Intensive Caring: Reminding Patients They Matter

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Introduction

Dame Cicely Saunders, the founder of the modern hospice movement and palliative care, famously said, *You matter because you are you, and you matter to the last moment of your life.*[1] This quote has become the central philosophical tenet of palliative care. It implores us to remind patients, who may be feeling helpless, hopeless, or worthless, that *they matter*. Even when they feel life is no longer worth living, we, their health care professionals, must affirm their intrinsic worth, for all that they are, all that they were, and all that they will become in the collective memories of those they will eventually leave behind. While Dame Cicely gave us this inspiring direction, missing is a well-articulated approach centered on affirming patients matter. This approach, which I will coin *Intensive Caring*, incorporates various empirically derived components that collectively describe a way of being with patients who have lost hope, who have lost any sense of meaning or purpose, and who ultimately feel they *no longer matter*.

Why It Matters to Matter

There is abundant evidence that patients approaching death are susceptible to feeling they *no longer matter*. Our own research demonstrates that patients approaching death may feel a burden to others[2]; that life is futile, and an affliction to those they feel encumbered by having to look after them. Self-perceived burden is contagious and self-perpetuating; patients who experience it may cause family members to feel helpless and exhausted, tacitly affirming that they are indeed a burden.[3] Feeling a burden has consistently been reported as a driver of desire for death, loss of will to live, and interest in physician-hastened death.[3] From the patient's perspective, death offers a way to relieve the burden they sense they have become, while ending a life they feel *no longer matters*.

I recall one such patient early in my career, who struggled with feelings of futility and hopelessness in the face of end-stage brain cancer. He'd been admitted to an inpatient neuro-oncology ward, where he felt a burden to his health care team and wanted me to help him die. He saw little point in continuing his life, which had been marked by bipolar disorder, polysubstance abuse, and family estrangement; he emphatically felt he no longer mattered. I told him that I could not and would not hasten his death, but was prepared to support him in any way that I could until the very end. We began to meet weekly, occasionally twice a week, while I delved into learning more about who he was, including the origins of his chronic self-loathing. He would often complain about things such as hospital routines, the medical staff—and one day began to berate me and the futility of my efforts to help him. Being young and naïve, I suggested that if our meetings were not helpful, neither of us was under any obligation to continue. He responded as if I had gone mad. "Are you crazy?" he said. "These appointments are the only thing that keep me going!"

Elements of Intensive Caring

Intensive Caring requires finding ways to remind patients that they still matter (Table 1). A foundational element of this approach is **nonabandonment**, which demands committed, ongoing care, and caring, even when patients no longer care about themselves. Dame Cicely wrote "suffering is only intolerable when nobody cares."[1] Absent someone who cares, suffering, like cancer, can grow, spread, and even kill. Studies have shown that when patients feel abandoned and bereft of care, they are more likely to contemplate or to die by suicide.[4] Other studies have reported that a sustained, quality connection between patients and their oncologist provides better protection against suicidal ideation than mental health interventions, including psychotropic medications.[5] Our studies on desire for death in the terminally ill found those who desire death report lower family support relative to those who don't.[6] Hence, the assurance of continued caring and support is a vital component of helping patients feel *they matter*.

Another component of *Intensive Caring* is **taking a keen interest in who the patient is as a person**. Our studies of the Patient Dignity Question (PDQ), which asks "what do I need to know about you as a person to give you the best care possible," helps patients feel they are seen as whole persons, rather than the embodiment of their disease or disability.[7] A recent study of more than 2,000 inpatients and outpatients being seen at a quaternary care cancer center in the

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TABLE 1. Elements of Intensive Caring

Element
Nonabandonment[4-6]
Committed, quality connection
Ongoing support
Taking an interest in the patient as a person[7-9]
Enhance empathy, respect, connectedness
Affirm worth of who they are, were, or tried to be and what they achieved or tried to accomplish
Holding/containing hope[10-15]
Finding hope for psychological, spiritual, and physical comfort
Hope for minimal suffering and a peaceful death
Finding meaning and purpose in
Relationships
Imparting words/sentiments that need to be shared, such as reconciliation, forgiveness, love, affirmation of feelings
Modeling how to die
Guiding families toward viable opportunities[15]
Time
Connection
Comfort
Forgiveness
Goodbyes
Dignity affirming tone of care/Therpeutic Presence[16]
Being compassionate and empathic
Being respectful and nonjudgmental
Being genuine and authentic
Being trustworthy
Being fully present
Valuing intrinsic worth of the patient
Being mindful of boundaries and being emotionally resilient
Therapeutic humility[16]
Tolerate clinical ambiguity
Accept and honor the patient's expertise
Trust in the process
Avoid the need to fix

United States reported that the PDQ can be used as a means of eliciting values among patients with advanced malignancies.[8] Being appreciated in this holistic way helps safeguard patients' dignity. Acknowledging personhood must follow principles of unconditional positive regard, conveying appreciation for who they are, what they are, and all they have tried to be.[9] It also enhances health care professionals' connectedness, respect, and empathy toward patients, establishing that besides the particulars of their clinical status, who they are as a person matters.[7]

When patients feel they *don't matter*, hopelessness is never far afield. Studies consistently show a strong connection between hopelessness and suicidality.[10,11] Our own palliative care research affirms that hopelessness is a strong predictor of desire for death.[10] *Intensive Caring* sees health care professionals hold or contain hope when patients can no longer do so themselves. This means expanding one's therapeutic imagination to include the possibility that patients may find psychological, spiritual, and physical comfort, tolerable suffering, and for those near the end, a peaceful death. Toward end of life, hope tends to conflate with meaning and purpose and may be nurtured through connections to those who, or things that, matter. This may include affirming that all that needs saying has been said or bears repeating. Studies have shown that clinical approaches that facilitate sharing this kind of information mitigate psychological distress, enhance end-of-life experience,[12,13] and provide families comfort.[14] Health care professionals can also guide families along a path marked by opportunities for connection, comfort, forgiveness, and goodbyes.[15]

Patients may also find meaning or take comfort in knowing they are preparing loved ones they will soon leave behind. I recall a young woman with metastatic breast cancer who, in the context of dignity therapy,[12] offered wisdom to help guide her infant daughter into the future, shared reminiscences to help her family sustain the memory of her all too short life, thanked her parents and siblings for the love and support that had shaped who she was as a person, and gave her husband permission to find happiness, including a new partner, as he moved forward into a life without her. These kinds of opportunities extend to the very end of life. As Dame Cicely said, "How people die remains in the memory of those who live on."[1] For some, meaning and purpose may reside in knowing that in their dying, they will have provided a template for how one leaves this precious life.

Intensive Caring requires **a tone of care that is dignity affirming**. We have studied this tone, which we labeled Therapeutic Presence.[16] The latter comprises being compassionate and empathic, being respectful and nonjudgmental, being genuine and authentic, being trustworthy, being fully present, valuing the intrinsic worth of the patient, being mindful of boundaries, and being emotionally resilient. Cumulatively, this tone of care, independent of words or actions, affirms patients' worth, provides the respect they deserve, while affirming they genuinely matter.

The Need for Therapeutic Humility

Intensive Caring requires **therapeutic humility**. The standard medical paradigm—examine, diagnose, and fix—is empowering but within the realm of human suffering, some problems simply defy repair. Therapeutic humility means relinquishing the need to *fix*, along with tolerating clinical ambiguity, accepting and honoring the patient as expert, and trusting in the process.[16] There are cancers that cannot be cured, depressions that resist treatment, and suffering whose intensity seems impenetrable. In those instances, the goal to *fix* can lead to feelings of failure and an inclination to withdraw. Colluding with the patient's hopelessness can find health care professionals

affirming that indeed, all is futile and life itself, inconsequential. Ironically, although this may heighten a sense of mutual understanding and even connectedness, it is a therapeutic dead end, with death the only apparent way to fix patients' suffering. Therapeutic humility sees notions of *fixing* yield to commitment to understand the nature of the patient's suffering, while creating a safe space to bear witness, to validate, and to comfort always. Health care professionals must also appreciate the therapeutic potency of having patients express their suffering, while acknowledging their experience, thus lightening their load and decreasing their sense of isolation.

Tolerating ambiguity is not easy as it means walking a clinical path fraught with uncertainty, in the absence of our usual therapeutic tools aimed at *fixing*. Collegial support can help sustain us through this kind of work. *Intensive Caring* can be especially taxing when caring for those teetering between life and death and applies, whether patients are living with advanced cancers or struggling with conditions where death is not reasonably foreseeable. For many years, I cared for one such woman, whose successful academic career unraveled after cancer surgery left her with chronic pain, leading to intense residual depression. Years of myriad treatments, hospitalizations, and electroconvulsive therapy were unable to help her reclaim the essence of who she once was. When she felt close to the edge, I would remind her that our work together *mattered, that she mattered,* and that I remained committed to seeing her. At times, it seemed our steadfast connection was the only thing keeping her tethered to life. One day, 2 weeks after introducing yet another (this time newly released) antidepressant, she sat down in her chair, turned to me, and declared "the office door is purple." I pointed out that it had always been purple, to which she gleefully replied, "I know, but now I care!" Continued involvement offers the opportunity to sustain patients and sometimes, even the potential for healing.

Conclusion

Intensive Caring, the therapeutic derivative of Dame Cicely "You matter because you are you" provides a way of being with patients who have come to believe their lives are no longer of any consequence. Just as intensive care was designed to address the needs of patients with severe and life-threatening conditions, *Intensive Caring* offers a way for *all* health care professionals to be with patients confronting the enormity of human suffering. While trying to fix what is intrinsically broken can leave health care professionals feeling helpless and like they are failing, *Intensive Caring* provides an opportunity to target achievable goals, focused on myriad ways of affirming that patients matter. Its individual elements are well described in the literature and collectively encompass presence, compassion, and hope. While cross cultural resonance of *Intensive Caring* remains to be seen, the notion of personhood and the need to feel one matters is universal and speaks to the essence of what it is to be human. It has been more than 50 years since Dame Cicely shared the wisdom informing this clinical approach. Decades later, when medicine's reach *to fix* exceeds its grasp, the time to consider the role of *Intensive Caring* is now.[17]

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