

Need for Palliative Care Services on Sint Maarten: A Preliminary Survey

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Abstract

Background: There is global evidence of increased need for palliative care; however it has been relatively neglected in health policy and research. In absence of such data on Sint Maarten, this current study aimed to assess the palliative care needs based on a broader construct of palliation beyond terminal-care relying on evaluation of health services use.

Methodology: The study assesses the palliative care need, for both alive and dead patients, utilizing health care services on the Island country of St Maarten for the period September 2014 until June 2015. The palliative care criteria were developed with inputs from the Radbound criteria and the criteria developed by the centre to advance palliative care (CAPC). A questionnaire was designed and data was collected by emailing the questionnaire coupled with personal interviews with stakeholders (primary care physicians and specialists). Data was cross-validated with the data obtained from other healthcare facilities on the Island to prevent duplication.

Results: Data included responses from 12 General practices and specialists which included internists/oncologist and psychiatrists. To minimize the duplication and over-reporting of data by the specialists, conservative estimates of responses was chosen and arbitrarily 5% of the responses were considered. The physicians/specialists were also requested to provide estimated subjects per practice and based on the estimate a conservative sample size of 30,375 subjects was obtained. A total of 160 subjects (39 dead and 121 alive) qualified the broad palliative care criteria during the study period yielding an estimated point prevalence of 0.5 %.

Conclusions: Our study emphasizes a substantial need for palliative care services on Sint Maarten. The data reported is comparable globally. The comparative data from literature review suggests a facility with a maximum of 5 beds, though this capacity may be reduced if the service delivery model is considered to be a combination of community based and nursing home based on the principles of case management and shared care.

Keywords: Palliative care; Dutch Caribbean

Background

Ageing populations are characteristic of many countries [1] and it is surmised that Sint Maarten, a small Island country in the Dutch Caribbean, is not likely to be an exception to this global observation. The proportion of elderly people, and particularly those over 80, has increased significantly in recent decades [2,3]. This is likely to have consequences in terms of mortality from long term illnesses such as heart disease, cerebrovascular disease including stroke, chronic respiratory disease and respiratory infections, and cancer with predictions already suggesting that these will be the five main global causes of death in twenty years [4]. In 2013, PAHO/WHO (World Health Organization) reported that 50 % of the cancer deaths in the Americas come from Latin America and the Caribbean [5,6]. Similar data exists with respect to the prevalence of Human Immunodeficiency Virus (HIV) that after Sub Saharan Africa Caribbean seems to be the next highly afflicted region for the disease [7]. In Latin America and the Caribbean specifically, chronic diseases are now the leading cause of premature mortality and account for two out of three deaths overall [8]. The Caribbean is the region of the Americas affected the most by

the epidemic of chronic diseases [8]. In context of St Maarten, the total amount of elderly persons according to the Civil Registry data for 2012 was 6,269 and about 70.2% of these had one or more chronic diseases [9].

The World Health Organization (2002) provides this definition of palliative care as "Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." [10] This concept embraces underlying principles such as provision of from pain and other distressing symptoms; affirming life and acknowledging dying as a normal process; integrating psychological and spiritual aspects of patient care; offering support systems to the client and their families in a team approach and enhancing quality of life.

Our current endeavor was to assess the need for palliative care services in country Sint Maarten. The term 'need' is frequently used in evaluating the effectiveness of health care, but is rarely defined [6]. It is important to define need in order to make objective assessments of health care requirements. In epidemiology, need refers to 'specific

indicators of disease or premature death which require intervention because the level is above that generally accepted within a particular society' [6]. As such, need is likely to depend on the type of society being evaluated and the evidence provided by both users (patients) and health care professionals. To estimate the need for palliative care two strategies may be adopted, either using the epidemiological approach or through the evaluation of health service use [6]. In absence of any epidemiological data available on St Maarten we relied on estimating the need through the latter measure and proceeded to provide a preliminary estimate based on the opinions of the local physicians and specialists entrusted with the job of treating these patients with complex care needs.

In the past, palliative care services have often been restricted to patients suffering from terminal cancer, with hospice services dealing almost exclusively with these patients. However, there is a growing recognition that other diseases require periods of palliation. There are three main disease categories that may require palliative care: cancer, non-malignant progressive diseases and children's terminal illnesses [11].

There is limited literature as far as the need and existence of palliative care services in the Latin American and Caribbean region [5]. As indicated in the PAHO/WHO report [6] the highest cancer mortality rates in the region are found in Trinidad and Tobago and Cuba. Kreitchitz et al. examined the end of life concerns among health care professionals, as well as people who lost a loved one on the island of Grenada [12]. In this instance, key themes that were uncovered were place of death, pain and suffering, sources of support for the deceased and their caregivers, and the use of herbal/ traditional medications, and concerns about end of life care. Physicians' opinions indicated that home care is often better than hospital care due to lack of resources within the hospitals [12]. On the other hand, Justo Roll et al. explored the palliative care needs of 91 Cuban patients with advanced cancer [13]. Results indicated that the most burdensome complaints were wasted time on appointments, as well as patient and family anxiety [13]. Additionally, Spence et al. performed needs assessment survey specifically for cancer patients on the island of Jamaica, on a sample size of 159 participants comprising of: health care professionals, patients, caregivers, and informants of the local community [14]. Results showed that barriers to seeking treatment included poor consultation experiences with health care professionals, beliefs in folk wisdom/myths, and financial barriers [14]. Most recently, Macpherson et al. documented the availability of hospices and palliation in the English speaking Caribbean [15]. Of the ten respondents, four had some form of home care provision and a protocol for pain management, while all respondents indicated oral morphine was medically available on their island [15].

We attempted to do a focused literature search to have some insight in the aspects of service organization in palliative care. In countries like UK where the palliative care service provision is at an advanced level of integration with other services, palliative care services are provided from three main sources: hospital, hospice and community services [6]. While the hospital services concentrate on symptom control and respite [16], home care services are chiefly perceived to provide support, symptom management and counselling [8]. On average, 90% of the time of terminally ill patient is spent at home, with home care being highly valued by patients and carers [7].

In England it has been suggested that 15-25% of cancer deaths receive inpatient hospice care, and 25-65% receive input from a support team or specialist palliative home care (e.g. Macmillan) nurse

[17-23]. Using these figures, it has been estimated that 700-1800 cancer patients per million (p/M) would require support, while 400-700 patients p/M would require inpatient hospice care per year. For patients with non-cancer progressing illness 350-1400 p/M would require a support team and 200-700 p/M would require inpatient palliative care [6]. In the UK, duration of terminal inpatient hospice care varies, though the average is generally between 2 weeks and 1 month prior to death [24-29]. This closely relates to the recorded deterioration in ability to perform activities of daily living 1 month prior to death [30]. Using the average inpatient duration of stay and bed occupancy in the UK, it has been estimated that 40-50 hospice beds are required p/M, however, these figures are likely to be an underestimate of need (6).

Furthermore, in UK, hospices that were principally established to meet the need of patients with cancer have until recently failed to provide services for patients with other progressing diseases [31,32] such as end-stage renal failure [33], heart failure [34], stroke [32] and pulmonary diseases [32]. There is evidence that patients suffering from non-cancer terminal illness may require at least as much palliative care as patients dying from cancer, yet proportionally fewer resources are used to alleviate suffering in these patients [21].

Community surveys consistently find that pain is an important symptom for around one-third of older people [1]. This problem makes people feel less positive about their health and is bad enough to limit activities in around one-fifth of people, although it tends to be under-reported and under treated [35,36].

Systematic reviews show evidence of effective pain relief methods and means of training health professionals to communicate well and give information to people with cancer. Coordinated care allows more people to die at home, if they wish, and specialist palliative care is associated with a range of better outcomes for patients and their families. There is also some evidence for the role of palliative care for cardiovascular, respiratory and dementia patients [1].

Dementia affects 4% of people over age 70, increasing to 13% over age 80 [37]. The median length of survival from diagnosis to death is eight years and during this time there is a progressive deterioration in ability and awareness. Common symptoms include mental confusion, urinary incontinence, pain, low mood, constipation and loss of appetite [38]. The physical and emotional burden on family members is well-documented, as is their grief at slowly losing the loved one [39].

Older people are more commonly affected by multiple comorbid problems. Minor problems may have a greater psychological impact and the cumulative effect of these may be much greater than that of any single disease [1]. Older people are at greater risk of adverse drug reactions and of iatrogenic illness and suffer the additional problems of mental impairment, economic hardship, and social isolation. This is shown most clearly by epidemiological studies asking key informants about the symptoms experienced by people in the last year of life [40]. In particular, seeing, hearing, bladder and bowel control difficulties, mental confusion and dizziness all increase with age. The problems causing suffering include, therefore, those that are regarded as "the troubles of old age," as well as those due to death-causing diseases [40].

Many studies of people diagnosed with life-threatening illnesses reveal that the way in which they are told information and involved in decision-making are important determinants of satisfaction with care. A large American cohort study of seriously ill patients recently confirmed that these factors were also important for families [41].

Dutch health policy on palliative care [42] is probably the most advanced in having recognized the need to develop services fully across a range of settings. Most people in the Netherlands die at home. Dutch policy developed in part as a result of open public debate about suffering at the end of life that might lead people to ask for euthanasia and how such suffering might be prevented [42]. More than 140,000 people died in the Netherlands in 2000 [43]. Approximately 55,000 of them died after a period of illness as a result of a non-acute disease [4]. Cancer is the most common non-acute cause of death-nearly 40,000 Dutch people died from cancer in 2000 [43]. Other common non-acute causes of death are chronic heart failure, COPD and cerebrovascular disease. People who are suffering from incurable cancer or another terminal non-acute disease can be expected to need palliative care to a greater or lesser extent.

There are figures about where certain groups of patients die. It is known, for example, that of the approximately 40,000 people a year in the Netherlands who die of cancer, 65% die at home, over a quarter die in hospital and around 6% die in a nursing home or a care home. The number dying in an independent professionally staffed hospice or a volunteer-run hospice is under 1% [44].

While current services in advanced centers appear to be geared towards the last few weeks of life, the World Health Organization (WHO) considers that palliative care should be initiated and developed from diagnosis onwards [30]. On the Island country of Sint Maarten there is at present no organized palliative care services available. Only incidental palliative care is given, by both family physicians and specialists.

Methodology

The main aim of the study was to estimate the need for palliative care services in Sint Maarten within a specified period of 2014 to current based on which an estimate of scale of services and service delivery model could be ascertained. The first big challenge was to define the criteria for palliative care since the available literature points out to varied understandings of the concept of palliative care. Our study initiated in September 2014 and finally culminated in June 2015. Our approach in evaluating the need for palliative care spanned through the following steps:

Development of criteria for assessment of palliative care needs: The issue of assessment of palliative care needs is a controversial topic in literature [6]. Most of the assessment criteria focus on palliative care models for diseases like congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), and cancer. The complex care requirements for other disorders such as dementia, chronic pain, multiple problems of ageing are little recognized [6]. Efforts were taken to research the available literature and develop comprehensive criteria for palliative care assessment for both cancer and non-cancer related disorders. The inputs from the Radbound criteria [45] and criteria developed by centre to advance palliative care (CAPC) [46] were reviewed to develop the criteria that were thought to capture the need on the Island. The criteria are shared in Appendix 1.

Development of a Questionnaire for Data Collection

Based on the criteria a specific questionnaire was developed to capture the salient responses desired from the respondents which were primarily general physicians and specialists. The questionnaire is shared in Appendix II.

The sample included all respondents (General practitioners/Specialists) indicating adult patients (>18 years age) in their practice fulfilling the criteria for palliative care as indicated in the appendix I for the time period 2014 till current. Responses on both alive and dead patients per practice were included. Responses on broader criteria of palliative care were included beyond the limited concept of cancer related palliative care concept. The responses on the palliative care needs for childhood population were excluded.

We had several discussions with the local physicians, both specialists and family physicians, met with other health care workers, gave information about the definitions and details of palliative care in general, sent out questionnaire about the palliative care, and organized information sessions with the aim of generating response on our criteria for palliative care and the corresponding questionnaire. Though we had incorporated the questions on deaths of patients qualifying for palliative care criteria in our questionnaire, we also approached the department of collective and preventive services (CPS), Sint Maarten to enquire about the data on death records for the year 2014-2015; however they did not have this data with them at the moment. We therefore proceeded to carefully have sessions with the local physicians not only about their alive patients meeting the palliative care criteria but also their patients who had died in the year 2014 up to current time who would have met the criteria for palliative care. We attempted to gather our sample not only by mailing the questionnaire to the local physicians but also having independent sessions with some selected physicians who according to general knowledge in the medical community were more likely to deal with the patients with complex care needs. A major quality addition to our data came from the White Yellow Cross Foundation facility which deals with home health care on the Island and deals with many patients who are likely to meet palliative care needs. Lists of patients in Sint Maarten Home and District Nursing (catering to elderly population) were generated and cross validated with the patient pool from the General physician and psychiatrists serving these to prevent duplication. The data generated from the group practice of local family physicians was considered as a combined response from the specific practice rather than responses from individual family physicians. Also attempts were made to yield death records of patients meeting the palliative care criteria from the St Maarten Medical Centre, the only hospital on the Dutch side of St Maarten. Though detailed records could not be obtained, the best estimate data provided by the internist after corroboration from the record section of the St Maarten Medical Center was approximately 3 deaths/month (Personal communication). The data was extrapolated for a year. Therefore, we managed to get responses from 12 General practices (including group practices), and specialists which included primarily the internist, oncologist and psychiatrists. The cross validation of data provided from the District Nursing of White and Yellow Cross Foundation led to identification of some active patients qualifying the palliative care criteria not only being treated by some of the family physicians who were inaccessible initially but also by the oncologist and surgeon as well. The data is presented in Table 1.

A major limitation encountered was a genuine possibility of the overlap and duplication of data reported by the internist, oncologist and surgeon since it would be logical to assume that most of their patients would be referred by the General physicians. Two prong strategy was adopted to minimize this confound, though possibility still remains that some overlap or missing data exists. The first correction was to take the lower end of the estimated numbers provided by the local physicians to minimize over reporting. We

assumed that there was a significant overlap between the data reported by the general physicians and that by the specialists (internist, oncologist and surgeon). If the probability of overlap is assumed to be statistically significant at $p=0.05$, this could give us a possibility of accepting only 5% probability that the data did not overlap.

We could have chosen to exclude the data given by the specialists to maintain homogeneity but since there remains a possibility that the specialists could come across patients out of the GP pool of patients and also to accommodate the fact that not all the GPs responded we arbitrarily chose to accept only 5% of combined data reported by the internist, oncologist and the surgeon as compensating for duplication

and missing data from other non-responders. If we consider the data (9) reported earlier from St Maarten, of the total sample of 366 elderly subjects studied those belonging to private, other and uninsured categories were 7.9%, 1.6% and 12.3% respectively yielding an accumulated 21.8% such subjects who are likely to fall in the gaps for health care. Our estimate of accepting 5% responses from the specialists' data was in line with being on the conservative side to prevent over reporting. Furthermore, the data reviewed from the list of patients in St Maarten Home was carefully assigned in the data reported from the General physician and psychiatrists serving the Sint Maarten Home. This corrected data is presented in Table 2.

Criteria for Palliative Care	GP1	GP2	GP3	GP4	GP 5	GP 6	GP 7	GP 8	GP 9	GP 10	GP 11	GP 12	I/O/S	PSY
Patients fulfill the Primary Criteria	15	10	15	5	10	10	5	-	-	-	-	-	30	15
Patients fulfill the Secondary Criteria	30	5	38	3	3	5	10	3	1	2	1	1	50	-
Patients, fulfilling these two criteria, died in your practice during the past year	4	3	5	3	2	4	15	-	-	-	-	-	36	1
Patients, fulfilling these two criteria, are still alive in your practice from the past year	40	5	15	4	5	11	14	3	1	2	1	1	75	15
Patients you believe need palliative care in your practice per month:	0-5	0-5	0-5	0-5	0-5	5-10	0-5	-	-	-	-	-	5-10	0-5
Is there a need for Hospice care on Sint Maarten?	Yes	Yes	Yes	yes	yes	Yes	yes	Yes	yes	Yes	Yes	Yes	Yes	Yes
How many patients per year?	10	5	10	-	5	10	5	-	-	-	-	-	10	5
How many patients die from your practice in a year on average	3	5	5	8	2	3	-	-	-	-	-	-	-	-
How many patients in your practice suffer with (As primary diagnosis):														
a. CHF	12	5	13	-	1	-	-	1	-	-	-	-	-	-
b. COPD	5	2	7	2	2	-	-	-	-	-	-	-	11	-
c. Cancer	5	15	21	-	5	-	-	1	-	-	-	-	5	-
d. Chronic pain	5	2	25	-	2	-	-	-	-	-	-	-	5	-
Other (Severe dementia, CVA, RF, complications of DM, immobility, social indications)	>20	>25	>30	>15	>15	-	-	1	1	2	1	1	>30	15

GP: General Physician Practice; I/O/S: Internist, Oncologist, Surgeon; PSY: Psychiatrists

Table 1: Responses on palliative care criteria from general practitioners and specialists.

Palliative Care Criteria	GP1	GP2	GP3	GP4	GP 5	GP 6	GP 7	GP 8	GP 9	GP 10	GP 11	GP 12	I/O/S*	PSY
Patients fulfill the Primary Criteria	15	10	15	5	10	10	5	-	-	-	-	-	2	15
patients fulfill the Secondary Criteria	30	5	38	3	3	5	10	3	1	2	1	1	3	-
Patients, fulfilling these two criteria, died in your practice during the past year	4	3	5	3	2	4	15	-	-	-	-	-	2	1
Patients, fulfilling these two criteria, are still alive in your practice from the past year	40	5	15	4	5	11	14	3	1	2	1	1	4	15
Patients you believe need palliative care in your practice per month:	0-5	0-5	0-5	0-5	0-5	5-10	0-5	-	-	-	-	-	5-10	0-5
Is there a need for Hospice care on Sint Maarten?	Yes	Yes	Yes	yes	yes	Yes	yes	Yes	yes	Yes	Yes	Yes	Yes	Yes
How many patients per year?	10	5	10	-	5	10	5	-	-	-	-	-	10	5
How many patients die from your practice in a year on average	3	5	5	8	2	3	-	-	-	-	-	-	-	-
How many patients in your practice suffer with (As primary diagnosis):														
a. CHF	12	5	13	-	1	-	-	1	-	-	-	-	1	-
b. COPD	5	2	7	2	2	-	-	-	-	-	-	-	1	-
c. Cancer:	5	15	21	-	5	-	-	1	-	-	-	-	1	-
d. Chronic pain	5	2	25	-	2	-	-	-	-	-	-	-	1	-
Other (Severe dementia, CVA, RF, complications of DM, immobility, social indications)	>20	>25	>30	>15	>15	-	-	1	1	2	1	1	>2	15

GP: General Physician Practice. I/O/S* Corrected data from Internist, Oncologist and Surgeon. PSY (psychiatrist) and GP7 (General Physician) include data from the St Maarten Home (Elderly facility).

Table 2: Corrected responses from respondents on palliative care criteria.

Results

The responses were obtained from 12 general physician practices and four specialists which included an oncologist, internist, surgeon and psychiatrists. Information on the death records from the general practices were obtained in the interview sessions as well as from the questionnaire. The average number of adult patients dying in the only hospital (SMMC) qualifying the palliative care criteria were communicated to be on an average 3/month. The data was extrapolated for a year. Responses could not be gathered from six general physician practices on the Island. In line with our study question we attempted to focus on the responses of health care specialists on the primary and secondary criteria of palliative care (Appendix I) and the data is displayed in Tables 1 and 2.

The general physicians were requested to give an estimate of the total number of patients per practice and conservative estimates were in the range of approximately 2500 patients per practice. For the specialists, in keeping with the 5% hypothesis as was considered for methodological adjustments as explained earlier resulted in a figure of approximately 125 patients per specialist practice over and above referred via general physicians. This gave us a best estimate of 30,375 subjects for all practices in the sample. Finally, synthesizing our data we were able to yield an estimate of patients both dead and currently alive who would fulfill the palliative care criteria from the year 2014 till current time. Table 3 shows that of our estimated sample a total of 160 subjects qualified for both the palliative care criteria during the study period. Out of these 39 subjects who qualified the palliative care criteria were dead and 121 were alive.

The estimated point prevalence of our data was calculated to be 0.5%. This data is represented in Table 3.

Total Estimated Sample (Average number of subjects/GP practice and specialists)	N=30,375
Dead Patients qualifying both palliative care criteria (2014-current)	39
Alive patients qualifying both palliative care criteria (2014-current)	121
Total patients qualifying both palliative care criteria (2014-current)	n=160
Estimated Point prevalence (2014-current)	0.5%

Table 3: Sample qualifying palliative care criteria using descriptive statistics.

We also observed that besides the important disease constructs such as CHD, COPD, cancer and chronic pain that patients requiring palliative care services suffered from, there was a significant proportion of patients who presented with other causes requiring palliation such as severe dementia, cerebrovascular accidents renal failure, complications of diabetes mellitus, immobility, social indications associated with increased ageing.

Our questionnaire also captured some of the narratives of the healthcare professionals on their ideas of palliative care need on the Island. The respondents were asked of their opinions as to why they thought that palliative care services were necessary the common comments were “Quality of Life of patients is impaired, physically, emotionally, psychologically and spiritually, Symptoms need symptomatic management which at times is difficult to provide with such a huge number of patients, at times these patients die alone, lack of social support, Lack of information and awareness in society further complicates the picture”. Some of the respondents were also categorical in commenting that many of the caregivers would appreciate if quality palliative care services would be available in the home setting of the patients.

Discussion

Our study indicated that the community of Sint Maarten expresses a significant need for palliative care services as assessed from the perspective and best estimate data provided by the local physicians and specialists treating such patients. We were able to generate a fairly representative data despite the limitations we encountered. All the respondents unanimously voiced the need for palliative care services on the Island. As is clear from Table 3, the total number of such patients estimated from 2014 to current time combining data from the death records and live data was 160. We estimate point prevalence for the estimated sample as 0.5%. This is comparable to the palliative care data reported for some advanced countries such as New Zealand with estimates of approximately 0.4% [47].

We attempted to do some focused literature review to draw some comparative data to indicate an estimate of palliative care beds for the population of the Island. The variables to be considered in arriving at such an estimate include size of the population, funding and resource availability, level of palliative care need, model of hospice care delivery, volume of patients requiring palliative care services, average length of stay/average length of care episode, admissions and readmission data and bed occupancy rate.

The two commonly quoted models for estimating the number of palliative care beds required for a population are from the United

Kingdom and Australia [47]. The National Council for Palliative Care (UK) originally suggested a rate of 52 beds per million for cancer patients, and 26 beds per million for non-cancer patients, or 7.8 beds per 100,000 of the population for the combined needs of cancer and non-cancer patients [48]. This ratio was subsequently recognized as being unachievable and was revised to 5.3 beds per 100,000 (based on available hospice bed numbers of 51:100,000 plus a 5% increase to accommodate non-cancer patient use), but with an added adjustment for resource need based on the number of deaths and relative deprivation of the local population [49]. Palliative Care Australia suggests a minimum of 6.7 beds per 100,000 population [50]. However, this figure is based on a slightly higher level of occupancy (85%) and an Average Length of Stay (ALOS) of 14 days. Some cities in New Zealand such as Whanganui with a population of 45,890 people has been reported to have 5 palliative care beds assigned, and other city such as South Canterbury with a population of 42,420 people have 7 palliative care beds assigned [47]. Based on these comparative data we might indicate that depending on the model of service delivery it might be prudent to start with a unit with a maximum of 5 beds.

We have provided data endorsed by different physicians as far as the primary and the secondary criteria for palliative care for their practice was concerned however we have refrained on commenting with respect to this categorization due to heterogeneity in the data as compared to their estimates provided by them for the patients who satisfied both the criteria. We were inclined to focus on data of the patients that satisfied both the criteria since that was our main research question.

It was interesting to observe that most of the respondents had a significant chunk of patients belonging to the “other” category besides the core category of disorders such as COPD, CHD, cancer and pain requiring palliative care. These patients were difficult to be designated into a main diagnosis for their condition and had multiple complicating conditions contributing to their complex care needs. This indicated the preponderance of factors such as severe dementias, complications of diabetes with amputations and immobility, chronic renal failure and patients with complications of dialysis, patients, conditions such as ALS and complex care needs due to social isolation and ageing. Therefore our study captures the construct of palliation in a broader sense with the felt need of the community besides the possibility of giving indications about the contents of palliative care programme and expertise that is needed on board when planning such services.

The narratives of the respondents as shared in the results strongly indicate the observed dimensions of need for availability of such a service in their home setting and stressed on the dignity and quality of

life in the terminally ill. This underlined the family cohesiveness and the strong care attitude in many of the care givers who would rather be open to professional expertise in the home setting so that their loved one can spend his or her terminal days within the company of his loved ones and in their own setting. Besides this the spiritual dimension was also emphasized which suggests that this would be an important component in any palliative care programme indicating liaison with religious organizations on the Island. This is in line with the data reported earlier in the Caribbean and Latin American region as a whole [12,15].

The island is likely to benefit from a combination of inpatient nursing home palliative care facility and community based service delivery model. This is likely to be not only in line with the expressed cultural opinions but might also be instrumental in efficiently utilizing the scale of the inpatient infrastructure as well as catering to off-Island needs. The planning of such a palliative care programme would capitalize on the natural home settings of the caregivers and provision of necessary expertise in the home setting of such patients.

We reviewed the existing literature to identify some effective elements in palliative care models that would drive planning a palliative care model for the Island country of Sint Maarten. Population-based models of palliative care should include elements that support case management via integration of specialist palliative care services with primary and community care services, and enable transitions across settings, including residential aged care [51]. White and Yellow Cross Foundation on St Maarten is unique in its organization of services to blend in smoothly in organizing such a service model. The following elements may be considered in planning the services:

Aim at supporting home-based end of life care, optimizing use of specialist palliative care expertise, avoiding futile treatments and providing support for family-care givers and community health professionals [52-63]. Efforts should support communication and coordination, engage and enable skill enhancement both for the primary palliative care team (including general practitioners [GPs]) and informal caregivers/patients, and clarify goals of care through advance care planning.

Inpatient palliative care unit should consist of specialist consultative services focusing on discussions about prognosis and goals of care; pursuing documentation of advance directives; discussion about foregoing specific treatments and/or diagnostic interventions; family and patient support; discharge planning; symptom management [64]. The decision will have to be made regarding the admission criteria for such a unit if the consideration is for a short stay hospice care.

In Sint Maarten Home identifying residents who would benefit from a specialist palliative care referral and negotiating this with their doctor and family, development of palliative care leadership teams, technical assistance meetings for team members, education in palliative care for all staff, plus feedback on performance and targeted symptom control strategies to improve discomfort [65].

Due consideration for expected challenges during transitions between care settings (community, aged care, palliative care unit and SMMC) where support is needed to avoid patients 'falling through the cracks' [66] and/or when a rapid response is required in the context of quickly changing clinical status or patient preferences for place of care (e.g. wishing to return home while still possible) [67]. As patients and caregivers may lack knowledge of what services are available and how to access them [67], navigating the transition from inpatient to

community based care requires intensive effort and coordination to put management plans and caregiver support in place.

It might be prudent to consider a combination of case management and shared care in planning service delivery. Case management [68] seeks to assess and meet the full range of each individual's palliative care and other needs, including those relating to activities of daily living (e.g. house-work) and social wellbeing. As a result, case management frequently requires coordination of services beyond the healthcare sector, including social services and pastoral care. Case management is informed by the principles of patient-centred care [69]; as such, patients and families themselves often play an active role in determining which services they receive. Shared care consists of an identifiable lead clinician working together with health professionals from other disciplines, a focus on communication and coordination, and a rapid needs-based response and navigational strategies [70].

Our study did not focus on the legal and ethical issues involved in end of life care. However these would be important elements of care such as advanced directives, do not resuscitate (DNR) protocol, discussions about euthanasia and procedures to incorporate.

The Public Health department St Maarten and the media are likely to have a significant responsibility in launching information campaigns and spreading awareness in public.

Conclusions

Our study emphasizes a substantial need for palliative care services on Sint Maarten. Despite some limitations, preliminary conservative estimate indicates a point prevalence of 0.5% with 160 subjects qualifying for palliative care criteria as endorsed by the physicians for the duration 2014 to current and inclusive of the subjects living and dead. The comparative data from literature review suggests a facility with a maximum of 5 beds, though this capacity may be reduced if the service delivery model is considered to be a combination of community based and inpatient care based on the principles of case management and shared care. Our study also indicates elements for effective palliative care service models based on our literature review. The best practice palliative care should be accessible to all who need it, tailored to individual patient and family's palliative care needs in a timely manner, and extend beyond organizational and disciplinary boundaries as required via strategies that support communication and coordination [51].

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