

## To Refer or Not To Refer? – Attitudes and Beliefs of Oncology Regarding Palliative Care Referrals

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### Abstract

Palliative care's integration into oncology is crucial, with early referral linked to enhanced outcomes. Survey results from Sarawak General Hospital suggest practitioner awareness and access to palliative care, yet tendencies to refer late persist. Our survey showed that senior oncologists tend to refer later in the course of disease compared to junior practitioners. More junior practitioners in contrast are more likely to refer for communication difficulties. Further research is needed to include the rest of Malaysia or Southeast Asia to better understand regional referral practices. National integration of palliative care into oncology training is recommended.

**Keywords:** Palliative care; Oncology; Referral

### Introduction

Palliative care is an integral component of oncology care. Over the last few years, there have been rapid advances in oncology, especially in immunotherapy and targeted therapy. Despite these breakthroughs, a significant number of oncology patients still do not qualify or choose not to go for oncological interventions due to personal reasons. Patients that do undergo oncological intervention also face the risk of relapse in their disease and may not be suitable for further oncological intervention. Therefore, it is important to integrate palliative care into the framework of oncology care. There is growing evidence that early integration of palliative care results in better outcomes, including improved quality of life, decreased depression, increased satisfaction, and reduced chemotherapy use at the end of life [1]. Recent evidence suggests that early integration of palliative care may even improve survival [2,3]. There is also recent research suggesting that patients in earlier stages of cancer may benefit more if referred earlier to palliative care [4]. In such a dynamic treatment landscape, the optimum timeframe for referral to palliative care remains one of the greatest challenges today.

Referral practices from oncology to palliative care globally vary widely. They are heavily influenced by the availability of resources (e.g., access to specialised palliative care units, nursing personnel, and oncology personnel knowledgeable and competent in palliative care). In developed countries, the main obstacle to integrating palliative care in oncology is predominantly focused on an inaccurate perception of palliative care, lack of knowledge of palliative care, and lack of uniform criteria for timely and accurate referral [5-7]. In developing countries, the main challenges revolve around inadequate access to palliative care resources. However, even in areas with access to palliative care services, there is still a need for more collaboration between oncology and palliative care, predominantly due to a negative perception of palliative care or that palliative care is not a priority in the treatment landscape [8,9].

Palliative care service is still in its infancy in Sarawak, Malaysia. Sarawak General Hospital in Kuching, Sarawak, is the primary referral centre for the state of Sarawak and the only hospital within the state with specialist-run oncology and palliative care access. Cancer care, including palliative care, is delivered based on the tumour's site for patients outside Kuching and its surroundings; this is usually provided by the general surgical or general medicine department in their local hospital. Palliative care service in the state's capital, Kuching, is divided into inpatient palliative care service, consult service and outpatient

home care service run by non-governmental organisation hospice groups and the Ministry of Health's domiciliary palliative care teams.

### Methods

#### Study design

The study is an exploratory, descriptive, cross-sectional, and quantitative study conducted in Sarawak General Hospital, Kuching oncology unit. A 12-item closed-ended questionnaire was developed to explore the attitudes and beliefs of oncology practitioners within the state regarding palliative care referrals for cancer patients. The survey had an extra item (13 questions total) if the practitioner discloses that he/she never or infrequently refers to palliative care. The survey was created and conducted on Google Forms. The local palliative care team in Sarawak General Hospital designed the survey in collaboration with the local oncology unit. The acceptance to answer the questionnaire was taken as consent to participate.

#### Inclusion and exclusion criteria

The oncology unit in Sarawak General Hospital was consulted regarding participation in the survey. It included all oncology practitioners working in Sarawak (oncology consultants, specialists, trainees, and medical officers), including public and private practitioners. This survey also included liaison oncology medical officers outside Sarawak General Hospital providing oncology services in satellite hospitals throughout the state. Oncology practitioners that did not respond after three contact attempts were excluded from recruitment.

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## Data collection

Survey participants were invited to fill in a Google Form containing the questionnaire in May 2023. The primary outcomes explored were referral habits of oncology practitioners and reasons for palliative care referrals. Secondary outcomes included exploring reasons for the lack of engagement with palliative care services and palliative care knowledge and competency amongst oncology practitioners. The study also examined the association between oncology practitioner demographics and their attitudes and beliefs toward palliative care.

Participants were asked about demographics, attitudes, and beliefs towards palliative care, including (age, gender, role in oncology, number of years in oncology, years since graduation from medical school, previous training in palliative care, self-perceived level of understanding about palliative care, accessibility of palliative care services, collaboration with palliative care and frequency of referral to palliative care).

For oncology practitioners who answered never or infrequently in the question "How often do you think you refer to palliative care?", the Google Form leads the participant to a separate section with an additional question exploring medical practitioners' attitudes and beliefs on perceived lack of engagement with palliative care. Options include: I can provide palliative care myself, palliative care is unable to fulfil this role in the same capacity / no specialised palliative care in my setting, long waiting time for palliative referral, patient would feel abandoned, palliative care approach is not meaningful/beneficial/a priority, patient is unable to come for palliative care appointment (logistic/economic reasons), disagreement with palliative care specialist.

All participants were asked to choose three options about what they think is the optimum moment for referral to palliative care. Options include limited survival, advanced disease with good functional status (ECOG 0-2), advanced disease with poor functional status (ECOG >2), presence of uncontrolled pain, presence of uncontrolled symptoms, no more oncological intervention/best supportive care, communication difficulties with patient and/or family members.

The final item in the questionnaire explores the beliefs of the oncology practitioner and asks which component of the World Health Organisation's definition of palliative care they consider the most important. Options include: "palliative care provides pain and other distressing symptoms relief", "it affirms life and regards dying as a normal process", "it intends neither to hasten or postpone death", "it integrates the psychological and spiritual aspects of patient care", "it offers a support system to help patients live as actively as possible until death", "it offers a support system to help the family cope during the patient's illness and in their bereavement", "it provides an interdisciplinary approach", "it enhances the quality of life and may also positively influence the course of illness", "it is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life".

## Data analysis

Descriptive statistics using frequency and proportions summarised all demographic and referral practice responses. Each participant's data was analysed and was divided into medical practitioners with formal oncology training (oncology trainees, specialists and consultants) and non-oncology trainees (medical officers). These groups of participants were then analysed regarding previous palliative care training and perceived top three optimum moments for referral to palliative care.

## Results

Thirty-eight oncology practitioners completed the survey, representing a response rate of 86%. Demographics and oncology practitioner characteristics are shown in Table 1. Most oncology practitioners were in the public sector, and nearly three-quarters (71%) were medical officers (oncology practitioners not in formal training programs). More than half of the respondents are relatively new to oncology, with less than three years of experience (52.6%), and graduated from medical school five years ago (57.9%).

Table 1: Demographics and oncology practitioner characteristics.

	Number (38)	Percentage %
Age		
25-29	12	31.6
30-34	11	28.9
35-39	11	28.9
40-44	0	0
45-49	3	7.9
50-54	0	0
55-59	0	0
60 and above	1	2.6
Gender		
Male	15	39.5
Female	23	60.5
Role in oncology		
Medical Officer	27	71.1
Oncology Trainee	2	5.3
Oncology specialist	5	13.2
Oncology consultant	4	10.5
Number of years in oncology		
0-2	20	52.6
3-5	5	13.2
6-10	6	15.8
11-15	5	13.2
More than 15 years	2	5.3
Years since graduation from medical school		
0-5	22	57.9
6-10	8	21.1
11-15	4	10.5
16-20	1	2.6
21-25	2	5.3
26-30	0	0
More than 30 years	1	2.6
Previous training in palliative care		
Yes	21	55.3
No	17	44.7
Self-perceived level of understanding about palliative care		
None	0	0
Poorly informed	1	2.6
Moderately informed	26	68.4
Sufficiently informed	11	28.9
Accessibility of palliative care services		
No	0	0
Yes-palliative care specialist service	30	78.9
Yes-palliative care resident-led service	7	18.4
Yes – palliative nurse-led service	1	2.6
Collaboration with palliative care		
Yes	38	100
No-lack of time	0	0

No-lack of manpower/medical personnel/ no available palliative service	0	0
No-palliative care referral is not necessary	0	0
No-disagreement with palliative care	0	0
How often do you think you refer to palliative care?		
Never	0	0
Infrequently	3	7.9
Often	35	92.1
What do you think is the optimum moment for referral to palliative care?		
Limited survival	13	34.2
Advanced disease with good functional status (ECOG 0-2)	7	18.4
Advanced disease with poor functional status (ECOG > 2)	29	76.3
Presence of uncontrolled pain	21	55.3
Presence of uncontrolled symptoms other than pain	18	47.4
No more oncological intervention/best supportive care	21	55.3
Communication difficulties with patient and/or family members	5	13.2
Which component of the WHO definition of palliative care that you consider the most important?		
Palliative care provides pain and other distressing symptoms relief	2	5.3
It affirms life and regards dying as a normal process	3	7.9
It intends neither to hasten or postpone death	0	0
It integrates the psychological and spiritual aspects of patient care	3	7.9
It offers a support system to help patients live as actively as possible until death	3	7.9
It offers a support system to help the family cope during the patient's illness and in their own bereavement	4	10.5
It provides an interdisciplinary approach	0	0
It enhances quality of life and may also positively influence the course of illness	17	44.7
It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life	6	15.8

Over half of the survey participants claimed they had undergone formal palliative care training at some point in their careers (either in a specialist-run palliative care service or formal courses). Only one participant felt "poorly informed" about palliative care, with the vast majority (97.3%) of respondents answering "moderately informed" or "sufficiently informed". All participants agreed that they had access to palliative care service and collaboration with palliative care, with more than 75% of participants (78.9%) having access to palliative care specialist service, with the remaining participants having palliative care resident-led service or palliative care nurse-led service.

When asked about the frequency of referrals to palliative care, only 8% of participants responded "infrequently" and the vast majority (92%) of oncology practitioners responded "often". For the practitioners who responded "infrequently" concerning their referral behaviours, a follow-up question was asked on their top reason for perceived minimal engagement with palliative care. All respondents who answered "infrequently" named the inability of patients to come for palliative care appointments due to patient's logistics/economical reasons as the top reason for perceived minimal engagement with palliative care.

All participants were asked about their top three reasons for referral to palliative care. More than 75% of participants (76.3%) named "advanced disease with poor functional status (ECOG > 2)" as their top reason for referrals. Followed by "presence of uncontrolled pain" (55.3%) and "no more oncological intervention/best supportive care" (55.3%). Interestingly, participants who chose communication difficulties as a reason for palliative care referral were more likely to be non-oncology trainees. It is also noteworthy that many oncology specialists recognise uncontrolled symptoms as the optimum referral timeframe. In contrast, younger oncology practitioners are more likely to consider advanced disease with good functional status (ECOG 0-2) as the optimum timeframe for palliative care referral. Oncology trainees and specialists who did not receive formal palliative care training in their careers were more likely to refer cancer patients later in their course of disease than their counterparts who underwent palliative care training. However, our study has shown that oncology trainees and specialists were generally more likely to refer later when the disease is symptomatic or when all oncological options have been exhausted.

## Conclusion

This study has shown that most oncology practitioners in our centre are aware of and have access to palliative care services. However, most oncology specialists/trainees are more likely to refer patients later during the disease. Our study has also highlighted the importance of palliative care competency, as oncology practitioners who underwent palliative care training were more likely to be better equipped to handle complex communication issues with patients and/or families. They were also more likely to refer cancer patients earlier in their disease course. Data analysis is limited in this study due to its small population, and it would be interesting to expand the scope of this research to include the rest of the country. If the attitudes and beliefs of oncology are consistent nationwide, as shown in our study, it would suggest an urgent need for formal integration of palliative care training as part of oncology training in this country.

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