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The *Australian Journal of Advanced Nursing* is the peer-reviewed scholarly journal of the Australian Nursing and Midwifery Federation (ANMF). The Mission of AJAN is to provide a forum to showcase and promote a wide variety of original research and scholarly work to inform and empower nurses, midwives, and other healthcare professionals to improve the health and wellbeing of all communities and to be prepared for the future.

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EDITORIAL

Up next on the agenda: evidence-based reforms and reform-driven research

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Over the last few years, there has been a discernible shift in the visibility and influence of healthcare workers beyond their usual sphere of impact. The silver lining of the very dark cloud of the pandemic might be that the advice of nurses, midwives, and other healthcare staff around the world was placed at the forefront of government decision making and media appearances. The public became very aware of the important roles that these essential workers carried out daily and how vital a functional healthcare sector is for the operation of a range of disparate sectors including the economy, travel, community services, and even food production and international trade. Nurses, midwives, and other healthcare staff comprise a vast proportion of the Australian population and when unified for a cause, can have substantial economic and political power. Abroad, this workforce has substantial influence also, and many countries are dealing with similar challenges, issues, and opportunities as Australia, where high-quality research inquiry and scholarship are critical to reform and improving health care access, experiences, and outcomes.

The Australian Nursing and Midwifery Federation (ANMF) is Australia's largest national union and professional association for healthcare professionals. Across the ANMF's eight state and territory branches, the ANMF represents the professional, industrial, and political interests of more than 322,000 nurses, midwives, and carers. The ANMF's diverse and dispersed membership works in many sectors including but not limited to public and private health, aged care, schools, vocational and tertiary education, research, the community, and disability care across a wide variety of metropolitan, regional, and remote locations. As the ANMF's scholarly journal, the *Australian Journal of Advanced Nursing* (AJAN) seeks to showcase and promote a wide variety of original research and scholarly work to inform and empower nurses,

midwives, and other healthcare professionals to improve the health and wellbeing of all communities across Australia and beyond and be prepared for the future.

Every two years the ANMF holds a National Biennial Conference, bringing together delegates from each State/Territory to discuss contemporary issues and necessary reforms pertinent to nurses and midwives. In October, the 16th National Biennial Conference was held in Sydney with more than one hundred delegates in attendance. The conference was themed around 'A Collective Force for Change' signifying the increasing influence that nurses, midwives, and care workers have gained over the past few years in driving and guiding reforms. With recent success in lobbying for major reforms to the Australian aged care sector,^{1,3} including requirements to ensure at least one registered nurse is onsite at all times in nursing homes, mandated minimum direct care minutes, and a 15% pay raise for aged care workers, the ANMF is keen to ride this momentum to pursue further reforms across a range of areas.

During the conference, Branch delegates put forward a range of important motions for discussion and resolution, highlighting ongoing issues with workforce shortages and the attraction and retention of nurses and midwives.⁴ As with many countries, nursing and midwifery shortages have been persistent in Australia,^{5,6} and were amplified due to the impact of the pandemic. Projected future shortages could total around 123,000 nurses by 2030.⁷ With increasing rates of complex presentations, an aging population, and greater individual healthcare needs, all of which were compounded by the COVID-19 pandemic, all aspects of Australia's healthcare system have been placed under extreme strain.⁸ Healthcare workers are in many contexts, spread too thinly and have borne this strain with a lack of staff and poor skills mixes leading to unsafe practices and

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missed care.⁹ These poor work conditions have resulted in increased rates of absenteeism, burnout, and decreased job satisfaction among nurses and midwives, with many expressing the desire to prematurely retire or leave the sector to work elsewhere.¹⁰ These issues are by no means unique to Australia, with international evidence highlighting the widespread detrimental and often distressing impact of the COVID-19 pandemic on the health care workforce.¹⁰⁻¹² Conference delegates put forward resolutions on topics from enhancing nursing and midwifery retention in rural and remote areas, improving recruitment of new graduates through incentive-based programs, encouraging the return to practice of nurses and midwives who have recently left the industry, and improving recruitment pathways of nurses and midwives from overseas. A range of financial-based incentives to improve retention were also proposed, including greater fringe benefit tax exemptions, making health care workers overtime hours tax-exempt, and improving salary sacrifice, superannuation, and tax deductions options. Other resolutions in this area include mandating minimum staff ratios in all private and public clinical settings to improve worker wellbeing and patient safety.

Related to workforce shortages and issues regarding attracting staff, considerable focus was placed on the need to improve educational pathways for aspiring nurses and midwives. Much of this focus was placed on alleviating the financial strains upon students resulting from the cost-of-living crisis that appears both driven by increased inflation as well as the reserve bank's blunt instrument of rising interest rates to combat inflation. Undergraduate nursing and midwifery students must undertake lengthy clinical placements during their studies. Students commit several weeks of each year which are not remunerated, can interfere with gainful employment, and make it challenging to balance study with work. Because of this, many students must give up their studies to provide for themselves or their families.^{13,14} Resolutions on this topic pertained to abolishing tertiary education fees for nursing and midwifery students with the provision that they agree to stay in working roles for a set number of years after graduation, and supporting students who are on clinical placements as part of their course/s by having the federal and/or state government provide payment for their time.

Several resolutions also related to providing protections for nurses and midwives against psychosocial hazards and occupational violence and aggression (OVA). Australian estimates suggest that around 67% of nurses are likely to have experienced some kind of OVA in the past year,^{15,16} and around 20% of nurses experience OVA on a weekly or daily basis.¹⁶ A systematic review identified that overall exposure to violence among nurses can be estimated at 36.4% for physical violence, 66.9% for nonphysical violence, 39.7% for bullying, and 25% for sexual harassment.¹⁷ The prevalence of OVA among midwifery is also alarmingly high, with around 63% of midwives likely to experience violence and aggression

at some point.¹⁶ Violence and aggression against midwives is most likely to be verbal abuse, physical abuse, or threats of harm with weapons.¹⁸ These rates are also unacceptably high around the world,^{19,20} and thus this issue is of international relevance. The risk of violence or aggression is only one of the many psychosocial hazards faced by nurses and midwives.²¹ As frontline workers in a high-pressure work environment, performing hazardous or challenging tasks such as injections, wound care, medication administration, and assisting in medical procedures, nurses and midwives are exposed to many occupational hazards.²² The stress of working in this environment is compounded by a range of psychosocial factors such as a lack of control over workload, shift work, low financial remuneration, and high levels of exposure to potentially traumatic events.²³⁻²⁵ Resolutions relating to psychosocial work hazards included; lobbying for further legislated protection for healthcare workers providing care, implementing preventative wellbeing measures for healthcare workers to help mitigate the known psychosocial risks associated with the professions, and lobbying for research into nursing and midwifery staff who are affected by and are required to care for patients who have been subjected to domestic violence.

Other resolutions of note related to lobbying for the inclusion of additional items under Medicare, Australia's universal health care funding system, making mental healthcare free for all Australians, and fully funding same-sex and single-parent fertility treatment. Resolutions were also passed relating to the appointment of nurse practitioners specialising in Gerontology at aged care facilities in Australia, mandating specific enrolled nurse direct care minutes in nursing homes, and the creation of regulation and registration standards for assistants in nursing.

The Biennial resolutions will guide much of the ANMF's work over the next two years and highlight a range of challenges, priorities, and issues that are also faced internationally. Many of these topics are likely to also provide an indication of the kinds of subjects that *AJAN* will be looking to publish over the coming months. As we move into the upcoming 41st volume of *AJAN*, the editorial team and Board will be considering a call for high quality papers that focus on; nurse and midwife scope of practice reforms, including nurse-/midwife-led models of care and safety of independent nurse practitioners; challenges faced by nursing and midwifery students at all levels, including the impact of clinical placements on financial wellbeing; the impact of occupational violence and aggression faced by health workers and strategies to reduce this; retention and attraction strategies and their effectiveness among health workers, including remuneration and financial-based incentives; and the delivery of safe and quality care of older people, particularly those residing in nursing homes. While research with a focus on the Australian regulatory space is welcome, as these issues are of international relevance, all authors from any country are encouraged to submit.

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As many healthcare workers face the challenges of providing quality and equitable care, maintaining work/life balance and rewarding careers, and keeping themselves safe in a post-pandemic world it is important that agendas for reform are underpinned by a solid foundation of high quality research. *The Australian Journal of Advanced Nursing* looks forward to working alongside our authors, reviewers, and readers to support a platform that ensures all nurses, midwives and personal care workers are empowered to meet this challenge, both in 2024 and beyond.

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RESEARCH ARTICLES

Barriers and facilitators to managing uncertainty in nurses' clinical reasoning in post-anaesthesia care units: a qualitative thematic analysis

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ABSTRACT

Objective: To describe and analyse barriers and facilitators to managing uncertainty in nurses' clinical reasoning in post-anaesthesia care units.

Background: The diagnostic process in complex clinical settings often involves uncertainty. This can bias clinical reasoning and compromise the safety of healthcare. Still, little is known about how nurses deal with uncertainty in their clinical practice.

Study design and methods: This study employs a qualitative descriptive design. Fourteen nurses working at a post-anaesthesia care unit were selected through convenience sampling. Data was collected through semi-structured interviews and analysed using thematic analysis. The deductive analysis was undertaken based on the Theory of Reasoned Action. This study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

Results: Two major themes emerged from the analysis: 'barriers' and 'facilitators'. Each major theme aggregated four themes: intention to perform the behaviour, attitudes, subjective norms, and external variables.

Discussion: The perceptions of barriers and facilitators provide valuable insights into current and desired practices that can help minimise uncertainty in nurses' clinical reasoning in post-anaesthesia care units. They provide knowledge and future direction for clinical practice improvements by addressing motivations for reasoning behaviour. The need to create more nurse-friendly working conditions and reduce the cognitive and emotional impact of uncertainty was also identified.

Conclusion: This study provides a comprehensive list of barriers and facilitators of uncertainty management in clinical reasoning based on nurses' perceptions. Recognising behaviours based on reasoned action is essential to manage uncertainty in nurses' clinical reasoning.

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Implications for research, policy, and practice:

These findings can be used by different stakeholders to better manage uncertainty in healthcare settings. They are valuable resources for health professionals, researchers, and healthcare institutions attempting to improve health practices and enhance safety in health services.

What is already known about the topic?

- The safety and quality of post-anaesthesia care is highly influenced by the clinical reasoning of healthcare providers.
- In complex clinical settings, such as post-anaesthesia care units, uncertainty in clinical reasoning is common and expected.
- Identifying barriers and facilitators of clinical reasoning is essential to support nurses cope with uncertainty in post-anaesthesia care units.

What this paper adds:

- Embracing uncertainty as an opportunity for personal and professional development is a facilitating factor.
- The barriers to managing uncertainty are related to individual personality characteristics and the nature of interpersonal and professional relationships.
- Maladaptation to uncertainty in clinical reasoning has a major impact on nurses' wellbeing in post-anaesthesia care units.

Keywords: Clinical reasoning, clinical decision-making, patient safety, post-anaesthesia nursing, postoperative period, uncertainty

BACKGROUND

The immediate postoperative period carries a significant risk of severe complications. Missed or delayed post-anaesthesia diagnoses were cited as contributing factors in 56.3% of cases resulting in the death of a patient.¹

Postoperative care is complex and involves making decisions in critical situations. The healthcare providers' ability to provide safe and appropriate care is dependent upon their clinical judgment and decision-making skills.² Controlling risks, planning care, and having adequate clinical reasoning skills are essential to maintain patient safety.³

Clinical reasoning is the process of applying knowledge and expertise to a clinical situation to develop a solution and manage a clinical problem.⁴ Although it is considered a core competence in clinical practice, clinical reasoning has been addressed as either a multifaceted construct or a 'black box' phenomenon.⁵ Decision-making depends on cognitive inputs from highly trained healthcare providers. Those cognitive inputs fall short of what clinical practice requires. The complex information process is under severe uncertainty, and the inevitable outcome is that decisions too often cannot be justified based on available knowledge, risk, cost, benefit, or patients' desires.⁶

A review, employing the Model of Uncertainty in Complex Healthcare Contexts (MUCH-S) taxonomy, considered uncertainty in nurses' clinical reasoning in Post-Anesthesia Care Units (PACU), examining it from personal, practical and scientific perspectives. The findings highlight an appreciation of nurses' intuitive reasoning, the perceived knowledge gaps and clinical (in)experience, providing valuable insights to inform and improve clinical reasoning in post-anesthesia settings. A review explored uncertainty

in nurses' clinical reasoning under uncertainty in Post-Anaesthesia Care Units (PACU) from a personal, practical, and scientific perspective using the Model of Uncertainty in Complex Healthcare Settings (MUCH-S) taxonomy.^{7,8} Another study offered archetypes applicable to various health ecosystems and proposed an overarching model of different types of uncertainty that demonstrated their interrelatedness in health systems.⁹ Moreover, Kalke and colleagues *underscored* the necessity for a more in-depth exploration of healthcare providers' encounters with uncertainty and highlighted challenges in researching uncertainty communication, particularly emphasizing probability, scientific issues, and patient experiences.

Clinical reasoning is an interpretive practice, and it consists of several processes. It is an intrinsically contextual clinical competence that develops with practice, reflection on experience, response to knowledge retrieval capacity, and the organisation of thought during the hypothetical cause analysis.¹¹

The universal form of conscious behaviour is an action designed to change a future situation inferred from a present one, which involves perception and twofold inference. Furthermore, we must infer what the future situation would have been without our inference, and what change will be wrought in it by our action. However, none of these processes are infallible, accurate, or complete. We do not infer the present as it is, and in its totality, nor do we infer the future from the present with a high degree of reliability, nor do we accurately know the consequences of one's own actions. In addition, actions are not always performed in the way in which they were imagined and desired.¹²

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In this sense, the Theory of Reasoned Action (TRA) intends to predict and understand intentional behaviour.¹³ It focuses on individuals' beliefs concerning the future performance of a given behaviour. The central construct is intention, a motivational determinant of behaviour. Intention reflects the extent to which an individual is likely to plan to make and invest efforts in pursuing a given behaviour. It is conceptualised as a function of two belief-based constructs: attitudes and subjective norms. Attitudes are polarised evaluations of performing the behaviour in the future, while subjective norms reflect beliefs that significant others would want them to perform the behaviour.¹³ According to the TRA, nurses' intentions are influenced by four subjective factors: their attitudes towards uncertainty management (i.e., their attitudes towards the behaviour), their perception of what other people would do (i.e., descriptive social norms), their perception of what others who are important to them would do (i.e. injunctive social norms), and their perception of whether they have the necessary internal and external resources to perform the behaviour (i.e., perceived behavioural control).¹³ Therefore, TRA seems relevant to describe nurses' attitudes and behaviours regarding barriers and facilitators to managing uncertainty in clinical reasoning, which may contribute to behaviour change.

OBJECTIVE

This study aims to describe and analyse the barriers and facilitators of uncertainty management in nurses' clinical reasoning in PACU. Given the current emphasis on safety and quality of healthcare, a careful understanding of the barriers and facilitators of clinical reasoning is essential to support nurses in PACU to manage uncertainty in complex clinical scenarios.

STUDY DESIGN AND METHODS

DESIGN

We conducted a descriptive exploratory study using a qualitative design. This study was designed to explore the underlying nature of the perceived barriers and facilitators of uncertainty management and uncover the full nature of the ill-defined phenomenon.¹⁴

The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to ensure a comprehensive report of the findings.¹⁵

PARTICIPANT SELECTION AND RECRUITMENT

Participants were recruited by email. The procedure was intentionally led by the head nurse to minimise personal bias in the recruitment. A pamphlet was sent by email describing the study, objectives, methods, and data collection techniques. Interested nurses contacted the first author who conducted further screening to verify their eligibility.

Convenience sampling was used to ensure maximum variation in demographic characteristics. The inclusion criteria were nurses who provided postoperative care in phase I in the adults polyvalent PACU,¹⁶ who agreed to participate in the study. As there is no specialisation in nursing anaesthesia in Portugal, all nurses working at the PACU were eligible regardless of their complementary training. Nurses in training/onboarding programs were excluded.

DATA COLLECTION

Data were collected using semi-structured interviews between April and May 2022. A pilot interview was undertaken with one participant to adjust the interview script and to refine the first author's interview skills. After the interview's transcription and discussion with the research team, no changes were made to the script. The pilot interview was included in data analysis.

After prior appointment with each participant, the interviews were conducted individually and took place in a meeting room of the anaesthesiology service, where privacy was guaranteed. All the participants were interviewed once. Only the researcher and the participant were present during the interview. All interviews were conducted by the first author, a female medical-surgical nurse specialist who also works in the PACU and who's a doctoral candidate. The interviewer discussed appropriate interview techniques and behaviours with the research team. Participants knew in advance the researcher's goals resulting from her academic studies. They reported no biases or pre-assumptions.

The interviews were audio recorded and lasted 30 to 64 minutes (mean 45 minutes). The semi-structured interview guide (Table 1) was developed based on the results of a previous literature review.⁷ Field notes were taken immediately after the interview to clarify speech pauses and write reflective memos throughout the research. Since the interview was conducted in European Portuguese, the interview excerpts were translated and back translated to ensure the original meaning was preserved.

TABLE 1. THE SEMI-STRUCTURED INTERVIEW GUIDE

Questions
1. What effects do you think uncertainty in clinical reasoning can have on nurses in the Post-Anaesthesia Care Unit? a) Do you consider it to be an irrelevant, stressful, or benign event? b) Do you consider it to be a harmful, threatening, or challenging event?
2. What are your thoughts and feelings when you experience uncertainty in nursing clinical reasoning? a) Describe the main cognitive, emotional, and behavioural challenges.

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Data saturation was reached with 10 interviews, which means that no new information emerged.¹⁷ However, the 14 nurses willing to participate in the study were interviewed to confirm the phenomenon of interest.

DATA ANALYSIS

The interviews were transcribed verbatim using Microsoft Word and returned to participants for validation. No requests for changes were received. The documents were stored in an encrypted file in Google Drive and later analysed using MAXQDA Analytics Pro 2022 software.

Data was analysed using deductive thematic analysis with a pre-identified theoretical framework: the TRA.¹³ Thematic analysis focuses on the perceived significance of ideas and how they connect practices, thus it is relevant to many perioperative concerns.¹⁸ It was considered the most appropriate and pragmatic method to understand nurses' experiences of uncertainty in complex settings.

Thematic analysis was performed following the six steps by Braun and Clarke.¹⁹ Phase 1, 'familiarisation with the data', consists of immersing yourself to become familiar with the depth and breadth of the empirical material collected through the interviews. Preliminary meanings and patterns were searched. In Phase 2, 'coding', codes were generated based on the theoretical framework's components, then data was classified into these predetermined theoretical relevant structures. From this stage onwards, two coders independently compared the analysis, identified points of convergence, divergence, and complementarity, and defined the coding guide. In Phase 3, 'searching for themes', data sets were coded and theme-organised using the coding guide arising from the theoretical framework. In Phase 4, 'reviewing themes', the themes were reviewed and refined by applying a hybrid interpretive/deductive analysis approach, that added interpretive patterns and themes to the coding guide. In Phase 5, 'defining and naming themes', the researchers involved in the initial coding and the other researchers (i.e., the independent reviewers) held two formal meetings to discuss discrepancies in data analysis and interpretation. Any discrepancies were resolved through a consensus discussion, to calibrate interpretations against each other or against baseline patterns. Additionally, the results were returned to participants to check for accuracy and resonance with their experiences. Phase 6 fulfilled the assumptions for producing the report. The results were the outcome of discussion and consensus among all authors.

RIGOUR

To ensure the rigorous criteria of qualitative research, were assessed the critical indicators of the TACT framework: (T)rustworthiness, (A)uditability, (C)redibility, and (T)ransferability.²⁰

Trustworthiness was ensured by the transparency of results generated by the participants, throughout the neutrality towards the phenomenon under study. The diversity of responses suggested the effectiveness of distinguishing between the role of colleague and researcher, which reveals the rational acceptance that participants felt comfortable sharing different points of view from the researcher. Consistency in data analysis was obtained through evaluation of intercoder reliability. The neutrality of the results was achieved through different perspectives.

Auditability was ensured by checking if the research process and the decisions taken within it were fully documented and described in the trail audit. Supervision, consciousness-writing, self-interviewing, and clarification of the insider-researcher role were means employed to overcome potential bias.

Credibility was ensured through several strategies: content validation to provide findings' feedback through member checking, where data are fed back to participants to ensure that the experiences described are recognised, and sustained engagement. The main researcher's dual role provided opportunities to address the ethical and practical issues, namely the longitudinal approach, which helped build rapport and trust with the participants, the familiarity, which facilitated understanding of the phenomenon, and the use of the 'hazarding' process, which reduced prejudices and clarified inconsistencies between narrative and behaviour.²¹ Self-reflection and a reflexive approach were necessary for the insider-researcher to be able to identify, construct, criticise, and articulate their positionality.²² Moreover, the researcher was also able to reduce the 'bureaucracy' required to engage with the participants, which enabled social interactivity. Plus, the researcher's deep familiarity with the cultural and political structure of the clinical setting provided a more in-depth understanding of the data, given the knowledge about the local reality. Data triangulation was used to identify the convergence of data.

Transferability was ensured by detailed descriptions to promote dependability of the procedure and data analysis, so that the readers can judge applicability in other contexts. Additionally, the contextual exploration related to the institutional mandate, the social mandate, and the conceptual structure of nursing allowed broader interpretations.

ETHICAL CONSIDERATIONS

The study was approved by the hospital's Ethical Committee (date: 14/04/2022, registration code 260/CES). Participants gave their informed consent prior to the interviews. Confidentiality was ensured by allocating an alphanumeric identification (e.g., P1) to each participant.

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RESULTS

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Most participants were female (71.4%), with a bachelor's degree in nursing (78.6%), and 7.14% were specialised nurses. The certification and job tasks of perianaesthesia nurses working in PACU differ across countries. The Netherlands, Ireland, and Australia are the only countries with formal education programs for perianaesthesia nurses.²³ As the qualification required of nurses to work at PACU is not formally required and defined in Portugal, some of the participating specialist nurses have a specialty outside the scope of the nurses' profile skills in the PACU. The socio-demographic characteristics of the participants are presented in Table 2.

TABLE 2. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS (N=14)

Demographic Characteristics	N (%)
Gender	
Male	4 (28.6%)
Female	10 (71.4%)
Age	
[30-39 years]	4 (28.6%)
[40-49 years]	7 (50%)
[50-59 years]	3 (21.4%)
Qualification	
Nurse Without Specialisation	8 (57.2%)
Medical Surgical Specialisation	3 (21.4%)
Mental Health Specialisation	2 (14.3%)
Community Health Specialisation	1 (7.1%)
Higher Academic Degree	
Bachelor's degree	11 (78.6%)
Master's degree	3 (21.4%)
Experience as a Nurse	
[10-19 years]	4 (28.6%)
[> 20 years]	10 (71.4%)
Experience as a Nurse at PACU	
[<10 years]	3 (21.4%)
[10-19 years]	7 (50%)
[> 20 years]	4 (28.6%)

MAJOR THEMES AND THEMES

Two major themes emerged from the hybrid interpretive/deductive analysis approach: 1) 'barriers' and 2) 'facilitators' to managing uncertainty in nurses' clinical reasoning in PACU – Figure 1. The following themes were identified: a) intention to perform the behaviour, b) attitudes (sub-themes: behavioural beliefs, evaluations of behavioural outcomes), c) subjective norms (sub-themes: normative beliefs, motivation to comply), and d) external variables (sub-themes: demographic, attitudes towards the event of uncertainty, individual traits). Given that the thematic

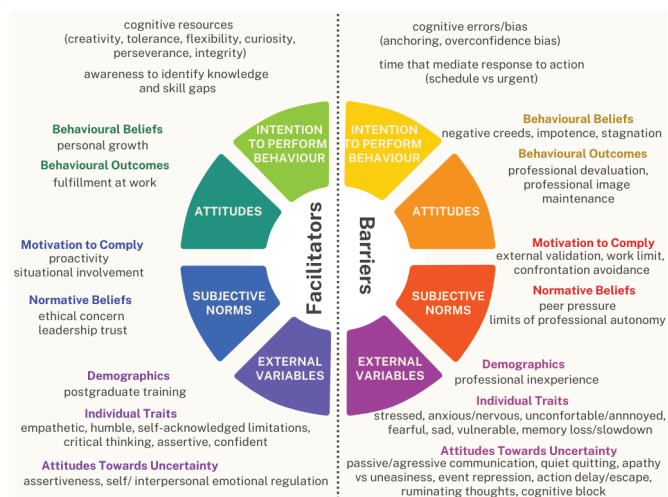


FIGURE 1. BARRIERS AND FACILITATORS TO MANAGING UNCERTAINTY IN NURSES' CLINICAL REASONING IN POST-ANAESTHESIA CARE UNIT

analysis was deductive and followed the assumptions of the TRA, the themes for barriers and facilitators were the same, with different codes distinguishing facilitators from barriers. A total of 51 codes were generated from the thematic analysis.

Barriers

The participants identified barriers to managing uncertainty in clinical reasoning in PACU based on their lived experiences.

Intention to perform the behaviour

Participants reported cognitive errors/biases (anchoring, overconfidence bias) in the intention to perform the behaviour as ineffective uncertainty management mechanisms. They reported that reaction times (scheduled versus urgent) influenced the response to a stimulus.

'I try to anchor myself in whoever is nearby. I have no problem in asking for help to minimise uncertainty.' P14

'The higher number of complex actions per unit of time, the likelihood of acting with uncertainty or insecurity. Even if a person is very confident in a given context, acting under pressure without being able to check whether good practices have been followed makes us feel insecure. If there is no time to go over this mental checklist, we might miss care.' P6

Attitudes

In the 'behavioural beliefs' sub-theme, participants identified negative creeds, impotence, and stagnation. In the 'evaluation of behavioural outcomes' sub-theme, nurses reported hiding their weaknesses to maintain their professional image. Professional devaluation was also listed as a barrier.

'As we do not want to convey an image of insecurity, uncertainty, or fragility, we end up making decisions alone, feeling unsure, which involves significant risk for the patient.' P6

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Subjective norms

In the 'normative beliefs' sub-theme, both professional interactions (peer pressure) and the limits of professional autonomy were identified.

'Each anaesthetist has their own agenda. I know the protocol, I know the algorithm, but then someone says: 'Oh no, we do it like this'. It confuses me. Do I follow the rules or the requirements?' P8

In the 'motivation to comply' sub-theme, the participants reported that they are influenced by the dependence on action/external validation needs, the work of limit/interdependence, and avoidance of confrontation.

'My perception is that nurses do not have the ability to argue scientifically. Some nurses stand up, while others just do what they're told. Which is even more serious, isn't it?' P10

External variables

In the 'demographic' sub-theme, the participants pointed out professional inexperience as a barrier.

'There are nurses with limited professional experience, and their uncertainty is even greater. I am worried that they might make some decisions on their own because they are afraid to ask questions or rely on older colleagues.' P14

In the 'attitudes towards the event of uncertainty' sub-theme, the participants reported barriers mainly related to emotional self-regulation: passive-aggressive communication, quiet quitting, apathy, event repression, action delay/escape, ruminating thoughts, cognitive blocking, behaviour of aggression, irritation, frustration, hyperreactivity, impatience, uneasiness, apprehension, projection, disappointment, and disorientation.

'Sometimes I am passive-aggressive. I send my messages subtly and sarcastically.' P13

'It does not slip my mind.' P14

'You know the guidelines, but it creates uncertainty when two patients get worse at the same time. It looks like incompetence! It makes no sense!' P4

In the 'individual traits' sub-theme, the following participant characteristics were listed as barriers: stressed, insecure, anxious/nervous, fearful/distressed, suffering/sad, uncomfortable/annoyed, vulnerable/weak, and memory loss/slowdown.

'Uncertainty, anxiety, insecurity, it is all related. The fear of failing and making clinical errors. The feeling of insecurity because you think you can't do it or you're not doing your best. Or even how the rest of the team feels about you. It always causes stress. These insecurities leave us increasingly vulnerable. On the one hand, we can try to overcome them with more theoretical support; on the other hand, we need positive reinforcements. And sometimes we may not even be

able to react, right? A series of negative feelings can lead us to stagnation, to giving up, to think it's not worth it.' P2

Facilitators

The participants identified facilitators to managing uncertainty in nurses' clinical reasoning in PACU. The facilitators were based on what the participants wanted to see happening in their clinical context (PACU).

Intention to perform the behaviour

The participants mentioned that awareness, the identification of knowledge gaps, and the use of cognitive resources (creativity, tolerance, flexibility, curiosity, receptivity, perseverance, reflection, integrity, concentration) could have a positive influence.

'The person is in a state of alert. I think this is it, but it may not be, so let me pay more attention, be more on top of it because if it's not this and it's something else, I have to take other measures to solve the problem in a timely manner.' P12

'Nurses who work for many years in PACU learn to deal with uncertainty and get used to not being right, to being flexible and tolerant. The big advantage is the flexibility.' P12

'It makes perfect sense to tackle uncertainty based on research, based on certainties. Fight uncertainty with certainty.' P9

Attitudes

Participants described personal development as 'behavioural beliefs.' In the 'evaluation of behavioural outcomes' sub-theme, the participants reported a positive impact of feeling that they have fulfilled their duty.

'We made it through that situation, we succeeded, and the outcome was positive for the patient. It boosts our self-confidence, our self-esteem.' P8

Subjective norms

In the 'normative beliefs' sub-theme, the participants reported their fear of causing harm to the patient and underlined the importance of leadership trust.

'I don't do certain tasks because I don't want to harm the patient by making a bad decision. Worsening the haemodynamic status, changing the breathing pattern, even exacerbating pain. So, I make a more careful and reasoned decision.' P13

Participants mentioned proactivity and not being directly involved in the situation in the 'motivation to comply' sub-theme.

'I can't recall ever having an in-service training in this unit. And that says a lot about what we intend to do for it. It is up to us to make these changes happen.' P9

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'I can think more clearly and confidently when I am not responsible for the situation. Uncertainty is less stressful. So, that uncertainty makes you grow. 'Whoa, I really didn't see it that way!' P13

External variables

In the 'demographic' sub-theme, the participants identified postgraduate training as a facilitator.

'The master's degree has broadened my horizons to how complacent we can be.' P9

Participants identified assertiveness and emotional regulation of others and self as facilitators in the 'attitudes towards the event of uncertainty' sub-theme.

'Maintaining safety, keeping a safe posture, speaking calmly, behaving calmly, avoiding running around, containing tics.' P3

In the 'individual traits' sub-theme, the following participant characteristics were identified as facilitators: empathy, humility/recognition of individual limitations, critical thinking, assertiveness, and confidence.

'Being humble is essential. No one is perfect, and it is through imperfection that we evolve.' P12

DISCUSSION

This study identified nurses' perceptions of barriers and facilitators at PACU for managing uncertainty in clinical reasoning.

The first major theme, 'barriers', reflects on the conditioning impact of uncertainty in nurses' clinical reasoning. The participants reported the situations experienced in their clinical practice and their impact on the personal and (inter) professional levels.

It is imperative to understand nurses' behaviour from the perspective of the TRA and the specific environmental influence.¹³ The contribution of perceived behavioural control related to the intention to perform the behaviour, the attitude toward the behaviour, and subjective norms may therefore be useful for the motivational force of change. Correcting misperceptions has been shown to reduce inadequate behaviours.¹³

An important aspect that emerged from this study is that nurses identified cognitive biases (anchoring, overconfidence) as adequate mechanisms for managing uncertainty. Nonetheless, these unconscious biases are not just individual; they also influence the organisational culture. Despite the most conscious efforts, the collective unconscious bias perpetuates the status quo and old patterns of behaviour and values. These unconscious norms of organisational behaviour exert an enormous influence over decisions and behaviours, influencing the effectiveness of practice improvement projects.²⁴

Time pressure, resource constraints, and the need to rely on cognitive shortcuts are likely to produce a lack of information, leading to negative outcomes. Nurses must work faster and stabilise patients as quickly as possible, without compromising their safety.³ The participants in this study also reported that reaction times influence the response.

Uncertainty can trigger aversive cognitive and emotional manifestations in individuals, which can lead to suboptimal decision-making and avoidance behaviours.²⁵ Underlining this, the occupational environment can also affect healthcare providers' wellbeing and mental health, leading in the short term to anxiety, concentration and sleep problems, headaches, and psychosomatic problems, as well as quality care problems.²⁶ The results of this study are consistent with the literature, namely regarding nurses' negative beliefs, sense of impotence and stagnation, need to hide professional fragility, dependence on action, avoidance of confrontation, and professional devaluation.

The participants mentioned that the lack of professional autonomy had an impact on their clinical practice. Labrague and colleagues also found that nurses with higher levels of autonomy tended to be high performing, satisfied, and committed in their jobs.²⁷ Organisational efforts are critical to fostering autonomy in practising nurses through adequate support, education, and training.

The attitudes towards the event of uncertainty revealed by participants suggest a risk of burnout. Self-regulation is impaired due to low motivation and poor ability to self-regulate behaviour.²⁸ Physical, behavioural, emotional, cognitive, social, and even existential problems presented by participants arise as a response to exposure to chronic occupational stress due to maladaptive strategies. Maladaptive regulatory resources lead nurses to self-blame (creating additional obstacles) and less job crafting (conditioning the balance between work demands and resources), negatively influencing their professional performance. Poor self-regulation, especially when nurses have low motivation and poor ability to regulate their behaviour, can lead to burnout.²⁸ In the perioperative environment, it may create an inefficient and toxic environment in which the organisation's goals, vision, and mission cannot be met.²⁹ Patient safety and access to surgical care may be compromised in organisations where nurses cannot manage uncertainty. Organisations must address the factors within their control to prevent burnout of their most precious resource, their staff.²⁹

Not everyone copes with potentially disturbing events in the same way. Some experience acute distress from which they are unable to recover. Others suffer less intensely and seem to recover quickly but then begin to experience unexpected health problems or concentration difficulties.³⁰ Hutchinson and colleagues had already highlighted the role of nurses'

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emotions in the development of clinical knowledge and skills.³¹ Emotionally informed situational awareness was described as an ability to rapidly recognise the significance of emotional information. Foregrounding emotional reasoning is a process of checking the meaning of emotions and deciding a path of action, prioritising technical issues.

The second major theme, 'facilitators', focused on the various psychological and behavioural responses to 'the subjective perception of ignorance' to maximise the positive potential of uncertainty.³² The more favourable a person's attitude is toward subjective norms and the greater the perceived control, the stronger the person's intention to perform the behaviour.¹³

Uncertainty may serve as a self-protective force, resulting in increased information-seeking.²⁵ The research on uncertainty in healthcare is mostly linked to negative and conditioning aspects of practice. However, this study also addresses the positive side of this phenomenon. The participants recalled the often-forgotten cognitive resources/soft skills (creativity, curiosity, integrity, alterity, proactivity) used to manage uncertainty. On the other hand, the notion of nurses' personal development, also associated with their emotional self-regulation, goes beyond the technical and operational aspects, adding the personal/emotional dimension.

Uncertainty has adverse effects on cognition and emotions. The information overload caused by information complexity can lead to a feeling of confusion. However, the participants saw uncertainty as a driving force, namely through alterity, humility, critical thinking, and self-confidence. The reported behavioural outcomes were proactivity and assertiveness, which is consistent with studies suggesting that positive evaluations of uncertainty contribute to psychological adjustment and are an opportunity for greater dispositional optimism.³³

In addition, uncertainty presents challenges for patients, families, healthcare providers, policymakers, and researchers, and its management is key to providing patient-centred care.³⁴ The open disclosure of uncertainty is an ethical and moral imperative.³⁵ Personalised healthcare requires translating population-based evidence to the individual, which requires sophisticated understanding and communication skills.¹⁰ If health professionals analyse their care experience based on their own individuality, they will make an approximation path in this sense.

Although uncertainty is not entirely synonymous with a lack of knowledge, it can emerge due to the characteristics and quality of available information. It seems natural that people would seek information when confronted with uncertainty.³³ This study corroborates these aspects, with the participants highlighting the importance of postgraduate training.

CONCLUSION

This study provides evidence supporting recent calls for the development of research and interventions to improve uncertainty management in ambiguous and complex healthcare settings like PACU. As uncertainty becomes a pervasive theme in healthcare, it is essential to recognise behaviours based on reasoned action and the realities of the context to undermine the barriers and maximise the facilitators. In moments of uncertainty, people are more likely to take refuge in non-analytical thinking that provides a sense of referential security. However, it is necessary to think about what is known, to see the phenomenon from another angle. Through uncertainty and doubt that the conscious construction of knowledge and the exercise of thought takes place.

IMPLICATIONS FOR RESEARCH, POLICY, AND PRACTICE

This study provides an overview of barriers and facilitators of uncertainty management in nurses' clinical reasoning in PACU. Understanding the moderators of uncertainty in clinical reasoning may have broad implications, impacting positively decision-making, patient safety, continuous professional development, professional communication and team collaboration, healthcare research, and the adaptability of healthcare providers to the complexities of their clinical practice. The crucial aspect of this research lies in exploring uncertainty within nurses' clinical reasoning, aligning with the goals of nursing knowledge and the imperative nature of evidence-based practice. Future studies on uncertainty in clinical reasoning should encompass both provider-centered and patient-centered outcomes.

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From residential aged care worker to Dementia Care Support Worker: a qualitative study of senior aged care staff perceptions of the role

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ABSTRACT

Objectives: The study investigated how senior residential aged care staff perceived the purpose, function, impact and challenges of implementing a new role in their organisation for an unregistered care worker with a Bachelor of Dementia Care: the Dementia Care Support Worker. The role was piloted over two years in an Australian organisation with three aged care facilities to examine its potential to address gaps in service provision for people with dementia.

Background: The residential aged care workforce is under pressure to care for residents with increasingly complex health conditions and where most care is provided by care workers. Presently no formal leadership role exists for care workers with specialised dementia knowledge in the aged care setting.

Study design and methods: A qualitative descriptive approach was taken to explore senior staff members' perceptions of the role at two time points. Twenty-three semi-structured interviews held in July-August 2017 (n = 12), soon after role commencement, and in February-March 2019 (n = 11) were thematically analysed.

Results: Three themes reflected senior staff members' expectations of the role: enhancing staff and management knowledge about dementia and dementia care practices; facilitating changes to improve care for residents living with dementia; and educating and supporting residents' families. Eighteen months later, participants felt the role was helping meet the need for improved care of residents with dementia, and staff understanding of dementia. They suggested communication and support structures to improve role effectiveness.

Discussion: Staff were receptive to the establishment of the Dementia Care Support Worker role and felt it resulted in improvement in dementia care. Success was contingent on strong organisational support and resourcing.

Conclusion: Improving dementia knowledge of care staff is an essential first step in driving care quality improvements. The Dementia Care Support Worker role for care workers has the potential to address knowledge needs and support improved care practices.

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Implications for research, policy, and practice:

This research models how a new role might be configured for unregistered care workers with specialist dementia knowledge. Further research is needed to explore the establishment of such a role more widely in other organisations, to investigate whether it could provide a new career development pathway for care workers and improve the skills and capacity of the aged care workforce. Substantial policy changes would also be required to support role viability, such as around increased salary. Research which examines the impact of such roles on care outcomes would complement the findings.

What is already known about the topic?

- While dementia is common in residential aged care, knowledge of dementia is typically low among the care staff.
- Consequently, care staff are not equipped to meet the complex needs of residents with dementia and their families.

- New roles for unregistered care workers with specialised dementia knowledge have been proposed, but not tested.

What this paper adds

- This research models how a new role might be configured for care workers with specialist dementia knowledge.
- Aged care facility leaders support a role for care workers with formal specialist dementia knowledge and skills, and perceive the role helps improve the quality of resident care and develop stakeholders' dementia knowledge.
- Appropriate communication and support structures are required for the effective establishment of the role.

Keywords: Dementia, nursing homes, professional role, qualitative research, quality of healthcare

BACKGROUND

The residential aged care workforce is under pressure to care for residents with increasingly complex health conditions and multiple comorbidities, particularly dementia.^{1,2} However, dementia knowledge is typically low among the unregistered care workers who comprise 70% of the Australian aged care workforce and provide the majority of care.³ Qualifications held by most Australian unregistered care workers vary in length and quality and often have limited dementia content.^{4,5} Consequently, care staff are not equipped to meet the complex needs of residents with dementia and their families,^{3,6,7} a key focus of the 2018–2021 Australian Royal Commission into Aged Care Quality and Safety.⁸ New roles for unregistered care workers with specialised dementia knowledge have been proposed.⁹ Such roles could capitalise on skills and experience obtained through work experience and training, and may help shift the focus from task-oriented care to more holistic person-centred care to enhance care quality.⁹ With unregistered care workers and their care practices being central to such roles, they differ to – and yet may complement – other dementia-focused roles like that of specialist dementia nurses.⁹

To address knowledge and skill deficits that underpin poor practice and outcomes in aged care, the Bachelor of Dementia Care program was developed by the Wicking Dementia Research and Education Centre at the University of Tasmania in 2012.¹⁰ This three year (full-time equivalent) online undergraduate program aims to develop students' knowledge of dementia, built from a comprehensive evidence-based focus ranging from the neuroscience

underlying the causes and symptoms to the care of people with dementia. The program is typically undertaken part-time by students who are active in a range of paid and unpaid roles, including registered and enrolled nurses, care workers, and family carers. Unregistered care worker graduates from this course could potentially fulfil a new role in aged care: the Dementia Care Support Worker (DCSW), integrating direct care experience with comprehensive knowledge of dementia. Facilitating change in this sector is most effective when underpinned by strong organisational support and appropriate access to resources.¹¹ Therefore, this study aimed to explore facility leaders' expectations of the DCSW role and their perceptions of the impact of the role following a two year trial.

METHOD**DESIGN AND SETTING**

This study forms part of a case study of implementation of this new role in one organisation. Facility leaders were a key focus of this study because of their whole-of-organisation perspective and responsibility for managing the delivery, rostering and assignment of tasks and personnel. A qualitative descriptive approach aimed to facilitate the production of 'data-near' findings from interviews with facility leaders to explore this new role in-depth.¹² The study setting was a large (>350 residents) not-for-profit Australian aged care provider with three sites in two cities for older adults with low-to-high care needs.

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The role was initially conceptualised as a combination of leadership, support, and hands-on care work reporting to the Executive Director Clinical, with general supervision by facility managers. Support was also provided by a DCSW project team comprising the Executive Director Clinical, managers and coordinators representing each site, and a Research Fellow (first author). The role aimed to provide care and assistance with maintaining a comfortable environment for residents, specifically to residents with dementia, provision of mentoring and support to staff, and facilitation of evidence-based approaches to dementia care. The DCSW appointee was a recent female graduate aged in her 50s with approximately 10 years' experience working with people with dementia. Prior to the appointment, she had been employed as a care worker at the organisation and was the organisation's first staff member to graduate with a Bachelor of Dementia Care. The DCSW began working full-time in the new role in May 2017 (working two days/week in each local site, one day/week at the third site located in a different city). The role was funded by the aged care provider and the Masonic Centenary Medical Research Foundation

To examine leadership perceptions of the DCSW role, interviews were held at two time points: initial ($n = 12$) in July-August 2017 soon after the DCSW commencement and final ($n = 11$) in February-March 2019 at the end of the two year trial.

PROCEDURE

Sampling was purposive, with facility senior staff recruited based on their leadership position and dispersion across the three sites. Participants were recruited via email at two time points: soon after DCSW commencement and two years later. Six participants had either left the organisation or were on leave at the second time point and were not available for interview; in this situation, attempts were made to interview the current incumbent. Recruitment was discontinued at each time point when data saturation occurred, that is, when no new codes (data categories) were being generated from interview data.¹³

Semi-structured interview guides containing open-ended questions were developed. Initial interview questions focused on the perceived function of the DCSW role, anticipated differences between the DCSW and care worker roles, early engagement with the DCSW, and anticipated and early benefits. For example, questions included 'What do you see as the function of the new DCSW role for a care worker graduate of the Bachelor of Dementia Care?' and 'How does this new role differ from the usual care worker role?'. Final interview questions focused on the impacts and outcomes including staff knowledge and care practices, preparation for the role, and role continuation. For example, questions included 'How did you engage with the DCSW over the last two years?', 'What do you see as the benefits of this role?' and 'What are the weaknesses of this role?'. Prompts were used when required to encourage participants to provide greater detail.

Face-to-face interviews were held in the workplace of each participant in a private space. Interviews were conducted by a PhD-qualified female Research Fellow, with over 15 years' experience conducting interviews in community and aged care settings and an interest in aged care workforce development (first author). Some participants knew the researcher through the DCSW project team; however, the majority had no prior relationship, with participants' knowledge of the interviewer restricted to her place of work and the information provided through the consent process. Interviews were up to 50 minutes in length (range: 15-50 minutes, median: 24 minutes). They were audio-recorded and transcribed verbatim. Field notes were taken during and after each interview and member checking was used to explore accuracy of data; three participants took the option to review and verify their interview transcript. Demographic and work experience information was collected at time of interview.

Interviews were up to 50 minutes in length (range: 15-50 minutes, median: 24 minutes). They were audio-recorded and transcribed verbatim. Field notes were taken during and after each interview and member checking was used to explore accuracy of data; three participants took the option to review and verify their interview transcript. Demographic and work experience information was collected at time of interview.

ANALYSIS

Descriptive analyses were conducted of the demographic and work experience questionnaire items. Interview transcripts were managed with NVivo (version 11, QSR International). Analysis was conducted separately for interviews from each time point. Following familiarisation with the data set through reading and re-reading transcripts and note-taking, a series of codes were developed from line-by-line analysis of transcripts. Themes were generated from the data by grouping relevant codes together using an inductive approach. Minor and major codes were developed based on level of frequency of related codes. Codes related to the categories of challenges and recommendations for the role were grouped. To help establish credibility,¹⁴ three (13%) of the transcripts were randomly selected for recoding by the last author. Inter-rater reliability (agreement between coders) was tested using this function in NVivo and rated as excellent (Cohen's Kappa = 0.78) across all nodes and transcripts.¹⁵ Exemplary verbatim quotes are provided in the main text for the themes and categories, attributed to interviewees with an interviewee number.

ETHICS

Approval was received from the University of Tasmania Human Research Ethics Committee (Ref. No. 16630). Interested staff were provided with Information Sheets. The project was then explained to them by the Research Fellow, and all participants gave written informed consent prior to their inclusion in the study.

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RESULTS

Twenty-three interviews were conducted with 17 individuals, comprising 12 initial and 11 final interviews; six individuals participated in both interviews. Demographic characteristics are provided in Table 1. The highest education level of the participants varied, and around a quarter (23.5%) had a higher level of education than the DCSW's Bachelor's degree. All but three of the participants had undertaken some form of dementia education previously, such as online courses, attending public lectures and workplace education, including workshops (not reported in the table).

TABLE 1: DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

Participant characteristics (N = 17)	n (%)
Gender and age	
Female	15 (88.2%)
Age (median, range)	52 (27-65)
Country of birth	
Australia	15 (88.2%)
Other	2 (11.8%)
Highest level of completed education	
Higher university degree (e.g. Honours, Graduate Diploma, Masters or PhD)	4 (23.5%)
Bachelor's degree	9 (52.9%)
Diploma/Associate degree	2 (11.8%)
Certificate or apprenticeship	1 (5.9%)
Secondary school	1 (5.9%)
Role and experience	
Manager (e.g. facility, executive, clinical)	9 (52.9%)
Registered or clinical nurse	6 (35.3%)
Supervisor	2 (11.8%)
Years of experience working with people with dementia (median, range)	13 (1-40)

Three major themes were generated from the analysis of expectations of the role: 1) Enhancing staff and management knowledge about dementia and dementia care practices; 2) Facilitating changes to improve care for residents living with dementia; and 3) Educating and supporting residents' families. There were two major themes and a third minor theme related to outcomes of the role: 1) Staff knowledge development; 2) Staff support and care development; and 3) Family support. A range of challenges and recommendations for the role were identified by participants.

EXPECTATIONS OF THE DCSW ROLE

Initial interviews revealed the primary issues that leadership staff felt the DCSW role could impact. The ultimate purpose of the DCSW was to facilitate delivery of quality care and improve quality of life for residents with dementia:

'We're looking to improve the care and the life of our residents... to strengthen the knowledge of our staff, and that can only come from the strength of the [DCSW] role' (P12).

Expectation Theme 1: Enhancing staff and management knowledge about dementia and dementia care practices

The DCSW was expected to develop staff education sessions, provide mentorship, and support a team of Dementia Champions. Mentorship would be operationalised through being a role model for care workers and through direct engagement, *'working one-on-one... to guide others on the right way to deal with things' (P6)* and to *'play a role educating and mentoring people on the management team [and] administration... because everyone has touch points with people in dementia care' (P11)*. It was hoped knowledge would change for all staff because *'we can't just keep doing what we're doing... I hope the change in how we approach dementia will be humungous' (P4)*.

Expectation Theme 2: Facilitating changes to improve care for residents living with dementia

It was envisaged that the DCSW could give *'more individualised attention' (P8)*, *'sit and observe how people [staff] are interacting with a person [resident]' (P4)* and conduct *'research on what works and what doesn't' (P4)*, and that they were ideally positioned to *'put research into practice' (P2)*. Secondly, the DCSW could encourage staff to implement and sustain evidence-based changes in care by: *'guid[ing] others along the 'right way' of dealing with things' (P6)*; *'researching best practice and supporting staff to learn that best practice' (P12)*; and demonstrating specific practices. Thirdly, as a mentor the DCSW could empower staff to initiate care improvements via enhancing their knowledge through a *'train the trainer model, teaching others along the way' (P4)*.

Expectation Theme 3: Educating and supporting residents' families

Some interviewees noted the DCSW could play a key role in supporting residents' families, given *'our biggest challenge really... is to support and reassure families' (P10)*. Interviewees suggested this could occur prior to admission, with ongoing support provided to address families' concerns.

'We've [P5 and DCSW] talked about working with family... so she [DCSW] can explain what to expect... give them some information and the time they need...' (P5).

OUTCOMES OF THE DCSW ROLE

Leadership staff interviews held at the second time point offered the opportunity to explore the outcomes and challenges of the DCSW role towards the end of the two-year pilot. Data from the final interviews aligned with the outcomes that were anticipated in the initial interviews.

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Outcome Theme 1: Staff knowledge development

Increased knowledge and expertise in dementia was one tangible benefit of the role. One interviewee noted how her own understanding of dementia had improved, as had that of other staff members: the DCSW 'answered my questions well so I can understand it easily, which is what people [staff] around here need' (P9).

'This role is fantastic for on-the-job learning. That really fits our industry because there are so many challenges with learning and development. It's cultural as well... Aged care staff have tended to be spoon-fed with their learning and so there's not always an awful lot of self-directed learning, so turning that around' (P17).

'I think that's a level of expertise that may not have been around 22 months ago. So I think it's trickling through' (P8).

Outcome Theme 2: Staff support and care development

The DCSW role alleviated some workload pressures and improved approaches to changed behaviours. It was reported that the '[DCSW] being available is fantastic; staff know she's there, they can save up an issue' (P17). This additional support for staff provided by the DCSW role was evident from commencement of the role. One interviewee noted how:

'Having that extra person there for support is just great... Nursing staff are enjoying the fact that they can refer on to [DCSW] if they need to, because quite often it's us trying to manage the behaviour [of residents living with dementia]' (P1).

'At the time they [area] only had one ECA [care worker] and one nurse, so it was quite hard to manage his [resident's] behaviour. They just did not have the time to offer him what he needed, so it was really good to just have [DCSW] there for that' (P1).

The benefits of having an objective and big picture perspective were also noted:

'...if your unit's in a bit of a muddle and you're in the middle of it, it can be very hard to step back and say, 'Well, we need to do this, or this and this.' Whereas I think someone [the DCSW] can walk in and view it more objectively and come up with different ways of managing situations' (P7).

There was also a perception that there was a shift from task-driven to a more person-centred approach:

'I saw a staff member taking an old fellow [sic] for a walk. They wouldn't have done that before [DCSW] came here. I think the staff are now feeling more comfortable in [doing things] like setting people's hair and sitting and talking to them. They're not so task orientated' (P13).

The combination of care worker experience and the Bachelor of Dementia Care qualification for building dementia knowledge and improving care practices was a clear benefit.

'To have that person focused on people living with dementia has been very valuable, knowing that what we're putting in place is evidence-based practice...they're across all that more than anybody else in the organisation' (P5).

Outcome Theme 3: Family support

Although a minor theme, the DCSW was reported to enable residents' family members to be better supported.

'[DCSW] is very knowledgeable and knows a lot [and] can speak to the residents' families if they don't know much about dementia. We can get [DCSW] to make an appointment and have a discussion around it...It has helped and got good feedback' (P14).

CHALLENGES FOR THE ROLE

Integrating the new role into work processes also brought challenges and unmet expectations. One interviewee acknowledged that 'I don't know that staff here have felt as engaged with [DCSW] as they could have, which has been a bit of a shame' (P7), while another noted that the DCSW could have been better integrated as 'a key part of the clinical team... valuable at a senior clinical review meeting, with senior clinical nurses, clinical leaders' (P5). One staff member noted that 'there were issues with the commencement of the role in terms of not giving staff enough knowledge about the role and how it would work' (P7). Compounding this, the DCSW was expected to work in three different sites, one of which was a three-hour drive away. The limited time available at each location presented 'a challenge to try and build relationships' (P7).

The DCSW was expected to be able to translate their own knowledge of dementia into practice and to facilitate this process among other staff. Education of staff was considered difficult in a time poor, task-focused environment and required specific skills:

'Trying to educate them [staff] on the floor...can be a challenge, because as we know everyone learns differently, some people are more receptive to others' (P5).

Interviewees acknowledged that the DCSW had moved from a role of care worker to a new, unique, dementia education and practice-focused role within a setting configured with a clear hierarchy; this raised the possibility of an 'us' and 'them' [mindset], between floor staff and the support worker role' (P11). This interviewee suggested one way to overcome this could be to 'set the expectations from the onset that, 'I'm here to support you, I'm not here to come and tell you what's going on'' (P11).

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RECOMMENDATIONS FOR THE FUTURE OF THE ROLE

Interviewees all supported further role development, continuation, and expansion, providing the role structure met organisational need, was adequately established, and had clear expectations (see Table 2).

'...if we could at least have somebody for two days in a row or two days a week, [they would] just come in as a bit more of the supportive part of the team' (P16).

They further noted the need for *'more role clarity about the reporting lines...really articulate the position description well, set some definite KPIs [key performance indicators] and a timeline'* (P17).

Finally, interviewees noted that attention to documentation and reporting of resident needs and changes to care was required to ensure that observations and recommendations could be more readily captured and acted upon. They suggested that tools such as templates may assist with guiding the level of detail needed.

DISCUSSION

Improving dementia knowledge of care staff is an essential first step in driving improvements in care quality,¹³ and establishment of new career pathways to upskill unregistered care workers with specialist dementia knowledge is a key strategy to driving such improvements.⁹ However, changing staff practice in aged care settings is complex as practices are often configured in accordance with ritual and tradition.¹⁶⁻¹⁸ Strong organisational support, such as that provided by managers, together with adequate resources is essential.^{2,11,17,19}

This study highlighted the readiness of senior staff to identify resource gaps that this role might fulfil,³ although further role clarification is warranted to ensure the functional fit of the DCSW. Similar challenges related to role clarity, role identity and establishment of new relationships with colleagues have been seen in other examples of role transition in healthcare, such as clinical nurse to the legally protected role of nurse practitioner.^{20,21} A major benefit of the DCSW role was influencing care workers to develop their dementia knowledge. As a care worker leader working with her peers, the DCSW engaged in an informal pedagogy: an approach which has shown promise as an effective communication strategy.²² This quasi peer-to-peer approach may reduce the cultural constraints that act as barriers to education and knowledge uptake among this cohort.^{19,23,24}

TABLE 2: PARTICIPANTS' RECOMMENDATIONS FOR THE DEMENTIA CARE SUPPORT WORKER ROLE

Theme	Key descriptors
Role structure	<ul style="list-style-type: none"> Carefully consider the role structure Two or more days per week at each site, possibly consecutive days, may facilitate team building Job-sharing may be appropriate in some situations, particularly where sites are geographically dispersed (potential advantages: facilitate brainstorming, decrease professional isolation; potential disadvantages: part-time hours will suit some but not everyone)
Communication, teamwork and leadership to effectively engage with staff and residents	<ul style="list-style-type: none"> Build relationships with managers and staff through formal (e.g., meetings) and informal means (e.g., notifying unit supervisors on arrival) from role commencement Leadership skills to initiate and implement new interventions and care practices Skills to facilitate education of staff in a challenging environment (e.g., how to facilitate short toolbox sessions, how to educate staff while they are carrying out their daily tasks, demonstrating new care practices and leading by example) Automatic referral to the DCSW^a when people with a diagnosis of dementia are admitted to the care facility may be a useful approach to ensure the DCSW is aware of residents that may need support
Clarity of scope and management of role	<ul style="list-style-type: none"> Scope of role and activities clearly outlined in the Position Description Reporting lines clearly outlined in the Position Description, with consideration to streamlining management Key Performance Indicators and associated timeline may be useful for driving and monitoring performance
Promotion of role	<ul style="list-style-type: none"> Whole-of-organisation promotion of DCSW's knowledge base (qualifications), role purpose, expected activities, and when and how to engage with DCSW, beginning prior to or from commencement of role
Knowledgeable about dementia	<ul style="list-style-type: none"> Detailed knowledge of dementia and understanding of aged care provided by the Bachelor of Dementia Care degree Evidence-based knowledge to support new approaches to care Ability to share information about dementia in a manner appropriate to the audience
Documentation skills	<ul style="list-style-type: none"> Detailed documentation in resident files and regular reports may assist with delineating key issues, strategies and outcomes related to individual residents and broader care interventions Detailed weekly-monthly reports may be useful to monitor and promote DCSW activities Tools such as templates may be useful for guiding the level of information needed to input into resident care plans and regular reports

^a Dementia Care Support Worker

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Nevertheless, consistent with others,^{25,26} our findings also reveal that having a care worker in a leadership role may challenge hierarchical power relations, and experienced care worker colleagues may see the DCSW role as an impost on their status.²⁷

Given the ongoing high level of staff turnover in aged care,^{9,28} the successful introduction of new roles like the DCSW will depend on staff understanding the purpose of the role and its likely impact on their work. Successful integration of DCSW activities into the current operating structure will require clear communication, active promotion, tangible support, and defined performance indicators. These are all necessary mechanisms to enhance communication and relationships between staff from different roles and departments in aged care.²

Knowledge translation was perceived to be central to the DCSW role despite the challenges this often presents in residential aged care.^{24,29} While modelling evidence-based practice was one useful approach adopted by the DCSW, expertise in leadership, teamwork, communication, documentation, and reporting were necessary attributes that were less well developed. For example, 'short burst' learning has been found to be suitable and useful in this setting for improving staff knowledge and attitudes towards people with dementia.³⁰ Such skills are not usually associated with typical care worker roles and may need further development via the Bachelor of Dementia Care qualification.

Poor resourcing is a major barrier to change in aged care,^{17,19} and our findings show the perceived effectiveness of the DCSW was associated with complementing the existing workforce with an additional resource. However, the expectations placed on the DCSW, with responsibilities across three geographically-dispersed sites, were unrealistically high.² While clear benefits of the role were tangible, a single resource was insufficient to address all needs.

In addition to the study findings specific to implementation of the DCSW role in one organisation, there are broader issues to consider that would likely act as barriers to wider uptake of the role. Firstly, there are the financial and time constraints faced by individuals working in relatively low paid care worker positions (despite recent salary increases), which means that undertaking a Bachelor of Dementia Care degree course may not be possible. Commonwealth support may be one way to partially overcome these constraints, with full Higher Education Contribution Scheme (HECS) fee waivers currently available to study this course up to a Diploma level. Fee waivers could potentially be extended to the full Bachelor course in future, perhaps as one strategy to help meet the Royal Commission into Aged Care Quality and Safety recommendations for aged care workforce dementia education and training.³¹ Secondly, if salary remains low for care workers who have undertaken

a Bachelor of Dementia Care or similar qualification and workers are not appropriately recognised or supported, these will act as a disincentive for role uptake. Policy changes, salary and financial support, and making the DCSW position registrable are some strategies which may help to establish the role.⁹ Regulation of aged care workers under a National Worker Registration Scheme is imminent in Australia, in line with recommendations from the Royal Commission.^{31,32} Monitoring of the implementation, effectiveness and impact of this scheme on recruitment of skilled and knowledgeable staff equipped to provide person-centred care for people with dementia will have implications for registration of any future DCSW role.^{32,33}

LIMITATIONS

The study focused on the first DCSW in one organisation, albeit across three sites, and addressed specifically the perspective of senior leadership staff who have responsibility for staffing and operations. Qualitative research studies such as this emphasise data depth,¹³ allowing rich data to be drawn from a smaller group of participants. Data reached saturation, demonstrating the salient issues were detected.¹³ Piloting the role in other sites with different DCSW staff and different facility profiles will further elucidate its potential and challenges. For example, this would enable exploration of the impact of factors such as the personal characteristics of the person in the DCSW role and the culture of the aged care organisation on the success of the role. Piloting the role in other sites would also help to overcome an additional potential limitation of the study, namely that the final interview data were collected over four years ago. However, the need for and the issues associated with such a role remain pertinent.^{34,35}

Exploration of outcomes were limited to the observations of senior leadership staff given the short time frame and the emergent and evolving nature of the role. The knowledge translation potential of the role warrants further investigation. It is likely that the DCSW role would need to be well-defined and firmly integrated and supported within an organisation and wider aged care sector to facilitate real knowledge translation, given the complexities involved.^{11,16} Otherwise, the role may be at risk of being viewed as a relatively simple extra resource to a suite of very complex issues, including multiple deficiencies in staff workload models, training and preparation.²

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CONCLUSION

This study found that a DCSW role for an experienced care worker with graduate qualifications in dementia was considered by senior leadership staff to be of value in residential aged care. In the context of the need in residential aged care for improved dementia knowledge and evidence-based practice,^{3,6,7} the DCSW role was found to have the potential to improve staff and family awareness of dementia and resident care. Additional research and piloting of the role is required to investigate whether – with adequate support structures in place – the DCSW role could represent a new career pathway for unregistered care workers. In this way, the potential of this type of role to complement and fill a gap between care worker and enrolled or registered nurse could be explored, which could address the need for aged care organisations to build and reshape their workforce to be more innovative and highly skilled.⁹ A future can be envisioned whereby such roles, supported by policy changes to increase salary and financial support via the funding instruments applied to the residential aged care sector, are a registrable qualification.⁹

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'Ice in the Family': Exploring the experiences of close family members when another family member is using methamphetamine. A longitudinal qualitative study

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ABSTRACT

Objective: To explore the experiences of close family members when another family member is using methamphetamine and how the family member responds over time.

Background: Methamphetamine use has widespread implications and harms for both people who use the drug and those that live with them. While there is a significant representation in the literature relating to family members of people who use drugs or alcohol, there are limited studies specifically considering family members experiences of methamphetamine use. Families have been shown to have both positive and negative impacts on people using drugs, but less is known on the impact on the family members themselves.

Study design and methods: Multiple semi-structured qualitative interviews were conducted with 11 families (17 individual participants) from regional and metropolitan Western Australia over a 12-month period. Interpretative Phenomenological Analysis was used in data collection and analysis.

Results: Four main themes were identified: 1. *the New Lifeguard* describes family members' unplanned insertion into a new role and their rapidly changing experience of the person using methamphetamine. 2. *Hit by the Wave* demonstrates participants' experience of repeated and unpredictable impacts on their lives. 3. *Life in the Ocean* describes the groundlessness associated with changes to goals and family structure. 4. *Learning to Surf* illuminates the changing strategies employed over time, moving away from trying to fix the person, to participants managing their own wellbeing.

Discussion: This study identified common aspects within the lived experience of close family members of people using methamphetamine and ascertained a commonality in the process of this experience. Significant impacts to all areas of life were reported, and distress was fluctuating and unpredictable in line with the cyclical nature of the drug use. Participant responses to these changes varied over time between resentment and trying to fix things,

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and acceptance and resilience, while gaining or maintaining like-minded supports.

Conclusion: Understanding the issues faced by families around this unique drug is vital in providing informed interventions for this group. Family members experience a broad range of financial, social and health impacts and harms over a protracted length of time. They are often not the focus of available support and in adapting to these issues, will themselves seek support away from treatment services for the person using methamphetamine.

Implications for practice

Understanding the complex journey of families has a broad range of implications (and opportunities) for a variety of areas such as criminal justice, family support and child protection. There is an opportunity for these areas to consider broader and more specific supports and approaches, and to develop more appropriate, bespoke, and inclusive treatment for families of people using methamphetamine.

What is already known about the topic?

- Methamphetamine is recognised worldwide as a harmful drug with few effective treatments for methamphetamine dependence.
- Few studies exist exploring the specific impact of methamphetamine on family members.
- Fewer studies explore the experiences over time.

What this paper adds:

- Family members with a relative who is using methamphetamine experience a range of harms in many areas of their lives.
- The impact of methamphetamine use is unpredictable and takes place over long periods of time, affecting both individual family members and impacting on the overall structure of the family unit.
- Families and family members adapt their approach over time, from attempting to fix the situation, to stepping back and seeking support from others who they perceive to be in similar circumstances.

Keywords: Family, longitudinal, methamphetamine, phenomenology, qualitative, stimulant.

OBJECTIVE

The objective of this study is to investigate the experiences of close family members in Western Australia (WA) whose loved one is using methamphetamine. It was anticipated that developing an understanding of their lived experience over the period of a year, including how they manage these experiences, how they engage with other family members and what strategies they use and discard over time, could be used to provide a basis for improvement in the quality of care for people using methamphetamine and their loved ones. Specific and informed interventions, programs and policies can be developed to meet the needs of family members who attend services for support in their own right or attend with family members using the drug. It is anticipated that the study findings could also augment existing approaches to provide support for the methamphetamine user and enable services to consider the family member as an ally in treatment.

BACKGROUND

Methamphetamine is a psychostimulant drug, which mimics naturally produced dopamine, causing the body to move its own supplies of dopamine, noradrenaline, and serotonin to flood the synapses between neurons in the brain.¹ This leads to feelings of euphoria, alertness, wakefulness, and feelings of wellbeing in the user. In Australia, methamphetamine is now of more concern to Australians than alcohol.² It is a versatile

drug that can be smoked or injected, but also snorted or ingested. The highest purity of methamphetamine is a clear crystal form, and in Australia, this is colloquially referred to as 'ice'.³ It is this form, that in the past decade in Australia, has become prominent in terms of health promotion campaigns, news headlines, and has garnered increased political attention in what has been referred to as the 'ice epidemic'.⁴ Despite an apparent drop in its use owing to restrictions imposed during the coronavirus disease (COVID-19) pandemic, methamphetamine (ice) is gaining increased media attention once again with headlines such as 'Crystal meth is resurgent and 'ravaging' regional Australia'.⁵ This has occurred in the context of a decrease in recent reported use in Australia from 3.4% in 2001 to 1.3% in 2019.⁶ However, in 2020, almost half (48%) of Australians who reported recent methamphetamine use also reported that it was 'easy' or 'very easy' to obtain.⁷

There has been a particular focus in the literature on the impact of methamphetamine use on health professionals in Emergency Departments.⁸⁻¹¹ In contrast, there is also a notable absence in the literature of studies exploring the impact on those who do not use methamphetamine but have the most regular contact with methamphetamine users (i.e. their families). Several studies have explored the impact on the parental relationship where a parent is using methamphetamine.¹²⁻¹⁴ However, there is less evidence in the literature from the perspective of other family members. Ward et al in their systematic narrative

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review of interventions to support parents who use methamphetamine, found only a limited number of studies, but some emerging evidence suggests that interventions may have a positive effect on parenting and reducing drug use.¹⁵ Therefore, without specific knowledge of what it is like for family members, targeted intervention can be problematic.

Sanatkar et al in their systematic literature review of interventions for families and caregivers of people using methamphetamine, reviewed 2,257 records finding a significant lack of evidence-based interventions for this group.¹⁶ Moreover, the authors found only four qualitative studies describing the experiences of caring for people who use methamphetamine, and these demonstrated participants faced substantial challenges including emotional suffering, disturbed family structure, and significant negative financial effects. The burden and stress on families with a member experiencing a substance use disorder of any kind was further demonstrated by Jones et al. in their descriptive phenomenological study of first responders working with patients who have used methamphetamine. Participants observed unsafe environments for families, negative social issues, and families often unable to cope.¹⁷

In the Australian context McCann and Lubman, explored the experiences of family members of people using drugs (not specifically methamphetamine), who had contacted support services.¹⁸ The authors argued the need for family members to adopt a flexible set of coping strategies in dealing with their relative's substance use. Arreola et al explored perceptions of social support as a predictor of treatment completion in methamphetamine-dependent individuals and found that '43.3% of the patients interrupted the treatment with family support and against expert opinion.'¹⁹(p.27) Furthermore, Gendera and others interviewed Australian First Nations families and service providers working with people using methamphetamine, highlighting the central role of family members in supporting and reducing harm associated with their family member's drug use.²⁰

Therefore, this study was undertaken in the context of a significant and ongoing issue of methamphetamine use in Australia, but with a lack of evidence regarding the impact on families or specific supports that might assist them. It was anticipated that understanding the impact of methamphetamine use on individual members and the family unit could illuminate the specific processes they adopt and discard over time and facilitate the development of supports in a broad range of sectors.

METHODS

This study was a longitudinal qualitative study using Interpretative Phenomenological Analysis (IPA). IPA emerged from the writings of Martin Heidegger (1889–1976) who argued the merit of looking beyond the 'what' of phenomenon to looking at 'how' people experience it. Within

the IPA methodology, a common research design includes the gathering of qualitative data from what is, to some degree, a homogeneous group of individuals sharing a particular contextual perspective on a specific experience.²¹

Convenience sampling was utilised initially, to recruit a volunteer sample.²² Participants were recruited via an initial open information session and distribution of flyers at a non-government organisation that supports families of people who use methamphetamine. It can be argued that families of people using methamphetamine are often overlooked in both research and treatment,³ and this method allowed the sample to identify themselves.

After flyer distribution, several family members of methamphetamine users contacted the researcher. Further participants were recruited via 'snowball sampling', where they were referred and recommended by initial participants.²² It had been anticipated that further flyers and advertisements in local newspapers in other geographical areas would be used to recruit additional participants. This was not necessary as the researcher was approached by three other families from different areas, who had read about the proposed study in a previous journal article or heard that it was taking place from other participants.³ Coyle noted that sample sizes for phenomenological research vary from one to 12.²³ The current study included 11 families composed of one or more members. The recruitment in this study allowed for the attrition of potential participants,²⁴ but there was no attrition during the study.

PARTICIPANTS

For inclusion participants needed to be over 18 years of age. They could be individuals or family groups. Each individual participant self-identified as close family member of someone using methamphetamine and saw themselves in a support role for that person. They either resided at the same address as the person using methamphetamine or were in regular contact with them. Participants seeking recent support for their own drug use were excluded.

Multiple qualitative interviews took place at three month intervals over 12 months. Although not specifically identified in terms of calendar points, it was anticipated that this process of interviewing over a 12 month period, would capture significant events in the lives of these families, such as birthdays and weddings, and encompass specific calendar events, such as Christmas and Easter. Participants attended three of four interviews within this period, depending on their availability. A longitudinal approach has been used extensively in research for establishing a temporal order of events, to measure change, to make stronger causal interpretations from the data, and to investigate change over time.^{25,26}

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Interviewing more than one family member from each family enabled the interviewer to explore a shared experience.²¹ Moreover, collecting data at multiple intervals provided data triangulation and increased credibility, and the researcher completed extensive memos with a reflexive journal throughout the data collection process and used these in the data analysis to ensure dependability.²² at each interview stage and throughout the research process. In addition, interviews were conducted by the primary researcher and transcripts and researcher notes reviewed by the researcher and the two other members of the supervisory team at all time points. Subsequent interviews also served as 'member checks', through which data and conclusions were rechecked with the same participants, ensuring reliability of both data and emerging themes.²²

All participants were offered individual interviews. Of the 11 family groups interviewed, two couples requested to be interviewed together at all four time points. One participant requested a single interview only. Using IPA as a methodology to interview more than one individual at a time has been considered contentious in the past but has garnered support in various areas of research in recent years,²⁷ for example Danielson and others used IPA for couples in exploring female partner family formation and Cox and others interviewed parents together as couples to explore parenting of adolescents with complex regional pain syndrome.^{28,29}

ETHICAL CONSIDERATIONS

This study was approved by the University Human Ethics Research Committee (HREC Ref. 2020-087F). Participants were offered emergency support numbers and provided follow-up calls and text from the researcher within 48 hours of the interview. No participants reported distress from the interviews, and several reported they had found the interview process itself helpful. Open interviews have been found to be a positive experience for participants, in particular for groups that are expected to have levels of distress, such as bereaved families.³⁰

Participants were provided with a clear statement of benefits, risks or discomforts and written consent was obtained. Participants were given the opportunity to review the transcripts alone or with other family members throughout the process and all participants were assigned a pseudonym.

DATA COLLECTION

A total of 53 interviews lasting around one hour each were conducted at four time points over a 12 month period (Sept 2020 – Sept 2021). A flexible semi-structured interview design was utilised, with open questions and probes to clarify meanings and encourage elaboration from the individual in their narrative. Interviews were simultaneously transcribed allowing the researcher to record recent thoughts and feelings and overall impressions of the interviews at the time to 'try to step into the participants' shoes'.³²

DATA ANALYSIS

Data was thematically analysed using IPA methodology. This process is iterative, and each stage involved ongoing revision of earlier stages in line with new interpretative decisions.³¹ The analysis commenced with the individual cases before considering any comparison with other cases or other family group members. The following steps (see figure 1 – IPA Process) were undertaken, consistent with Smith and Nizza's IPA process.³¹

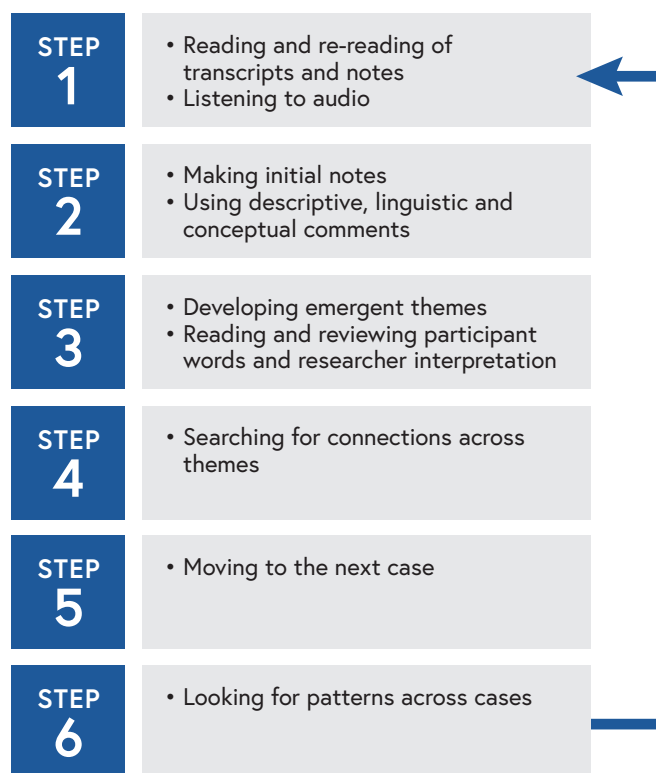


FIGURE 1 – IPA PROCESS

Individual analyses were then compared and synthesised at the within-group (individual family) level. Following this, they were then compared and synthesised at the between-group (other families) level.³³ More specifically, this process involved line-by-line analysis and coding of the words and conceptions of each individual participant.³³ The generated initial themes were recorded in clusters of similar potential themes. These clusters emphasised both convergence and divergence and were refined and reviewed together with ongoing reference to the researcher's notes and reflexivity journal,³⁴ to reach both a higher conceptual level and a chronology.³¹ From this process four superordinate themes were named.

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RESULTS

Eleven family groups were interviewed (individual participants $n = 17$), ranging from one person to three in each group ($M = 4, F = 13$). The average age of participants was 55 years. Each participant reported that their family group included multiple generations and therefore participants reported multiple roles within the family unit. For example, parents of the person who was using methamphetamine were also frequently grandparents to either the children of that person or to other children in the family (see table 1). The average age of the person using methamphetamine in each family was 36 years. For reference, in 2019, the median age for people reporting methamphetamine use in Australia was 32.²⁵

TABLE 1. PARTICIPANTS

Participant in each family group (pseudonyms)	Age and gender	Relationship to person using methamphetamine
Carla	60 / female	Mother
Karen	59 / female	Cousin of mother
Siobhan	60 / female	Mother
Lorraine	58 / female	Mother
Tabitha	66 / female	Mother
Selena	41 / female	Sister
Sharon	69 / female	Aunty
David	64 / male	Father
Robyn	62 / female	Mother
Steven	52 / male	Brother
Rachel	50 / female	Mother
Marco	62 / male	Father
Portia	26 / female	Stepdaughter
Jenny	58 / female	Mother
Clare	40 / female	Sister
Pauline	55 / female	Mother
Mike	56 / male	Father

The study yielded four superordinate themes which are detailed in Figure 2: The Iceberg – Themes. Within IPA methodology, development of themes is a comprehensive but creative process. In identifying these overall experiential themes, the researchers considered the key aspects that effectively describe the experience for these family members.³¹ The superordinate themes are represented using an ocean motif and are presented visually surrounding an iceberg. This representation was chosen because it reflects the visible and less visible aspects of the phenomenon as described by participants. The use of the image of an iceberg was also reflective of the colloquial term, ‘ice’, which is commonly used to describe methamphetamine in Western Australia. Moreover, the concept of ocean waves and surfing to describe both the impact of methamphetamine and participant adaptation to it, reflects the WA landscape. Within the concept of ocean, too, there is a representation of an overwhelming force to be experienced and adapted to.

THEME 1: THE NEW LIFE GUARD

The New Lifeguard theme presents an image of an inexperienced lifeguard. Family members are thrust into a role they did not expect or want and in this role they are observing someone in the water, sometimes struggling and sometimes swimming well. This theme illuminates participant reported experiences of the highly variable presentations of the person using methamphetamine and their own frustration at what they were seeing. ‘It kills me because all I want to do is help him, but I can’t.’ (Lorraine)

The term ‘new’ was used to indicate participant’s sense of passivity and the lack of ability or time to adequately prepare, ‘It’s hard to offer advice, because we’ve just found that you’re just never prepared for anything, and it just changes in a flash. Yeah, it’s pretty hard.’ (Robyn)

The New Lifeguard specifically relates to the family member’s perception of the person using methamphetamine, rather than on their own life as more of an observer than a participant, ‘Because seeing a person in so much turmoil and pain as she, you know, it’s not fair for even an animal to be like that.’ (Selena). Conversely within this theme, there were glimpses of the person participants felt they knew before drug use commenced, illustrating the observed cyclical nature of methamphetamine use. ‘I’ve watched him the last four days just sleep... Because he’s come down off it. Last night, he went over to someone’s house, and I reckon he stuck the old needle in the arm, and today he’s quite chirpy, a different person.’ (Carla)

For the New Lifeguard these glimpses are akin to seeing a more competent swimmer. Rachel describes these times as recurring and said they were often a sustaining factor. She said, ‘I always see glimpses of the child that I brought up with morals, kindness, hard-working, respectful, all those things, there were glimpses there, and I held onto the hope that she would pull herself out of this’.



FIGURE 2. THE ICEBERG – THEMES

Adapted From *Iceberg – Hidden Danger and Global Warming Concept – 3D Illustration* [Photograph], by R Tavani, 2017, with permission <https://www.istockphoto.com/photo/iceberg-floating-in-arctic-sea-gm693474546-128066809>.

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Sometimes the new Lifeguard observes this more competent swimmer for longer, albeit still temporary, periods. Pauline said, 'It took most probably two weeks to get a smile out of him. And ... it was, like... this is the old [name] back, you know'. There was a degree of comfort for the participants, as Siobhan stated, 'I feel that it is going to be good... she's climbed out the hole a little bit'.

However, there was a consistent recognition that this change might be temporary, and the risk of dropping down into the water again. Siobhan commented, 'You know that those four or five days are going to end... everything's really nice, and then all of a sudden, she just disappears off the face of the earth for four or five days or two weeks.'

In Figure 2, the New Lifeguard theme is above the level of the ocean and represents the concept of seeing someone struggling at the surface of the water, being observed by the onlooker. The individual experiences of the participants themselves (conceptualised in the remaining three superordinate themes) are less obvious to onlookers and are listed below the 'surface' of the figure.

THEME 2. HIT BY THE WAVE

The Hit by the Wave theme embodies the sometimes overwhelming and repeated impact on the lives of the participants over time of what is seen in the first theme. This image of waiting to be hit from nowhere is evidenced by Karen's use of the wave metaphor when stating, 'Yeah, she's like a tidal wave ... it just gets worse'. There is a sense of being continually on edge, even when the person using methamphetamine was not physically present, with Robyn stating, 'As much as we can sit down and make the rules of how we're going to treat the next episode, the next episode just throws all our planning out the window ... it's just like the roller-coaster when it's come down again ... you're on edge, you couldn't sleep.'

For all participants, this impacted them with emotional and often physical pain, either for themselves or observed in others. Portia was seeing a psychologist because, 'I don't sleep well anymore. I'll wake up every couple of hours. There's obviously an internal stress'. Similarly, Pauline had recently commenced antidepressant medication because, 'I got to the point where I couldn't continue like I was'.

The impact on overall health was described by all participants as enduring, but with periods of improvement and decline, and was often attributed to the sense of constant, unrelenting anxiety. For instance, Tabitha explained, 'Last year I went on antidepressants; I told him I didn't want to go on them long. And then around Christmas, I've put myself back on them again'. Lorraine too reported this ongoing situation was taking a toll on her own health, and said, 'Oh, my back's giving me grief ... still got bad depression'.

THEME 3: LIFE IN THE OCEAN

The Life in the Ocean theme describes the changes to family life and structure experienced by participants, and describes a sense of groundlessness and loss. Bruce, in talking about his parents, said, 'I think it's actually undone their retirement sort of thoughts about how life would be'. There is an inherent dissatisfaction with their new life expressed by all the participants to different degrees. For example, Siobhan described taking part in this study saying, 'I thought, why am I here when I'm not the one with the drug problem, and yet you don't see the drug-taking kids here, it's the parents that are here'.

All participants described changes to their own and other family members' position in life based on their age and previously planned trajectories. These changes included unexpectedly becoming a carer, becoming a parent again (in the sense that they felt their children should now be independent) and being forced to put their retirement on hold. David had explained to his son, 'Financially, we've got nothing left. You've taken us down that path, we can't go any further'. Robyn also spoke of the impact on her retirement plans, 'there's so much what we wanted to do but we didn't get to do it because of him'. Lorraine, said, 'We didn't expect him to be living with us and dependent on us'.

The changes to family structure, particularly those resulting from parents' attempts to manage the person using methamphetamine, affected the siblings in different ways, but always with a degree of groundlessness. For example, Bruce said 'The idea of sleepovers [with grandparents] all went by the by. They don't have that anymore'. One participant stated that they did not want to be involved in the situation with her parents and sibling because, 'I don't want him [father] to have to choose between us ... but I think deep down, to, I'm frightened of the choice he'll make. So, I don't put him in a position where he has to make one'.

THEME 4: LEARNING TO SURF

The Learning to Surf theme embodies the participants' nonlinear journey towards acceptance of this situation. Conceptually it is compared to learning a skill, in this case a surfboard, with cumbersome efforts at the beginning, but emerging confidence in employing different approaches over time. Frequently participants reported their initial urgent sense of hope that the situation would end quickly. Lorraine said, 'I thought once he'd sold his business, he'd clear his debts, but he kept on spiralling downhill'. Robyn said of her earliest reactions, 'If I could have grabbed him and stuck him in rehab, and made him stay there, I would have'. For Siobhan, there was initially a sense of hope, that she now sees as naïve, 'At the beginning, ... you did have a little bit of hope... let's try rehab, let's do these counselling sessions with these people. None of it worked'.

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Over time, there was an emerging, often tentative sense of acceptance of their situation by participants. Despite the continued episodes of crisis and then apparent calm in the lives of the person using methamphetamine, over the 12 month period, there were internal changes for the family members. Carla said, 'Recognising it [long term methamphetamine use] was the hard one... Don't bury your head, it's not going to go away'. Jenny reported that her husband had now come to this point, 'He actually admitted ... only last night that Sam has got a drug problem, and he actually admitted this is going to probably be for evermore'.

Some participants perceived they had changed their approach and developed (an often fluctuating) degree of competence in managing their situation over time. This was evidenced by changes in their choice of social supports and reported behaviour towards the person using methamphetamine. Participants reported a deliberate movement away from people they saw as not understanding their situation, towards others who do. Marco said he had found comfort in communicating with other families or individuals who had someone using methamphetamine, because there was 'comfort knowing that there's no real normal families anymore'. David explained this deliberate choice, 'Lots of people say they'll be there to support you and help you ... all with good intentions, but they don't really get it'.

Family members described an initial, often naïve, attempt in their journeys to fix the person, but then a gradual change to accepting the situation and stepping back, Selena said there is, 'nothing you can do... you can't pin them down ... all you've got to do is rally around each other and protect yourselves'. Sharon too contrasted her previous attempts with her current approach to her daughter, which she described as 'just be there for her. Because I can't do anything for her. She needs to do it herself'. Lastly, Portia commented on this view with her perception that 'every part of me feels like this is not over and that it's not getting closer to an end.... And we can't help him if he's not going to help himself'.

DISCUSSION

The findings of this study illustrate that family members experienced a variable and often prolonged journey, with significant highs and lows, as members observed the changes in the person using methamphetamine (the New Lifeguard theme). Methamphetamine use is unpredictable, leads to anxiety and harm to family members (reflected in the Hit by the Wave theme) and is tempered with occasional glimpses of the person they knew before they started using the drug. Family members experience changes to their lives both individually and collectively (Life in the Ocean theme) and move at different paces (Learning to Surf theme) to a realisation and acceptance of the emotional impact of the experience, impact on family dynamics and on individual

goals and plans. Their responses change over time but in a nonlinear fashion that may regress and advance. Support is increasingly found in those with personal or professional experience and understanding of the experience.

In the somewhat helpless observations of family members, they noted the fluctuations in behaviour of the person using methamphetamine in the New Lifeguard theme. Participants highlighted the cyclical nature of methamphetamine use compared to other drug use that they said they had observed. This changeable presentation is particularly apparent when used in a binge pattern consisting of several days of high dose use followed by several days of abstinence.³⁵ This characteristic methamphetamine use can be described as a 'binge and crash' cycle of use and relapse, often triggered by withdrawal symptoms and cravings following its use.³⁶ Isoardi et al found in their study of ED presentations for methamphetamine that the primary reason for attending was acute behavioural disturbance. However, the vast majority (84%) of patients were managed only in the ED without a transfer to a ward, and the average length of stay was relatively short, at around 14 hours.³⁷ The rapid change from acute presentation to discharge home reflects the changeability described by participants in this current study by the New Lifeguard.

Family members had experienced times when they felt they had reconnected with, what they felt was, the person they knew before methamphetamine use commenced. This created a tentative sense of optimism tempered with hesitancy and fear of not getting their hopes too high, because of the likelihood of further or ongoing drug use. Moreover, this also led to a state of vigilance, regarding the person using methamphetamine. This is reflected in the Australian study by McCann and others which found affected family members 'constantly vigilant in case of another crisis.'^{38(p.902)} Similarly, Titlestad and others explored the grief of family members who had experienced a drug-related death of their child, finding a theme of 'constant preparedness', referring to the participants' perception of being fearful for years that they would lose their loved one to narcotics.³⁹

Furthermore, within the Hit by the Wave theme, having a family member who was using methamphetamine negatively affected the health of participants over time. This finding is reflective of Di Sarno and others' systematic review of studies relating to affected family members of substance users, which showed family members experienced a high level of stress and poor mental health.⁴⁰ Similarly, Sampson and others in their study of the impact of methamphetamine use on relatives and close friends of users, found participants reporting their mental health and physical health deteriorating over time.⁴¹

More specifically, the impact on family members differed, depending on where they were placed in the family. For example, siblings conveyed anger at their parents' new,

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and unwanted, life situation and towards changes to family dynamics. This reflects Ólafsdóttir and others' findings of siblings worried about modifications to family gatherings and siblings concern over the impact on their parents with anger towards the family member using methamphetamine.⁴² Moreover Gabriel's study, also found siblings of drug-using family members (not specifically methamphetamine) struggling to place themselves within the experience and feeling like both an insider and outsider to the family.⁴³

The feelings of groundlessness in our study, within the Life in the Ocean theme involved having to put plans on hold, becoming a parent again (in the sense of increasing responsibility) or becoming a carer. This is reflective of Lavoie's findings in a study of family carers' experiences of emergency psychiatric crises, where engagement with social networks were progressively more restricted and carers found themselves using ever-increasing amounts of their time and resources in supporting their relative.⁴⁴ Lindeman and others, in their meta-ethnography of studies relating to the impact of adult family members' substance use on family life, found 'an unknown invisible intrusion', which they described as impacting 'their family dynamics and relations, their everyday life and holidays, and their dreams for the future and stories from the past.'^{45(p.7)} These breakdowns of social networks reflect the third-party observations of the first responders in Jones and others who observed family members at 'breaking point'.¹⁶

Moreover, grandparents (of the children of the person using methamphetamine) in this study described the stress of needing to adopt a more parental role for their grandchildren. This is well acknowledged in the literature, including within Australian studies.⁴⁶⁻⁴⁷ Fernandes and others suggested that the needs of grandparents caring for grandchildren are overlooked in the development of policy and organisational practice.⁴⁸ The overlapping effects of changes in role, plans and family structure are reflected in Sampson and others who found friends and family members of people using methamphetamine experienced grief and loss, and stigma.⁴¹ This also resonates with findings of McCann and Lubman in their 2018 study of affected family members of people using drugs (in general), who reported findings of shame and embarrassment in the context of perceived stigma.¹⁸ Stigma was less significant in this study, and when referred to by participants was often in the past tense.

Within the Learning to Surf theme, Participants reported initially trying to fix the problem with various interventions. There is little in the literature to suggest that trying to achieve a quick fix for methamphetamine use is a functional approach. Brookfield and others, reported the choice to cease using the drug as a process of 'ageing out of it'.⁴⁹ Moreover, there is little evidence that pharmacotherapy treatments for methamphetamine use are effective,⁵⁰ and there is a high relapse rate for other interventions,⁵¹ with multiple lapses and relapses during treatment episodes.⁵²

Over time, participants reported a degree of acceptance, and development of support networks consisting of primarily those they perceived as understanding their situation, rather than trying to resolve it. McDonagh and others found family members of people using drugs reported hesitancy in approaching other family members for support, and a tendency to access informal support networks away from their own family members.⁵³

While participants in this study reported increased confidence and acceptance over time, this process was not always linear, reflecting the findings of Lindeman and others who found 'a continuous process of adaptation to an ever-changing intruder.'^{45(p.9)} This is similar to Subekti and others findings in their systematic literature review of stress adaptation among families with adolescent substance use, of 'tolerating', 'engaging' and 'withdrawing'.^{54(p.479)} Moreover, this is further reflected in Maltman and others 'holding on' and 'letting go', where 'holding on' refers to the parents' attempts at influencing their adult child's drug using behaviour.⁵⁵ Conversely 'letting go' describes relinquishing control over their relative, giving them freedom to continue their methamphetamine use, but hoping that, in doing this, they will cease using drugs or seek support.

LIMITATIONS

This study was a qualitative study with a relatively large number of participants. The participants were recruited from areas around and within regional and metropolitan WA, and thus, the findings may be considered context bound to the participants and the particular region where the study was undertaken.⁵⁶ However, while in any qualitative study, it can be argued there is a risk that the findings are not generalisable, Levitt argues that it is indeed possible to generalise qualitative findings to the phenomenon rather than to the population.⁵⁷

CONCLUSION

This study's findings contribute to the limited literature on the specific impact of methamphetamine use on other family members. Both individually and collectively, family members experience a protracted and unpredictable journey. Understanding the experience of family members and what they find both helpful and unhelpful can lead to revision and development of focussed treatment, policy and interventions aimed at both support and prevention of harms for this group. Furthermore, as argued by Hogue and others the involvement of families in the care for substance use disorders in general can be powerful resources for improving the success of treatment and the likelihood of sustained recovery.⁵⁸ Treatments focussing primarily on how to manage the substance use only, do not meet the needs of this group, and frequently end in frustration and failure. This study provides a clear picture that can be used

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to develop a focussed approach to what is often a hidden and long-lasting problem for networks of people. Thus, this study has demonstrated that methamphetamine is a family issue, rather than an individual concern and must be addressed as such.

Conflict of Interest: The authors have no conflicts of interest to declare. All co-authors have seen and agree with the contents of the manuscript and there is no financial interest to report. We certify that the submission is original work and is not under review at any other publication.

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Human ethics: The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007, updated 2018). The proposed research study received human research ethics approval from the University of Notre Dame Australia Research Ethics Committee (ECoo418) Approval Number # 2020-087F.

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REVIEWS AND DISCUSSION PAPERS

Preventing care factor zero: improving patient outcomes and nursing satisfaction and retention through facilitation of compassionate person-centred care

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ABSTRACT

Aim: A discussion of empathy and compassion including patient and nursing perspectives, barriers and enablers, and the potential for development, teachability, and sustainability of empathy and compassion in nursing.

Background: Whilst compassion and empathy have long been recognised as prerequisites for the provision of effective nursing care, there are many interpretations of their meanings and the two are often transposed. The presence or absence of compassionate and empathetic nursing care has multiple positive and negative effects on nursing satisfaction and retention and on patients' experiences and health outcomes.

Design: Discussion paper.

Data Sources: Embase, Emcare, Medline, ProQuest, and PubMed were searched from 1 January 2015 to 16 January 2023 for scholarly journals with full text articles in the English language.

Conclusion: Compassion and empathy are sine qua non in the provision of nursing care. Empathy is a core component of compassion. Compassion and empathy may be innate characteristics, but they can also be taught and fostered through

education both pre- and post-graduation, which is based on experiential rather than didactic methods of teaching. Organisations have a pivotal role in supporting a compassionate environment through their leadership by developing policies and practices to ensure appropriate staffing levels, having consideration for skill mix and workload which will facilitate the provision of compassionate and empathetic nursing care leading to improved patient outcomes and satisfaction, and also increase nursing job satisfaction and retention.

Implications for research, policy, and practice:

Pre- and post-graduate nurses in particular, should have access to targeted education and support from peers, senior nurses, and educators, especially positive role modelling. For all nurses to be able to provide compassionate care, it is important that organisations' leadership and management recognises the time required to do so without pressure to complete clinical tasks. Indisputably, the prevailing clinical implication is that reducing staffing shortfalls and excessive workloads is essential to foster a compassionate environment.

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What is already known about the topic?

- Compassion is a prerequisite for the provision of effective, person-centred patient care.
- Empathy and compassion are often used interchangeably and there is some confusion between the two.
- Absence of compassion has a detrimental effect on patient experiences and outcomes together with nursing job satisfaction and retention rates.

What this paper adds

- Whilst empathy is considered a separate concept from compassion, it has also been identified as a core component of compassion creating some perplexity.

- It is possible to effectively teach empathy and compassion using non-didactic, experiential strategies both pre- and post-graduation.
- Organisations play a pivotal role in supporting a compassionate environment which positively impacts on nursing satisfaction and retention rates thereby improving patients' experiences and health outcomes.

Keywords: Compassion, empathy, nursing practice, nursing retention, nursing satisfaction, patient outcomes

INTRODUCTION

VIGNETTE – CARE FACTOR ZERO

The night RN was responsible for over 100 residents in the aged care facility with the assistance of two AINs. One resident (Mrs A) was palliated and on two-hourly subcutaneous morphine injections. At midnight, the RN commenced rounding on all her residents, firstly attending to Mrs A to give the injection on time. Mrs A had soiled her incontinence pad and the RN requested one of the AINs to wash and change her because she had to continue her rounds. By the time the RN had completed her rounds, it was time to prepare and administer the next morphine injection. On attending Mrs A, the RN found she had not been washed or changed. She administered the injection and then tended to washing and changing her. Afterwards, she found the AIN and asked why she had not washed and changed Mrs A as directed more than two hours previously. The AIN replied, 'What matter? He [sic] die anyway'.

Worldwide, especially during recent years, nurses have faced many difficulties in healthcare situations including increasing professional demands on their workloads and the provision of person-centred patient care. These demands have negatively impacted not only on them, but also on the healthcare facilities, and on their patients who have noted a lack of attention and compassion from nurses. This discussion paper considers what factors might contribute to the perceived lack of empathy and compassion in nursing care, and the increased levels of stress, burnout and attrition of nurses, and decreased positive patient outcomes.

AIMS

The aims of this paper are to present and discuss (1) an examination the similarities and differences between empathy and compassion, especially as they relate to nursing; (2) understanding of empathy and compassion from both patient and nursing perspectives using the research findings; (3) examples of enablers and barriers which may influence nursing behaviours relating to empathy and compassion in the provision of patient care; and (4) consideration of the potential for development, teachability, and sustainability of empathy and compassion both pre- and post-graduation.

DATA SOURCES

The databases of Embase, Emcare, Medline, ProQuest, and PubMed were searched from January 2015 to January 2023 for scholarly journals with full text articles in the English language. Keywords used were 'empathy' and 'compassion' jointly and severally which yielded in excess of 275,000 results, necessitating the following inclusion criteria: Articles in which the primary focus was on empathy and compassion from nursing, patient and organisational perspectives and included the word/s 'empathy' and 'compassion' in the title. Articles excluded were those which focused only on compassion fatigue, self-compassion and burnout, and those in which physicians/doctors, and/or allied health were the intended audience. Any results that were opinion papers, editorials, letters, personal views, conference papers, study protocols, or commentaries were also excluded. This reduced the final results to 91 articles that were subsequently categorised thematically into definitions; perspectives, perceptions and concepts; enablers and barriers; and education.

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BACKGROUND

Compassion in nursing practice is not a new concept; in the 19th century, Florence Nightingale included compassion when describing the virtues of a good nurse.¹ Worldwide, the demonstration of compassion in practice by nurses is a requirement and documented in multiple ethical guidelines and policies.²⁻⁵ It is unanimously considered an integral aspect in delivery of nursing care and its absence is known to adversely affect patient outcomes because care is substandard and potentially harmful,^{2-6,10-15} leading to major inquiries, as evidenced by the English report which attained international notice in 2013.¹⁶ Over the past three decades, more research has been conducted on the construct of compassion and there are many definitions and concepts for compassion and empathy in the literature, however, their use is often transposed.¹⁷⁻²⁰

When compassionate care is practiced, nurses, patients and their families/carers derive positive effects which improve their health outcomes,^{6,11} enhance their therapeutic relationships, and increase their satisfaction with the healthcare service.³ Furthermore, nurses benefit from the improved sense of wellbeing in their workplace and increased job satisfaction which leads to lower turnover.^{7,12,21} Whilst the importance of the provision of compassionate care is well recognised, support at an organisational level is necessary to create a compassionate workplace setting.^{12,22}

VIGNETTE – HISTORICAL FIGURES KNOWN FOR COMPASSION

From the inception of the nursing profession, compassion is evident in its narrative. Historically, compassionate nursing care was recognised with Florence Nightingale's ministering during the Crimean War, and five years later, during the American Civil War, Clara Barton is known for her compassionate care of wounded soldiers. Helen Boylson, a nurse from the First World War, embodied compassionate care as she empathised with her patients during painful procedures and dressings.²³

Empathy is identified as a crucial aspect of compassion, and its presence in the workplace has been shown to increase employees' efficiency, innovation and engagement²⁴ together with job satisfaction;²⁵ and the patient's self-esteem, which, in turn, improves nursing and patient wellbeing on an emotional level.²⁶ Like compassion, it too has been a subject of interest since the 19th century and is included in professional nursing standards and competencies.^{27,28} Empathy is also well recognised as an essential facet of nursing care which facilitates therapeutic communication,^{20,28-33} improves patient outcomes and satisfaction,^{28,29,33-36} and is a key element of person-centred care.^{32,37,38}

Although nursing education frequently refers to compassion and empathy, there is much speculation on whether compassion is an inherent trait, and its teachability.^{4,5,10} From the patients' points of view, expressions of empathy have been shown to be low and/or declining leading to sub-standard patient outcomes.^{34,36,38,39} As compassion arises from empathy, it is essential that nursing educators and nurses (students and practicing) be able to clearly distinguish between both concepts and education programs should include examples of each,⁴ especially since empathy impacts positively on both patients, as mentioned earlier, and nurses, leading to a reduction in stress levels and burnout.^{32,36}

DISCUSSION

As noted in the data sources previously, findings from the research for this discussion paper were categorised thematically under the four main areas identified as definitions; perspectives, perceptions and concept; enablers and barriers; and education.

DEFINITIONS

Compassion and empathy are frequently used synonymously.^{2,19,20} Feeling or identifying with the suffering of a person is recognised as empathy and the antecedent to compassion.⁴⁰ Indeed empathy has been identified as a vital component of compassion.^{13,41} Nonetheless, the interchangeability of terminology has made the difference between empathy and compassion less clear.²⁰ Jeffrey posits that compassion is a *reactive response* whilst empathy is a *skilled response*.^{9(p.449)} Further distinction between the two is made by Nijboer and Van der Cingel who note that empathy is being able to put oneself in another's position, whilst compassion also involves alleviating actions.⁴²

The general consensus of the meaning of compassion is not only feeling for another's suffering (i.e. empathy) but also the desire to alleviate it. These authors further identify five components of compassion

Recognition of suffering; understanding its universality; feeling sympathy, empathy, or concern for those who are suffering; tolerating the distress associated with the witnessing of suffering; and motivation to act or acting to alleviate the suffering.^{41(p.25)}

whilst Aagard et al., identified *listening, developing a relationship, alleviating suffering, touching, and going beyond the role of the nurse* as features of compassion and caring.^{43(p.6)} Interestingly, these authors note that the terms compassion and caring are used synonymously in United States research, with the majority of literature citing caring in lieu of compassion. Conversely, compassion and caring are noted as two separate qualities,⁴⁴ and a distinction has been made between compassion and caring in that caring has a broader range than compassion, which is centred on the alleviation of suffering; therefore

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compassion is most likely an element of caring.³ A systematic review in 2018 documented 11 traits found in compassionate nurses, being *character, connecting to and knowing the patient, awareness of needs/suffering, empathy, communication, body language, involving patients, having time for patients, small acts, emotional strength, and professional competence.*^(pp.51-52,54-55) Strauss et al., Booth, and Aagard et al., all refer to the desire or motivation to act, with only Strauss et al. referring to 'acting'.^{9,41,43} Whilst compassion infers a desire to assist, this may not always result in the finite act of assisting.¹⁹

The concept of suffering may differ due to the caregiver's values and cultural background and, to facilitate effective compassion, cultural understanding is important.⁴⁵ Thus an addition to the meaning of compassion could incorporate: and being culturally appropriate by considering the patient's background.⁴⁶

Empathy is recognised as the ability to understand an individual's emotions and to share them.^{25,30,47-49} This instinctive reaction,⁵⁰ conventionally considered to be a personality trait, has had a gradual recognition that it is a skill, moulded by individual experiences and academic input.^{31,39}

PERSPECTIVES, PERCEPTIONS AND CONCEPTS

The merits of compassion have been chronicled over time and more recently investigated from a neurophysio- and psychological viewpoint,¹⁷ and attention to compassion as a necessary element of care which benefits not only patients, but also healthcare staff and organisations, has also increased,^{9,51} especially as it is recognised as a foundational element of person-centred care.^{52,53}

The concept of compassion is a known nursing trait as well as an ethical standard required for nursing care.⁵⁴ It is accepted that compassionate nursing care is essential to promote more positive outcomes for patients and facilitate a therapeutic relationship.¹³ Moreover, it is a requirement of nurses and other healthcare workers, as a fundamental ability, that compassionate care be provided,^{8,13} and patients and healthcare facilities expect the staff to deliver compassionate care.¹⁸ When the provision of compassionate care is lacking, patient outcomes are negatively impacted.¹³

There is also the element of cultural competence in compassion which includes self-awareness of beliefs and values, interaction with others from culturally diverse backgrounds, and sensitivity to the way the patient is perceived.⁴⁵

Compassionate care encompasses not only words, but also actions, such as kindness, a gentle manner and touch.¹ Touch is crucial for human development throughout the life cycle and especially when providing nursing care.⁵⁵ Nurses typically touch patients during the provision of usual care, however touching with compassion is distinct from touch in that it is employed by nurses to give comfort rather than

providing usual care.⁴³ This comforting touch not only eases the patient's distress, but also provides reassurance, creates a rapport, and facilitates trust which has a favourable effect for both.⁵⁵ However, differing ethnicities may interpret touch as inappropriate, for example, if the nurse and patient are not the same gender.⁵³ Cultural awareness, referred to earlier, should be considered an important element of compassionate care; indeed, customs relating to end of life care, values and beliefs, spiritual requirements, and traditions differ across ethnicities and must be recognised and understood in order to provide culturally appropriate compassionate care.^{46,53}

Nurses not only appreciate the importance of compassion in practice, but also believe that it can be taught, although they note there are inadequate levels of compassion teaching being provided.⁴⁶ They recognise multiple traits associated with the provision of compassionate care which include respect, understanding, treating the patient as an individual, easing their suffering, advocating, kindness, and empathetic communication.³

Patients have observed that empathetic and compassionate provision of care by nurses validated them and enhanced their experiences.²² Elements of compassion identified by patients as attributes of quality care include the provision of care which is person-centred, mutually communicative, and responsive.^{1,22} Time and again, both patients and their families have evaluated traits of compassion, such as effective interaction, kindness, gentleness, and providing reassurance, in their most important needs when receiving healthcare.^{3, 56,57} Indeed, patients recognised the receipt of compassion from nurses when they felt that the nurse had spent time with them in order to get to know them as a person, and nurses who were kind, respectful and honest when caring for their patients were perceived as more compassionate.^{3,58}

The introduction of the word empathy into the English language occurred in 1909 when an English psychologist, Edward Titchener, translated it from a German doctoral thesis.⁵⁹ Whilst its concept has been hard to describe, typically it is recognised as an environment which provides patients with recognition using benevolence and cordiality.⁴⁷ Empathy has also been described as a feeling or state of mind that is circumstantial and relies on the clinician's capability to be moved by the patient's suffering.⁶⁰ It is both cognitive and affective;^{26,35,61} Strauss et al. and others recognise cognitive empathy,^{41,61} which is intelligently comprehending the emotions and views of others, and affective empathy, which means feeling affected by others' emotions and sharing same; whilst Jeffrey identifies two further aspects of empathy, being behavioural, which refers to skill, and moral, which refers to the desire to alleviate suffering, although this could be more correctly classified as the defining feature of compassion.¹⁹ The presence of empathy is necessary to enable compassionate behaviours and plays an essential role in effective communication between the nurse and patient.^{4,47,62}

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The nurse's ability to empathise with patients facilitates positive outcomes for them, supports their treatment adherence and promotes patients' satisfaction.³⁸ This lets them feel known, valued and validated, and alleviates levels of anxiety and stress associated with hospitalisation,^{49,63} especially when they are seen not as a disease or illness, but rather as an individual.¹³

Patients describe empathy positively, noting that empathetic nurses were engaged and adapted to their (the patients') emotions when they reacted to the patients' suffering, which enabled a person-centred therapeutic relationship to develop. Whilst empathy was valued, patients recognised that it was not associated with actions, unlike compassion.²² From the patients' points of view, compassion is a moral, honourable response which attends to their suffering both emotionally and through actions, especially when their needs are prioritised. When nurses responded to the patients with supererogatory demonstrations of kindness, the patients reacted positively, noting an amelioration of their suffering, improved comfort and increased satisfaction with the calibre of care provided.²² For the nurse, empathy acts protectively against stress and fatigue, and a decline in empathy has been linked to increased levels of stress and fatigue.⁶⁴

VIGNETTE – EMPATHY OR SYMPATHY

Empathy is not to be confused with sympathy which is an emotional response of pity. Whilst sympathy has been known to be used interchangeably with empathy, patients have referred to the construct of sympathy in a negative manner, describing it as an emotion that was superficial, and thus an unwelcome and mistaken response based on pity which showed a dearth of understanding because it was more focused on the giver's self-preservation. This engendered feelings of depression, dejection and self-pity.²² *I hate sympathy, it feels shallow ... and it doesn't feel genuine to me. Sympathy is very easy, it's an emotion, probably one of the easiest emotions to fake. I hate sympathy! Sympathy is like flattery, it sounds pretty but it goes nowhere and it does nothing. I don't want somebody to feel sorry for me, I want you to help me.*^{22(p.443)}

ENABLERS AND BARRIERS

Enablers

Nurses have identified that personal attributes have a positive effect on the ability to provide compassionate care,⁶⁵ especially selflessness; and patients have also identified elements of selflessness, such as humility and kindness, as influencers of compassion.⁶⁶

Having emotional strength enables nurses to manage situations which can be emotionally taxing and this strength develops resilience which facilitates ongoing compassion for their patients.⁵⁸ Indeed, these authors propose that

traits of compassion should rather be deemed strengths and outline the indicators for *character, connection, empathy, communication, interpersonal skills, engagement, self-care, and competence* as the eight strengths they consider necessary to practice the art of compassionate care.^{58(p.2919)}

Organisations have a major part in the provision of a supportive environment.⁶⁷ Environments which are supportive and encourage professional education to recognise and cultivate nurses' capacity for compassion have been shown by a plethora of research to facilitate person-centred care, thereby increasing both patient and nursing satisfaction.^{11,12,47,62,66,68} The provision of Schwartz Rounds, which enable open and safe discussion of emotional, psychological, and social issues, have been shown to contribute to employees' perception of a compassionate workplace.^{12,69} Healthcare organisations have recognised that facilitating compassion leads to improved wellbeing, increased job satisfaction, and higher retention rates.⁷

It is recommended that if nursing leaders undertook compassion focused education, this would equip them with the necessary skills and knowledge to cultivate a workplace culture which supported the provision of compassionate care, especially when combined with adequate staffing levels and support.^{57,70} Indeed, nurses who felt they were supported were more capable of expressing compassion in their practice.^{58,71} This is especially so when positive role modelling by more experienced nurses displayed the provision of compassionate care for both students and newly registered nurses.⁷¹ Providing effective leadership has been recognised as essential for the provision of safe healthcare that is not only superior, but also compassionate.⁷² Nursing leaders who have participated in a program which focuses on the delivery of compassionate leadership have overwhelmingly advised that their learnings were applied to their practice and had increased their motivation to facilitate the delivery of compassionate nursing care.⁷³

Barriers

Barriers which negatively affect compassionate care include both personal and workplace stressors.⁷⁴ By labelling compassion as inherent to nursing, the contribution of all healthcare staff, particularly at management level, to facilitate the provision of compassionate care is side-lined, and cultural or structural aspects are therefore overlooked.¹⁶

Beginning with education and training, the focus is on attaining competency in knowledge and skills which take precedence over nurturing compassion, and this is confirmed by newly registered nurses who believed they were ill prepared in the provision of compassionate care.^{56,58}

Other areas frequently identified as barriers to empathy and compassion were lack of time, insufficient staffing levels, and inadequate support and resources. A surfeit of evidence supports that these barriers may be further

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compounded by burnout, stress, exhaustion (both physical and emotional) and a heavy workload,^{6,13,30,47,48,57,69,75} not to mention confronting behaviours exhibited by some patients, for example, those with dementia and those identified as difficult, citing resistiveness, aggression, and boundary transgressions.^{18,47} These factors compound demands on nurses and often lead to compassion fatigue, job dissatisfaction, emotional exhaustion, and subsequent failure to consider patients as kindred humans.^{19,69} Nurses having the intent to act and following through on this intent are often impeded by these barriers, and this includes nursing students whose levels of compassion have been found to lessen over the course of their practical training.¹³ It has been noted that when students and newer nurses observe negative role modelling by their senior co-workers, this adversely affects their ability to practice with compassion and highlights the necessity for positive role models, especially in leadership roles, who then motivate others to display compassion.⁵² Furthermore, empathetic care has been identified as a cause of emotional vulnerability.⁴⁷

Patients recognise that nursing not only involves the provision of care, but also increased documentation and technical skills which, when combined with insufficient staffing levels, often led to lack of time for those ministrations which involved displaying compassion through person-centred care.⁷⁰ Most patients shared the perception that nurses who displayed compassion had inherent personality attributes which enhanced their nursing skills, however, the demonstration of compassion was often negatively influenced by heavy workloads and understaffing.^{52,70} The demonstration of empathetic responses towards patients can be negatively impacted by circumstances such as lengthy shift work and lack of sleep, especially with demanding workloads.⁵⁹ Time constraints which demand task oriented care more than person-centred care negatively impact upon the nurse's ability to spend meaningful time interacting with patients, especially when understaffed.^{42,57,70} Unintentional reactions, such as fear or disgust, have also been shown to adversely affect the provision of compassionate care.⁷⁶

Compassion can be modified to resentment and even anger when nurses perceive that the patient is culpable for their injury or suffering.^{40,76} Further, the nurses' aptitude for compassion is influenced by their underlying qualities, which can be fostered or worn down as their education and subsequent clinical practice continues.^{18,60}

Cultural diversity and values may also be a barrier, for example, a patient may consider a nurse from a different ethnic background will not be able to relate to them and, as a result, this will impede the development of a therapeutic relationship and meaningful connection.^{32,53} Likewise, nurses may have an unspoken or unconscious predisposition to less empathy due to societal influence regarding race and ethnicity.⁷⁷ These social prejudices relating to ethnic

backgrounds and other differences, such as political or religious views, can inhibit activation of empathetic responses.⁵⁰

Organisational barriers include the ever present financial limits, for example investor profits in the private sector and government reductions in funding for the public sector, staff shortages,^{44,78} lack of resources, increased technological reliance, disobliging administration and the prioritisation of efficiency and cost effectiveness over sufficient time for nurses to have meaningful interactions with their patients.^{47,69} It is evident that there is a need to address the lack of funding and allocation of resources. Nurses have reported organisational barriers, especially high workload and little control over staffing levels and shifts as barriers to the provision of compassionate care.²

Currently, there is the added complication of providing care during the COVID-19 pandemic which increases stress and worry about personal health,³⁶ together with burnout and the wearing of masks makes it harder for nurses to display empathy.³² With the limitations on the presence of family support for hospitalised patients,³⁶ there are added tasks for nurses to complete within the same timeframes and often with reduced staff.

EDUCATION

It should be noted that passive or didactic education alone has little or no impact upon behaviours. In fact, it has been rated as the least effective approach and seldom brings about sustained changes.⁷⁹ However, combining modalities of various educational approaches has been shown to increase the likelihood of sustained changes, especially when the education is ongoing and not a stand-alone intervention.⁶⁴ Nursing curricula require the incorporation of sound methods to foster empathetic and compassionate communication skills which will enable the development of therapeutic relationships between nurses and patients.⁸⁰ For some years, there has been an expectation that educators should cultivate compassion in nursing students.³ Whilst there are a number of educational strategies available to facilitate the provision of compassionate care, most have been developed with a focus on medical and nursing students and often concentrated on singular aspects of compassion rather than a multimodal approach which covered attitudes and behaviours, knowledge and skills, and ongoing evaluation.⁷ Effective communication as an element of the provision of compassionate care is acknowledged as an educable skill.⁵⁶ Indeed, caring and attentive listening are prerequisites of empathy.²⁰

Although empathy is well recognised and valued as important for effective interaction with patients, it has been noted that this is often inadequate, especially in nursing students, which may be due to their limited clinical placements that focus on clinical skills and knowledge

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building, rather than social skills.^{28,80} Experiential learning has frequently been found to be an effective strategy for fostering empathetic reactions, as well as role-playing, storytelling and simulation.^{28,29,32,39,49,64,80-82} Heidke et al., also found that exposure to consumers' stories, especially from minority groups, is an empowering learning experience.²⁸

Nurturing the development of compassion together with clinical and theoretical learning is important to the provision of nursing care which should begin at university as nursing students' aptitude for compassion and empathy will strongly influence their professional career.^{9,83} Further fostering the skilled response of empathy should be a pragmatic aim in education,¹⁹ and more academic time needs to be dedicated to the advancement of interpersonal proficiency.²⁷ Whilst we recognise compassion and empathy, together with good communication skills are social values, they are not always instinctive. As values differ between societies, it is reasonable to assume that these are learned behaviours and can, therefore, be taught.^{25,27,61}

The cultivation of compassion during student education depends upon the presence of an innate ability to feel compassion,⁸⁴ and some believe that if this is lacking, teaching it is not possible.⁵⁸ However, the more common viewpoint is that inspiring lecturers, together with varied teaching approaches, for example, active learning including simulation, scenarios, role modelling, and reflective tasks, would enable nursing students not only to learn compassion, but also advance their aptitude for problem solving.^{54,58} It is interesting to note that patients believe compassion can be taught contingent upon the learners' attributes and an experiential learning method which included person-centred communication skills, reflective practice and compassionate role modelling, as opposed to didactic methods.⁶⁰

Over the past decade, several reports have identified the need for nursing students to receive compassion tuition; evidence suggests that traits of compassion can be fostered and that compassionate actions are teachable, with experiential learning being the preferred format.⁸ Younas and Maddigan identified four characteristics common to all educational methods, being *active engagement of students and teachers; student centred learning environments; a focus on building students' reflective skills; and an emphasis on affective learning* and proposed policy directions which included targeting affective learning, promoting reflective thinking, and assessing understanding and expression of compassion.^{3(p.1631)} This should also include intercultural education which fosters understanding of the diversities in different cultures and enable culturally appropriate and respectful care to be delivered.⁸⁵

Whilst it is recognised that compassion is primarily a result of innate qualities, it is believed that education can foster compassion, particularly through professional socialisation, for example, role modelling by experienced nurses.^{11,70}

Conversely, should the experienced nurse not practice compassionate care, this will negatively impact upon a less experienced nurse's ongoing development and ability to display compassion on a day to day basis.^{57,70}

Nursing students' empathy can be enhanced with appropriate training, such as simulations,^{49,81} but should not end at graduation. Education should be ongoing in employment as empathy levels have been shown to decline in post-graduate nurses. This enhances patient care,^{29,32} improves job satisfaction and, subsequently, nursing retention rates. Ongoing education also enables nurses to feel accomplished, appreciated, and supported by their peers, managers, and organisations.⁴⁷ Learning and reflective activities included as part of this education are essential for the preservation of empathetic feelings.^{29,64}

LIMITATIONS

Searching only results with empathy and/or compassion contained in the title to make screening more manageable may have excluded high level evidence of relevance. Further, limiting the search parameters to full text English language only, also recognises that high level evidence may have been excepted, consequently introducing language bias. To moderate this, Embase and Medline were included, as both databases include translations from journals in other languages.

FUTURE RESEARCH

It is clear that further investigation into and development of non-didactic teaching methods pre- and post-graduation, such as experiential learning and simulation, together with the development of strategies to facilitate positive and proactive changes in nursing, managerial, and organisational perspectives will facilitate empathetic and compassionate provision of person-centred care. Exploration of innovative approaches at an organisational level, for example, interdisciplinary collaboration and technology integration may alleviate resource limitations.

IMPLICATIONS FOR NURSING

Pre- and post-graduate nurses, in particular, should have access to targeted education and support from peers, senior nurses, and educators, especially positive role modelling. For all nurses to be able to provide compassionate care, it is important that organisations' management recognises the time required to do so without pressure to complete clinical tasks. Indisputably, the prevailing clinical implication is that reducing staffing shortfalls and excessive workloads is essential to foster a compassionate environment.

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CONCLUSION

Compassion and empathy are sine qua non in the provision of nursing care. Empathy is a core component of compassion. There is general consensus around the meaning of compassion, although the addition of culturally appropriate care should be added. To facilitate and preserve the provision of empathetic and compassionate care, together with job satisfaction and retention, it is imperative that healthcare employers and management develop organisational policies which provide nurses with appropriate levels of staffing, having consideration for both skill mix and workload, and educational resources. The provision of education covering compassion and empathy, and strategies for developing and sustaining these skills are a priority. Rather than traditional didactic education, experiential education, along with role playing, simulation, and exposure to lived experiences, is more effective for nurturing, improving and inculcating compassion and empathy. Role modelling by experienced nurses who practice compassionate care cultivates an ongoing ambience of kindness and person-centred care. However, education on its own is inadequate and ongoing support from senior staff and management, who have undertaken compassionate leadership training, to provide a compassionate environment, together with the appropriately developed policies, procedures and guidelines, are necessary to facilitate the provision of empathetic and compassionate person-centred nursing care for patients.

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