An exploration of the methodological challenges in examining student nurses' perceptions of preparedness for palliative care delivery at the point of registration.

Michelle Brown and Gerri Mortimore

Introduction

In a Lancet editorial (2013), there was a call for more research that was not based purely on economic gain but on impact for patients and to support the experience and health of individuals; they cited Chalmers and Glasziou (2009) suggesting that perhaps research that had not been conclusive or exciting is abandoned, potentially hindering publication and inherent learning. Dissemination of findings is crucial to advance understanding, even when the results are not necessarily those expected (Derman and Jaeger 2018). This research is presented through a determination to share experience in research conducted with 3rd year adult nursing students. Following the introduction of the Skills Annexe in the Future Nurse Standards (Nursing and Midwifery Council [NMC], 2018), the researcher aspired to determine whether adult nursing students felt more prepared for the delivery of palliative and end-of-life care (PAEOLC) as they completed their pre-registration degree programme. The premise being that improving their preparation and knowledge may have the potential to improve PAEOLC delivery for patients and their loved ones in the future.

Palliative and end-of-life care should be person-centred encompassing physical, psychological, social and spiritual needs (National Institute for Health and Care Excellence [NICE] 2019). Patients and their loved ones may have additional worries or concerns, for example environmental or financial support needs. The factors contributing to distress as one enters the end-of-life or when faced with a life-limiting illness require a compassionate approach that encompasses and facilitates a dignified and supportive experience for both the patient and their loved ones. There are many variables that influence the quality of this essential care, and these include: inadequate symptomatic relief, poor communication, ineffective response to changes in needs, and these can all have a significant and detrimental impact on the patients experience as they reach the end-of-life and for that of their loved ones (Brown 2016).

The World Health Organisation [WHO] (2018) stated that poor preparation and education can have a negative impact on patient care. Currently, there is little in the way of educational provision for post-registration nurses to support their ongoing development in this challenging and emotive healthcare provision where patients share their innermost thoughts, feelings, and fears (WHO, 2020; Brown, 2016). Nurses being faced with existential questions from patients is not a recent concept, but one that has been experienced by many nurses who suggested they had received little theoretical preparation (Tan et al 2006). In 2018 the NMC introduced palliative care skills into the Skills Annexe within the standards for education for pre-registration to support nurses to respond to this essential element of nursing care. There has been a plethora of evidence suggesting nurses feel ill-prepared for PAEOLC and this may engender an element of reticence with feelings of guilt and withdrawal (Cross, 2019; Barker, et el., 2021; Melvin 2012). They distance themselves from the patient for fear of upsetting or 'making things worse.' As the nurse withdraws, care is compromised and the journey for the patient is one of inadequate care and the potential for suffering. Furthermore, feelings of being ill-prepared can have a negative impact on staff wellbeing with self-deprecating behaviour leading to poor self-compassion and stress, nurses being unkind to themselves. This lack of self-compassion has been linked to lack of compassion for others (Gilbert 2009). A compassionate approach to those who are struggling with a life-limiting or end-of-life diagnosis is fundamental. The desire to have a positive impact on patient experience and that of their loved ones should be inherent on the philosophy of PAEOLC (National Palliative and End of Life Care Partnership [NPELCP] 2021, NICE 2019, Brown 2016).

Moon (2009) discusses the challenges in the assumption that as a teacher teaches, a learner learns and so the question surrounding whether the annexe addresses student proficiency in PAEOLC is the focus of this research. Does exposure to a specific skill mean they are able to undertake the skill? To complicate this further, undertaking a skill may be associated with proficiency or competence but that may not include emotional preparation. Tan et al (2013) outlines the challenges of understanding how to practice a skill and cites Benners (1984) taxonomy of learning suggesting that the holistic understanding comes as the newly qualified nurse progress through from beginner up to advanced beginner and so on. How can we assure emotional preparedness for the delivery of such intimate and life affirming care? When a patient's whole life footprint and the role and impact they have had on the people they love and others around them are threatened with a life limiting diagnosis, the potential for distress and that of their loved ones can challenge our own life and world views. Personalising experience, comparing our lives is a human response which, when dealt with repetitively, and being ill prepared for, may have an impact on our own wellbeing, leading to burn out and anxiety (Andersson, Salickiene and Rosengren, 2016).

Understanding whether the introduction of PAEOLC education into the skills annexe has made a positive impact on the education and preparedness to deliver this care is fundamental in the drive for improving the experience as the patient approaches the end-of-life. Following the inception of the latest NMC (2018) standards for education, there has been a paucity of data to suggest perceived changes in preparedness of nurses for delivering PAEOLC. This is the fundamental question underpinning the proposed research but only when the full programme has been delivered can one identify whether learning and preparedness has taken place. The aim is therefore to determine whether this NMC requirement for competency in end-of-life care has prepared student nurses as they embark on their career as a registered nurse.

The research question

Has the introduction of end-of-life care in Annexe B: Nursing procedures as part of the Future Nurse Proficiencies supported the preparation of students as they transition to registration?

Research challenges and limitations

Research is fundamental in contributing to understanding and shaping health and social care, examples include; National Health Service England (NHS) (2023) how research may support integrated care systems, the World Health Organisation (WHO) (2023) advocating the importance of research in supporting public health challenges and inequalities in health. As we understand why we need to research, the need to understand how to research is equally important. Considering the ontological as well as the epistemological suppositions is pivotal in guiding questions and subsequent design of a research study (Hitchcock and Hughes 1995). Whilst one can consider how to understand and plan research methodology to address the question, there are inherent challenges associated with conducting any research. One may assume that the hypothesis will be proven, that adequate numbers of participants will come forward as planned and that the research will contribute to the body of knowledge and inform practice.

Methodology

This aim of this study was to examine student nurses' perceptions of their preparedness to deliver PAEOLC as they complete their BSc adult nursing programme. This was an exploratory study design to understand whether the underpinning requirement to prepare those entering the NMC register in caring for and managing these patients who have life-limiting illness or entering the end-of-life has been achieved through the introduction of specific elements relating to PAEOLC contained within the NMC skills annexe (NMC 2018).

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) was selected as the methodology for this study (Smith Flowers and Larkin 2021). There is a need to not simply see the way nurses care for the dying but to understand the nurses lived experience which is deeply rooted in the phenomenological approach to qualitative enquiry. IPA transcends beyond the lived experience to one of relationships with that experience and the involvement and meaning within the situation or experience of study. Interpretation must be part of this process and is referred to as hermeneutics (Smith Flowers and Larkin 2021), however this research will involve the researcher trying to understand the understanding of the participant referred to as double hermeneutics (Smith and Osborne 2003). The ideography involved allows us to examine the language and meaning. This is not a linear activity and involves a cyclic approach whereby the research intersects between individual text, individual sentences, individual words and back again to immerse the researcher in the language and the relationships inherent in the experience.

As a researcher the author did not want to pigeonhole participants responses into categories that were pre-defined to provide insight but rather, were trying to understand and develop meaning from the individual's lived experience as expressed through their terms and insights and build from their standpoint. It is their reflection of what they do, which in this case, it is their engagement in the delivery of PAEOLC and the impact that this has on them in an existential manner i.e. how this affects their purpose, behaviour, beliefs and learning as well as on them as an individual who will experience dying themselves.

As the researcher, the author's interpretation is fundamental but detailed notes regarding tone, words or phrases can support understanding and perceptions of the participant in their experience. The analysis is a reflective engagement between the researcher and the participants narrative where the researcher must make sense and extract understanding from their own understanding (Smith, Flowers and Larkin 2022).

Whilst this methodology does not require large numbers of participants, because, unlike focus groups whereby the group voice is the area of study, it is the individual's interpretation of their experience that is of interest and then the researcher's interpretation of that interpretation. Having more than 1 participant to support similar meanings and perception of meanings within the experiences in PAEOLC will ensure individual nuances for the participants (Smith, Flowers and Larking 2022).

Reflexivity

IPA allows the researcher to reflect on their own subjectivity thereby facilitating a transparency in relation to the researchers' interest and experience. The researcher, in this study has significant experience and holds expertise in the field of PAEOLC with several years based in palliative care and oncology. This is referred to as reflexivity and it values the researchers experience in the subject area and allows them the transparency in how they perceive and interpret the subject experiences (Lumsden 2019). Reflexivity is deeply rooted in social science research however, it is paramount that the participants voice is truly heard to ensure a deep understanding and interpretation of their lived experience. The deep application and immersion of the researchers' experience is utilised to understand the student's interpretation of their experience during the analysis is the strength in IPA.

Only two participants were recruited in this research which presented fundamental issues in the analysis. Recruitment for volunteer studies carries risk for participation but it is imperative that participants provide full informed consent and do not feel pressured or coerced into taking part in a study. This need to maintain ethical standards is imperative however variables that will be addressed in this paper, contributed to low recruitment numbers.

Ethics

Following University ethical approval for the research, information was provided verbally and electronically via a member of the BSc adult nursing programme team. On the electronic information sheet, a link was provided to a Microsoft consent form thereby minimising any risk of manipulation and feeling compelled to consent. Contact numbers were provided for further information, and if students had any concerns regarding the ethical conduct of the researcher, reporting processes were made available. The participants were anonymised and allowed to select their own anonymised identification code.

Following this, interview appointments were scheduled using a Teams link at a time suitable to the participant. Great care was taken to minimise burden to the participants and convenience by choosing suitable times. At this point in the programme the students were completing their final piece of assessed work and under pressure to achieve the classification they were aiming for and to successfully source employment on completion of the programme. In addition, the financial insecurities placed on student nurses during a challenging financial crisis and rising costs had a significant impact on students with many having to seek additional employment to support their ongoing studies (Grant-Smith and Zwaan 2019).

Discussion

Although the target number was 4, only 2 participants were recruited to the study in the 6-month timeframe given for recruitment. These were purposively selected to assure of exposure to the phenomena. Adult student nurses are extremely likely to have been exposed to palliative and end-of-life care during their 2300 hours of required clinical practice and the skills annexe supports exposure and understanding (NMC 2018). Identifying students from this group fulfilled the purpose of the study and the rationale for selecting IPA methodology. The experimental phenomena and context was end-of-life care, as a student nurse and examining their understanding of this lived experience of preparation for end-of-life care delivery. Single cases may be useful for this methodology however aiming for a greater number of participants for this question was considered as Smith, Flowers and Larkin (2022) suggest that generalisation requires care and consideration. Although Smith Larkin and Flowers (2022) discuss generalisation, for qualitative research methodology, identifying where we may be able to transfer findings would be more pertinent in the philosophical approach of the method. Transferability of findings have been considered and important learning in order to inform future work of the researcher and fellow researchers undertaking research which seeks to address or answer similar questions. On reflection IPA may have been inherently flawed in this study and other methods like ….

The method of recruitment was designed to refrain from the potential participants feeling pressured into taking part. This was operationalised by only one, face to face discussion with a member of the programme team who were not actively involved in the research. The information was then provided electronically on their university subject information site. No further reminders or requests for volunteers were undertaken. These students were at a particularly stressful point in their programme where final coursework was due and final placement was looming. Engaging students at this point was challenging and resulted in the poor response rate. Setting a tight time frame for recruitment was naïve and this has generated a greater understanding for the researcher regarding recruitment to studies where very specific factors such as student workload and academic stress may influence participation.

Despite the low recruitment, an examination using IPA of the participants responses was undertaken and generate potentially transferable understanding to our experiences and future support for adult nursing students. Indeed, it may also be transferable to other healthcare professionals as they may often succumb to experience in supporting patients with end-of-life or palliative prognoses. This research provides a foundation for understanding the preparedness and the experiences in being deemed 'ready' for PAEOLC at the point of registration and suggest whether further research is warranted. The participants were within the final few weeks of completing their BSc adult nursing programme. One of the participants had undertaken a nursing associate programme prior to recruitment at the 18-month entry point of the BSc, the 2nd participant had undertaken the full three-year BSc adult nursing route which facilitated diversity in programme and clinical experience.

Utilising IPA methodology and the hermeneutic principles allowed an examination of the participant responses. Having only two participants carries the assumption that there is little credibility to the research study. Whilst we acknowledge the failure to recruit the target for the study, an exploration of the participants responses is worthwhile to identify the perceptions relating to the phenomena of delivering EOLC as the student reaches the final phase of their pre-registration adult nursing programme.

The initial analysis suggests students, whilst theoretically prepared continue to refrain from examining their own emotional responses and affirming the rationale behind their response. Whilst one understands that the patients' health, wellbeing and welfare is a nurses priority (NMC 2018), understanding one's own responses and wellbeing to ensure a healthy approach to ones working role is also fundamentally important. In the interview with participant one, they spoke about support and the availability but also about and the importance of talking to peers. They suggested these options "if you are really upset." This suggests a extreme response to experience and it is only then you should seek support. There is the perception that you carry on if you are not “really upset.” This need to be seen to cope and carry on may not be a sustainable means of managing the emotional stress and burden associated with PAEOLC. Participant one almost suggested that dealing with it helped to make you a better nurse suggesting it was a means of “building resilience.” Therefore, suggests a perception that you become less affected the more you have to deal with. Compassion fatigue has been identified in professional’s who have extended exposure to the suffering of others Rimmer 2021) therefore renders this belief a little disquieting and concerning.

Participant two spoke of their own bereavement and how they forgot what they had been taught and termed the “backlash” of not being prepared for how caring for a patient might resonate with their loved one. They spoke about “fear of backlash” therefore utilising very distressing and meaningful tone and language to describe a moment that they found disturbing and did not fit with their caring role and responsibilities. They articulated a sense of a façade and an acting role demanding a behaviour that, although it was not deficient of compassion and care for the patient, it appeared to be absent in caring for themselves. What was clear was that performing was enabled through preparing themselves, insinuating an ‘acting the part’ approach and moving personal distress to one side to enable them to do the best for their patient. When analysing both participant narratives, similar perceptions and beliefs are evident. These themes relate to emotional control and regulation and that help seeking behaviour hold be saved for when things are ‘bad.’

Conclusion

This paper has addressed and discussed some of the dilemmas in recruiting purposive samples, but also the ethical and moral challenges in trying to allow potential participants the time and space to consider participation without feeling pressured into taking part in research. Understanding and selecting a methodology that supports the research question is vital and seeking support and advice from more established researchers may provide insight and more positive research outcomes.

The analysis of the participants responses in their experience in PAEOLC carries transferable insight but requires further research and understanding surrounding how we can prepare our future workforce for the emotional demands in PAEOLC delivery.

To determine how we can achieve this we need to further examine the lived experience of pre-qualifying nursing students. This dichotomy requires further thought to ensure a solution is achieved as those delivering Pre-registration nursing programmes need to be assured of the students psychological and physical preparedness, not only to embark on their registered careers but also to care for patients and their loved ones in very challenging and emotive circumstances.

Although this was focused on adult nursing students, the potential to examine other disciplines should be considered. Patients and their loved ones require healthcare from staff who feel prepared physically and emotionally for the demands ensued in PAEOLC.

References

Andersson, E., Salickiene, Z., Rosengren, K. (2016) To be involved — A qualitative study of nurses' experiences of caring for dying patients. *Nurse Education Today* 38: 144-149.

Barker, R., Wilson, P., & Butler, C. (2021). How does English national EOL care policy impact on the experience of older people at the EOL? Findings from a realist evaluation. *Primary Health Care Research & Development*, 22, E57.

Benner, P., (1984). *From Novice to Expert: Excellence and Power in Nursing Practice*. Addison Wesley. California

Brown, M (2016) *Palliative Care in Nursing and Healthcare.* London, Sage

Chalmers, I. and Glasziou, P., 2009. Avoidable waste in the production and reporting of research evidence. *The Lancet*, 374(9683);86-89.

Cross, L.A. (2019) Compassion Fatigue in palliative Care Nursing. A Concept Analysis. Journal of Hospice & Palliative Nursing 21(1):21-28.

Derman R. J., Jaeger F. J. (2018) Overcoming challenges to dissemination and implementation of research findings in under-resourced countries. *Reproductive Health*. Jun 22;15(Suppl 1):86. doi: 10.1186/s12978-018-0538-z. PMID: 29945654; PMCID: PMC6019998.

Gilbert, P (2009) *The Compassionate Mind: A New Approach to facing the Challenges of Life.* London: Constable Robinson

Grant-Smith, D., de Zwaan, L. (2019) Don't spend, eat less, save more: Responses to the financial stress experienced by nursing students during unpaid clinical placements. *Nurse Education in Practice* 35;1-6.

Hitchcock, G., Hughes, D. (1995) *Research and the teacher* (second ed). London, Routledge

Lancet (2013) What is the purpose of medical research? Editorial. *Lancet* 381(9864) 347, February 02. Accessed on 9/5/24 at:
https://doi.org/10.1016/S0140-6736(13)60149-X

Lumsden, K. (2019) Reflexivity. Theory, method, ad practice. Oxon, Routledge.

Melvin, C.S. (2013) Professional compassion fatigue: what is the true cost of nurses caring for the dying? *International Journal of Palliative Nursing*. v. 18 (12). doi.org/10.12968/ijpn.2012.18.12.606

Moon, J. A. (2009) *A Handbook of reflective and experiential learning. Theory and practice.* London. Routledge Falmer

National Health Service England (2023) *maximising the benefits of research: Guidance for integrated care systems*
Accessed on 13/5/24 at:
NHS England » Maximising the benefits of research: Guidance for integrated care systems

National Palliative and End of Life Care Partnership (2021) *Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026*

Accessed on 13/3/24 at:

https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf

Rimmer, A. (2021)How can I manage compassion fatigue? *British medical Journal* 2021;373:n1495 http://dx.doi.org/10.1136/bmj.n1495

Smith, J. A., Flowers, P., Larkin, M. (2022) *Interpretative Phenomenological Analysis Theory, methods and research*. 2nd ed London, Sage.

Smith, J. A., and Osborne, M. (2003) *Interpretative Phenomenological Analysis. In J. A. Smith (Ed.) Qualitative psychology: A practical guide to methods*. London, Sage.

Tan, J., Low, J., Yap, P., Lee, A., Pang, W.S., Wu, Y., (2006). Multicultural aging. Caring for dying patients and those facing death in an acute-care hospital in Singapore: a nurse's perspective. *Journal of Gerontological Nursing*. 32 (5), 17–24.

World Health Organisation (2023) *Research*

Accessed on 13/5/24 at:

Research (who.int)

World Health Organisation (2022) *Palliative Care*

Accessed on 14/9/22 at:

https://www.who.int/health-topics/palliative-care

World Health Organization (2018). *Integrating Palliative Care and Symptom Relief into Primary Health Care: A WHO Guide for Planners, Implementers and Managers; 2018.*

Accessed on 15/9/22 at:

https://apps.who.int/iris/handle/10665/274559