

The lived experience of palliative homecare nurses in Singapore

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ABSTRACT

Introduction: Homecare nurses had been and still are the backbone of palliative care services in Singapore. Although extensively documented by overseas researchers, the local perspective of their identity has not been evaluated. We aimed to uncover the lived experience of palliative homecare nurses so as to understand the meaning and interpretation of their experience of being homecare nurses.

Methods: The research methodology was underpinned by the tenets of hermeneutic phenomenology. Two focus group discussions were held to gather responses from a purposive sample of ten nurses who belonged to five agencies that provide palliative homecare in Singapore. The discourses were audiotaped and transcribed verbatim for qualitative analysis.

Results: The common themes that emerged were organised into six domains: Introduction to palliative care; Initial experiences; Challenges; Working in a team; Working with the doctor; and Support. Despite the different settings, most of the experiences were consistent with those described elsewhere.

Conclusion: The palliative homecare nurse assumes a prominent role as part of a team, since she often has in-depth connections with her patients. Although it can be depressing and trying at times, she grows to see this role as both a privilege and a calling.

Keywords: nurses, palliative care, qualitative research

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INTRODUCTION

The hospice movement in Singapore started in the mid 1980s; it mainly supported patients with cancer who were dying at home.⁽¹⁾ Since then, it has developed into a framework where services are rendered in

different settings at various levels of our healthcare system. Palliative care is offered in some hospitals at the tertiary level, while inpatient hospices and several homecare organisations serve patients residing in the community. The homecare nurse had been and still is the backbone of the palliative care services. Supported by a multidisciplinary team comprising doctors and social workers, she makes periodic visits to the patient at home to assess and manage the myriad symptoms and care needs, including out-of-hours care in some instances.

With time, the role of the palliative homecare nurse has evolved to include education, administration and research.⁽²⁾ Community and palliative care nursing is described as both complex and challenging, where the ideals for care are often compromised by competing practice demands.⁽³⁾ Palliative nurses often work more than their contracted hours, with few breaks during the working day. Despite this, they have consistently displayed a high level of commitment and injected a sense of meaning and purpose to their work.⁽⁴⁾

Although extensively documented by investigators outside of Singapore, the experience and the local perspective of barriers or challenges faced by our nurses have not been evaluated. The aim of this study was to understand homecare nurses in the context of the work that they perform. It informs us about how we can better attract and retain this limited pool of vital resource. Both the structure and processes of our services, as well as the way we interact with our nursing colleagues can then evolve toward achieving this objective. Most importantly, our patients will benefit from a better-equipped and happier workforce.

METHODS

To elicit and examine the experiences of palliative homecare nurses in detail, the focus group discussion (FGD) method was selected for data collection. FGD emphasises the collective testimony rather than the individual narrative. Thus, it promotes the free expression of ideas in a safe environment among people from a similar background.⁽⁵⁾ By applying this technique of enquiry, a lot of contextual information can be generated in a short time.⁽⁶⁾

Underpinning the research methodology is

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hermeneutic phenomenology. It begins by respecting the person/participant as self-knowing. Hermeneutics encourages the investigator (etic viewpoint) to reflect on the individual narratives (emic viewpoints).⁽⁷⁾ The study design therefore combines the characteristics of both descriptive and interpretive phenomenology. Van Manen's research framework is used.⁽⁸⁾ It highlights the importance of identifying the essence of each experience, but stresses the search for meaning between the lines and tries to find the language that captures these essences. Van Manen's six research activities are: (1) Turning to the nature of the lived experience; (2) Investigating experience as we live it rather than as we conceptualise it; (3) Reflecting on the essential themes that characterise the phenomenon; (4) Describing the phenomenon through the art of writing and rewriting; (5) Maintaining a strong and orientated relation to the phenomenon; and (6) Balancing the research context by considering parts and wholes.

Following the tenets of phenomenology, this study used purposeful sampling in which participants were selected based on the specific knowledge they possessed and their willingness to share.⁽⁹⁾ Nurses were invited from the five local homecare agencies that provide palliative care at home. They all had varying professional experiences in the field to enable collection of a wide spectrum of views. The inclusion criterion was at least one year of experience in providing palliative homecare in Singapore. Only female nurses were included, as they are representative of our present workforce. They also had to be comfortable conversing in English. Nurses who held full administrative or research positions were excluded. If two nurses were from the same organisation, one could not be a direct superior of the other so as to reduce the influence on responses from power differences.

Two FGDs were held separately one week apart in August 2009. They were both facilitated by the first author. The investigators recognised the bearing that the facilitator (a physician and colleague in the palliative specialty) might have on the 'authenticity' of interaction, with an impact on the conclusions that might be drawn eventually. However, intrinsic to the FGD method of data collection, the 'horizontal' interaction among the participants often reduced the influence of the facilitator on the discourse to a minimum. Participants were briefed at the beginning about the nature of enquiry, emphasising the search for meaning in their individual experience. They were asked simple and neutral questions for a start. The flow of dialogue was determined by the responses generated by the participants. An example of the way we opened each FGD would be a question like "Tell us how

you come to be a homecare nurse". The second author observed and took field notes. He also obtained consent and demographic information from the participants before each session. Each FGD lasted about two and a half hours and terminated when a participant felt that she had nothing more to add. Proceedings were audiotaped and transcribed verbatim by the first author. The analysis, which began once the FGD ended, was done by carrying out repeated reviews of the recordings. Preliminary findings from the first FGD informed and refined the discourse in the second FGD.

Data was analysed using the phenomenological approach described earlier, based on the Utrecht School of Phenomenology by Van Manen.⁽¹⁰⁾ Transcripts were first coded and then categorised manually into different physical folders after repeated readings. The focus was on the meaning ascribed to experiences shared. The early themes that emerged were organised in writing into a construct that best described the common views of the nurses, bearing in mind the particularity of individual perceptions. The first author reflected on the material with his knowledge of the field and then returned to the data to refine them for veracity. Eventually, the final themes were again assembled in script when a cohesive narrative was found. The second author, who has extensive experience in qualitative research and who was the Director of Nursing of an inpatient hospice when this study was being conducted, performed 'peer debriefing'. This occurs when an expert on the method follows the audit trail and checks the analytic steps, such as the reduction of categories to themes. The researcher's biases are explored and the basis for any interpretation is clarified. This process helps to establish credibility through external validation.⁽¹¹⁾

The study was approved by the NHG Domain Specific Review Board. From analysis to reporting, participants were identified only by number codes in order to maintain confidentiality. No incentives or remuneration were given for participation. All nurses attended the FGDs in their own time during two weekends.

RESULTS

The participants comprised ten palliative homecare nurses from five organisations that provide palliative homecare in Singapore. The organisations were Agape Methodist Hospice, Assisi Hospice, HCA Hospice Care, Metta Hospice Care and the Singapore Cancer Society. HCA Hospice Care is the biggest in terms of staff strength, and was represented by four nurses (two in each FGD), while the rest were from the other organisations. Six nurses took part in the first FGD and

Table I. Profile of participants in the two focus groups.

Nurse	Age (yrs)	Marital status	Religion	Palliative care experience (yrs)	Professional qualification
1	44	Single	Christian	6	Grad Cert in Pallcare
2	53	Single	Christian	7	State Registered Nurse
3	41	Married	Christian	3	Grad Cert in Pallcare
4	42	Married	Free thinker	12	Grad Cert in Pallcare
5	57	Divorced	Christian	6	State Registered Nurse
6	54	Married	Christian	12	State Registered Nurse
7	53	Single	Christian	12	Degree in Nursing
8	28	Married	Buddhist	1	State Registered Nurse
9	53	Single	Christian	3	State Registered Nurse
10	52	Married	Christian	6	State Registered Nurse

four in the second FGD. Their profiles are described in Table I.

The investigators organised the themes that emerged from the analysis into six domains: (1) Introduction to palliative care; (2) Initial experiences; (3) Challenges; (4) Working in a team; (5) Working with the doctor; and (6) Support. Although the domains are listed separately, they are intimately related to each other. Extracts of transcripts (in italics between inverted commas) are quoted with the notations, "...": significant pause; "[]": material omitted; and "[my boss]": explanatory material added by researchers.

Introduction to palliative care: Most of the nurses had limited knowledge about palliative care before they started. Geriatric medicine and chronic care were some preliminary notions. Almost all the nurses had been introduced by friends who were already in the field. The reasons for a switch to this field varied. Some had felt a need to move on or to learn new things. Others longed to do something more meaningful. Nurse 10: *"I have been more than ten years in my previous job. Getting to find that life is quite meaningless. I wasn't serving anybody in any way. [] So I started looking around for another job that is more meaningful for me. [] I did not even know of palliative care that time. [] My friend mentioned that her good friend is working in palliative care. [] So she said she will introduce me. [] After going out with her one day, I was very impressed with pallcare and how it helps people."* Another nurse had personally experienced the loss of a loved one, which prompted a journey of self-discovery. In time, she embraced palliative homecare. Among those who had religious faiths, the majority sought divine direction before the transition. Nurse 5: *"I prayed very hard... for you know, something suitable for me. [] And I thought this was it."*

Initial experiences: The beginnings were largely tentative for the nurses. Palliative care took the form of part-time service or volunteering. In the early days and

even in some cases presently, it was mostly experiential training at commencement. After a month of following a senior, the nurse started rendering palliative care on her own. Nurse 6: *"I was following the sister [] and for also about one month, then after that I was on my own. Then slowly my workload increased, you see. Then sort of separate [from the supervisor] out. [] Our time is so many years ago. We don't have this kind of basic foundation course [available now]. We sort of learn on the job."* Some nurses said that they felt unsure and stressed when they worked on their own. The nature of the job was perceived to be radically different from the hospital setting where they had trained and worked. Nurse 8: *"It is not an easy job... it is very different from the hospital setting. First you have to be in the frontline. You have to very accurately assess the patient's symptoms."* Nurse 2: *"When you are struggling alone out there, it can be quite frightening... especially in the beginning. [] You kind of feel vulnerable because you don't know what's going to happen when the next call [telephone] comes. [] After a few months, I was more steady. Only later then I start to feel... what a privilege it is, to be given permission to enter a patient's life and make a difference."* All the nurses felt that in palliative care, exceptional quality care was expected from them, as the patients were more sick. There was always a need to carefully evaluate patients' symptoms and make sound decisions. Nurse 1: *"Our patients are very sick. And you cannot afford to make the wrong assessment. [] A high level of care is required compared to other homecare. [] We learn to work independently although we have the doctor."* This sense of unease persisted for several months. During this period, many of the nurses recalled that they felt like giving up. Nurse 3: *"At first I was so afraid I will make a mistake and get sued. Actually thought of throwing in the towel and quit."*

Challenges: A participant shared the perils of going on call and providing out-of-hours coverage. This is not

a universal practice and happens in smaller organisations where services are wholly nurse-led. Difficulties arise when actively dying patients come under the nurse's care. Such circumstances necessitate frequent calls and visits. It is more formidable since the nurse is faced with the prospect of a full load the next day. Nurse 6: *"The stress comes in the form of having to go on call. [] They keep on calling you like that in the middle of the night, you know, call you when the patient is dying, this and that many times, so that, get not enough sleep. The next day, got to work again. [] So sometimes, you are so tired, when you are driving, you close your eyes, you worry, you get accident because not enough sleep."* Despite this, nurses still accept this responsibility graciously, as they believe they are catering to a genuine need. Nurse 6: *"That was the stress, but personally we don't care because I understand that when they call you, they are already in stress, the family. They really need your help. [] So I am very willing to help."* Nurse 5: *"Once you set your mind to it, you get used to it. [] You sort of say to yourself, that's what you like to do. Focus on it and then do your best."*

Some nurses shared the limitations of not being able to initiate treatment during their home visits other than those for routine conditions like fever, thrush or constipation. This occurs especially when one is new on the job, where there may be a lack of trust on the doctors' part, or when there are no designated doctors in the service. A second visit would often have to be made before orders are given and treatment instituted. In these instances, a sense of frustration and powerlessness prevails. Nurse 8: *"She wanted to take tablets instead of syrup medicine. But when I spoke to the doctor, he felt that syrup will be better rather than tablet form. But in the end, after having much discussion with the doctor, for few times we... it was actually the next day. We actually switch to tablet. But at that point in time, when I was with the patient, I actually felt that I cannot do anything for the patient. [] So sometimes certain medications we have to start on the spot. [Patient] May not be around for the next visit already."*

A few nurses shared feelings of isolation despite being in a team, as they worked alone most of the time. One participant suggested that this was a reflection of the volume and pace of their work. Nurse 10: *"I mean we hardly see each other. I go my case, and all. [] At least I still know you have got a new hairstyle or what. Put on weight or what. [] I mean, in an organisation, you do this work, people don't even know what is happening. I don't even know what cases you have or what."* However, not all nurses felt the same way.

The additional roles of educator and preceptor to visitors, such as student nurses, medical undergraduates and postgraduate physicians, added to the burden of work. However, this was perceived by different nurses as a boon or bane. Nurse 10: *"There was one stage, it was very frequent. My colleagues were grumbling, with all this work, I still have to bring this person out to train and all that."* The daily quota of cases imposed by some organisations was vigorously discussed during both FGDs. The nurses' opinions differed as to the ideal number of cases, but all agreed to the fact that factors such as the severity of cases, geographical coverage and caseload should be considered. This would mandate the maximal number of cases to be attended to, including working overtime, whether a quota exists or not. Nurse 9: *"If your total is so high, you die die go and see more patients, because if not...having seen the patient is better than never seen."* Nurses in this system complained about occasional compromised care and frequently feeling drained. Nurse 10: *"Sometimes you want to spend a bit more time when there is some issue, but you can't because the next one is due and then the next one is due. Then you will push back, push back. [] Sometimes you need time to focus, you need time to organise. [] Yah, I think it is compromising the care."*

The emotional burden of care was also discussed. The nurse and patient/family bond built over a long period of time was much stronger in homecare than in the hospital setting. Although it led to a greater overall satisfaction, this arrangement obligated a higher emotional investment and accountability on the nurse's part. Nurse 3: *"When we follow them for a while, we become very good friends. When something happens they just call me. You know, it is a heavy responsibility."* At a personal level, some nurses found it difficult later to share bad news because of the special relationship that existed between them and the patient's family. Fear of getting blamed was a concern that was brought up and resonated among them. Nurse 4: *"After knowing them for a while, it gets harder to tell them when the patient is dying... you still want to keep maintaining hope. You also want to make sure everything is done correctly."* Many nurses experienced anticipatory grief due to the nature of the job. Learning how to 'switch off' when one leaves the patient, 'strike a delicate balance', 'be tough' or even remain 'emotionally detached' were factors that most nurses felt were paramount to surviving the job. An unexpected death may sometimes be conceived by the nurse as a 'failure'. Nurse 1: *"I will think back, wondering whether I have missed out anything."* The nurses complained of experiencing a frequent tussle

between balancing the role of a traditional task-oriented nurse and being a compassionate friend.

Working in a team: The nurses openly shared numerous amusing anecdotes and unforgettable incidents related to team-work. While some were pleasant, others were upsetting. The common concepts of a 'team' distilled from the two FGDs are as follows. The team was felt to be as much a concept as it is a unique entity. It is convened at the outset to achieve a common goal. Individual members complement each other not only in learning and service delivery, but also in support and inspiration. Nurse 2: *"You can say we work both together and separately. Each of us are good in our own field. We have meetings together to discuss what's best for the patients. [] We learn from each other. [] The patient is under my name... it is an interesting relationship, us."* Nurse 5: *"You must work in an environment that keeps you going. [] Because you see the passion of that person. [] In the same boat, for the same aim."* The second point is particularly prominent as this was the common sentiment of almost every nurse about their own teams. The opportunity to share everything, good or bad, with a team and to receive offers of help and encouragement when the going gets tough keeps everyone in the race. Nevertheless, the team is also where differences can give rise to implacable and bitter conflicts. Nurse 6: *"What has it [previous incident related to disagreement with team] taught me? I can only say that I learn. I find that, you know how to say... I was very disappointed with the team I was on. [] I don't want to say some more yah [looking and sounding emotional as she closed]."* Learning stops when there is no more open sharing, especially when it is discerned to be 'unsafe' to do so. In its present form, a delicate balance of roles and responsibilities for nurses exists and this continues to be negotiated with time. Nurse 7: *"We used to share openly during her [former medical director] time. But now, let's say we learn to keep our mouth shut. [] After a while, we do work better together. Then people come and go, or they change teams. You learn to deal with constant change."*

Working with doctors: As their main co-workers, the nurses had much to say about their physician colleagues. They reported skirmishes and struggles with budding doctors, doctors on rotation or outsourced doctors. Nurse 10: *"Sometimes it is so difficult. You call them, they also say they can't do anything. So it is like call or don't call make no difference."* The traditional hierarchy or divide between the two professions has an impact on how differences in opinion on what is best for the patient are negotiated. The physician is still the one

who makes the order, as nurses have no prescribing rights beyond anti-pyretics or laxatives. Nurse 9: *"A doctor wanted to start one dosing of medication. But I felt that it was not enough. [] But that person don't listen. Fine, we go to your way. You are a doctor, we follow you. [] But then the outcome was no good. Because this is not a junior doctor, I sort of let him be, out of respect for one another. [] But if it is not going to work, you know, we can still come back to the patient lah."* Strategies that have worked for some nurses include giving a succinct summary and clearly spelling out the active issue when discussing a case. Keeping the patient as the focus above personal differences helped. By setting up a clear work culture or ethic, the organisation can play a big part in preventing clashes and optimising the performance of the team as a unit. Nurse 9: *"But it depends on the organisation. What does the organisation expect the nursing staff to behave? If the organisation feels that you have to address the doctor as doctor so and so, we are ready to. [] The philosophy of the organisation, how the organisation want to organise the services. [] Is it a service whereby here we are working in a team? There is no barrier. There is no hierarchy?"* Despite these situations, nurses and doctors share a special bond in a palliative care team, a unique alliance that is not commonly seen in an institution setting. Nurse 10: *"Sorry in homecare, the doctors have a closer bond to us than in the hospital. You are struggling together for the patient sake. [] Whether got drive Mercedes [luxury car] or not, rain or shine, you go out together. And both of you are focused on how best to help the patient. The bond is very strong."*

Support: This was expressed at two levels, organisation and individual. At the organisation level, it was felt that supervisors and colleagues (including team managers, medical social workers and doctors) have been helpful. This help comes in the form of joint visits, counselling or simply just lending a listening ear. Debriefing was recognised to be helpful, whether for every case or just for the challenging ones. Attendance at funeral wakes or bereavement visits was considered valuable. Nurse 10: *"I owe myself a closure. To say goodbye to this patient."* Most nurses did so in their own time. Some, however, felt that these should be considered as standard of care. At the individual level, support came from prayer or church, family and friends. Self-reflection and journaling were extremely useful tools for one nurse in particular. Others went on holiday breaks whenever carer stress set in. Some found crying to be therapeutic. Nurse 6: *"You go home, before you sleep, you think about it, you cry. Then after that okay."*

For me it's like that. I won't talk to my other half. [] I just keep to myself. I just pray. I pray."

DISCUSSION

This is the first local study to document the experiences of our palliative homecare nurses. The first author was prompted to conduct this research having had the opportunity to work previously with these nurses from various organisations. The investigators adopted a methodology that would reveal how our nurses view their job and make sense of it. Hermeneutics complements phenomenology, as it assists the researcher in gaining a deeper insight by paying attention to the nature and meaning of the language used to describe the experience. It guides the researcher in interpreting with his foreknowledge, the written (in this case transcribed) description, to unravel the underlying meanings.

The accounts of how most of our nurses 'stumbled' into palliative care points to the need for more concentrated efforts to attract nurses to join this field. The ubiquitous shortage of homecare nurses certainly suggests that this issue deserves more attention. A large proportion of our nursing colleagues have rich life experiences and professional careers behind them. Human resource administrators can work at better defining the job description of palliative homecare nurses to appeal to nurses looking for a different experience. The prevalent feelings of vulnerability and unease that nurses experience at the beginning cannot be ignored. Veteran practitioners in this field are familiar with the refrain "if they make it past the first six months, they will stay." The fledgling homecare nurse needs help to settle in and stay. Orientation and mentorship at the early phases have helped. However, further enquiry and constructive action are warranted. Otherwise, the trend of losing the precious few nurses who join the service with great passion but leave prematurely will continue.

Among the many challenges cited by the nurses, the emotional burden of care was particularly pronounced. Eventually, the nurse finds her own way to deal with this. In view of the peculiarity of the job, where the client is both a patient and friend, finding the right balance between professional boundary and humane empathy can be elusive. This is the redistribution of balance of power in a nurse-patient relationship described by other authors.^(12,13) Our nurses also struggle with this. Failure to recognise this at the outset and to develop coping strategies could lead to gradual compassion fatigue.

This is where the team, which is a common concept in palliative care, comes in. Community palliative care nurse specialists not only work as autonomous

practitioners, but also as members of a team.⁽¹⁴⁾ However, it is not always easy. A lack of well-defined roles has previously led to tension between nurses and their managers or organisations.⁽²⁾ A few nurses had intermittently felt a sense of isolation despite working in a team. This has also been reported previously in other settings.^(13,14) The significance of this phenomenon should be explored in future research.

Another interesting dimension is the doctor-nurse relationship in a team. The dynamics in this relationship are fluid and differ among organisations. In our study, we found that although care had not been compromised, it had been challenged sometimes. The nurses still regarded individual members as complementing each other and pooling strengths toward a common goal. Over time, all learnt to work better at the job and on the job. Unfortunately, by the time the right formula has been worked out, individual members may change team or leave the job. This interesting interaction has not been previously reported. The observation about support provides lessons not only in preventing burnout or resignations, but also in attracting new blood. From the nurses' responses, we have come to appreciate the fact that coping strategies are unique to the individual. This is a result of differences in personality, social background, religion and culture.⁽¹⁵⁾ However, the practice of a healthy work ethic that recognises the burden associated with this line of work may be constructive.

Other authors have highlighted that grievances surrounding working 'out of sight' in patients' homes and being 'relegated to the margins' have a negative effect on job satisfaction and progression within the nursing profession.^(16,17) We did not encounter this at any time during both FGDs. Our sample represents approximately a quarter of all active palliative homecare nurses in Singapore. With this purposive sample, we may not have revealed every facet of their experience, which we believe is unique to each nurse. However, in the second FGD, the investigators received homogeneous responses that substantiated our preliminary impressions after the initial FGD. A semi-structured interview format, where one nurse is interviewed at a time, may elicit alternative narratives. Experiences of a personal nature that may not be shared in a group situation could then surface in a presumably 'safer' setting, potentially yielding richer data.

Primarily, it was the first author's desire to understand the persona who has healed and inspired many. However, this study has multiple implications, including staff recruitment, education, welfare and palliative care practices, which administrators, co-workers and other

stakeholders can take note of. Others who have studied nurses' experience have discussed the repercussions on staff training and support, well-being and ultimately, patient care.⁽⁴⁾

In conclusion, we have discovered that a palliative homecare nurse is often one who has been searching for meaning in life. The positive experience from caring for the dying, away from a pure clinical focus, demonstrates the true value of a nurse to care. The small number of patients under her care encourages in-depth connection. Although it can be depressing and trying at times, resilience is the key to overcome the inherent challenges. Through this voyage, she grows to see the role of a palliative homecare nurse as both a privilege and a calling.

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