ORIGINAL RESEARCH

The practice of palliative care clinical nurse specialists in the care of cancer patients in the State of Qatar

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ABSTRACT

Background and objective: There is an annual increase in the number of metastatic advanced cancer patients who require palliative care; this is paralleled by the necessary increase in the workload of palliative care Clinical Nurse Specialist (CNS). Palliative care CNSs are crucial members in the palliative care multidisciplinary team. The aim of this paper is to describe the role of clinical nurse specialists by clarifying the ambiguity of their responsibilities in advanced cancer patients' care in the state of Qatar.

Methods: Data used in this descriptive study were extracted from a shared Excel data registry system that has been created by palliative care CNSs. Data were retrieved from the 1st of January 2021 till the 31st of December 2021 and translated into numbers and percentages.

Results: A total of 3,571 patients' encounters were captured starting from the 1st of January 2021 till the 31st of December 2021. National Center for Cancer Care and Research (NCCCR) inpatient's encounters (33%), followed by telephone consultations (32%) were the highest two approaches to palliative care services delivered by CNSs. Pain and non-pain symptoms management, early introduction to palliative care, patient and family education and support, end-of-life care, and coordination of care with other health care professionals are few examples of the other services offered by palliative care CNSs for cancer patients at Hamad Medical Corporation (HMC).

Conclusions: Palliative care CNSs' roles are multidimensional and highly needed. Some of their clinical activities are unnoticed, especially due to the high number of patients' encounters and the different geographic locations at HMC that CNSs cover. Future research is highly needed to describe the role of palliative care CNSs in areas, such as research, education, and leadership.

Key Words: Clinical Nurse Specialist, Palliative Care, Role, Clinical Practice, Advanced Cancer

1. INTRODUCTION

Cancer is one of the most leading causes of death globally. In Qatar, there were 1,482 new cancer cases and 704 cancer-related deaths in the year 2020.[1] The number of new cancer cases is increasing yearly in Qatar; therefore, a National Cancer Program (NCP) was launched by the Ministry of Public Health in May 2011 through the National Health System (NHS). The program included recommendations to establish the NCCCR as part of HMC, to improve the experience of cancer patients through active and holistic approaches. The program was taken forward by establishing the supportive and palliative care unit that aims to improve the quality of life of patients and their families by managing pain and non-pain cancer-related symptoms during all stages of disease treatment including survivorship and end-of-life care.[2] This palliative care unit involves a highly specialized team of palliative care physicians, clinical nurse specialists, nurses, psychologists, physiotherapists, occupational therapists, social workers, dietitians, spiritual advisors, and clinical pharmacists. This multidisciplinary team is committed to manage

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cancer pain and other cancer related-symptoms as well as to provide psychological, social, and spiritual support for cancer patients and their families/caregivers.[2]

To ensure excellent quality of care and outcomes for those patients, the National Cancer Strategy introduced a new nursing role within the cancer and palliative care Multidisciplinary Team (MDT). The clinical nurse specialist, which is an advanced nursing specialty in palliative and cancer care. A clinical Nurse Specialist (CNS) is an advanced registered nurse with master or doctorate graduate preparation to function as a clinical expert with a special population.[3] A CNS acts as a change agent, who certainly influences patient care and enhances the health care system through several domains including seven core competencies: direct clinical practice, expert coaching and advice, consultation, research skills, clinical and professional leadership, collaboration, and ethical decision-making.[4]

The CNSs incorporate specialized evidence-based nursing knowledge in patient care to ensure optimal and effective health care plan as well as to meet the needs and expectations of cancer patients and their families. The role of palliative care CNS is complex and varying aiming to improve the quality of care of patients and their families or caregivers. The CNS attains different palliative care needs for patients and their families, such as pain and non-pain symptoms management, end-of-life care, and emotional and psychological support.[5]

In 2012, expert CNSs were recruited initially from abroad then, in 2015 due to the evolution of nursing career and for sustainability purposes in Qatar, HMC partnered with University of Calgary in Qatar to launch master's in nursing program to equip local registered nurses with higher degree of education and prepare them for the role of clinical nurse specialist in cancer and palliative care.

1.1 Current Practice of Palliative Care CNSs in Qatar

Due to the expansion of the palliative care service, as well as the concept of early integration of palliative care in the management of patients with advanced cancer, a total of 3 palliative Care CNSs are currently working in the service with patients, their families, and caregivers to maintain the delivery of high quality of care and ensure continuity of care in NCCCR and the other 14 facilities under HMC as well as in the community.

Palliative care CNSs receive referrals from physicians, nurses, oncology CNSs, and other allied health care providers. The palliative care CNSs review referrals and triage them based on the patient's symptoms and palliative care needs. The complexity of patients with advanced cancer require frequent and close monitoring and follow-up to minimize patient/caregiver suffering and ensure continuity of care. The following chart presents the palliative care CNSs' clinical workflow (see Figure 1).

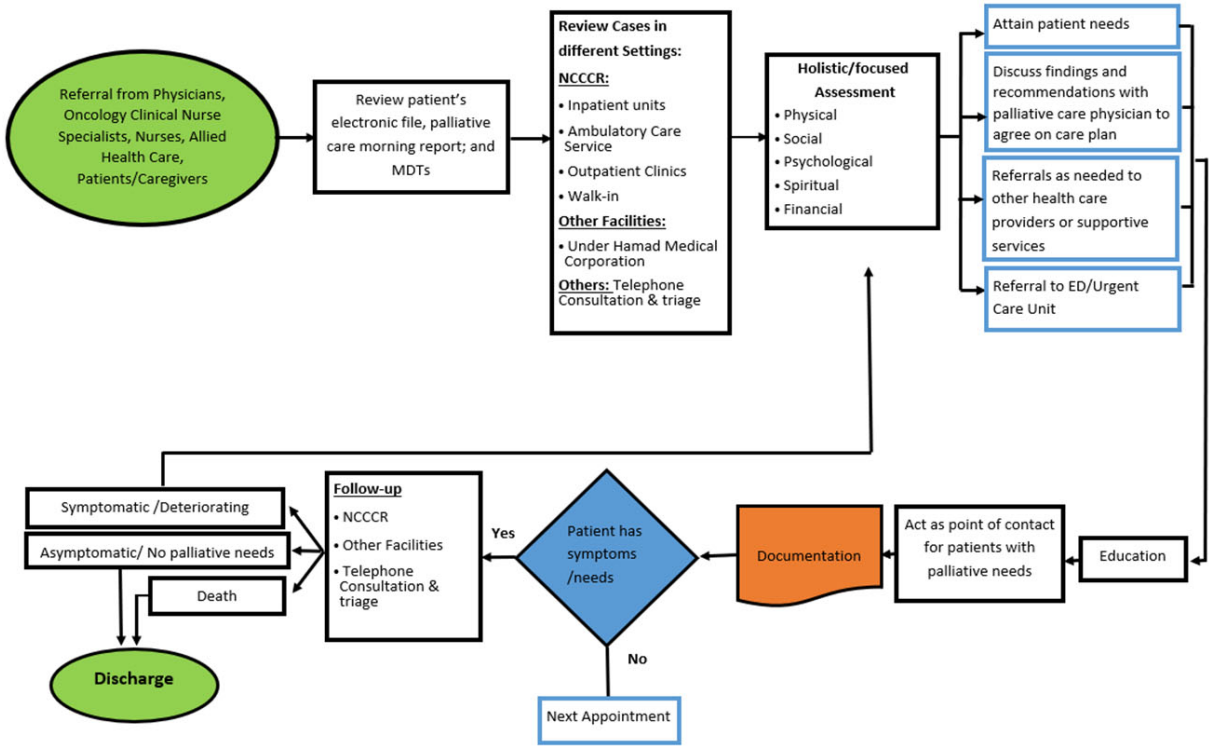

Figure 1. Palliative care clinical nurse specialists' workflow

Although the role of CNS in Qatar is integrated into the oncology service since 2011, there is a lack of clarity associated with their roles and responsibilities. This issue is in accordance with most of the literature concerning the ambiguity of the CNS profession among health care professionals. CNSs work as members of a multidisciplinary team, but their roles remain poorly recognized and difficult to articulate worldwide.[6,7] Role ambiguity and differences in role expectations increase the challenge of full integration of CNSs in the healthcare system.[8] To help in understanding the impact of CNSs role, this article aims to describe the palliative care CNSs' clinical domain in advanced cancer patients' care in the state of Qatar.

2. Methodology

This paper is a descriptive report describing the role of palliative care CNSs in clinical settings. Data used was extracted from a shared excel data registry system; which was created by palliative care CNSs. Each CNS entered data of different clinical tasks and types of care provided for palliative care patients. For instance, those included documented reasons for referring a patient to the palliative care CNS, type and level of CNS intervention, and many other important elements. For the purpose of this report, data from January first, 2021 to 31st December 2021 were extracted from the Excel sheet of the registry form. Retrieved data were summarized into numbers and percentages for a better presentation of the role of palliative care CNSs.

3. Results

The results of this study showed that the palliative care CNSs are performing holistic assessments and involving patients and their families comprehensive care plans for effective palliative care. The CNSs were also providing several interventions according to patients' needs, such as pain and non-pain symptoms management, end-of-life care, health education, and psychological and emotional support. The CNSs ensured continuity of care for palliative patients by referring them to the needed allied health care providers. They also coordinated care among the MDT. During 2021 palliative care CNSs had 3571 patient encounters. The huge number of follow-up patients represent each encounter with CNS to meet patients' palliative care needs. It is also important to report that palliative care CNSs provided care for 502 new patients with variable palliative care needs during 2021.

A unique feature of palliative care CNSs services is the ability to provide patients' care and meet their needs in various hospital settings and through different approaches (see Figure 2). The palliative care CNSs provided care for 2350 patients encounters at NCCCR, (33%) in inpatient wards, short stay unit, day care unit, and urgent care as well as (29%) in the outpatient clinics. Telephone consultations ranked the second highest approach (32%) in attaining palliative care needs.

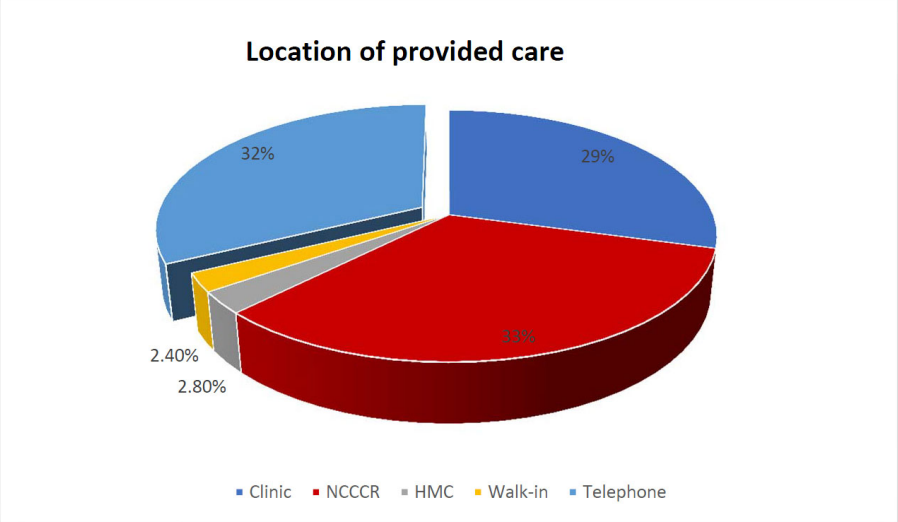

Figure 2. Location of provided care and telephone consultations

The high number of patients' encounters in the year 2021 confirms the need for the role of palliative care CNSs. One of the important roles of palliative care CNSs in this descriptive study is the initial assessment of palliative care consultations received from locations at NCCCR or other HMC facilities. The goals include an early introduction to palliative care, addressing pain and non-pain symptoms, as well as managing the psychological, social, and spiritual care needs of these patients. Also, comprehensive management of end-of-life care and other reasons for referral as shown in Table 1. It

is worth noting that the management of pain and non-pain symptoms were the two most common reasons for palliative care CNSs involvement. Introduction to palliative care was the reason for referral in 121 patients, while end-of-life care was requested for 40 patients.

Figure 3 shows that palliative care CNSs coordinated care for cancer patients in 679 encounters to attain their palliative needs. They were also involved in several other patients' encounters (e.g. 692 were referred to other healthcare professionals for assuring continuity of care).

Table 2 shows the variable levels of palliative care CNSs' intervention. Levels 2 and 3 represented 86% of the palliative care CNSs interventions.

Table 1. Reasons for palliative care CNSs involvement

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec
Introduction to palliative program	9	12	7	7	5	6	7	17	17	16	8	10
Pain Management	113	138	106	101	63	79	53	90	89	105	79	115
Symptom Management	101	93	122	121	107	83	59	139	134	114	73	135
Education	6	13	7	17	8	5	15	19	14	8	18	15
Support	5	8	7	26	13	28	2	9	15	11	17	18
Palliative take over	4	6	5	1	0	8	1	3	12	3	13	7
End of life care	6	10	1	4	0	2	0	4	9	2	0	2

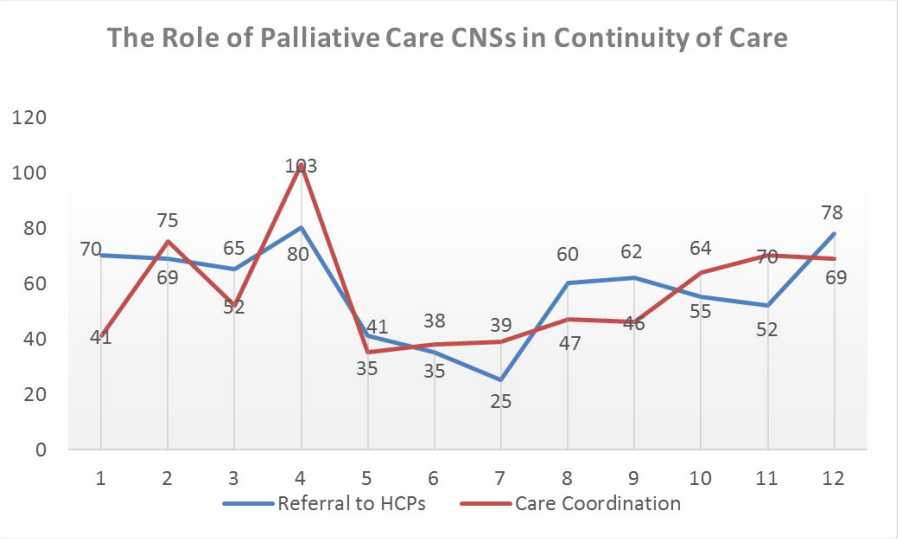

Figure 3. Role of palliative care CNSs in continuity of care

Table 2. Palliative care CNSs level of intervention

	Total	%
Level 1 = Advanced and Support- for Staff - No contact with patient	215	9
Level 2 = Single contact with patient for specific problem	1242	50
Level 3 = Short term involvement for multiple problems	889	36
Level 4 = On-Going support for complex issues	110	4.40

4. Discussion

The findings of this paper describe the role of palliative care CNSs in the management of cancer patients. The high number of patient encounters in these twelve months clarify the workload of the palliative care CNSs and their contribution to clinical responsibilities and roles in the MDT. This is in agreement with Fallon, Cassidy, and Doody (2018)[9] regarding the variety of responsibilities of oncology CNSs. Most

of CNSs who participated in this study described themselves as being "pulled in all directions" and "jack of-all-trades."

4.1 Location and Approaches of Palliative Care

The palliative care CNSs provide care to inpatient wards, and ambulatory care units including urgent care and emergency department, day care unit, and walk-in patients. In addition to direct care, telephone consultation is an important approach that palliative care CNSs often use because it is convenient for patients, especially during the period of the Covid-19 pandemic. It is also important to report that telephone consultation plays a significant role in reducing the number of walk-in patients, who constitute an unseen overload. The high rate of telephone consultations represents the wide range of using this approach. For instance, this approach resulted in patient assessment, coaching, and psychological and social support which lead to patient and family satisfaction. A prospective study was conducted in the UK by Warren, Mackie, and Leary (2012),[10] addressing the role of CNSs using telephone consultations to manage the variable needs of 229 patients and caregivers for a month. Incoming calls resulted in the delivery of 1282 interventions and accounted for 30% of the total working time of the CNS. Another study evaluated the effectiveness of this approach in meeting the psychosocial needs of ovarian cancer patients.[11] They reported that the study participants met their needs and had significant improvement (p = .016) in psychosocial well-being and reduction in emotional problems without having to come to the hospital.

4.2 The Role of Palliative Care CNS in Patient Care

The palliative care CNSs in NCCCR focus on the early integration of palliative care services, particularly for metastatic cancer patients. The CNSs introduce the program, its services, and CNS role. A comparison study by Temel et al. (2010)[12] showed that the patients who were early introduced to palliative care had significantly higher scores in quality of life and mood outcomes than did those who were only on standard cancer care. Palliative care CNSs act as a point of contact to ensure continuity of care and facilitate access to the palliative care program following the national cancer framework 2017-2022.[13] Palliative care CNSs receive referrals for variable reasons as the palliative care team aims to promote the highest quality of life for patients and help in relieving pain and non-pain symptoms management. This renders the crucial role of these CNSs in delivering optimal palliative care services. Palliative care CNSs also focus on holistic approach of management and patient-centered care to meet the patient and caregiver needs. They attend and hold family conferences to promote understanding of the underlying disease process and the expected future course of their patients' illness and the transition from active cancer treatment to palliative care. When the patient is actively dying, CNSs assist the patient's families in preparing for and managing end-of-life issues and maximizing comfort measures. Literature supports the need for palliative care CNS as part of patient care. In a mixed study by Connolly and colleagues in 2021,[14] the health care professionals who participated, viewed palliative care CNS's role as a role that focuses primarily in end-of-life care and symptom management. It has been reported also that cancer patients who had CNS involvement experienced decrease in the intensity of their symptoms including pain, fatigue, and anxiety, as well as increase in health-related quality of life, and other outcomes, compared to patients who had no CNS involvement.[15]

Palliative care CNSs are core members of the palliative care MDT weekly meeting. Their role is to update and discuss patients' conditions, advocate for patient and family needs, and fulfill their wishes by focusing on patient and family-centered care approaches. In addition to palliative care MDT, palliative care CNSs are active members in other oncology MDTs to identify and support patients who may benefit from palliative care services, such as thoracic and breast MDTs.

Palliative care outpatient service includes five clinics per week for new, and follow-up patients. Three clinics are joint clinics run by a palliative care physician and a palliative care CNS. In addition to those three clinics, when patients or families contact the CNSs for a particular concern or medication refill, the CNSs conduct telephone triage, review the patient's file, discuss findings and recommendations with the palliative care physician, and add the patient to two full day refill clinics.

Palliative care CNSs build a therapeutic relationship with patients and their families and use advanced communication skills to identify their preferences and expectations. Palliative care CNSs perform sensitive communication with emotionally distressed patients and families about end-of-life issues and transfer from the anticancer treatment phase to total palliative care. They also deliver education regarding disease progression and its related symptoms. Given all the above roles, palliative care CNSs spend a considerable amount of quality time covering all aspects of patient and caregiver needs. In this report, the rates of education and support elements do not reflect the duration needed to deliver these elements, as well as the challenges encountered, and the high quality of care delivered. An integrative literature review by Kerr and colleagues (2021)[15] found that providing psychological support for cancer patients was a key component of the CNS role. They reported CNS went through challenging communication when providing emo-

tional support and reassurance for cancer patients, and their families. They also found that families and caregivers who had a holistic and supportive approach from CNSs had less burden with their concerns.

4.3 CNS Work Liaison and Continuity of Care

Besides their direct clinical interventions, palliative care CNSs are the key workers and first-line professionals who effectively communicate and collaborate with multiple health care professionals across primary, secondary, and tertiary care settings as well as other private and charitable organizations to improve patients' satisfaction and care outcomes in order to prevent readmissions and emergency visits. Furthermore, palliative care CNSs facilitate hospital admissions to acute services and communicate and coordinate with the palliative care team patients' plan of care. This facilitates smooth patient access to different health care services not only in NCCCR but also across all HMC facilities; thereby, navigating the health care system and improving patients' experience during their disease trajectory. Palliative care CNSs act as champions for continuity of care and ensure a smooth transition from cancer treatment to palliative and supportive care. The CNS role in cancer care was reported in an integrative literature review by Kerr and colleagues (2021)[15] as making a positive impact on improving service delivery. This was significant in the continuity of care, increased access to health care services, and timely delivery of services; resulting in improved cancer patients' experiences. The authors also reported that CNSs use their advanced skills to accurately assess their patients and timely refer them to the appropriate relevant services.

4.4 Level of Palliative Care CNSs Interventions

While palliative care CNSs achieve patients' demands, they provide clinical interventions with different levels. The patients' needs are addressed based on the complexity (see Table 2). In most encounters, palliative care CNSs ensure meeting patients' needs within the appropriate level of intervention. However, there are times when the CNSs provide the needed care without direct contact with the patients or their families. For example, they review critical laboratory values or imaging results and discuss findings and recommendations with appropriate health care professionals accordingly. There are also cases where patients need and different approaches to meet their complex palliative needs. Literature supports the fact that interventions delivered by CNSs are complex, consist of several interacting components, and are sensitive to contextual conditions, which makes their role in evaluation challenging.[16] For instance, palliative care CNSs deliver several levels of interventions, that involve telephone consultations, provision of recommendations to other health care providers, and monitoring changes in patients' conditions such as signs of deterioration, thus providing a patient centered-care approach.[16]

4.5 Limitation

The palliative care CNSs were able through this paper to describe their clinical activities and workload. Nonetheless, they found some limitations that necessitate further development for better outcomes of CNSs practice auditing. One significant limitation is the inability to measure CNSs workload when there are several interventions for the same patient which requires also multiple follow-ups and interventions on the same day. Another limitation is that these data did not measure the duration that has been spent in each intervention, such as providing emotional support and education. In addition, palliative care CNSs experienced some challenges in complete manually data entry for their practice because of their workload with multiple tasks and high patient numbers on daily basis. Therefore, the data is not reflecting the actual number of patients that have been cared for by the palliative care CNSs. It is important also to report that this paper does not represent other domains of the palliative care CNS's role, such as leadership engagements, staff educational activities, and research and quality improvement initiatives. These are other aspects of palliative care CNSs' competency that require and consume time, and are as important as clinical responsibilities. In short, these limitations suggest future reports that would comprehensively describe the actual role of palliative care CNSs in the overall care of patients with advanced cancer in the state of Qatar.

5. Conclusion

The role of Palliative Care CNSs is an innovative and unique one to enhance patients' and families' care in Qatar. Palliative care CNSs' roles are multidimensional and diverse in nature, those involve combination of direct and indirect patient care to support complex cases throughout their disease trajectory. This paper provides a solid platform on the impact of palliative care CNSs and their role in supporting the palliative and supportive care program at HMC. It also emphasizes their role as a key member of the multidisciplinary palliative care team. To the best of our knowledge, this is the first paper that describes the role of palliative care CNSs in the state of Qatar. This paper captures only a brief description of palliative care CNSs' role in the clinical domain only. Future research is required to explore the palliative care CNSs contribution to leadership, education, research, and consultation domains.

Conflicts of Interest Disclosure

The authors declare that there is no conflict of interest.

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