Milestone of Palliative Care Facing Our History, Paving the Path to Our Future

CHAPTER 1

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"I think one's feeling waste themselves in words:
they ought all to be distilled into action which bring results."
—Florence Nightingale

Scutari Barracks were near where I went to high school for a few years, on the Asian side of Istanbul… I would be awestricken each time we visited this place. I would try to imagine what a challenge it must have been for a small group of young, foreign women to find themselves there one hundred and one years before I was born. It was not only an imposing building on vast grounds like it was then but it was in a deplorable condition with very poor sanitation and full of men, some sick, wounded and dying. What will and commitment these women must have had to be able to perform the arduous task of improving the living conditions and actually to create a healing environment. One of those women who went to Scutari would eventually lay the foundations of the profession I already knew I was going to pursue…

Florence Nightingale in her "Notes on Nursing" states: "I use the word nursing for want of a better" "… the very elements of nursing are all but unknown"

The name she gave to this knowledge already covers such a broad area. The word that originates from Latin—to nourish. First it was used in 13th century to refer to wet nurses and later in 14th century implying a person who cares for the sick or infirm. In daily usage, it can mean not only to feed/to take nourishment from the breast, but also a licensed health-care professional who practises independently or is supervised by a physician, surgeon, or dentist and who is skilled in promoting and maintaining health, one that looks after, fosters, or advises, to attempt to cure by care, to manage with care, to take charge of and watch over, to hold in one's memory or consideration, to rear and educate. A nurse tree in forestry is a tree that is planted to protect plants. All these definitions seem to be very closely related to what a nurse does, who a nurse is or should be.

Shortly after her return to England in 1860, Florence started the Nightingale School of Nursing at Saint Thomas' Hospital. This is a significant step toward proper education for nurses not merely for the hospital but with the intention to send them in groups to different institutions to undertake nursing reforms.

She continuously emphasized the impact of the environment on the health and well-being of the individual. She believed, controlling the environment would meet a patient's basic needs hence help him to retain his vitality.

Her notes also mention physical, psychological and social environments that can contribute positively or negatively to one's well-being.

Therefore, she is also credited with introducing the holistic aspect of nursing, encouraging the need for the nurse to recognize that a patient is a person who is more than his/her illness. Nurses were expected to build trusting relationships with the patients connecting the four pillars and keeping a balance.

She describes comfort measures, small frequent meals, stimulating environments-colorful flowers, music, reading, needle work, etc.

She emphasizes the importance of communication and warns about "false hope", giving sufficient information to patient and his family regarding the disease, its treatment and prognosis. She also warns against whispering or talking too loudly at the bedside. She mentions the concern for confidentiality as well: "A nurse should be one who is to be depended upon in other words capable of being a confidential nurse."

As it clearly resonates in nurses' pledge, she teaches us to be dedicated to our profession and serve mankind with love and compassion, in kindness respecting her patients' dignity and rights regardless of race, caste, creed, religion and nationality.

She even sent messages to grieving families (bereavement notes…) telling them stories of the last days of the ones they lost.

She talks about the importance of observation as she exemplified by rounding on patient even at night.

Fast forward another 100 years and there comes yet another remarkable woman who is a nurse, a social worker and a doctor.

She tells us to help the patients as they matter a lot to us, they are not dying patients but living persons and our commitment is not only to help them die peacefully but let them live until they die.

She also tells us to put what we already know in a kaleidoscope, give it a shake and see things differently…

Hence comes another wordage to describe what we ought to be doing… To cover the symptoms, we can no longer cure, to protect, to cloak: to palliate. Hospice and Palliative Care movement begins.

Dame Cicely Saunders founded St. Christopher's Hospice in 1967 with the mission to pain and other symptoms, to render compassionate care and for clinical research.

First Hospice in Connecticut, USA opened its doors in 1974.

American Holistic Nurses Association started in 1981. However American Nurses Association (1896) did not recognize holistic nursing as a nursing specialty until 2007.

American Hospice Nurses Association was founded in 1986. In 1997, its name and mission expanded to Hospice and Palliative Care Nurses Association. In 1994, National Certification Exam for Hospice and Palliative Care was launched.

In 2017, ANA and HPNA jointly issued Call for Action encouraging nurses to lead and transfer Palliative Care in Practise, education, administrative roles and in research.

In ancient Ayurvedic texts there are clear principles and guidelines for Nursing. During King Ashok's reign there were mostly male nurses and some elderly women. Due to illiteracy, caste system, political unrest and the lowly state of women nursing made no progress. It was limited to military nursing.

Since the first nurses training for Indian girls at St. Stephen's Hospital in Delhi in 1867 nurse education has come a long way in India. Basic informal trainings and Hospital certificate programs are moving on to degree programs in Nursing Colleges. Today be it government or private, there are numerous institutions offering BSc, Post Basic BSc, MSc and PhD in nursing education. There are even attempts to have Nurse Practitioner programs. There are nurse specialists who prove guides with their wisdom and knowledge as they carve out a much-needed niche for themselves in the system. All of this, is quite a leap from earlier attitudes toward nursing as a profession in India. In 1908, the Trained Nurses Association of India was formed with the objective to uphold the dignity and the honor of nursing profession, to promote the sense of spirit de corps and to enable members to counsel together on matters related to their profession (TNA, 2019). Many other societies are being formed by nurses who practise different disciplines such as ONAI, IANN, SINN, CCNS and recently Society of Cardiac Nurses—India. It is also notable that today there are more male nurses entering the profession. In the 1930s, they were mostly bound to military hospitals. However, having overcome many hurdles and after their recognition in the 1950s, they are employed alongside their female colleagues, synchronizing their practise and contributing tremendously with exemplary skills to the advancement of nursing.

On the Palliative Care front "formal" progress has been extremely slow. First hospice in India—Shanti Avedna—opened in 1986 in Mumbai and two others within five years in Goa and Delhi. This could be partly due to inaction of the Indian Nursing Council. Although Palliative medicine and nursing training started in early 2000, there has been no approval from Nursing Council. National program was declared in 2012 has no standards, no recommendations for nursing besides description of programs available. It is also sad to see that there is hardly ever a mention of hospice nursing. To many people, "Hospice" implies death and dying and seems like there is not much effort to explain that it does not. There are many hospice nurses in the remote tribal areas, in the cities providing home care or working in hospice houses tucked in here and there. They work tirelessly

with passion and commitment to help their patients live full, comfortable lives and assure dignified death.

Most nurses in hospitals are not assigned to one unit only. They may be trained in Palliative Care and doing a wonderful job in a Pain and Palliative OPD but this does not guarantee that they will not be floated to other units. Usually, they are floated to chemo daycare or oncology in patient or other units where patient to nurse ratio is very high. There are safety concerns and there is knowledge deficit regarding chemo mixing and administration as well. They are expected to do an astonishing amount of register recording which can be easily done by a clerk. They barely have time to pass medicine properly. They are also expected to respond to multiple demands from their superiors. The nurses, especially the young, new graduates in most hospitals really do not have any support. Patient care takes a back seat, family is ignored and nurses are distraught. With some, apathy replaces empathy and what they do becomes mechanical, boring and tiring. This is truly heart wrenching scenario which exists from Gujarat to Kolkata, Delhi to Chennai and so many places.

Nurses are usually asked, in some cases are encouraged to attend trainings. Certificates are appreciated and on rare occasions are even recognized and they receive proper increments. However, I cannot help but have an image of a plant getting too much plant food but not enough light or water to flourish. While these unfortunate working conditions do exist in one too many hospitals, there are also institutions where nurses do flourish and accomplish wonderful things. They become leaders, advocates and teachers. They give exemplary nursing care with compassion, and skill, comfort families and patients, do great symptom management and are truly a pillar of interdisciplinary team, changing lives including their own. This is the way it needs to be everywhere on a small or a large scale.

Maybe it is time to seriously consider changing the environment instead of blaming the plants and start doing things differently. It is unfair to expect different results as we do the same things over and over. Sometimes, this only allows mistakes to imbed them themselves deeper in our system instead of allowing healthy, beneficial practises to spread…

Increasing our knowledge through nursing education and professional development is essential to improve patient care. We simply cannot practise what we do not know.

How we teach, learn and follow up is just as important as what we teach and learn. We need to consider involving and also teaching Chief Nursing officers, nursing superintendents and charge nurses.

We also need to be prepared to be solid mentors and liaise with administrations of colleges and hospitals. We need to advocate in every level to change the environment so that what we are planting can grow.

Nurses can be reformers as we have seen with the humble origins of our profession. While an individual nurse can begin by making a meaningful change in the lives of one family, one patient, the nurse leaders can create opportunities to make changes happen. At least they can start by initiating a dialogue, collaboration and eventually creating of solutions or models for the betterment of care systems.

"Palliative Nursing Leadership is a fundamental aspect of health care reform and assurance to quality palliative care. Hospice and palliative nurses are essential to the delivery of palliative care" (HPNA, 2014).

Nursing leadership can be exhibited in all areas of nursing: clinical care, education, research, management and administration, policy making, advocacy and quality assurance.

Our role is to care with empathy as we let it flow while we anticipate what lies ahead for patient and family as we plan for comfort and good quality of life, educate patient and family to prepare for the future. Think ahead to prevent crisis by teaching family about pain and symptom management, treat our patients with nursing ways to increase comfort and decrease suffering. Advocate for our patients by helping them say what they need, and letting the team know about it. Also, by helping the patient and family to get what they need, teach the patient and family how to do care, provide comfort and give medications.

We need to remember the nurses play an important role in improving palliative care. Recognition that quality of life (QOL) is determined by the unique needs of the patient and family assists the nurse in remaining focused on goals of care. Building trust, maintaining a realistic, perspective and flexible approach is essential to meet the changing needs of the patient and family.

And also, that some things cannot be "fixed" (Berry, 2010): Death is inevitable, anguish felt when someone dies, but is not erasable, we all will die, no matter how hard we try, words can rarely address the distress of families, patients. This is why our presence is our unique gift (Borneman & Brown-Saltzman, 2015) to express our compassion and empathy.

Therapeutic presence is a powerful tool as a means of communicating care for the patient and families.

Palliative nursing is not only "doing for," but is also largely "being with" patients and families in a non-judgemental way with total presence.

Langston Hughes once said, "Hold fast to dreams, For if dreams die life is broken-winged bird, that cannot fly."

Today as I see Hospice and Palliative Care Nurses working on founding their very association to give themselves a louder voice, creating NGOs to serve the sick and needy at their home, as I experience with an amazing group of instructors how (ELNEC) (created in 2000) across India is creating wide ripples in Palliative Care education and in nurses' lives, as I work with nurses whose commitment and passion are stronger than any surmountable obstacles as they carry on caring

across settings tirelessly, as I listen to them counsel wisely, with care and tact, as I see them doing their treatments with such tenderness, as I read policies and procedures they are writing, care plans they are initiating, I am humbled to be a mentor and dare to aspire.

Nurses have a tremendous potential and commitment. They need support and room to grow, to spread their wisdom, to refill their hearts.

I dare to hope when nurses are expected to perform duties in acceptable environments, not spend their time with tasks that others can do but spend more time with their patients giving them the gift of their therapeutic presence. I dream for HPNA India joining hands with the Indian Nursing Council to issue a Call for Action for nurses to lead and Transform Palliative Care.

I dare to dream for days when nurses are treated as colleagues, with respect and empathy, there are working care plans for goals of care, there are truly multidisciplinary teams which not only help patients live and die with dignity but also help the families to keep living.

I can imagine brilliant young nurses; female and male teaching others far and wide, working at the bed side with pride not minding their education, meticulously caring for patients, tending to their needs, mentoring with all their heart, truly practicing the art and science of this gift which we gratefully call our profession.

I have humbly tried to highlight in a sketchy way, how the sound nursing values are very much alive and are still guiding the way in all kinds of nursing even after 160 years. This once again brings us to the point I try to make time and time again: no matter what kind of nursing we do, the core values and human skills are the same. Good nursing will always be there to guide the way to fulfilment for patients, families and nurses too. Palliative Care Nursing is simply good, exemplary nursing. It is also about time we really heed to a timely quote by who else?

Further Readings

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