

Research Paper

Barriers and facilitators in providing quality end-of-life care to patients with haematologic malignancies: the nurses' perceptions

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Abstract

The 'cure culture' present in a haematology oncology unit in Malta poses a challenge to end-of-life care provision for patients with haematologic malignancies. Extant literature focuses on the perceptions of medical practitioners regarding the non-referral of these patients to palliative care and the avoidance of end-of-life discussions. Yet, although nurses provide twenty-four hour care to these patients, there is a dearth of research regarding their perceptions of barriers and facilitators in quality end-of-life care provision for these patients. The aim of this paper is to explore the perceptions of Maltese nurses regarding barriers and facilitators in quality end-of-life care provision for adult patients with haematologic malignancies in a haematology oncology unit in Malta. Five female nurses were recruited by purposive sampling and each participant was interviewed twice using semi-structured interviews. The data were transcribed verbatim. Two themes "Addressing the unique needs of each patient" and "Obstacles to providing quality end-of-

life care" were extracted. The first theme represents the nurses' perceptions of facilitators necessary to provide quality end-of-life care namely, keeping the patient physically comfortable, ensuring that their spiritual needs are met, and working with patient concerns to enable closure. Conversely, the barriers perceived as hindering the provision of quality end-of-life care include the lack of patient privacy in the ward, the non-inclusion of nurses in care plan decision making, the provision of false hopes to patients, and care provision within a cure-oriented ward culture. The findings demonstrate how end-of-life care with these patients should not be task and cure-oriented, but rather, should adopt a palliative modus operandi, that prompts care practices utilising a holistic and person-centred approach, with a focus on quality of life as opposed to quantity.

Keywords: haematologic malignancies; end-of-life care; interpretative phenomenological analysis; barriers, facilitators

1. Introduction

Haematological malignancies (HM), such as leukaemias, lymphomas and myelomas, are a highly heterogeneous group of diseases that induce alterations in the immune system (Maglie et al., 2020). Whilst the survival period for people with HM has been prolonged, providing care to these patients often proves challenging as they are more likely to undergo aggressive treatment that may

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sometimes lead to death. Additionally, when compared to people with solid tumours, patients with HM are more likely to receive aggressive treatments and less palliative care towards the end-of-life (EOL) (Beaussant et al., 2017; Oeschke, 2019). This is similar to the situation in Malta, with results from Grech et al.'s (2018) study, showing how the majority of patients with HM receive EOL care within the haematology oncology unit (HOU) or critical care setting, rather than a palliative unit. Consequently, nurses working in a HOU are either helping these patients to cope with the disease or preparing them for the eventuality of losing their life (Leung et al., 2011).

Providing quality EOL care presents a multitude of challenges for staff as they strive for adequate pain and symptom management, comfort for the patients, avoidance of inappropriate prolongation of life and relief of suffering for both the patients and their loved ones (Cotogni, Saini, & De Luca, 2018). These challenges are exacerbated in a HOU environment that generally embraces a curative culture with minimal referrals being made to palliative care, wherein the EOL care needs are managed by haematologists (Grech et al., 2018; McGrath & Holewa, 2006). Indeed, results from a study by Wang et al (2016) that examined the differences between acute hospitals and palliative care units in EOL care for patients with terminal pancreatic cancer found that patients at the palliative care unit tend to have shorter inpatient stays and less aggressive treatment. Palliative care at the EOL aims to enable a 'good' death for the patients by addressing patients' and their families' needs and concerns, providing for their comfort and by encouraging authentic engagement (Lannie, Haraldsdottir & Spiller, 2021).

As suggested above, nurses strive to provide quality EOL care and this is shaped and guided by their personal understandings of a 'good' death (Becker et al., 2017). There is a general consensus amongst the stakeholders of the characteristics constituting a 'good death' in relation to broad concepts such as emotional, spiritual and physical wellbeing (Becker et al., 2017; Meier et al., 2016; Oliver & O'Connor, 2015). Notwithstanding this, there is evidence to show how diverse cultures and traditions give rise to significant differences amongst nurses, both in relation to their understanding of a 'good death' and the strategies to help patients achieve this (Gysels et al., 2012; Meier et al., 2016; Shepherd et al., 2022). Furthermore, there is a myriad of literature that highlights the challenges that nurses face to provide optimal care to their dying patients, as guided by these different understandings

(Shepherd et al., 2022) and the resultant distress if they perceive that they have failed to do so (Becker et al., 2017). It is in view of this that literature specific to the Maltese setting, and which places a focus on the challenges and facilitators that nurses face when caring for patients with HM in a HOU was deemed necessary. The present study is a continuation of the study by Grech et al. (2018) that addresses the nurses' general experiences of caring for these patients.

2. Methods

A qualitative inquiry was selected for this study as it enables an in depth exploration of the social reality of individuals or groups of people and the meaning that they ascribe to a phenomenon, namely the nurses' perceptions of the facilitators and barriers of quality EOL care provision. Furthermore, the principles of Interpretative Phenomenological Analysis (IPA) as described by Smith et al. (2009), were applied to enable an in depth understanding of ascribed meanings and participants' experiences.

2.1. Participants

An intermediary recruited a purposeful homogeneous sample of five Maltese nurses working in the HOU. The nurses' ages ranged between 25 to 55 years, and they were all female, reflecting the gender of most nurses working in the HOU. Inclusion criteria were nurses that: (i) were currently working in a HOU and (ii) had been working in a HOU setting for over a year to ensure that the nurses had experience in providing EOL care. At the time of the study, the participants did not have any training in palliative care, except for some hours provided during their basic undergraduate training.

2.2. Data Collection

Two audiotaped in-depth, face to face semi-structured interviews were conducted in English with each participant. It was decided to use the English language during interviews considering that: (i) tertiary health related education in Malta is conducted in English, and hence these professionals are competent in the language and (ii) there would be no need to translate the transcripts from Maltese to English, due to challenges in ensuring that translated excerpts accurately reflect the participants' experience. The interview schedule was formulated following a scoping review of the literature.

The nurses were asked about their experiences of caring for patients with HM at EOL and how providing such care affected them. They were also asked regarding barriers and facilitators in providing quality EOL care to persons with HM within a HOU. Nurses also were invited to share their experiences of how they coped in their work environment and what type of support was perceived as beneficial. Probes such as ‘Why?’ or ‘Can you tell me more?’ were also used during the interview. The duration of the first interview was approximately one and a half hours long. The follow – up interview lasted approximately thirty minutes, during which aspects raised in the first interview could be explored further in depth.

2.3. Ethical Considerations

Ethical approval and data protection clearance were obtained from the relevant institutional boards of the University of Malta (FHS/087). An information letter providing details about the study was provided to potential participants by an intermediary. Those nurses who were willing to participate were requested to sign a consent form. The identity of the participants was safeguarded through the use of pseudonyms. The data collected, recordings and transcripts were kept safely locked to ensure data protection.

2.4. Data Analysis

The data were analysed on a word processor following transcription of the tapes, which were repeatedly read. Comments and points deemed to be interesting/ important to the researcher were noted down. These exploratory comments were then analysed to identify the emergent themes. Patterns and connections between the various themes were then identified to determine how they fit together. The cyclical process of IPA was then used with all the transcripts where each one of them was repeatedly read and analysed.

The primary analysis was conducted by the first author (A.G); the second and third authors contributed

through the joint review and agreement on a final set of themes. A diary of field notes was kept during the interviews, in which biases and observations of the first author were noted. Reflexivity was practised throughout the research process to mitigate any researcher influences or biases.

2.5. Rigor

The guide recommended by Yardley (2000) was used to assess trustworthiness and quality. The four aspects in this model were sensitivity to context, commitment and rigor, transparency and coherence and impact and quality. Sensitivity to context was demonstrated in the provision of the relevant literature and verbatim extracts to support the data. Commitment was ensured by giving a clear description of the research process, such as the recruitment of the participants and details regarding data analysis. The coherence of the research was demonstrated through consistency with the underlying theoretical assumption being implemented namely that of IPA. The impact and quality of the study were addressed by targeting the extant gap in the literature regarding obstacles and facilitators that should be incorporated in EOL care for patients with HM.

3. Results

The participants described their experience caring for EOL patients in a HOU and perceived it to be a different experience to working in other wards *“because here the patient stays for a long time, and you build a strong relationship with them”* (Carole).

The following table (Table 1) presents the themes and corresponding sub themes extracted from the data analysis. The theme ‘Addressing the unique needs of each patient’ highlights those aspects that facilitate the provision of quality EOL care for these patients. Whilst the theme ‘Obstacles to providing quality end-of-life care’ addresses those aspects perceived as hindering quality EOL care in patients with HM.

Theme	Sub themes
Addressing the unique needs of each patient	Providing physical comfort to the patient Addressing the spiritual needs of patients Working with patient beliefs to enable closure
Obstacles to providing quality EOL care	Providing palliative care in a cure-oriented care setting Non-referral to a palliative unit Non-inclusion of nurses in patient care plans Giving patients false hopes Ward environment-lack of privacy

Table 1: Themes and subthemes relating to nurses' experiences of facilitators and barriers in providing quality EOL care

3.1. Addressing the unique needs of each patient

All the participants emphasized their responsibility to ensure that quality EOL care is provided to each patient, hence facilitating a good death. They further elaborated on the 'battles' that they engaged in when serving as the patient's advocate. The participants described how they strove to provide quality person-centred care by addressing the unique needs of each patient.

"if the patient has medicine prescribed then that is provided. If he does not and I know of a medication that can help, I ensure that a doctor is contacted, and I continue to advocate for the patient's needs to be addressed. I am aware that I cannot cure the patient, but I can ensure that he is comfortable at EOL. In this way I feel a certain satisfaction." (Mary)

Melanie further explained that relatively 'small' actions on the part of the nurse, such as moistening the lips of patients at EOL, can make a significant difference in the patient's well-being. She further explained that the passage of time is experienced differently by a person who is suffering at EOL, as time is perceived to pass slower.

"small things are done, which mean a lot to them, for example, you moisten a bit their lips, they are so dry... you are lessening that extra suffering, you turn their position every 2 hours, two hours in the same position is a long time for the patient but not for you, change his position, give him a back rub, you relieve him from that extra pain" (Melanie)

Four participants emphasized the need to address the patient's spiritual needs at EOL. One nurse (Stephanie)

described the importance of her own physical presence and her interaction with the patient during a meaningful spiritual experience.

"they [the patients] tell you that at the end I want to end up praying...I want to stay quiet and say certain prayers... sometimes I just sit down beside them and we pray together" (Stephanie)

Losing a patient is very difficult as it is very hard for the nurse to let go. However, Carole described that preparing the patient and their relatives for the impending death, enabled the patient to die in peace. Such preparations include helping to address any pending concerns expressed by the patients and/or their families, such as the need to draw up a will. By targeting such concerns where possible, the patient and/or family can obtain closure.

"you would have prepared them and their relatives, for instance by exploring any pending concerns and supporting them, such as for example the drawing up of a will. The patient can then die in peace. If you know that you did everything for them, then it helps you accept the situation, and it is less challenging to let them go." (Carole).

Hence, working with the 'patients' concerns' to enable closure, ensuring that their spiritual needs are met and keeping the patient physically comfortable were perceived as facilitators ensuring quality EOL care.

3.2. Obstacles to providing quality EOL care

Nurses working within a HOU described struggling to cope with the 'competing' demands of patients actively undergoing treatment and those requiring palliative care

at EOL in the same ward. These struggles were further compounded by staff shortages as highlighted by all the participants, that left them feeling frustrated and disillusioned.

“We are short of staff, so although you would like to spend some more time with the patient you just can’t. Here [in the HOU] you find patients undergoing aggressive treatment and others at EOL who need your presence, your comfort... you cannot provide the care that each requires effectively and that angers me”. (Stephanie).

In fact, Carole further highlighted the lack of referrals by doctors to palliative care as an obstacle that hinders quality EOL care. She states:

“When a patient is at EOL, I do not think that they [medical professionals] make any referrals to palliative care and because they do not refer, I believe that that hinders a good death” (Carole)

The lack of inclusion in meetings and consultation between doctors and nurses in formulating and evaluating patient care plans hindered optimum patient care. The nurses expressed that they spent a considerable amount of time caring for the patient and hence, they felt the responsibility to voice the patient’s specific needs and concerns. Only ward managers and doctors attended clinical meetings that discussed patient care and this was perceived as an obstacle hindering the quality of care provided.

“I agree that as part of a team we can discuss the condition of the patient and contribute to the formulation and evaluation of their care plan at EOL. We nurses are at their [patients] bedside twenty – four hours a day and we really know the needs of these patients who at this stage are very vulnerable and need to be provided with comfort and support” (Ruth).

Mary shared that she had experienced such inclusive teamwork at other entities providing EOL care. She reiterated that the nurse’s role at EOL should not just be task oriented, but rather nurses should collaborate within a multidisciplinary team. In this manner, the holistic needs of patients could be discussed, targeted and a person-centred care plan formulated and implemented.

“... I was placed as a student in other hospitals, and I’ve seen these types of meetings being held by multidisciplinary teams about patients at the EOL. I

believe that these types of meetings are beneficial for the patient as they would be treated as a person, not a bed number or just a case. Their holistic needs can then be addressed” (Mary).

The provision of false hopes to patients is seen as an obstacle by nurses, as unfinished business may not be resolved, and closure will not be achieved. However, according to Carole, at times, relatives and patients may remain in denial and this poses an obstacle to EOL care.

“You keep the patients and the relatives hoping when you continue with aggressive treatments. I think that they do tell them that it is in vain, but who is going to accept it? If the doctor gives you a bad diagnosis, you continue to hope just the same.” (Carole).

Environmental issues in the care setting, such as a lack of privacy, was another obstacle identified by nurses. Patients with HM spend a considerable amount of time in a HOU and often formed strong bonds with both staff and other patients. Hence, the death of a patient profoundly impacted other patients within the ward. Ruth also referred to the presence of equipment that served as barriers, preventing close physical and emotional presence between the patient at EOL and their relatives.

“In the five bedded room they cannot die peacefully. Only the curtain separates them from other patients. It is very traumatic when a patient dies in front of others and even more so for our patients, as they develop strong bonds due to their long hospital stays. The equipment attached to them also hardly leaves enough space for the relatives” (Ruth)

Hence, the non-inclusion of nurses in care plan decision making; the lack of patient privacy in the ward; the non-referral of EOL patients to a palliative unit and care provision within a cure-oriented ward culture were perceived as obstacles to quality EOL care provision.

4. Discussion

Further to Grech et al’s study (2018) that explored the emotional burden on nurses and their perspective of medical futility, this paper contributes to extant literature by exploring the nurses’ perspectives of facilitators and barriers to quality EOL care in patients with HM in a HOU. Current literature tends to focus mainly on the perceptions of haematologists regarding the following

barriers in EOL care, the avoidance of EOL discussions and the non-referral of patients to palliative care.

Although the nurses described the challenge of “*letting the patient go*,” they also expressed satisfaction and closure when they managed to provide quality EOL care. Conversely, when barriers were encountered, the nurses expressed anger, disillusionment, and frustration at not providing quality person-centred care and closure was not achieved.

4.1. Facilitating the provision of quality end-of-life care

Ensuring the physical comfort of the patient is imperative to nurses in EOL care. However, addressing the need for comfort in EOL patients may sometimes prove challenging in a fast-paced acute hospital setting, having a cure-oriented, high-technology culture (Cotogni et al., 2018). Nurses providing EOL care highlighted that physical comfort can be provided even through ‘*small things*’ (such as moistening the patient’s dry lips) that mean so much to the patient. Providing quality EOL care requires nurses to be flexible, whereby they can deviate from set tasks, priorities and daily routines to engage with the patient in these person-centred moments, where their unique needs can be addressed (Lannie et al., 2021). The nurses acknowledged that although they could not cure the patient through their actions, they could mitigate some of the challenges being experienced by the patient and provide comfort.

Participants in this study also emphasized that the patients’ needs were multifaceted and that their spiritual needs should also be addressed. All the participants agreed that by working with the patients’ values and beliefs, a spiritual sense of well-being could be achieved. In fact, Ross and McSherry (2018) state that nurses could provide ‘care that is spiritual,’ by exploring 2 questions with the patient, namely: ‘What is most important to you now? How can we help?’. By exploring this topic in a non-judgmental manner, nurses provide patients with an opportunity to reveal what they are comfortable to discuss and disclose (Fitch & Bartlett, 2019). In this manner the patient’s foremost needs can be identified. This was exemplified in the present study where one participant described supporting the patient through her physical presence and by accompanying the patient in prayer. Whilst it is tempting to attribute the participants’ emphasis on spiritual care to the strong presence of religion within Maltese society (Gellel & Sultana, 2008),

it would be premature to do so, as this was not explored in great depth and warrants further examination. Accepting a poor prognosis was an obstacle for patients with HM and their families. Yet, a recognition of dying was essential to achieve quality EOL care (Taylor et al., 2017). One participant described that both the patient and their relatives often hoped for a miracle. Nurses further struggled with an internal conflict of having to burst the bubble of hope to all concerned including themselves (Leung et al., 2011). However, the participants stressed the importance of assisting the patient to accept their prognosis. This enabled the patient to resolve any ‘unfinished business’, dying peacefully and in comfort achieving a ‘good’ death.

4.2. Barriers hindering the provision of quality EOL care

Identifying the obstacles in providing quality EOL care for patients with HM highlights aspects that need to be targeted to improve the patient’s experience of EOL care (Kuczmarski & Odejide, 2021).

All of the participants emphasized a lack of sufficient time to dedicate to each patient, as a barrier that hindered quality EOL care. In fact, EOL care by nurses in a non-palliative setting is often described as mainly task oriented (Lai et al., 2018). Participants further identified staff shortages as aggravating the situation, with nurses struggling to cope with two different patient demands, that of patients receiving curative care, juxtaposed with those requiring comfort care at EOL in a HOU. Consequently, working with loss and caring for patients at EOL within a curative care setting such as a HOU, can be challenging and distressing for nurses. The implementation of ‘Schwartz Rounds’ whereby opportunities are provided for staff to reflect on the emotional impact of their work have been reported to have a positive impact on professional practice (Maben et al., 2021).

Palliative care is reported to provide expert symptom-directed support that addresses the physical and emotional symptoms of patients and is associated with a consequent improvement in the patient’s quality care (El-Jawahri et al., 2021). The non-referral of haematology patients to palliative care was highlighted by participants as instigating distress, since they felt that they themselves, were unable to provide quality EOL care to patients with HM. At the time of the study, the sole Palliative Care Inpatient Unit in Malta was located in a

different hospital to the HOU and despite a change in this situation, with both units having shifted to the same building, anecdotal evidence suggests that non-referral of these patients is still an issue. Moreover, the lack of a palliative care physicians with a specialised focus on patients with HM, possibly results in the specific and complex needs of this patient cohort being overlooked (Wedding, 2021). This highlights the importance of supporting nurses to assertively communicate their views within the multidisciplinary team, in relation to palliative care referral and in so doing, enable them to adopt the role of patient advocate, as opposed to the role of supporters (Blaževičienė et al., 2017). The importance of a multidisciplinary team that fosters integration and equal collaboration of each team member has been mooted as essential to the satisfaction of patients' complex end of life needs (Borgstrom et al., 2021).

The provision of false hopes to patients which is a consequence of a cure-oriented culture that the nurses previously highlighted, was additionally identified as a barrier in providing quality EOL care to these patients. A cure-oriented culture is reflected in an environment that is not conducive to ensuring patient privacy, a serene setting and one ensuring adequate space for intimate patient-family interactions highlighted as enabling a good death. In such circumstances, patients and relatives find it more difficult to accept the EOL stage. This also poses greater challenges for nurses as it hampers their goal of enabling effective quality of EOL care and a good death for the patient. Additionally, the proximity of all patients poses greater challenges to nurses who must address the needs and concerns of other patients who develop strong bonds with each other due to long hospital stays in the unit and who become greatly upset when one of them is at EOL.

4.3. Limitations

Although the study has contributed to extant literature by identifying nurses' perceptions on barriers and facilitators that influence the provision of a good death, several limitations should be highlighted. Typical of an IPA study, the number of study participants was small, and this may impact on the generalizability of the study. However, the aim of the study was not to generalize

findings, but rather to provide an in-depth account of the nurses' experiences. In addition, all the participants were females, reflecting the gender composition of this ward. Despite this, future research could explore the experiences of male nurses caring for EOL patients in a HOU.

5. Conclusion

This paper draws on the findings of a qualitative study and through the two identified themes, namely "*Addressing the unique needs of each patient*" and "*Obstacles to providing quality end of life care*" highlights nurses' perceptions of facilitators and barriers in the provision of EOL care to patients with HM in a HOU. In this study, participants identified the facilitators as those factors that enable them to provide what they perceive to be quality EOL care for their patients that ultimately leads to a 'good death'. Conversely, the barriers were associated with those factors that generally emanated from a cure-oriented environment and that obstructed nurses from providing quality EOL care and a 'good death' for their patients. Furthermore, their perceptions on the quality of EOL care that they provided had an undeniable emotional impact on these nurses, veering between feelings of satisfaction when they believed they enabled a 'good death' and feelings of distress if they believed that they had failed to do so. Recommendations that emerge from these findings, include further research that examines the HOU's cultural orientation and the impact of this on the quality of EOL care. Additionally, an exploration of the experiences and perceptions of all the key players would help provide a holistic picture of the present reality and could lead to the identification of strategies to strengthen the facilitators and minimise the barriers to quality EOL care provision. Further recommendations include multidisciplinary education for all healthcare professionals in the HOU, in relation to the benefits of palliative care at the EOL and the identification and implementation of strategies to improve the functionality and effectiveness of the multidisciplinary team towards the common goal of providing their patients with quality care at the end of their lives.

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