be realised in practice. *Palliative Care and Social Practice, 15*. https://doi.org/10.1177/26323524211058895

Thiel, M., Harden, K., Brazier, L., Marks, A., & Smith, M. A. (2020). Evaluation tools for interdisciplinary palliative care learning experiences: A literature review. *Journal of Palliative Medicine, 23*(5), 698-702. https://doi.org/10.1089/jpm.2019.0394

Vetter, V. J. (2022). Palliative care screening tools in the gynecologic oncology population: A narrative review. *Annuals of Palliative Medicine, 11*(10), 3263-3272. https://doi.org/10.21037/apm-22-728