Taking the Pain out of Pain Management

The Concept of Total Pain

Host and Moderator: Amanda Tevelde

Presenters: Kathlene Bartlett, RN

Laura Bates, RN

Date: January 25th, 2024

Project ECHO® Palliative Care - Canada BY Pallium Canada

NSMHPCN North Simcoe Muskoka Hospice Palliative Care Network

Land Acknowledgement

We would like to acknowledge that the land which we are gathered on today is the traditional territory of the Anishinaabek Nation; specifically, the Chippewa Tri – Council comprised of the Chippewas of Beausoleil, Rama and Georgina Island First Nations and more recently the Mississaugas of the Credit River First Nation.

Ontario is covered by 46 treaties and other agreements and is home to many Indigenous Nations from across Turtle Island, including the Inuit and the Métis. These treaties and other agreements, including the One Dish with One Spoon Wampum Belt Covenant, are agreements to peaceably share and care for the land and its resources. Other Indigenous Nations, Europeans, and newcomers were invited into this covenant in the spirit of respect, peace, and friendship.

Most of us have come here as settlers, immigrants, or newcomers in this generation or generations past. **We are all Treaty people.** Every day we are mindful of broken covenants, and we strive to make this right. We commit to collaborating based on the foundational assumption that Indigenous Peoples have the power, strength, and competency to develop culturally specific strategies for their communities. We are dedicated to honouring Indigenous self-determination, history, and culture, and are committed to moving forward in the spirit of reconciliation and respect with all First Nation, Métis and Inuit people.

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

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Thank You

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada.

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Health Canada Santé Canada

Introductions

Host and Moderator

Amanda Tevelde
Communications, Fundraising and Community Relations Specialist
Hospice Orillia

Presenters

Kathlene Bartlett, RN, BScN, CHPNC(C)
Palliative Pain and Symptom Management Consultant (PPSMC)
Indigenous Portfolio Navigator
North Simcoe Muskoka Hospice Palliative Care Network

Laura Bates, BScN, RN, CHPCN (C)
Education Facilitator
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Thank you for joining us today!

Please remember to complete the satisfaction survey following todays session.

Learning Objectives

By the end of the session, participants will be able to:

- Define the concept of total pain.
- Use validated tools to assess for total pain.
- Describe how physical pain, spiritual pain, emotional pain, and social pain are connected.
- Describe the barriers to assessing and treating total pain.

REVIEW

What we've learned so far…

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Let’s Review What We’ve Learned So Far

- Pain is a multidimensional symptom, an unpleasant emotional or sensory perception shaped by disease process, underlying psychosocial suffering, and past experiences with pain and it’s management
- Pain is subjective and is whatever the person says it is
- Patients can use a variety of terminology or language to describe and explain their symptoms and experiences

Let's Review Continued

- Thorough assessment of pain is required to determine the probable causes and best choices for intervention
- Patients who are not able to verbalize or who are unresponsive require the use of specialized pain assessment
- Pain can be controlled through a combination of pharmacological and non-pharmacological interventions approximately 85-95% of the time
- Poor pain control is still a leading cause of suffering at end of life

What is Total Pain

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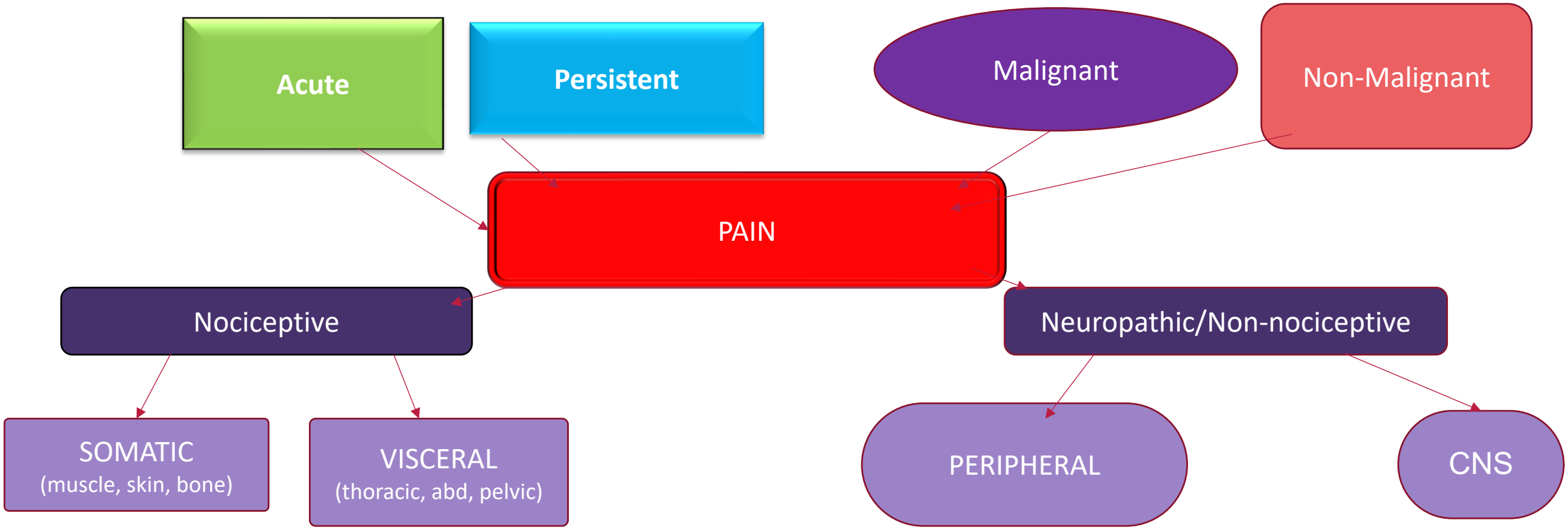
Classification of Pain



What is Total Pain?

- Dame Cicely Saunders originally coined the term “total pain” to showcase the multifaceted nature of a palliative patient’s pain experience
- It Includes but is not limited to distress in a person’s physical, social, psychological, and spiritual domains
- Pallium Canada also includes the definition of somatising:
  - “…occasionally used to describe a phenomenon where a patient may be experiencing and expressing pain… but the mechanisms of the pain do not appear to be due to physical or physiological damage caused by the disease process.”

What is Total Pain?

Dame Cicely Saunders:

- Each death is as individual and unique as the life that was lived prior to it and the dying process reflects that
- The goal of hospice palliative care is the best possible quality of life for patients and their family

Four Areas of Total Pain

Presenters: Kathlene Bartlett, RN, BScN, CHPNC(C)

Laura Bates, BScN, RN, CHPCN (C)

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The Four Areas of Total Pain

- Physical
- Social
- Spiritual
- Emotional


•Usually needs treatment, ie drugs
•Cause variable degrees of distress
•Interferes with other aspects of life
• Guilt/remorse
• Fear of what happens after death
• Sense of connectedness
Physical
Spiritual
Social
Emotional
• Distress over family members/carers
• Loss of role
• Participation issues
• Adjustment disorders, anxiety and depression
• Frustration and hopelessness

How is Total Pain Connected?

Total pain is typically evident in those suffering with serious or life-limiting illnesses. The components of physical, spiritual, social, and emotional pain are intertwined with one another.

As health care providers, we must continually assess the patient and their family in all domains of illness in order to appropriately manage and treat their symptoms.

Four Areas of Pain: *Physical Pain*

Presenters: Kathlene Bartlett, RN, BScN, CHPNC(C)

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Assessment of Physical Pain

- Use validated tools appropriate for the patient/client and be consistent in which tool is used
- Examples: Wong-Baker Faces Pain Rating Scale, PAINAD, Numerical Scale (1-10), OPQRSTUV Assessment, CCO Pain Algorithm
- Use open-ended questions to promote conversation and to gather the most information possible

Physical Pain Interventions and Management

- Ensure pain management plan follows the WHO three-step analgesic ladder, including the use of adjuvants and non-pharmacological interventions
- Ensure side effects of pain medications are well managed
- Health teaching to patients and caregivers regarding optimal use of routine and breakthrough medications to maximize pain management
- Referral to physiotherapy/occupational therapy/pain specialist if appropriate

Always consider a non-physical source for physical pain that is not well managed despite the above

SOCIAL

Four Areas of Pain: *Social Pain*

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What is Social Pain?

- Fear of dependency on others or loss of previous level of independence
- Loss of role within relationships and the community
- Loss of dignity
- Loss of sense of self-worth
- Fear of the unknown during their illness trajectory and after death (regarding relationships and roles)
- Can include practical or financial issues/concerns

Assessment of Social Pain

- A psychosocial assessment should include questions about the following subjects:
  - Patient's thoughts and feelings about illness, treatment and care
  - Coping with emotions, functional changes, symptoms, etc.
  - Culture influences
  - Social Context
  - Lived Experience of illness, impact on self, others, and quality of life
  - Suffering and the existential/spiritual domain
  - Financial and/or practical needs and concerns

Social Pain Interventions and Management

- Provide supportive counselling
- Refer to social work and/or therapist
- Support groups or links with organizations supporting people with the patient's diagnosis (i.e. Alzheimer's Society, ALS Society, etc.)
- Encourage legacy work, memory making
- Encourage maintaining social connections
- Assist as able with paperwork required for financial or practical assistance

Four Areas of Pain: *Spiritual Pain*

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What is Spiritual Pain?

- Despair from the inner realization that life is finite
- Loss of previous definition of meaning of life
- Feelings of abandonment or disconnection from a person's community or deity/higher power
- Involves questioning the meaning of life and/or the dying process
- Does not always involve organized religion
- Can be described as "soul pain"

Assessment of Spiritual Pain

- Assess for outstanding spiritual needs by asking questions about the meaning or purpose in their life and what gives them strength
- Most commonly used is the FICA tool to assess spiritual needs
- Other tools: HOPE, LET GO, FAITH, SPIRIT, FACT, FFFF

FICA Tool

F – Faith, Belief, Meaning: Do you consider yourself spiritual or religious? Do you have spiritual beliefs that help you cope with stress? If the patient responds No, the health care provider might ask, What gives your life meaning? It is important to contextualize these questions to the reason for the visit – e.g., wellness, stress management, breaking bad news, the end of life. Meaning might be found in family, career, nature, arts, humanities or other spiritual, cultural or religious beliefs and practices.

I – Importance and Influence: What importance does your faith or belief have in your life? Have your beliefs influenced you in how you handle stress? Do you have specific beliefs that might influence your health care decisions? If so, are you willing to share those with your healthcare team?

C – Community: Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?

A – Address/Action in Care: How should I address these issues in your healthcare? Would you like to talk to someone about these matters? Would you like us to arrange for a member of your faith community to come and see you? This is also to remind clinicians to develop a plan to address patient spiritual distress or other spiritual issues.

Spiritual Pain Interventions and Management

- Provide supportive counselling
- Refer to chaplain/social work/therapist
- Encourage or facilitate use of clergy/religious leaders as appropriate
- Legacy work and memory making
- Visiting hospice volunteer

Four Areas of Pain: *Emotional Pain*

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What is Emotional Pain?

- Feelings of hopelessness, despair, and helplessness
- Anxiety and/or depression
- Difficulty adjusting to changes
- Disengagement from care or excessive control over care
- Poor sense of wellbeing even when symptoms well controlled

Assessment of Emotional Pain

- Use validated screening tools for depression and anxiety
- May require a referral to a psychiatry
- Depression: Beck Depression Inventory (BDI), Patient Health Questionnaire (PHQ-9)
- Anxiety: Patient Health Questionnaire (PHQ-9), Generalized Anxiety Disorder (GAD-7)

Emotional Pain Interventions and Management

- Provide supportive counselling
- Referral to social work/therapist/chaplain or religious leader
- Medications (antidepressants and/or antianxiety medications)
- Use non-pharmacological interventions for depression and/or anxiety (cognitive behaviour therapy, exercise as able, improved sleep and diet, alternative therapies (i.e. reflexology, acupuncture, etc.), herbs/supplements
- Ensure all other physical symptoms and medication side effects (i.e. nausea & vomiting, dyspnea, constipation, etc.) are well managed
- Ensure that all comorbidities (physical and psychological) have optimal treatment

TOTAL PAIN

BARRIERS, MANAGEMENT & CONSIDERATIONS

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Barriers to Managing Physical Pain

- Stoicism, inability to communicate, or cognitive impairment
- Patients use different language and terms to describe pain that the health care provider is not familiar with
- Health care providers conducting the assessments are not trained on how to use these tools appropriately
- Some may rely strictly on their own observations, this however does not allow the person to describe their own feelings of pain or how their other domains are being impacted.
- Fears/myths about the use of analgesics or adjuvants (i.e. addiction, negative side effects)

Barriers to Managing Social Pain

- Lack of a trusting relationship with health care provider or with the healthcare system
- Patients who are unable to communicate their needs
- Patients who may not have someone to speak of who they are or who they were
- Fear of “getting in trouble” (i.e. having child welfare authorities involved, losing their residence/job/friends)
- Health care providers who do not use a trauma-informed approach
- Health care providers who do not believe that their scope of practice includes the psychosocial domains

Barriers to Managing Spiritual Pain

- One study provided in the Pallium Palliative Pocketbook, 2nd Edition, noted that 15-20% of people do not want clinicians exploring their spiritual beliefs. Patients rarely voice the concerns of spiritual pain
- Health care providers are uncomfortable/untrained or hold biases
- Differences in religious/spiritual practices between patient and health care providers

Barriers to Managing Emotional Pain

- Stoicism, anger, hostility, withdrawing, masking true feelings from the patient
- Incorrect belief that all dying patients must be anxious or depressed and all require treatment
- Incorrect belief that because the patient is dying, anxiety and depression are a normal expected outcome and do not require treatment

Cultural Considerations in the Management of Total Pain

- Cultural stereotyping: assuming a person will act a certain way in regards to their pain experience and management
- Cultural competence: skills that enable effective and appropriate communication and interaction with people of other cultures
  - Requires that you:
    - be aware of your own cultural and family values
    - Be ware of personal biases and assumptions about people with different values than yours
    - Be aware and accept cultural differences between yourself and patients
    - Understand the dynamics of the difference
    - Adapt to, and respect, diversity

Trauma-Informed Care

Trauma-informed care shifts the focus of care from “What’s wrong with you?” to “What happened to you?” and provides a more complete picture of a person’s life situation, both past and present

The Principles of Trauma-Informed Care (from Trauma-Informed Care Implementation Resources Centre):

- Safety
- Trustworthiness & Transparency
- Peer support
- Collaboration
- Empowerment
- Humility & responsiveness

The Total Pain Dream Team

- Patient, including family and friends
- Physician
- Physician Assistant
- Nurse Practitioner
- Disease Specialist *(i.e. Oncologist, Urologist, Cardiologist, Neurologist, etc.)*
- Nurse (RN, RPN)
- PSW
- Pharmacist
- Respiratory Therapist
- Speech and Language Pathologist
- Registered Dietician
- Social Worker
- Counselor/Therapist
- Occupational Therapist
- Physiotherapist
- Spiritual Leader – chaplain, clergy/religious leader
- Traditional Healer
- Elders
- Community members

Case Studies

Let's Discuss

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Case Study #1 - Joe

Joe is a 14 year old male with T-cell lymphoma who has been hospitalized after developing chest pain and severe dyspnea. Further testing finds evidence that he has new tumors and that he also has a large pleural effusion. The pediatric ward is at capacity so he is admitted to the adult floor in a ward room.

Joe's parents meet with his medical team without him and are given Joe's poor prognosis. His parents make the decision not to inform Joe of his prognosis at this time until his pain and dyspnea are better controlled.

Case Study #1 - Joe

The next day, the person in the next bed suffers a cardiac arrest and dies despite CPR. In the commotion, no one thinks to move Joe and he ends up witnessing most of the code including CPR, intubation, and defibrillation. This is the first death Joe has witnessed.

Joe is traumatized and alternates between needing sedation for inconsolable screaming and crying and being withdrawn, quiet and apathetic. He expresses fears of dying and believes that what he witnessed is how everyone dies. He refuses to call any of his friends and refuses to do any schoolwork or hobbies.

Case Study #1 - Joe

Joe frequently questions his disease status to his medical team and to his family, wondering about the connection between his symptoms and whether his disease has returned. He expresses that his life is meaningless now that he is unable to play on his soccer team, hang out with friends, go to youth group at his church, or attend school.

What are your initial thoughts?

Where do you start your assessment?

Is Joe showing signs of total pain?

Case Study #1 - Joe

Physical:

- Assessment: full pain assessment
- Intervention: use of WHO ladder for pain management and titrate analgesics and adjuvants; additional chemotherapy

Social:

- Assessment: full psychosocial assessment
- Intervention: referral to social work/therapy/child life specialist; arrange for teachers and friends to visit; tutor to come to the hospital to assist with school work; referral for family to social work/support groups

Case Study #1 - Joe

Spiritual:

- Assessment: FICA tool or similar tool
- Intervention: referral to chaplain/child life specialist; encourage clergy/youth leader to visit and make plans to have regular visits

Emotional:

- Assessment: depression/anxiety screening and referral to psychiatry
- Intervention: move to a private room in the pediatric ward as soon as possible; anti-anxiety medications

Case Study #2 – Jane

Jane finished chemotherapy for metastatic lung cancer which was found to have spread to nearby lymph nodes approximately 6 months ago. Her other diagnoses include arthritis to the bilateral knees, high blood pressure, and type 2 diabetes that is controlled by oral medications.

She is a 55 year old female who is single and lives alone in an apartment that she rents. She smoked 1.5-2 packs of cigarettes a day before her diagnosis and was unwilling to quit at first, but managed to reduce her smoking to a ½ pack a day last month. Jane had a new job in a fast food restaurant before her diagnosis but was let go from her job when she couldn't continue working while undergoing treatment.

Case Study #2 – Jane

Jane has no children and has previously expressed that she is estranged from her family due to a history of abuse. Jane's best friend took a leave of absence from work to support her and drive her to appointments during treatment, but has returned to work. Jane was told last week after a follow up CT scan that her treatment was not successful and that there was further evidence of disease in her ribs and spine.

Jane arrives at the office via taxi for an appointment for a complaint of increasing pain to her back and knees not relieved by her usual routine medication. Usually calm and good natured, Jane gets upset with the reception staff upon arrival, yelling and cursing because appointments are running behind.

Case Study #2 – Jane

Once her appointment begins, Jane becomes weepy and difficult to console. She tells you “everyone has abandoned me, it looks like no one really even cared about me” and “what’s the point to doing anything anyways?” but refuses to discuss it any further.

What are your initial thoughts?

Where do you start your assessment?

Is Jane showing signs of total pain?

Case Study #2 – Jane

Physical:

- Assessment: full pain assessment of both back and knee pain; imaging of knee(s) to rule out further metastases vs. other disease
- Intervention: use of WHO ladder for pain management, referral to orthopedics for specialised treatment (i.e. corticosteroid injection or surgery for knees), palliative chemotherapy or radiation therapy for metastatic disease

Social:

- Assessment: full psychosocial assessment
- Intervention: visiting hospice volunteer, referral to social work/therapy, support groups, referral/applications for practical support (home care/housekeeping, transportation assistance, financial assistance)

Case Study #2 – Jane

Spiritual:

- Assessment: FICA tool or similar tool
- Intervention: visiting hospice volunteer, referral to social work/chaplain

Emotional:

- Assessment: screen for depression and anxiety
- Intervention: refer to social work/therapy; supportive counselling

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Questions?

We hope you enjoyed todays session. Please remember to complete the satisfaction survey.