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How registrar palliative care training affected palliative care integration in South African oncology

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Background: The current state of cancer care in Africa necessitates intervention to enhance accessible cancer prevention, treatment, rehabilitation, and integrated palliative care services. Achieving integration of palliative care within oncology requires both functional and normative integration. Decisive strategies are required to address misconceptions, lack of awareness, and comprehension regarding integrated palliative care (PC) services.

Aim: This research aims to describe how intermediate-level palliative training affected PC integration in Oncology at Groote Schuur Hospital in South Africa.

Setting: Groote Schuur Hospital is a tertiary, quaternary academic hospital with 975 beds. The oncology unit sees approximately 2800 new patients per year and qualifies 3–4 registrars annually.

Methods: This is a small qualitative study combining secondary thematic analyses of qualitative data from focus group discussions ($n = 2$) from a previous study, and new interviews ($n = 3$) and purposively sampled documents analysed through thematic analysis using NVIVO.

Results: Including PC education seems to enhance patient and family-centred care, contributing to improvements in the normative aspects of integration. Nevertheless, focussing solely on training registrars has proven insufficient in achieving crucial functional aspects of integration. The misalignment between policies, guidelines, and registrar education constrains effective integration of a PC approach. Consultants' lack of training in palliative care poses difficulties in implementing comprehensive patient care. Clinical leadership in palliative care is provided from outside the oncology department which inhibits 'functional integration'. Addressing these shortcomings is vital to successfully integrating palliative care within cancer care settings.

Conclusion: Training registrars in PC is undoubtedly necessary but insufficient. Clinical PC leadership within oncology in Africa is essential for integration.

Contribution: This article highlights the importance of PC in oncology and how training contributes to its integration. Furthermore, the role of clinical PC leadership within oncology in Africa is essential to this integration and will play a vital role in improving cancer care in Africa.

Keywords: palliative care; palliative medicine; education; registrars; integration.

Introduction

An increasing cancer burden, failing health systems, the coronavirus disease (COVID-19) pandemic and limited resources have moved advocacy groups, patients, and healthcare workers to call for better and more accessible cancer prevention, treatment, rehabilitation, and palliative care (PC) across the African continent. In Africa, oncological services, such as radiotherapy and chemotherapy, are limited, and access to PC is even more limited.[1,2] Access to PC in oncology is equally important as prevention and treatment of cancer, hence the necessity of its inclusion in strategic plans for comprehensive cancer care. The integration of PC into African health systems, especially cancer care, therefore, requires urgent action.[3] This article describes how educating registrars (trainee oncologists) is used as a strategy to integrate PC into cancer care in an Academic Teaching Hospital (ATH) in South Africa.

Palliative care is vital in the African setting, especially in oncology, as most patients present with advanced cancer, causing severe suffering.[2] Many patients are far from health services and have limited access to surgery, radiotherapy, and chemotherapy.[4,5] In addition, culturally competent and psycho-social and spiritual care is necessary in the context of traditional beliefs and the poverty burden in Africa.[6] Delivering holistic care in overburdened healthcare systems and witnessing suffering may also cause distress to healthcare providers. It is, therefore, important that these providers have the skills to provide holistic care, as well as the knowledge and support to practice self-care and counter burnout, to retain them in the health care system. Furthermore, PC has been demonstrated to be cost-effective and value-added care.[7,8] Palliative care, with its bio-psychosocial and spiritual approach, thus needs to be integrated to relieve this multifactorial health-related suffering in oncology.[3]

An integrated healthcare approach is usually followed when complex long-term problems are addressed through a multiplicity of services, service levels, and providers.[9] Functional integration implies that the key support function and activities are structured around the support service delivery to ensure accountability between the organisation and the professionals.[10] Drawing from the literature on integration and PC, this research suggests that the following nine domains are required to achieve 'functional integration' of PC in an ATH: the provision of patient and family-centred care[10,11,12]; the provision of collaborative care[10,12]; information systems[13]; education[10,14,15]; leadership and governance[10,14,15]; guidelines and policies[15,16]; palliative care workforce[15]; drug availability[15,17]; and research.[15]

Functional integration of all aspects within the domains depends on the interconnectedness of the domains, which can only be achieved within an organisational culture that values and believes that a PC approach is critical to the health care system and is an essential element of basic oncological care.[18] According to Valentijn et al., mutual values, vision, trust, and culture, which are core aspects of normative integration, are essential to ensuring an integrated approach.[10] Thus, we can theorise that PC integration is dependent on functional and normative integration being achieved.

Education as an integration strategy

A comprehensive PC education programme was developed for oncology registrars in ATHs in South Africa. The programme was based on the assumption that successful integration of PC into oncology practice requires strategic actions, such as effective teaching and training. The programme aims to equip oncology registrars with the necessary competencies to provide PC to patients with advanced cancer. It emphasises both functional and normative integration of PC within the oncology setting.[19] The first cohort of students completed the course in 2017. This programme has continued across four universities for the past 5 years. Palliative care education is currently an examinable component of oncology training. In Groote Schuur Hospital (GSH), although there are specialised PC services, the oncology team does not refer to these specialised services because of a lack of capacity within the specialised PC team, which mainly cares for patients outside the oncology wards. However, the specialised team and the oncology team have a weekly combined ward round. This study aims to describe how intermediate-level PC training affected PC integration in an ATH in South Africa, drawing from the theoretical framework of integrated PC. Understanding this process may assist in further strategies to strengthen PC within oncology.

Methods

This is a small qualitative descriptive study that combines secondary analysis of existing data from a previous evaluation of the registrar training (2019),[19] with primary interviews of supervisors (2022) and documentary analysis. The triangulation of data sources, together with observations of the research team, assists in trustworthiness and confirmation of the results. The study site was the oncology unit in GSH, which sees approximately 2800 new patients annually and qualifies an average of 3–4 registrars annually. Registrars are trained from across Africa, and approximately 50% of the registrars are from countries outside of South Africa.

Firstly, data from the 2019 training evaluation pertaining only to University of Cape Town (UCT) registrars and supervisors were extracted. Data had been obtained via two Focus Group Discussions (FGDs) informed by a semi-structured interview guide. The first group comprised 10 registrars (this group is identified as *FGD reg*) and the second group comprised two supervisors (this group is identified as *FGD sup*). Written consent was obtained from all the participants.

Secondly, individual interviews were conducted with supervisors (n = 3) who had not been involved in the training evaluation but who had been involved in the training of registrars before and after the programme in 2021. Only three supervisors consented and met the inclusion criteria. They are identified in the result as *Sup 1, 2,* or *3.* Recruitment was purposively done, and all interviews were anonymised. Face validity of the interview guide was ensured by presenting the questionnaire to experts in the fields of normative and functional integration and PC. Construct validity was derived by aligning this tool with the theoretical framework described in the introduction. Reliability of the tool was established by piloting it with consultants who were involved in the PC training and the evaluation, but who were outside of GSH. All interviews were conducted in English by a single research assistant trained to conduct them.

All the transcripts were imported into NVIVO version 14.23.0 for deductive thematic analyses. Coding was informed by literature on the theory of functional integration, aspects of normative integration, barriers, facilitators, and processes in the integration process. The research team familiarised themselves with the data within transcripts (two FGDs and three new interviews). The group discussed the existing themes, and subthemes and developed a coding framework, which was discussed and agreed upon with the research team. As the agreed frame was applied to the full dataset, additional subthemes were identified and incorporated into the coding frame. Selected quotes were used to illustrate the resulting themes of the analysis.

Lastly, document analysis was conducted on purposively sampled guidelines and policies within the oncology department, as guided by the interviews, policies, and guidelines on key conditions where a PC approach is needed. One guideline and two standard operating procedures were identified and analysed. This was done by importing the transcripts into NVIVO14.23.0. The documents were analysed to identify as to where and how PC had been integrated into GSH oncology care and identifying gaps. All the documents had been created after 2021.

Rigour was ensured by using multiple data sources, member checking of transcripts, and discussion within the research team. This was embedded research as the primary researcher (R.K.) works within this setting and also led the implementation and training of registrars. To limit bias, key training and service delivery participants were consulted.

Ethical considerations

Ethical clearance to conduct this study was obtained from the University of Cape Town, Faculty of Health Services, Human Research Ethics Committee (No. 071/2020). Informed consent was obtained from the interviewees and patients or their families on the database. All consented to their data being included.

Results

The deductive analysis produced the themes and sub-themes enlisted in Table 1.

Normative integration

As discussed, PC was seen as separate from oncology care before the integration of training and was not a fundamental component of oncology care. Normalising PC in oncology is a core component of PC integration.

Normalising and valuing a palliative care approach

All interviewees from the FGDs and individual interviews acknowledged the need for PC and its importance in oncology. The supervisors in the FGDs observed that the registrars also identified the shift in mindset to recognise that PC is an integral component of the job. Furthermore, registrars are more confident to stop aggressive care and are more at peace with stopping interventions at the end-of-life:

> ‘It is easier always to give more like chemo regulation, etc, but now I have started noticing, especially at end-of-life care, people seem to have more confidence in terms of … stopping.’ (FGD Sup 1)

Assumptions about the nature of palliative care

Multiple assumptions of PC were challenged with this programme. In both FGDs, the first assumption that was challenged was that PC was not an important part of oncology care. Secondly, registrars, as indicated in the registrar FGD, did not recognise their own role in delivering PC and only saw their role in curing cancer. Thirdly, PC is only for end-of-life care.

> ‘Biggest one [*assumption*], of course, is the fact that you should only implement PC when the person’s dying.’ (FGD Reg6)

Strengthening positive resilience through training

Self-care and building positive resilience are core components of a PC curriculum. These skills were not previously taught in the oncology curriculum. The education programme pro-actively addressed this for registrars to gain a better understanding of the concept of suffering and resilience skills in dealing with health-related suffering as highlighted in the registrar FGD and Sup 1.

The need for and importance of these skills are appreciated when interviewing a supervisor with no PC training who indicates that the mechanism to deal with suffering is detachment from the situation:

> ‘So, I’m old. And I’ve been doing this for many years. And so, to a certain extent, one has to become, sounds harsh, but blunted. And I don’t mean that to sound harsh, but if when, you know, if I were to get emotionally involved or upset about all the patients that I see that, you know, are going to be managed with palliative intent, I, I wouldn’t, I probably wouldn’t be able to function.’ (FGD Sup 2)

The provision of patient and family-centred care

The programme provided the registrars with the competencies in comprehensive care for patients, especially in communication skills, pain management, and symptom control. The registrars were able to identify total pain, and a comprehensive approach was valued. Families are also recognised as important care team members and valued as being core in care:

> ‘[*R*]egistrars have got a framework in terms of how to deal with palliative patients in terms of symptom management but also holistic care.’ (FGD Sup 2)

The provision of collaborative care

Oncologists are used to working in multidisciplinary teams, but the PC programme has expanded these teams to look outside the hospital to hospices and to include more of the health and rehabilitation workers. Previously, referring to a social worker within oncology was the extent of collaborative care:

> ‘And that’s not only the teams within oncology, we also rely quite heavily on our multidisciplinary teams.’ (FGD Sup 1)
>
> ‘We’ve, we’ve tried to implement a more community-centric approach to palliative care.’ (FGD Sup 1)

The presence of information systems to monitor palliative care

There are no palliative-specific monitoring and evaluation nor integrated reporting systems in which PC outcomes are measured as confirmed by Sup 1 and as observed by the research team.

Education in palliative care

Palliative care educational activities for the registrars are limited to this programme and a mentorship ward round

TABLE 1: The themes and the subthemes identified together with the sources of the information.

Themes	Normative integration	The provision of patient and family-centred care	The provision of collaborative care	The presence of information systems to monitor PC	Education in PC	leadership and governance specific for PC	Guidelines and policies in the oncology service	Availability of a palliative care workforce	Drug availability for PC	Research in PC	Limited resources as a barrier to integrating PC
Sub-themes	Normalising and valuing a PC approach. *[Sup 2, sup 1, FGD reg]*	Pain and symptom management. *[Both fGDs, Sup 1 and sup 2 and Importance mentioned 2 documents]*	The expansion of multidisciplinary care. *[all the interview sources and 1 document highlight the importance of multidisciplinary care]*	Monitoring and evaluation tools for PC. *[Sup 1 and mentioned in douments but not specific to PC]*	Limited to intermediate-level training in the department. *[FGD reg, sup 2 and 1]*	The need for collaborative leadership. *[Sup 1]*	Integrated policies *[Protocol for managing adenocarcinoma of the colon, the standard operating Procedure for non-small cell lung cancer and the protocol for treatment of Gynaecological Mallgnancies]*	The availability of a multi-disciplinary PC trained workforce. *[FGO sup and Reg]*	Essential medication as specified by the WHO Essential PC Medicine list. *[as per hospital douments]*	No PC specific research. *[SUP 1]*	The resources are too limited to provide PC. *[Sup 2]*
	Assumptions about the nature of PC. *[FGD reg]*	Psycho-social and spiritual care. *[FGD reg, Sup 2 and importance mentioned 2 documents]*	Continuity of care beyond the hospital. *[all the sources highlight the importance of continuity of care]*	-	-	The importance of mentornship. *[Sup 1]*	Stand-alone PC policies *[nill foundl]*	Emotional and organisational support for palliative care workforce. [sup 1]	-	Integrated PC research in registrar portfollios. *[Sup 2]*	-
	Strengthening positive resillience through training. *[Sup 1]*	The family are active members of the team. [FGD reg, Sup 2 and importance mentioned 2 douments	-	-	-	Limited clinical leadership within oncology. *[FGD reg]*	-	-	-	-	-

Sup, supervisor; reg, registrar; FDD, focus discussion group; PC, palliative care.

once a week. The programme focusses only on registrars in the team as indicated by both the registrars in the focus group and the individual interviews with sup 1.

Leadership and governance specific to palliative care

The programme assisted oncologists in taking ownership of developing a PC programme for oncology in the hospital, but they admit that a PC consultant is pivotal to PC integration in a hospital, as indicated by both the supervisors. Collaborative leadership assisted in making the programme successful:

> 'And we've always had her [*PC consultant*] working together with one of the oncologists.' (FGD Sup 1)
>
> 'So having her [*PC consultant*] in the hospital for several hours a day and available to our registrars and our patients or for teaching and also for the continuous care ward round has made an absolutely massive difference.' (FGD Sup 1)

However, consultants need to be trained as there can be discord around decision-making:

> 'I think, I know it is probably idealistic thinking but I do think that maybe if you could have like a crash course version for even consultants because sometimes you find that we learn these very good principles and then you want to apply them, but you know if the head is not in sync with the neck, then there is a problem you know.' (FGD Reg 4)

Guidelines and policies in the oncology service

The protocol for managing adenocarcinoma of the colon (PCC), the Standard Operating Procedure for non-small cell lung cancer (SOPNSLC) and the Protocol for Treatment of Gynaecological Malignancies (PGM) were evaluated. Only one of the authors of one of the documents had PC training. Multidisciplinarity is recommended in one document but not seen as core. Palliative care is integrated into protocols for the management of cancers in three specific ways:

- As a palliative chemotherapy or radiotherapy intervention (SOPNLC)
- A separate section as an addendum (PGM)
- The use of supportive care versus PC is not clearly defined (PCC, SOPNLC)

> 'Patients with performance status ≥ 3 should be managed supportively.' (PCC)
>
> 'A multi-disciplinary team and home support are strongly recommended.' (PGM)
>
> 'The clinical protocols that are specific for each disease site, certainly in GIT oncology going to the, you know, the chemotherapy regimens, the side effects to look out for and how to manage them and when to … in which situations you would get other team members involved, you know, when to get a surgeon involved.' (FGD Sup 2)

Availability of a palliative care workforce

There are no dedicated PC personnel in the oncology services. One oncology consultant works with the PC consultant to deliver the training and lead the mentorship ward rounds per the researcher's observations.

Drug availability for palliative care

All the medications advised by the World Health Organization (WHO) as essential PC medicines are available in the hospital as per the Essential Medicine List and Standard Treatment Guidelines.[20]

Research in palliative care

There is very limited PC research. It tends to be confined to case studies in registrars' portfolios and to research led by PC consultants, as indicated by Sup 2.

Limited resources as a barrier to integrating palliative care

As observed, expressed in the FGDs, and stated by Sup 2, limited time with patients because of resource limitations remains a universal barrier to providing holistic care:

> 'Part of the challenge is that these are really busy clinics. They have … they … basically too many patients and too few doctors, so we don't have adequate time to spend with the patients once we introduce them to PC, whether it includes chemotherapy or radiation or not.' (FGD Sup 2)

Discussion

The oncology service at GSH has used the education of registrars for the past five years as a strategy to achieve integration of PC. This has normalised a PC approach among registrars and is moving towards patients receiving the right care at the right time; for example they know when to stop aggressive care. According to Kaasa et al., PC integration in oncology is based on both organisational structure and patient-centred care plans. Education assists the registrars to have the tools to provide better patient and family-centred care, and also ensures that the culture in oncology changes so that the PC approach is valued.[11,18] Furthermore, the PC training programme challenged registrars and addressed embedded assumptions, for example, that PC is only for dying patients.[19] These are essential components of integrating PC in oncology services. However, this research study has demonstrated that educating young trainees is insufficient to ensure that PC is fully integrated into oncology services because PC is still not integrated in important documentation as a clear and uniform element of care. Furthermore, no research dedicated to PC is conducted in the unit, although most of the patients are for palliative intent.

Knowing when to integrate a PC approach and knowing when to stop chemotherapy or radiation therapy are core skills all oncologists need to have. There are well-known normative reasons why these skills are hard to practice, for example, fear that PC provision may be seen as giving up on patients.[21] In the African setting, these complex decisions are further amplified because many patients present late with advanced disease hoping for a cure.[6] In addition, there are few PC services to refer to and also not enough time to develop comprehensive care plans for patients and families.[22] It may be easier and quicker to give another dose of chemo or radiotherapy than to have a complex conversation, especially if the treating team does not have advanced communication skills or is not equipped to provide culturally appropriate care as needed when making decisions. This programme improved the registrars ability to rationalise and stop aggressive treatments and use of the wider multidisciplinary team to care for patients. In addition, the training impacted their own resilience, the multidisciplinary team, and understanding and confidence in managing difficult decisions.

The resilience needed to be compassionately present during suffering is a disposition that requires proactive skills with targeted actions and role modelling to address distressing situations.[23] These skills come in the form of communication skills, debriefing sessions, knowing when to integrate psycho-social actions, working with colleagues in the multidisciplinary team, understanding spirituality and culture in patient care. These skills are known to assist with preventing burnout and managing the moral distress experienced by the oncologist.[24] This course created a structured programme where these skills were taught and openly discussed to ensure that they were relevant to their own African setting.[19] Unfortunately, these competencies are newly taught and have yet to be part of the expected competencies of many senior healthcare workers. Previously, oncology training was rooted in mainstream medicine, focussing on acute care.[11] Most senior oncologists did not receive the above-mentioned training, which may have contributed to a situation where they did not have the competencies to manage complex situations requiring PC and 'blunted' them to suffering. This may have contributed to the subsequent loss of oncologist to the public sector. Depersonalisation of these situations often causes inner distress and may affect their long-term commitment to the profession.

The moral distress experienced by healthcare workers and the subsequent loss of healthcare workers leaving the public sector or the profession is a concern in Africa. Connel et al. evaluated this exodus of trained South African health professionals to other countries, naming the toll of HIV with emotional exhaustion compounded by limited resources within the health system causing healthcare professionals to leave the country.[25] These factors resonate with the moral exhaustion and lack of resources evident in African oncology practice. In low-to-middle-income countries where the need for PC is the highest, access to PC is at its lowest.[26] Limited resources, the high incidence of patients presenting with incurable cancers, and limited access to PC specialists are some of the main reasons why PC training is essential to the whole oncology team in Africa. The training of oncologists needs to change to ensure that oncologists have both the emotional and clinical competencies to care for their patients. To ensure the full impact of PC on the health care system, the training must extend beyond junior trainees. The training must include the whole team, which includes surgeons, senior oncologists, social workers, and rehabilitation professionals, to ensure 'head is in sync with the neck' (ref from FGD Reg interviews). This may assist in integrating the PC approach in every aspect of cancer care. This is, also, important to ensure that cost-effective PC is practised along the whole continuum of care. In addition to improved quality of life of patients and families, the economic value of PC is undoubtedly one of the reasons for its inclusion in a health care system.[3,8] However, the benefit goes beyond the cost effect on the health system and extends to household poverty prevention. In low-to middle-income countries, many of the direct and indirect costs of care are the families' responsibility, and the cost of futile care can have devastating effects on households.[7] The consequences of not providing comprehensive training to the entire team to incorporate a PC approach become even more apparent when we examine the additional components required for the successful integration of PC.

The findings suggest that the strategy of training registrars for the past 5 years has had limited impact on integrating PC in core functional aspects of integration beyond the clinical service provided. Although the training may be an investment in the future for PC integration, more extensive integration is needed to ensure that inputs, delivery, management, and organisation of services are aligned to achieve greater access, better quality, user satisfaction, and efficiency.[9] Currently, the hospital needs the following PC inputs: policies, monitoring and evaluation tools, and dedicated PC teams in the oncology services. Training registrars has thus led to better linkage with PC services but no standardised care pathways have been created.[27]

The lack of standardisation is evident, especially in guidelines, for example, the absence of uniformity in the meaning of PC compared with supportive care.[28] The result of using different words is that no action or different actions are linked with these words. Furthermore, in the guidelines, the initiation of palliative chemotherapy and radiotherapy are seen as the action required to initiate PC, a further indication of the lack of the understanding of the comprehensive nature of PC. A misalignment between clinical guidelines, standard operating procedures, and the training provided can lead to confusion among young trainees. It is also a concern that PC outcomes are not monitored and evaluated to provide outcomes data. Monitoring and evaluating outcomes and service delivery is generally not well conducted because of the lack of automatic systems but even more so for PC which is currently not integrated as an essential component of hospital reporting in South Africa.

Leaders in oncology have been at the forefront of recognising the need to integrate PC and being supportive in the process.[19] However, in GSH, the day-to-day leadership for the integration of PC comes from outside the oncology department. Most research on PC integration identifies a PC specialist as an enabler for PC integration.[15,26] The lack of recognised PC leadership within oncology contributes to the absence of a PC strategic plan and many other functional aspects of PC integration that need to be actualised. The recognition of PC as a subspecialty of oncology is a recent development. Consequently, there is a scarcity of these subspecialists within the country. While establishing a career pathway for oncologists in PC is a positive advancement, there is a need to train more leaders in this subspecialty from oncology. The limited number of subspecialist leaders, combined with the already limited number of oncologists in mainstream oncology, presents a significant barrier to oncologists being able to devote time to PC. Although PC is aligned with oncology, it possesses a distinct body of knowledge. Therefore, successful integration requires more dedicated and recognised leadership to ensure long-term sustainability.

The lack of many functional aspects of integration is evident in GSH oncology department. However, the culture of including PC as a fundamental aspect of cancer care is now recognised. These young trainees are the leaders of tomorrow and will also work across Africa and hopefully will integrate PC more sustainably.

Limitations

This is a small descriptive study which relies on embedded research. Furthermore, the researcher also plays a role in service delivery and PC programme development. This study was conducted in only one hospital in South Africa.

Conclusion

Palliative care education and training is currently a recognised element in the oncology curriculum. This training has contributed to registrars delivering better patient and family-centred care, assisting with their distress in managing complex situations and valuing PC. However, to achieve full PC integration in oncology, a strategic plan has to be developed to include all the aspects of integration. Ideally, this strategic plan must be led from within oncology.

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Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

S.R.K., Z.M. are responsible for editing, analysis, and conceptualisation; J.O. is responsible for supervision and editing; L.G. is responsible for supervision, analysis, and editing.

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Data availability

The data that support the findings of this study are available from the corresponding author, S.R.K., upon reasonable.

Disclaimer

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