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End of Life Research and Care: New Avenues

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I. Introduction.

When I think about what it is to be courageous and graceful in the face of a serious and ultimately life-threatening illness, I think of my beloved father who left this beautiful earth one month shy of his 54th Birthday. His life and his passing left me with deep sorrow but also with clear messages - about life and living, about courage, and about Grace in the face of the most difficult tests we all will face one day.

Many of you who are reading this Paper may also have faced similar moments and feelings.

To live is to one day face the challenges of illness, declining health status, and death. This is not a negative comment - it is rather a marching order for us as doctors and health professionals to learn and be informed about better ways of helping those we love and those we provide care for as doctors, especially during the final part of the *continuum of life.*[1]

Those we love most should leave this earth, this life, knowing that they are loved, that they will be missed, and that we will never forget them![1]

Thankfully, we are now at a point in time in Medicine where empirically tested, methodologically strong studies in this field of science are being encouraged. Many important studies have been completed and have led to an ever growing number of publications that address valuable topics in *End of Life and Palliative Care research.*

The research and care goals for the ensuing years, in this area of science, is to continue the cycle of research so we may learn to be better, more humane, and ethical doctors who practice "Good Medicine" in accordance with the best values and ethical tenets of Medicine, and in a manner that affirms dignity and elevates personhood of all patients, including those needing palliative care and /or end of life care! Given the special sensitivities surrounding the care of patients at the end of their lives, we must always remain mindful that the care we provide remains in accordance with personal, ethical, and altruistic concepts of Caring, and the *tenets of Autonomy, Beneficence, Justice, and above all, Non Malfeasance at all times!*

What we learn from research and evidence based practice will allow us to provide better care to our patients, and be sensitive to the needs of their families and loved ones who also are suffering because of the impending loss of a beloved family member! The care we offer must therefore also remain sensitive to all needs,and must take into account the patient's personal wishes, and provide them with comfort and relief from physical and emotional concerns.[1,2,3,4,5]

In Medicine we encounter issues pertaining to serious illness, disability, and death virtually every day among our patients and loved ones. And, we see in our patients eyes the Hope that we will be able to offer them help regarding the symptoms and signs of serious illness or advanced age that are of particular concern to them. These include but are not limited to emotional issues such as anxiety, depression, grief, sadness, and fear on the one hand, alongwith physical /medical symptoms such as pain and fatigue on the other.[1,2]

There is no doubt that, as doctors aspiring to help and heal our patients, we must develop a familiarity with the profound concepts and concerns relating to the end of life, and learn about or find ways to offer specific help to patients and families as they traverse this inevitable part of the continuum of life. As doctors we have sworn to uphold the ethical tenets of Autonomy, Beneficence, Justice, and above all, Non-Malfeasance! It is indeed our duty to uphold these tenets and values, and to offer help to our patients at every phase of the continuum of life.[1,2]

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This paper describes the "End of life" as a concept and discusses some of its related care and research needs. It also will introduce an important concept of care for patients at the end of life known as "Intensive Caring", and will introduce the concept of "Dignity" as a foundational tenet or strategy underlying Intensive Caring for patients at the end of life due to age, infirmity, or as the final phase of serious life limiting illnesses such as heart disease or advanced cancer.[1-5]

II. Some Important Terms and Concepts in Palliative Care and End of Life

A. Definitions

End of Life: The term *"end of life"* refers to the final stage of a person's life when facing a terminal illness or the impact of advanced age.[1-5]

End of life Care: refers to the medical and /or emotional care, comfort, and support provided by caregivers and family members to a loved one needing such care, and/or the end of life care provided by formal care providers such as physicians, nurses, psychologists and others to a person facing or dealing with the final stages of terminal illness, or those who are as a function of age approaching the time point medicine and/society identifies as the end of life.[1,2,4,5]

Goal(s)of end of life care: The most important goal(s)of end of life care is not *primarily* the cure of underlying diseases or health issues, but rather the:

- management of symptoms such as pain
- provision of care that adds to a person's comfort
- maintenance of a person's dignity - promotion of quality of life
- mitigation of a person's distress
- mitigation of suffering[1,2,3,4,5]

The above goals of care also represent potential areas for future research relating to end of life.[1,2]

B. The Domains of End of Life Care and Research

The physiological and emotional domains of end of life care and research include: [1,2,3]

Physical: such as the management of pain, nausea, breathing difficulties, and other distressing symptoms.[1]
Emotional: provision of counseling and support to help patients and loved ones process grief, anxiety, fear, suffering, agony and poor quality of life[1]
Spiritual: Addresses existential questions such as religious beliefs or inner peace, honouring a patient's personal wishes and also benefit funding, personal growth, and inspiration [1]
Practical: providing assistance with daily tasks, advance directives (e.g., living wills), and family support[1]

C. Types of Care At The End of Life

The ***General Types of Care*** subsumed within the rubric of end of life care depends on a given patient's condition and prognosis, and may include but are not limited to the following: [1,2,3,4,5]

Palliative Care: Specialized medical care focused largely on the relief of symptoms. *Unlike end-of-life care, it can be provided alongside curative treatments at any stage* of a serious illness. [1,2]
Hospice Care: A specific form of end-of-life care for patients with life expectancies of six months or less, when curative treatments have ceased.[1,2]
Comfort Care: The provision of care that focuses only on symptom management and provision of comfort. Definitionally, this type of care occurs only when a cure is no longer possible.[1,2]

D. Settings

Simply put, "settings" refer to those places / areas where EOL Care May Be Delivered.[1,2,4,5]

End-of-life care can be provided at home, or hospice facilities, or within hospital units that specialise in the delivery

of such care. Certain Nursing Homes may also be certified as appropriate for providing EOL Care.

The key factor common across these care settings is the consideration that care should be delivered in a setting (or settings) where a patient feels the greatest level of comfort.[1,2]

E. Diagnoses and Health Conditions Important in End of Life Research and Care

a) Serious Illness: Conceptually, "Serious illness" refers to a health condition that carries a high risk of mortality, and impacts negatively a person's daily function or quality of life. Such conditions may also place excessive strain on family caregivers and alternatives may need to be explored. [1,2,3]

b) Chronic Serious Illness: A *chronic serious illness* is a long-lasting health condition that may persist a year or more, and which requires ongoing medical care, or limits to daily activities, or both. [1,2,3] Unlike acute conditions that appear suddenly and resolve quickly, chronic illnesses require continuous management and significantly impact a person's quality of life.[1-5] Additional terms one may encounter often within end of life research and care, and the mitigation of associated adverse issues or symptoms include Distress. Suffering, Misery and Agony. An understanding of these terms and how they affect End of Life is also important for health care providers and researchers.[1,2,3]

c) Distress: extreme sorrow or pain. Distress implies that "there is an external and usually temporary cause of great physical or mental strain and stress".[1,2,3]
Suffering: the state of undergoing pain distress or hardship. Suffering implies conscious endurance of pain or distress.[1,2]

d) Suffering: the state of undergoing pain distress or hardship. Suffering implies conscious endurance of pain or distress.[1,2]

e) Misery:A state or feeling of great physical or mental distress or physical discomfort. Misery is a state of being where stressors may exert stresses on a patient or person and lead to or cause unhappiness, sickness, or loss.[1,2,3]

f) Agony: Extreme physical or mental suffering or the final stages of a difficult or painful death. Agony suggests pain that is too intense to be borne and needs to be mitigated.[1,2,3]

All four terms, Distress, Suffering, Misery or Agony, essentially mean that patients are living in "states that are causing or may lead to great trouble & difficulty". [1,2,3]

g) Love and Grief: Two additional terms encountered in palliative and end of life care are, perhaps not too surprisingly, Love and Grief! [1,2,3] The Late Queen Elizabeth is famous for the statement, "Grief is the price we pay for Love"! She mentioned this when her husband's life was nearing its end, and also at a couple of times in relation to major historical occurrences involving great destruction.[1]

What we as doctors, care providers, and researchers need to understand is that ***both Grief and Love can be thought of essentially as two sides of the same coin or two ends of a linear or curvilinear spectrum or relationship!*** This is a prevailing, cross-disciplinary consensus frequently shared by a number of grief counselors, psychologists, and writers such as Alan D Wolfelt, CS Lewis, and Mark Twain.

Love is an essential component of the most positive ***affirming*** relationships among human beings. The loss of a loved one creates varying levels of grief and pain that can demand prolonged, and intense levels of, care. Both emotions are inextricably linked because their core psychological framework is similar, linked.

To love someone essentially means that a person has extended his or her emotional boundaries to include another. It is perhaps among the greatest of human connections and it may well be likely to be linked to a future loss! Thus grief can be seen as the culmination of a deep bond of Love. An intense or prolonged sadness is among the manifestations of Grief that may occur because of the loss of the loved one, and a relationship that had been very strong. In some, the grief encountered during the period of mourning may not go away and may appear to have been transformed into a heavy ache, or a sorrow that stays and needs therapeutic care.

As doctors we need to recognize that a profound, long-lasting grief may actually be the outward manifestation of a profoundly deep emotion. Love does not vanish when a person dies and thus both the love and the grief may well continue past the death or even forever – in such instances, the depth of the grief is due to the reminiscence of a transformative love!

As doctors, we should be mindful of such a possibility when the grief we observe is particularly refractory to therapy! In such instances, facilitating a peaceful closure may be the most important step during Intensive Caring. This is among the "viable opportunities" we are reminded to seek out and address if possible while offering Intensive Caring!

III. Intensive Caring in End of Life Research and Care

An important approach in palliative care for seriously ill patients, or for those who are approaching the end of life due to age, is called **Intensive caring!** [4,5]

Intensive Caring is an approach that shifts the focus away from aggressive life sustaining treatments towards comfort and dignity. It calls for symptom management of pain and other distressing symptoms like dyspnoea etc, with a focused affirmation of the patient's intrinsic worth (dignity). In essence, the approach attempts to balance medical complexities with Dignity affirming non curative comfort based support.

The approach has been conceptualised proposed and tested by professor HM Chochinov and is based philosophically on a quote by Dame Cicely Saunders, the founder of the modern hospice movement and palliative care. She is famous for saying, ***"You matter because you are you, and you matter to the last moment of your life"*** [4,5] This quote places emphasis on mattering, and reminds doctors, health care professionals, and family to tell, to remind, ***patients with serious illness or those at advanced stages of an illness, and those in older age ranges associated with the end of life, that they matter, and that they are important***. [4,5]

This issue is especially relevant among those patients who may be feeling that they are helpless, hopeless, or worthless. These patients especially must be reminded they ***Do Matter.*** [4,5]

Feelings of not mattering may in turn give rise to thoughts that life is no longer worth living!! Thus, feelings of not mattering may, especially if uncorrected, give rise to hopelessness and when extreme to potentially even suicidal ideation.

"Intensive Caring" tells us that it is incumbent on us, as doctors and health care professionals, to remind repeatedly those under our care, especially when facing the enormity of human suffering, that they matter, that they have intrinsic worth and that they will always remain in the memories of their loved ones! [4,5]

The message has been refined further! It exhorts us as the doctors of patients who are demonstrating hopelessness, to tell them that they matter for what they are, or were, or will become in the memories of their loved ones who will be left behind to mourn them. [4,5]

Importantly, "Intensive caring" also addresses the patient's existential and emotional needs by focusing on compassion, active listening, non-abandonment, and Dignity and reassures patients that they are valued and they matter"!

While Dame Cicely provided the essential philosophy for Intensive Caring, she did not describe the way to operationalise it, deliver it, or create specific parts, aspects or components that feed into the overarching philosophy or construct of intensive caring. [3,4,5]

In order to develop the unique and novel method or type of care that focuses on life affirmation, and which keeps

the focus on the importance of reminders about "mattering" among patients, the discipline needed a way to operationalise the concepts and components that underly intensive caring so that a well-articulated approach could be described. [4,5]

"Intensive Caring" as proposed and tested by Professor Chochinov now includes five (5) **empirically tested components** that are collectively linked to the philosophy of life affirmation among patients who have:

- lost hope,
- lost their sense of meaning or purpose, and
- developed the feeling that they no longer matter.[4,5]

This approach as described by Dr Chochinov is now a palliative care strategy for those end-of-life patients who are without hope or sense of meaning.

The most important goal of Intensive Caring is to make such patients feel valued, feel hope, feel that they have good quality of life. In essence, that they matter![4,5]

In other words, ***Intensive Caring focuses on enhancing the Emotional, Psychological, and spiritual support of patients for whom cure is no longer possible.***[4,5]

Importantly, intensive caring now shifts the medical paradigm
from: *examine -> diagnose -> fix*
to*:* a framework emphasizing, enhancing *"Presence; Compassion; Dignity; Affirmation of Intrinsic Worth and Humility!*

IV. Five Key Tenets/Elements of Intensive Caring

Intensive Caring requires us as doctors to find ways to remind patients that they still matter.

A Key foundational element of this approach is Non-Abandonment. This element tells us that we must provide committed, ongoing care, and caring, even when patients no longer care about themselves. It has been shown that a sustained, quality connection between patients and their doctors (tested among oncologists) provides protection against suicidal ideation! In addition, the assurance of continued caring and support is a vital pillar of a strategy that is aiming to facilitate among patients the feeling that they matter.

Another critical component that reassures the sense of Mattering amongst patients occurs when we as doctors take a keen interest in the patient and attempt to find who they are as persons! In other words. taking pains to ask who they are and what they want us to do (instead of the converse) facilitates a feeling among patients that we as doctors are seeing them as whole persons, instead of a diagnosis! We want to know them! And they are not synonymous with their diagnosis. This is profoundly important!

Seeing patients as persons is a way of acknowledging their dignity and personhood! It tells our patients that we can and do appreciate our patients for who they are, what they are, and all they have tried to be. As a result, patients feel more connected to us, they feel respected, and feel as if we have empathy for them, and that we sincerely care about them, and what happens to them in terms of their clinical status.As patients approach the end of life, hope meaning and purpose can be nurtured because of caring and connectedness! By facilitating the sharing of information we may be able to mitigate psychological distress, or make the the end-of-life period more tolerable for patients, and provide families with comfort. We may also, if we try, guide families along a path that allows for connection, comfort, forgiveness, and goodbyes.

The five elements of Intensive Caring are summarized below:

a) **Non-Abandonment:** This means a steadfast commitment to being with the patient, ensuring that they feel supported and never left alone in their suffering. [4,5]
b) **Affirmation and Personhood:** This aspect of intensive caring recognises and engages the patient as a whole human being with a unique life story, instead of focusing solely on a patient's disease. [4,5]
c) **Holding Hope:** Nurturing hope by focusing on achievable goals, meaning, purpose, and peaceful closure. [4,5]
d) **Therapeutic Presence:** Communicating care through a dignity-affirming tone—being compassionate, empathetic, and respectful, sometimes without needing words.[4,5]
e) **Therapeutic Humility:** Accepting that some forms of suffering or physical decline cannot be fixed, focusing instead on comfort and dignity. [4,5]

An infographic describing Intensive Caring has been developed by Dr Chochinov (see figure 1).[4,5] The infographic has also been translated into Urdu by this author (see Figure 2).

It is hoped that both infographics will facilitate the utilisation of the tenets of intensive caring among doctors and their patients facing end of life issues.[4,5]

This approach (Intensive Caring) may also be beneficial for the family, caregivers, and loved ones of patients. [4,5]

As their doctors, their health care professionals, it is ***incumbent on us*** especially as doctors to affirm to every patient that they have intrinsic worth because of:

- all that they are,
- all that they were, and
- all that they will become [4,5]

The infographic describes and defines these points and contains the collective strategy of "Intensive Caring", and its five elements. [4,5]

The five (5) elements of intensive caring

These are listed in the infographic, alongwith specific examples of actions! They provide clear ways for doctors and health care personnel to help patients and their family members and loved ones sadly facing the end of life. [4,5]

The elements and examples of actions denoting each may also provide caregivers, family and loved ones with a way to be with such patients (presence) and to do something tangible to help them by focusing on ways to demonstrate affirmation of life and conversations that convey the Importance of patients who may otherwise have been feeling hopeless. [4,5]

The medical literature supports the inference that patients approaching death are vulnerable and feel that that they *no longer matter, or that they are* a burden to others, or that life and living is now futile. [4,5]

Such patients may also perceive that they are a burden to their family or loved ones. Importantly, they may in turn cause their family members to feel helpless or exhausted and thus tacitly confirm the erroneous message to the patient that they are indeed a burden. [4,5]
The presence of such feelings are consistently reported as indicative of a desire for death or loss of the will to live. [4,5]

In the developed world, an Interest in physician hastened death has also been reported among patients with illness that is incurable. [4,5]

Intensive Caring requires us as physicians to find ways to confirm to patients with life threatening diseases that they matter. [4,5]

In sum, taking **a keen interest in who the patient is as a person affirms their personhood and helps them to feel valued.** [3,4,5]

V. The role of Dignity and the impact of the Patient Dignity Question (PDQ) in Intensive Caring [4,5]

Dignity is a key concept in Intensive Caring and should be assessed! A Patient Dignity Question (PDQ) has been developed and tested by Dr Chochinov and others.

The PDQ states: ***"what do I need to know about you as a person to give you the best care possible,"*** [4,5]

This question is asked by the doctor when taking care of a patient with serious illness or at the end of their lives!

This one question allows a patient to feel that they are indeed being seen as persons, and not as an embodiment of their diagnosis, disease or disability. [4,5]

The patient and the physician then prepare a legacy document that is a record of the patient's life in terms of his past his present and how he wants to be remembered and what he wants to be remembered for. [4,5]

The legacy document has been shown to be of great importance to both patients and their families!

Asking the dignity question should be an expected behaviour when physicians are taking care of or enrolling seriously ill patients at the end of their lives due to serious illness, or due to age. It's role in improving quality of life and decreasing suffering should be explored, alongwith its use as a communication tool between patients families and physicians or healthcare personnel.

VI. Discussion and Conclusion

Patients suffering from serious life threatening, life limiting illnesses face tremendous challenges not the least of which is the knowledge of their impending death. The inexorable passage of time serves as a constant reminder that their life, like the tide, is ebbing away with a frightening certainty.

And it is at such a time that we meet our "end of life" patients! The scope of our challenge is enormous - provide comfort and support, do not offer false hope, but do try to offer something of value, something that is tangible and helpful. something we can help our patient(s) to accomplish, a goal met that helps them to focus on the here and now!

Patients approaching death experience a number of negative outcomes that may include the loss of their sense of self, their innate intrinsic dignity! Thus, focusing on ways to rediscover who they were or who they want to be and how they wish to be remembered through a "legacy document" may be the positive tangible element that helps to lift their spirits and stills the further fracture of their sense of personhood and the hopelessness that comes with that! Intensive caring offers an empirically tested strategy to address and respond to a patient who is suffering.

Intensive Caring is also of great value to us as doctors because it can guide us clinically. Dame Cicely Saunders told us decades ago that it is imperative to tell patients who are suffering with serious illnesses **that they matter!**

At the end of life this is one message that must never be forgotten especially among patients with serious or incurable illness or those at the end of life who are demonstrating feelings of helplessness, loss of hope, depression, or fear, and / or those who feel that life is no longer worth living [4,5]

The 5 elements described and examples of actions denoting each (see figures 1 and 2) may provide doctors, caregivers, family and loved ones with a way to be with patients at the end of life (presence) and to do something tangible to help them by focusing on ways to demonstrate affirmation of life and conversations that convey the

Importance of patients who may otherwise have been feeling hopeless. [4,5]

The medical literature supports the inference that patients approaching death are vulnerable and feel that that they no longer matter, that they are a burden to others, or that life and living is now futile.[4,5]

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In the developed world, an Interest in physician hastened death has also been reported among patients with illness that is incurable. [4,5]

Intensive Caring requires us as physicians to find ways to confirm to patients with life threatening diseases that they matter. [4,5] In sum, taking a keen interest in who the patient is as a person affirms their personhood and helps them to feel valued. [3,4,5]

Intensive Caring is a way for *all* health care professionals to help patients confronting enormous levels of human suffering. [1,2,4,5]

While trying to fix what is intrinsically broken can cause doctors and health professionals feelings of helplessness because they are failing, *Intensive Caring* provides target goals that represent an opportunity to focus on achievable goals, and on the multiple ways to affirm that patients matter. [4,5]

The five individual elements of Intensive Caring are well described in the literature and include presence, compassion, and hope. [4,5]

Personhood and feeling that we matter are the very core of what it is to be human. [4,5]

In the 50 years since Dame Cicely shared her wisdom regarding intensive caring, we, decades later, are at the point where we realise that while medicine may reach *to fix more than it can, there are conditions and diseases and the nature of life itself that preclude the ability of Medicine to fix everything! There is much that cannot be fixed by Medicine! In fact these are the very conditions where the patient himself or herself is the best expert, and that role of patients should be acknowledged! which!* [1,3,4,5]

It is my hope that this paper and the Infographics will facilitate a dialogue between us.

The cultural connotations and contexts surrounding the terms and the approaches mentioned in this paper have not been examined fully. It is my hope that this paper will show us new avenues to pursue and validate and add to our knowledge regarding end of life and palliative care research!

I will be delighted to converse with the readers about this paper and the next steps for research.

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In a globally acclaimed career in research, service and teaching, Dr. Aziz has developed & prioritized International Research agendas in Hormonal Cancers Survivorship Multimorbidity and Palliative Care. She serves as Professor of Survivorship, Post-Doctoral Fellowship Preceptor, and Breast & Gynecological Cancer Faculty at the NIH USA, the largest research and research funding body across the globe!

Dr. Aziz has been Honoured with numerous Merit & Special Acts of Service Awards, the Eminent Scientist International Research Award & the Professor of Survivorship Award in an internationally acclaimed career!

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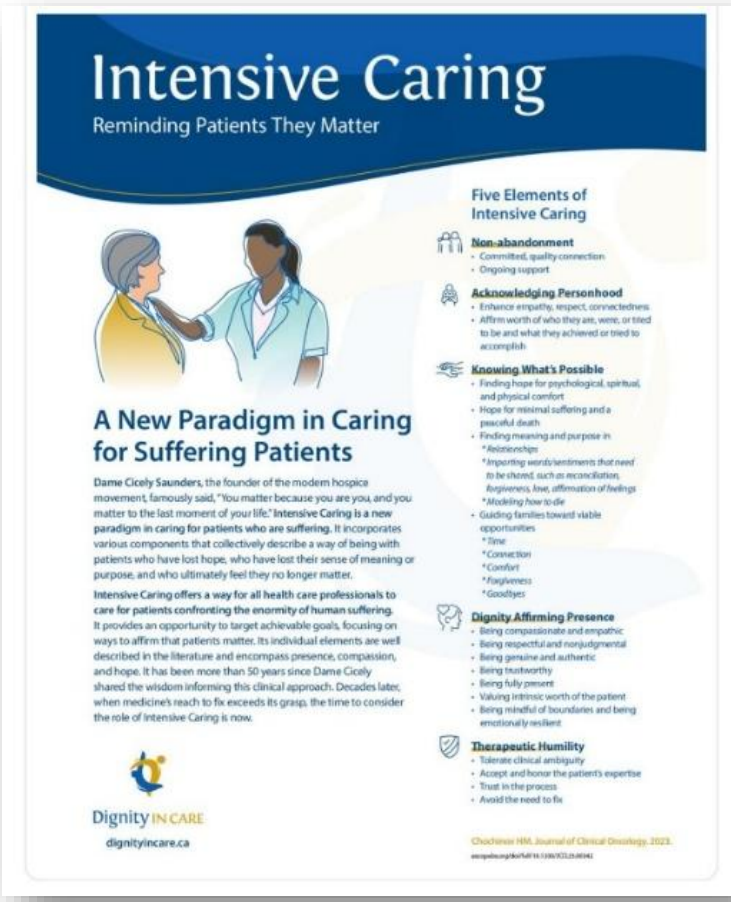

Figure 1: Intensive Caring by Professor HM Chochinov

Figure 2: Infographic translated into Urdu by Prof Noreen M Aziz