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Short communication

The overwhelming contribution of women to the development and establishment of palliative care as a recognized medical specialty

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Introduction

The first homes that were specifically assigned for institutional care for the dying were initiated in the nineteenth century by religiously and philanthropically inspired women. Because this work was an essential precursor of hospice development in the twentieth century, their place in palliative and hospice history is assured. It served as a massive inspiration to Cicely Saunders' pioneering work in the 1950s and 1960s. The focus of endeavor in most of these homes was on saving lost souls from sin, on caring for the 'deserving poor' and on reaching into deprived communities to offer the glimpse of a better life beyond poverty.1 While attending physicians offered help, support and guidance with the management of distressing symptoms, daily care was traditionally the concern of female nurses, many of whom were in religious orders.

The short review presents a brief salute to these women, who were principal founders of a movement that gained rapid momentum after their death: Jeanne Garnier, who formed L'Association des *Dames du Calvaire* in Lyon, France, in 1842 is the earliest founder so far identified.

Mary Aikenhead of the I*rish Sisters of Charity* opened St. Vincent's Hospital, Dublin, in 1834. Her activities extended to England, where the Sisters developed St. Joseph's Hospice, in the East End of London. This hospice gained an essential place in the narrative of modern palliative care history. Frances Davidson founded the first home for the dying in Britain in 1885.

A Catholic woman, Rose Hawthorne established premises in New York's Lower East Side, where she opened what was purportedly the first home in America for the free care of "incurable and impoverished victims of cancer." Under the title Mother Alphonsa, Hawthorne formed the Dominican Sisters of Hawthorne, and like her contemporaries, she was part of the increasingly common tendency for middle-class women to engage with charitable work among the poor, sick and disadvantaged. Florence Nightingale promoted in the USA what is known today as palliative care [1].

All these distinguished women shared a common purpose in their concern for the care of the dying, and in particular, the dying poor, thereby creating some preconditions for future developments in modern hospice and palliative care which got underway in the decades after World War II [1]. The early hospices and homes associated themselves with three main concerns: religious, philanthropic and moral.

The originator of the contemporary practice of palli-

ative care in the late 1940s was Dame Cicely Saunders, a nurse in London, UK. Later, in the 1960s, Dr. Saunders developed St. Christopher's Hospice in London, which later became the mecca of modern palliative care. It is, therefore, not a coincidence that females worldwide became pivotal persons and palliative care specialists, as female health professionals are known to be concerned with "both the persons and as persons". Specifically, female nurses in the community serve as a natural bridge between patient and physician, who often works in a remote hospital setting.

Dr Anne Merriman is one of the great pioneers of palliative care in Africa and internationally. Anne joined the Medical Missionaries of Mary at age 18 and after graduating from Dublin University, she worked in Nigeria as a young doctor.

After leaving her life as a nun she initially worked in the UK as senior lecturer and head of the Geriatric unit. She introduced Palliative Care models in Singapore whilst working as an associate professor in community medicine. She subsequently moved to work in Hospice Nairobi and then to Uganda with the plan to build a Palliative Care model for Africa.

Hospice Africa was developed with an affordable and culturally acceptable hospice model. Oral morphine became more widely available. She was a founder member of the African Palliative Care Association and has received innumerable international awards including nomination for the Nobel peace prize. Dr. Merriman's motto is: 'Palliative care is a special calling. Of all the work I have done as a doctor, this has brought me the most joy.'

As a genuine successor of the palliative care pioneers, American former First Lady Barbara Bush who died this year at her home in Houston, decided to decline further medical treatment for health problems and instead to focus on "comfort care," which made her a "great woman," advocating for an alternative approach for suffering patients [2].

Discussion

The hard work of hospice and palliative medicine: A glimpse at a few pioneer women

More flexibility is required in these difficult areas. Palliative medicine is an exceptionally hard discipline. Medicine has worn down resilience [3]. Consequently, dedicated strategies are needed to overcome the challenges facing women in clinical medicine and global health professions. Their advancement requires empowerment of women in leadership positions and the establishment of support systems on local, regional and global levels. In this review, 12 prominent professional women from different societies shared their opinions as to how they cope with ongoing challenges and discrimination:

Dr. Samaher Razzaq Fadhil of Iraq offers a personal viewpoint that hard work and academic degrees are the means to assist women's professional progress in the complicated mosaic that characterizes today's Iraq. Conversely, Dr. Nahla Gafer of Sudan offers some intriguingly original insights into how women combat social, economic or professional disadvantages. Essentially, they are forced to become strong and independent and learn how to convert their disadvantages into advantages by thinking out of the box: By looking "at the other side" of the discriminatory situation, they find clever ways to manipulate circumstances to their benefit. For example, if a man with inferior qualifications is appointed to a senior position over a better qualified woman, the latter—unburdened with bureaucratic tasks—will use the extra time at her disposal to pursue her career goals. "They have to work harder and learn skills to overcome these obstacles," says Dr. Gafer.

Specialization in various fields can benefit women professionally. Drs. Azza Adel Hassan and Azar Naveen Saleem of Qatar report that globally 78 percent of the healthcare workforce consists of women, with higher percentages predicted for the future. Their experience is in the realm of palliative care medicine where women predominate. She indicates that women provide a superior level of empathy and better care than men in aiding hospice patients suffering from severe physical and psychological stress. Moreover, female hospice patients prefer to have female staff care for them. Hassan concludes that women have an innate advantage over men in this specialty: "Women are better than men at taking other people's perspectives, feeling their pain and experiencing compassion for them."

Similarly, Prof. Maryam Rassouli of Iran highlights the prominence of women healthcare professionals in the fields of gynecology and midwifery. Interestingly, Iranian governmental policy of limiting these areas of medicine to women has promoted the advancement of highly qualified women within the field. Moreover, Prof. Rassouli feels that the significant 60 percent admission rate of women to Iranian universities in the last three years "can play a significant role in changing men's attitude towards women, their socialization, and the quantity and quality of their presence in society." She suggests that promoting public discussion of "women's role in society and social management," and sociological analysis or "studying the influential factors" for women's success can identify and overcome socio¬cultural challenges.

Prof. Lea Baider of Israel offers pragmatic suggestions that focus primarily on empowerment through education. Stressing the necessity of community acceptance, Baider advocates enhancing the motivation of unskilled women who need psychological boosting by training "women leaders within their society or/and community," while respecting traditional systems of belief

and values. She emphasizes that women in developing societies need basic training such as "electrical skills, computer, mechanics," could join advanced healthcare occupations such as medicine, nursing, dietetics and physiotherapy. Moreover, successful professional women should serve as models in the preventive healthcare and health education fields and also act as "front line advocates" for promoting female health and wellbeing. National and international seminars and workshops must be developed for different educational levels to impart acquisition of new practical skills.

Prof Lily Tang of Beijing, China, criticizes "unjustified inequalities in the workplace," and notes that women in China face more challenges and have fewer opportunities than men, since they still bear most of the burden of childcare and eldercare. Lack of daycare for children under three and earlier retirement typify the problems they face. Judiciary reforms are therefore needed to promote equal status. Prof. Tang not only advocates "practical and psychological support" systems for Chinese women on the community level and in the workplace, but a policy of affirmative action to redress gender discrimination.

Prof. Paz Fernandez-Ortega, from Barcelona, Spain, argues that "Life is a changing pattern for a woman practitioner in health science today, inherent to a career that implies caring for others. For a long time the prevalent view was that doctors and nurses should have total control over their feelings or suppress them, hiding their emotions. This contradictory behavior implies a conflict between one's logic and emotions, but for human beings managing both was always a perennial conflict. In our Mediterranean context, the struggle has historically been linked to cultural, family and social values."

"What does it mean today to take care of others without mixing emotions and logic? Certainly this is a concept that is different for women than for men, not only in those activities related to health, but also in everyday life."

On one hand, women are more sensitive to emotions, so their patient care involves both an "emotional interchange and a readiness to meet their spiritual needs. Part of end-of-life care is the ability to recognize and respond to both physical and emotional needs of patients. Because the educational and health systems do not include these factors in their priorities, doctors and nurses have many conflicts when they have to face these issues in clinical care."

"A combination of a logical mind and of emotional management skills is crucial for facing the challenges of real life. Most end-of-life patients realize the relativity of some issues, and the importance of others. Do not be afraid to use your feelings to take care of patients in a more creative way, and to innovate in your team-work discussions and care plans!"

Dr. Jeannine Brant from Montana, USA, commented on balancing career and family: Balancing a career and family has been a significant challenge for me during my 35 years of nursing and my 27 years of being a parent. It helped to have my career somewhat established before I had kids. The balance has been compounded by my passion for cancer and palliative care and my desire to make a significant contribution."

"But there was always this teeter-totter effect. While I was at work, I desired to be home with my kids, and I felt incredible guilt because I had also chosen to have a career. However, I made some very good decisions early on that allowed me to sustain and excel in both the career and family world. All along, the entire family contributed to the overall functioning and success that we had."

For my 50th birthday, I gathered 10 of my closest friends and showed them some of my work. I remember crying during the presentation, because I did not think they realized my passion and the work I do. I also still had some of that left-over guilt. It was a time of healing for me, as some of their words to me were, "Your kids turned out amazing! Many of our kids are struggling, and yours have stayed the course." So, while the balance was often difficult and exhausting, the reward has been great, and I am truly blessed to live in both worlds.

Prof. Rejin Kebudi from Istanbul, Turkey strongly endorsed Dr. Brant's views concerning the balance between professional career and family life. Already in high school Prof. Kebudi realized her inner desire towards a career whereby she could develop relationships while supporting people. Following her specialization in Pediatric Oncology, she understood the importance of palliative care throughout the trajectory of the malignant disease. "As a wife and mother of two children, I had to balance my academic life and family life." This year Prof. Kebudi was awarded by the American Society of Clinical Oncology (ASCO) the 2018 International Women Who Conquer Cancer (WWCC) prize, and in the award ceremony she thanked all her mentees, most of who were women. Her motto has been: "Females can combine an academic medical career while raising a family, only if they are well-educated, self-confident, well programmed and work very hard." She continues: "In Turkey, we women are fortunate to dominate Pediatrics and Pediatric Oncology".

As far as the interrelationship: Palliative care - Women, Dr. Daniela Respini, a psycho-oncologist from Sicily stated: "Dealing with terminal patients often raises the question: What is the meaning of life if you have to die? It also makes you see life differently. On such occasions you feel that there is something that goes beyond human being, something very strong and intense that accompanies you every moment and gives you inner strength. Dr. Respini continues: "Staying next to the patient and his suffering pushes you to review your own life, makes you deal with your conflicts and makes you think that death is not just an idea but is part of your life."

Dr. Respini added: “Probably my passion for psycho-oncology has been facilitated by my being a woman, as in my daily work I use my maternal protection.” Moreover, “Being a woman has given me an extra step in establishing an empathic relationship with the patient, as time has a different meaning, and for me it is an honor to enter the soul of a patient and read his/her emotions.”

Professor Mary Ann Muckaden from Mumbai, India believes that “Palliative care looks at holistic care of mind-body and spirit; and as a part of close families, especially in Asia, where I come from that is what women do as part of their daily lives. Would that equip us to be good palliative care physicians, nurses and carers from other para-clinical branches to take care of families undergoing multi-dimension suffering? Yes, yes, yes.” Professor Mukaden continues: "Teamwork begins in a family at a very young age to give our best to help others in the family. As a woman, I believe the pivot is the mother; and it is no wonder that there are more women than men in the field of palliative care".

"As a radiation oncologist I could very easily empathize with a feelings of a patient and family, but when there is no more treatment to be offered, they would need to go away devastated. That was when I switched my career to become a palliative care physician. As a multi-specialty team, we are able to do so much in the hospital and at home to help patients and families cope with their grave situation".

"We are as competent as men in education and research, and we are in the process of integration into mainstream medicine – all kudos to women!"

"Economically also, more women stay at home to take care of their family. When children are grown, they make the best volunteers and counsellors for the palliative care team. “Time and money is often of no consequence on the job”. And she concludes: "Personally, as a woman, palliative care has given me an opportunity to grow tremendously as an individual. Our patients and families teach us resilience, and we have much to learn from them, to emulate even in our personal lives. I salute our patients and their caregivers who have made me what I am; a strong and dedicated female palliative care physician".

After taking these varied views into account, we believe that advocating for women's professional development on the micro or community level, whether clinical or scientific, will in turn contribute to broader and beneficial changes worldwide.

Hospice and palliative care female nurses feel that it is a privilege to spend time with the dying, to be allowed into a person’s and a family’s life when they are at their most vulnerable, and when they most need help. Some nurses believe that easing patients into death makes them the closest you can get on earth to the presence of God, while Elisabeth Kübler-Ross’s book “On Death and Dying” brought to public attention the idea of a “good death.” Moreover, women are more adept at figuring out conflicts and rivalries between family members, their unresolved feelings of bitterness, grief and anxiety about how to take care of the patient and what to do. Females for the most part understand better the importance of touching the patient [4].

As societies age, and governments attempt to manage their constrained health budgets by shifting more care into community settings, women will be called upon to provide more palliative care at old age.5 Women worldwide will have to shoulder a significantly heavier caregiving burden as a direct result of their governments’ attempts to move palliative care into the community. How will this disproportionately affect women? [5].

The current situation indicates a significant gender inequality at the heart of palliative care. Literature indicates that the duty of provision of care falls considerably more on women than men. Differences in the construction of gender across countries and cultures have reinforced the power of normative ideals of gender on how people conduct themselves and explain their actions and behavior. All studies show that women were more likely to be carers than men.

Further research should take into account that gender is a malleable product of particular sociocultural contexts and influenced heavily by the distribution of power within societies. Other identity-shaping factors, such as age, ethnicity and class can modify normative conceptions of gender [5].

This review shows how women mainly shoulder caregiving responsibilities. Further, it outlines the importance of health professionals developing gender-sensitive strategies. For that reason, there is a need for more gender analysis in palliative care literature.

Palliative care, although extremely important to the care of sick patients, and which has for decades struggled for recognition as a medical specialty, gained an additional great supporter in Barbara Bush. Bush possessed courage, vision, charisma and humanity. She told the world she was opting for “comfort care,” or relief of suffering, which in many places, and for many physicians, is not considered medical therapy. Bush’s aim was not to prevent her death, but to enable her to live her life fully until death arrived. Like her great female predecessors, Bush’s decision, revelation and acts strengthened the notion that palliative care should be available on demand for the millions who struggle without it. With that, Bush joined the Hall of Fame of palliative care’s most distinguished persons, by offering hope of relief from anguish to suffering patients [2].

Medical careers are hard on women. Gifted physicians are forced to choose between family and career, because the system is not designed to accommodate both.

The system is damaging for both genders, and exists in part because the current family structure is built on one parent spending more time at home, to enable excessive work hours and expectations for their partner.

Summary

Hospice and palliative medicine seem much more balanced than oncology. Thus, women in palliative care have a better shot at changing the culture, because the specialty is new. Women have a unique opportunity to negotiate and define these roles as they become part of the fabric of healthcare. Women here may be a beacon of hope that can become a model for other outdated specialities [3].

Young women such as Lucy Watts (14 years old) from the UK and Huyaam Samuels (19 years old) from South Africa have tirelessly advocated for hospice and palliative care for all who need it. Both owe their lives, quality of life and success to the support of palliative care. Huyaam, who is also a founding member of Palliative Care Voices, declares: "Through Palliative Care Voices, we aim to address needless suffering by empowering ourselves to raise our own voices to demand quality palliative care for all." And, "as a palliative care recipient, I know from experience the struggle of the failure to recognize the importance of palliative care myself in my country. It took years for a doctor to believe how much pain I was in daily, how I needed my lifestyle adapted, and most importantly that I needed palliative care" [6].

Conflicts of Interest

The authors state no conflict of interest.

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