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Retrospective Study

Experiences and Challenges of a New Palliative Care Service in the United Arab Emirates

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ABSTRACT

Introduction
Palliative care as a medical subspecialty in the United Arab Emirates (UAE) is very much in its formative stage of development. There are a small number of healthcare facilities that provide a specialist palliative care service, the most recent of which is the Palliative and Supportive Care Service at Burjeel Medical City (BMC), a private hospital in Abu Dhabi.

Aim
This retrospective review of all the referrals to our palliative and supportive care service within the first 9-months of operation is a direct reflection of the challenges we currently face in the day-to-day delivery of palliative care in the UAE.

Result
Of a total of 360 referrals received during the study period, under 50% were for local, Emirati patients with international expatriates making up the rest. Most of the referrals received were for symptom control (including pain) and end-of-life care (EoLC), with 85% of the patients having a diagnosis of cancer. One third of the referrals received were for EoLC, with 90% of the patients who received EoLC on a hospital ward having a valid do not attempt resuscitation (DNAR) status in place. For the patients who received EoLC, all but one patient received EoLC in the hospital setting.

Conclusion
Our experiences are consistent with the challenges that other colleagues in the Middle East and North Africa (MENA) region face in providing palliative care. The majority of referrals to the palliative and supportive care service were for patients with a diagnosis of cancer with only 15% reflecting a non-cancer diagnosis. Of the 150 decedents cared for during this study period, more than 75% had a valid DNAR status in effect suggesting a growing awareness and acceptance of a less medicalized EoLC period.

Keywords
Palliative care in the UAE; End-of-life care; Burjeel Medical City (BMC); United Arab Emirates.

INTRODUCTION

As a medical specialty, palliative care within the United Arab Emirates (UAE) is still very much in its formative stages. There are unique challenges associated with the provision of palliative care services within the Middle East region and the desperate need for more coordinated palliative care services was highlighted as far back as 2018.[1] Palliative care services have traditionally been restricted to larger hospitals with an oncology program, typically with a single-handed palliative care-trained physician, as has been the case with The Tawam Hospital in Al Ain, Abu Dhabi, and The American Hospital in Dubai. There are now a growing number of hospitals within the UAE that provide some degree of palliative care service (Figure 1).

The most recent of these is the new palliative and supportive care service at Burjeel Medical City (BMC) in Abu Dhabi. A BMC, a private hospital within the VPS Healthcare ecosystem,

was designed to be a tertiary and quaternary treatment hub with a specific focus on oncology, long-term care (LTC), rehabilitation, and palliative care. The palliative and supportive care service was initiated in May 2020, just after the UAE entered a period of lockdown due to the coronavirus disease (COVID) pandemic and became the first palliative care service in Abu Dhabi city. The palliative and supportive care team is made up of a palliative care consultant, a dedicated palliative care nurse and a General Practitioner covering the inpatient unit. Patients are seen in all clinical settings from the outpatient clinic, Emergency Department (EM), ward consults and in-patient care for both symptom control and end-of-life care (EoLC) in our dedicated 18-bed ward. Our team has a very close working relationships with the oncology team, with the majority of oncology inpatients receiving a palliative care review early on in their admission. We also have access to the full range of supportive services including physiotherapy, occupational therapy, dieticians, massage therapists, interventional pain, rehabilitation and psychology. The BMC is unique in that it is the first medical center within the UAE to achieve European Society for Medical Oncology (ESMO) accreditation as a Center for Integrated Oncology and Palliative Care.[3]

At present, there is no national level palliative care strategy or clinical data available, and in presenting this account of our experience of our new palliative care service, we believe this to be the first publication of palliative care data within the UAE. These experiences are a direct reflection of the challenges we currently face in the day-to-day delivery of palliative care in the UAE.

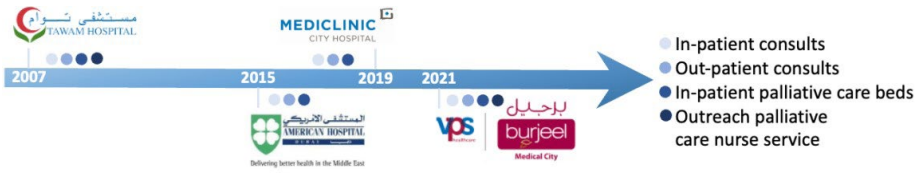
METHODOLOGY

This was a retrospective review of the medical records of all patients referred to the palliative and supportive care service at BMC, Abu Dhabi from 20th May till 31st May 2022. Demographic data collected included age, sex, nationality, diagnosis, reason for referral, date of initial review and date of death. For the patients that died, we looked at the time from initial review to death, place of death (ward or Intensive Care Unit (ICU)) and whether there was a valid do not attempt resuscitation (DNAR) status in place at the time of death.

RESULTS

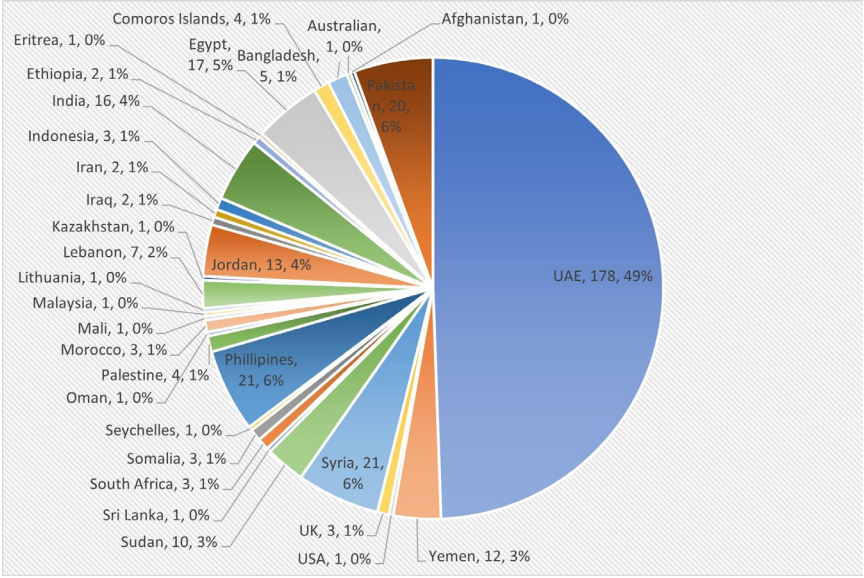
A total of 360 referrals were received from 20th May till 31st May 2022, inclusive. 184 (51.1%) were female, 176 (48.8%) were male with the average age of male patients being 58.33 and 58.43 for female patients. There were four referrals for patients aged 18 and under and all had a diagnosis of an advanced stage malignancy. As expected with the predominantly expatriate population in the UAE, our patients span 32 nationalities (Figure 2), with Emirati patients comprising 49.4% of the referrals, The Philippines (5.8%), Syria (5.8%), Pakistan (5.5%), Egypt (4.7%), India (4.4%).

Figure 1. *UAE Palliative Care Landscape Timeline*



Source. Nijhawan[2]

Figure 2. *Nationalities of Patients Referred to the Palliative and Supportive Care Service at Burjeel Medical City*



The majority of referrals were internal (within the VPS healthcare ecosystem) 250 (66.7%), 113 (31.4%) were external and 7 (1.94%) self-referred.

Most of the referred patients, 305 (85%) had a diagnosis of cancer with 55 (15%) having a non-cancer diagnosis. The breakdown of cancer diagnoses is given in Figure 3, with upper gastrointestinal (GI) and colorectal cancers the most frequent.

The most common reasons for referral to the palliative care service were for pain control (35.3%), EoLC (29.7%) and symptom control other than pain (24.7%). This is represented graphically in Figure 4.

Of the 360 referrals received, just over 40% (150) died during the study period. All but one patient (died at home) received EoLC in the hospital setting. Because these referrals include patients initially seen in the outpatient clinic, those seen *via* in-patient consult and those admitted to the hospital for inpatient palliative care, the time from initial review to death varied dramatically, with the shortest being less than a day and the longest, 433-days. The average time to death was 49.8-days and the median time to death 21-days.

For the patients that died in hospital; 101 (67.3%) died on the ward, 37 (24.7%) died on the intensive care unit with the data being incomplete for 12 patients (includes patients lost to follow up, those who sought treatment at other hospitals or abroad). Of the 150 decedents, 114 (76%) had a DNAR in place, 33 (22%) had no DNAR, 3 (2%) had nothing recorded. For the patients that died on the ICU, 17 (45.9%) had a valid DNAR compared with 91 (90%) for patients who died on the wards. Of the 64 decedents of UAE nationality, 42 (65.6%) agreed to a DNAR while 21 (32.8%) did not.

DISCUSSION

The UAE demographic is unique,with almost 90% of the population comprising working-age expatriates (and their families)from around the world.[4] This diversity is reflected in our patient group, with 32 nationalities represented with the highest proportions of expatriates coming from the Philippines, Syria, Pakistan and India. Emirati patients comprised the largest demographic cohort and this may be accounted for by the fact that BMC is the only facility in the city of Abu Dhabi one of only two facilities providing a comprehensive inpatient palliative care service within the Emirate of Abu Dhabi, the other facility being at Tawam Hospital, some 125 km away.

Over two thirds of the referrals to the service were generated internally from within the VPS healthcare ecosystem. Although most referrals (85%) were for patients with a diagnosis of cancer, we received direct referrals from the oncology team, internal medicine, LTC, surgery, emergency medicine and the intensive care unit. The 15% of referrals for patients with non-cancer diagnosis included patients with chronic, non-malignant pain – reflecting the changing paradigm that palliative care is based on the patient's need not just the diagnosis.[5] More pertinently, it provides supporting evidence that there is a need for the palliative care service and that it can be financially viable with patients reviewed in clinic, admitted for symptom control and/or EoLC.

Symptom control (including pain) and EoLC were the commonest reasons for referring to the service, mirroring trends seen by hospital palliative care teams in Europe and Japan.[6] Just over two-thirds of the patients that died in hospital died on the ward compared with one third dying on the ICU. Those who died on the ward were twice as likely to have a DNAR status (90%) as compared with those patients who died in the ICU (45.9%). This reflects the prevalent cultural norms that even in the context of a patient in the terminal stage of their illness (1) prolongation of life is essential and (2) that it is important to 'try everything', including CPR, ICU and mechanical ventilation, even if felt to be clinically futile.[7] There was significant variability in patient/family perception about what aspects of medical treatment were felt to be consistent with their spiritual beliefs and the lack of formal spiritual

Figure 3. *Number of Referrals by Cancer Subtype*

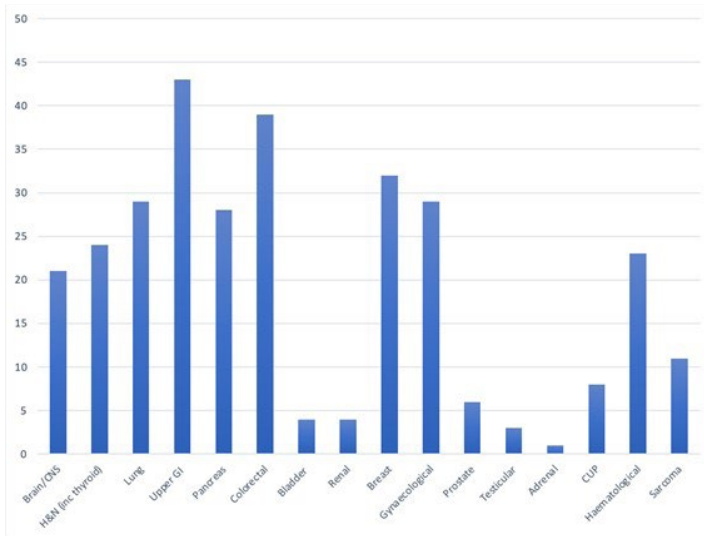
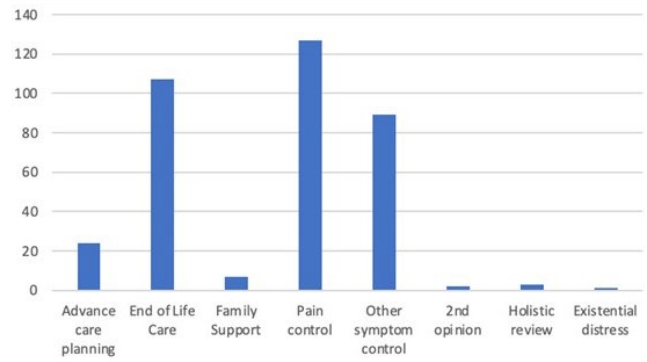


Figure 4. *Reasons for Referrals*



care/chaplaincy support was highlighted on numerous occasions. With approximately one-third of the referrals received for EoLC, we had significant concerns about how our patients/families would respond to a gentler, less interventionist approach (i.e., avoiding escalation to ICU and cardiopulmonary resuscitation (CPR)). Although the UAE has had an allow natural death (AND) law since 2016,[8] which permits medical staff to allow natural death to take its course and refrain from performing CPR on dying patients who are suffering from an incurable condition, many medical staff remain both unaware of its existence and uncomfortable with the concept. Of the 150 decedents, 76% had a confirmed DNAR status at the time of death. Unsurprisingly, patients who died in the ICU were less likely to have a DNAR status (45.9%) compared with patients who died on the ward (90%). Although there is no national-level data for benchmarking, we were encouraged that such a large proportion of dying patients had a valid DNAR in place at the time of death.

Of the 150 patients that died during the study period, all but one-patient received EoLC in the hospital setting. Although there was no published UAE data on preferred or the actual place of death, anecdotally, this is reflective of what is happening across the UAE. Our experience has been that providing EoLC at home is complicated by a lack of coordinated community-based palliative care services, the inability to prescribe injectable controlled medications for home-based patients[9] (including opioids, benzodiazepines, antipsychotics and antiemetics), the cultural expectation that hospital is the best place to be if a loved one is unwell and the mismatch between the reality of a patient approaching the end-of-life (EoL) and patient or family's expectation of what modern medicine is able to achieve. On numerous occasions, the relatives of patients (all of whom had metastatic cancer with brain metastases), who were dying very peacefully on the ward asked in all seriousness why their family members simply could not have a brain transplant.

The sole patient (expatriate) that did receive EoLC at home required the combined efforts of privately funded home care nursing team, family members and regular telephone and social support from her oncology and palliative care teams. This is in stark contrast to the majority of expatriate patients who have neither the financial means to pay for this level of intensive healthcare nor the support from members of the extended family being physically present. With the majority of patients receiving EoLC in the hospital setting, this only serves to highlight the importance of improving the palliative care education and training that health care professionals receive.

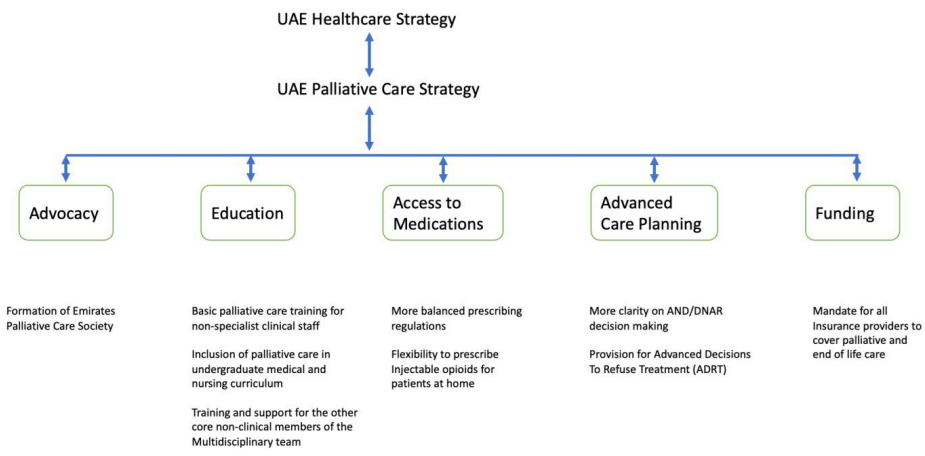
Our service was initiated in early 2020, right at the start of the COVID-19 pandemic. Subsequent travel restrictions meant that many cancer patients seeking treatment abroad were unable to do so and patients who were receiving anti-cancer treatments abroad were repatriated home rapidly. A proportion of our patients fell into this category[10] although specific data regarding which country they were receiving their cancer treatment was not initially recorded.

As a new hospital, some consideration of how new healthcare services are funded is necessary. In Abu Dhabi, there is a statutory requirement for employers to provide a basic-level of medical insurance that must cover emergency medical care.[11] Each hospital has specific arrangements with different insurance providers and not all hospitals have arrangements with all insurance providers. With a third of our referrals coming from external healthcare facilities, having arrangements with as many insurance providers as possible will ensure that more patients are able to access palliative care services. Although there is currently no palliative care-specific remuneration, patients requiring in-patient symptom control, for example, for severe pain, are admitted acutely under Diagnosis Related Group (DRG-billing), typically for 10-days to 2-weeks. For patients requiring a more prolonged in-patient admission, either for symptom control or EoLC, the situation is more complicated. If a patient is admitted acutely, but continues to deteriorate and the duration of admission exceeds the DRG limit, then this results in net negative cost for the admission. For patients who are able to satisfy the specific criteria for admission to a LTC unit, then it may be possible to qualify for remuneration under LTC billing. The majority of medical insurance providers offer home care as an add-on option.

CONCLUSION

The experiences presented here are consistent with issues raised by other colleagues in the MENA region and across the world – this

Figure 5. *Recommendations for Improving Palliative Care in the UAE*



is reassuring and reaffirms our belief that there are more similarities than differences between geographically disparate populations requiring palliative care. Future collaborative research projects will focus on trying to understand what constitutes a good death from the viewpoint of bereaved relatives of patients who received EoLC here in the UAE. Trying to improve palliative care provision within the UAE will require a more nuanced, structured, approach than a simple transfer of the Western approach to palliative care. Our recommendations for improving palliative care in the UAE were highlighted in our previous publication,[12] these have been refined further and represented diagrammatically (Figure 5).

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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