

## Narrative Palliative Care: A Method for Building Empathy

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### Abstract

Palliative care can be provided in acute care settings, hospice, patient's own home, ambulatory clinics etc and aims to provide dignity, respect and humane care to the sick with objective of managing pain, understanding their needs, emotions, requiring careful understanding and observation skills. Patient's needs are acknowledged and utmost holistic care is provided with optimistic attitude and hope. Active listening is an important skill as it enables to understand what the person is saying and to comprehend about their feelings through empathy. Patients develop self-awareness and self-confidence by externalizing their feelings, thoughts and emotions, thereby leading to decrease in their emotional discomfort and suffering. This review article describes about palliative medicine, narrative palliative medicine, empathic process and compassion in brief.

**Keywords:** Palliative Medicine; Narrative Palliative Medicine; Empathic Process.

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### Introduction

The word Palliare means "to cloak, deceive, or cover", Palliate is "to lessen or mitigate without curing". The term Palliative Care was first coined in 1974 by Dr. Balfour Mount and is a contemporary embodiment of age-old concept of "good death". 'Narrative Palliative care integrates clinical practice with ability to recognize, interpret, absorb and move by stories of prolonged illness. It aims to provide relief from pain and affirms life and considers Dying as a normal process. It integrates spiritual and psychological aspect of care of dying ones, and neither hasten or postpone the process of death. The term "narrative medicine" was coined in by Rita

Charon, a literary scholar, in year 2000. Narrative palliative care integrates narrative medicine with palliative care and provides an effective way to manage healing process in cases of serious chronic illness and death [1].

Narrative medicine involves listening to patient's story and make meaning of suffering, illness and death via narrating a story. Telling and listening to patient's perspectives helps in better understanding and validating the experience of suffering and illness [2]. Narrative helps caregivers such as family members, relatives, professionals attend to humanness and address aspects of giving care which include:

1. Their own and patient's needs to make sense of a particular situation,

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2. Accept and strengthen intimacy
3. To assert control at times when they thought they were powerless.

Palliative care can be provided in acute care settings, hospice, patient's own home, ambulatory clinics etc and aims to provide dignity, respect and humble care to the sick with objective of managing pain, understanding their needs, emotions, requiring careful understanding and observation skills. Patient's needs are acknowledged and utmost holistic care is provided with optimistic attitude and hope. Active listening is an important skill as it enables to understand what the person is saying and to comprehend about their feelings through empathy. Patients develop self-awareness and self-confidence by externalizing their feelings, thoughts and emotions, thereby leading to decrease in their emotional discomfort and suffering.

### Knowing Empathy

Empathy is defined as the capacity to understand rationally what the patient is experiencing emotionally and denotes seeing with the eyes of another person, feeling with the heart of another and listening with the ears of another. *Listening to another person is an actual meaning of empathy, understanding their perspective, happiness, sadness, challenges, and world view is empathy.* It is expressed as "I" and "You" is "I am You" or "I might be You". Empathy according to origins from literature denotes what we feel, and knowing the emotions that accompany the facts. It is an essential and critical tool in narrative palliative care in managing end of life care. It brings a homely feeling, as one's own and not as a stranger. Empathy differs from sympathy which involves an

emotional reaction of pity towards misfortune of another; it also differs from compassion which means deep awareness of suffering of another person with wish to relieve the same [1-3]. The following are summarized in Table 1.

#### *Historical Aspect*

The empathy is not a new concept but has a deep ancient root in Indian Mythology. In the epic war of Mahabharata, when Bhishma was on death bed for 58 days, what Pandavs especially Arjun did was no less than the act of empathy. They lend an ear to the sufferings of dying Bhishma and to make him comfortable on death bed, Arjun made a double arrow pillow for Bhishma's head rest and when he asked for drinking water, he produced a water stream from the earth with the help of an arrow in the battlefield. This whole act thus gone beyond empathy and involved their compassion for dying person. The same concept is now applied in our ICUs in form of empathetic palliative care [4].

#### *Types of Empathy*

There are two types of empathy as:

1. Cognitive empathy and
2. Affective empathy

While cognitive empathy defines understanding of the distressed situation based on a sense of duty with due acknowledgment, whereas Affective empathy includes elements of cognitive empathy together with acknowledgement and understanding of patient's situation by feeling with the person. It allows develop a deeper understanding of the suffering thereby allowing the caregiver to address issues in an effective and personalized manner.

**Table 1:**

Categories	Themes
Sympathy	An unwanted Pity-based response A shallow and superficial emotion based on self preservation An unhelpful and misguided reaction to suffering
Empathy	Engaging suffering= Pity + Emotions Connecting to and understanding the person Emotional resonance: putting yourself in the patient's Shoes
Compassion	Motivated by love The altruistic role of the responder involves action oriented small Supererogatory acts of kindness= Pity + Emotions + Action

## Empathic Process

Empathy Process (as defined by Gallop, Lancee, & Garfinkel, in year 1990) is a tri-phasal, time-sequenced process, which include:

1. Inducement phase
2. Matching phase
3. Participatory-helping phase

In each phase, different mediators can either hinder or advance the empathic process. The final successful and acceptable outcome of each phase acts as a catalyst for next phase in a sequential manner [5].

### *Outcomes of Inducement Phase Include*

1. *Disinterested*– observer proceeds directly to next event without any attention to the symptoms of the patient. The process ends there itself.
2. *Overwhelmed*– observer only focuses on his/her narration. Observer may assume that the other person experiences similar feelings and somehow convinced with him. This sets stage for next step.
3. *Engaged*– observer attends the patient with full feelings and wishes to proceed to next phase. Here observer may feel a personal bonding with the patient.

### *Outcomes of Matching Phase Include*

1. *Over identification*– Observer experiences loss of self due to associated distress and hence cannot help the observed. He overrates the symptoms and finds himself unable to help the patient.
2. *Perplexed*– generated hypotheses do not contain observed content and affect. This is due the puzzling effect from the mixed symptoms and this may lead to a hypothesis which may not match with the narration.
3. *Defensive State*– Observer experiences a personal hit and the need to defend oneself is stronger than the desire to help. Here observer feels loss of self-esteem and try to avoid the confrontation.
4. *Match*– hypothetical situation matches observed situation. The observer fully acknowledge the sufferings of the patient

### *Outcomes of Participating Phase*

1. *No action* – it does not mean a perfect match or action to narration. Observer tries other ways to

help which may involve different type of helpful activities not directly related with the treatment

2. *Nonspecific emotional support* – observer wants to “make person feel better”. Here observer employs emotional bonding and support and tries to rebuild self confidence in patient.
3. *Instrumental problem solving* – in the final step, observer attempts to solve patient’s problems. This leads to next process of Compassion.

### *Implications of Empathic Process*

Empathic process aims to reflect on previous dialogues and identify which stage and by which mediator an empathic process ended, it helps communicate meaningfully and therapeutically. In using this process, it becomes easier to distinguish between empathy and other similar concepts such as Empathy vs. Sympathy and Road to compassion

## Empathetic Communication

The success of empathic communication skills depends on: understanding, respect, support and exploration to the best of the patient.<sup>6</sup> The key elements involved are:

1. Basic skills in communication with patients with active listening
2. Differentiate between good and poor communication techniques
3. Know how to break bad news and
4. Know how to handle patient reactions

Ethical communication leads to trusting partnerships.

- Communication + Empathy = empathetic communication = trusting partnerships.
- “The feeling of being deeply understood reinforces a sense of connectedness between the practitioner and dying person.

### *Guidelines of Empathetic Communication*

- Clear your mind
- Be silent
- Make eye contact Relaxed and be open
- Be compassionate
- Listen without interruption
- Listen for more than words

- Send acknowledgements
- Use touch – but only with permission

**Empathetic Statements**

More than 80% of the “message” is in the how and not the what. One should be able to express clearly, by using a “common language” of words and body language. One should prefer asking open-ended questions, and avoid giving advice. One must Listen with empathy and Respect silence [7].

Name	N	‘I imagine this must be upsetting’ (naming the emotion)
Understand	U	‘I expect most people would feel that way in a situation like this’
Respect	R	‘I’m impressed with how well you’ve handled such a tough situation’
Support	S	‘I’ll be here to help you through this’
Explore	E	‘Tell me more about how you’re feeling, and what this means for you’

**Nurse Module for Empathy**

**Acknowledging Feelings**

1. Noticing and naming the feeling: “There’s a word for that.”
2. Responding to feelings: “Now I named it, what do I say?”
3. Validating feelings: “Your feelings make sense.”
4. Expressing care: “I care about you.”
5. Handling strong emotions: “It’s hard, but we can get through this.”

**Breaking Bad News (Spikes Protocol)**

Setting	S	Private room, silence pagers/phones, adequate time, key participants available
Perception	P	‘Tell me your understanding about the situation
Invitation	I	‘Is it okay if we talk further about this?’
Knowledge	K	Give the news in short, digestible, clear, non-technical language, then be quiet and wait
Empathy	E	Use NURSE or similar strategy to demonstrate empathy
Summary/ Strategy	S	‘What kind of information would be helpful for you right now?’ ‘Let’s talk about the next steps . . .

**Biological Basis for Empathy**

Yes what we empathize, is completely scientific and has a deep biological basis. When we feel upset at giving someone bad news, our brain is feeling the bad news as if it applied to us only. This is because of a neural mechanism called as “mirror neuron systems”. Some scientists believe that these ‘mirror neuron systems’ may help us to understand what others are going through. There are some corresponding areas in our brain as certified by MRI brain and PET imaging that exactly mirrors the feeling of the patient and generates a feeling of empathy in our brain [8].

**Factors Against Empathy**

Many people worry about using empathy in palliative care for a variety of reasons:

1. First and foremost is lack of time
2. Second is Fear of getting overwhelmed by the patient’s emotions,
3. Few of the concerns caregivers demonstrate while giving empathy include:

- *It is not relevant, and I'm too busy focusing on the acute medical problem."*
- *"Giving empathy is emotionally exhausting for me."*
- *"I haven't had enough training in empathetic communication."*
- *"I'm concerned that if I use up all my empathy at work I won't have anything left for my family."*

### What Next after Empathy - Compassion

Compassion is a step beyond empathy and acknowledges and understands suffering and includes a process of acknowledging, understanding, seeking help and performing actions to aim at a solution and seeks small supererogatory acts of kindness and at the same time receiving personal satisfaction.

### Conclusion

Empathy - 'seeing the world from another's position' - is a key skill in Narrative palliative care. Being empathic one needs to demonstrate their empathy to the patient. This is done using empathic statements as well as other verbal and non-verbal techniques. Empathic responses or statements will help to build a rapport with patients and families and will encourage them to share their pain, concerns and sufferings with you. Attentiveness to

patient emotions is thus a key aspect of palliative care practice, and one of the ways in which this practice can put into practice the ideals of Palliative care.

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