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## RESEARCH ARTICLES

# The safety and feasibility of a regional nurse-led abdominal paracentesis service: A retrospective analysis

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## ABSTRACT

**Background:** Recurrent ascites is a common complication of liver decompensation that often requires repeated abdominal paracentesis for symptom management. This study was to retrospectively analyse the safety and feasibility of a nurse-led abdominal paracentesis clinic at a regional health service ambulatory care unit.

**Methods:** The Advanced Practice Nurse (APN) identified to lead this service had ten years of post-graduate nursing experience, six of which included specialised hepatology training in a role as a Hepatology Clinical Nurse Consultant. She was enrolled for further study as a Nurse Practitioner. The APN observed five paracentesis procedures by Interventional Radiologists and Medical Officers. She was then supervised for five paracentesis procedures, before attempting the procedure independently. A retrospective analysis was conducted to assess the safety and feasibility of this service.

**Results:** From July 27, 2022, to March 22, 2023, 59 abdominal paracentesis procedures were performed by an APN. The overall success rate was 97%. The average amount of ascitic fluid removed was 7.57 Liters. The average time of the procedure within the ambulatory care unit from admission to discharge was 5.75 hours. There were no episodes of abdominal wall haematoma, hemoperitoneum,

intraperitoneal haemorrhage, infection, spontaneous bacterial peritonitis or death post-paracentesis. There was 1 episode of excessive leakage at insertion site (1.69%), 1 episode of pain at insertion site (1.69%) and 1 episode (1.69%) of localised erythema to the insertion site. These complication rates are comparable to published studies of nurse-led paracentesis in other countries.

**Conclusion:** Nurse-led paracentesis is a safe and feasible way to manage patients with abdominal ascites secondary to liver disease. Expanding the scope of practice of an APN would improve access to care and support for those living with cirrhosis in regional and remote areas. This would help address the current health workforce maldistribution and consequent disparate health outcomes within regional Australia.

**Keywords:** Alcoholic liver diseases, alcoholic liver cirrhosis, ascites, abdominal paracentesis.

### What is already known about the topic?

- Recurrent ascites is a common complication of liver decompensation that often requires repeated abdominal paracentesis for symptom management.
- The complication rates for nurse-led paracentesis in this study are comparable to published studies of nurse-led paracentesis in other countries, ensuring safety and proficiency in service delivery.

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**What this paper adds**

- This model of care is the only known regional hepatology service providing nurse-led abdominal paracentesis in Australia and New Zealand.
- A nurse-led abdominal paracentesis service would help address the current health workforce maldistribution and consequent disparate health outcomes within regional Australia.

**INTRODUCTION**

Liver cirrhosis is a term used to describe an advanced stage of liver fibrosis. The most common risk factors for cirrhosis include excessive alcohol use, chronic viral hepatitis infection, autoimmune hepatitis, and less common risk factors including hemochromatosis, Wilson's disease, alpha-1 antitrypsin deficiency and cystic fibrosis.<sup>1</sup> The combination of increasing portal pressure and decreasing liver function can contribute to the development of ascites, gastrointestinal bleeds, hepatic encephalopathy and jaundice, thus marking the transition of compensated cirrhosis to decompensated cirrhosis.<sup>2</sup> The presence of decompensated disease is significant, as it can reduce a person's life expectancy from 12 years to 2 years.<sup>3</sup> The Child-Pugh score, which incorporates albumin, bilirubin, prothrombin time, and the presence of ascites and encephalopathy, measures the severity of disease and predicts mortality in a person with liver cirrhosis.<sup>2</sup> Ascites is the accumulation of fluid within the peritoneal cavity.<sup>1</sup> The first-line treatment of ascites is a combination of diuretic therapy and dietary salt sodium restriction.<sup>4</sup> Diuretic therapy can induce complications such as renal impairment, electrolyte disturbance and hepatic encephalopathy and thus, patients should be closely monitored on these medications.<sup>4</sup> Large-volume paracentesis is considered a second-line therapy for patients who do not respond to diuretic therapy.<sup>4,5</sup> Patients who do not respond to first or second-line treatments for ascites, may be considered for the insertion of a transjugular intrahepatic portosystemic shunt (TIPSS) and liver transplantation.<sup>3,4,6,7</sup>

The burden of liver disease in Australia has been projected to increase significantly from 2019 – 2030.<sup>8</sup> Between 2019 and 2030, the population with Fibrosis stage 3 (F3) (pre-cirrhosis) is predicted to increase by 70%, compensated cirrhotic cases are expected to increase by 85%, and cases of decompensated cirrhosis, primary liver cancer and liver transplants, are expected to increase concurrently.<sup>8</sup> In anticipation of the projected rates of liver disease and liver cirrhosis, it is critical to assess the current management of liver-related care in all healthcare settings. A multidisciplinary approach ensures people affected by chronic liver disease receive adequate access to care.<sup>9</sup> However, this approach may not be feasible in all healthcare settings which have disparate access to resources. According to the Australian Institute of Health and Welfare (AIHW), remote, rural, and regional populations have disparate access to healthcare resources in comparison to their metropolitan counterparts.<sup>10</sup> Most of Australia's

population live in major cities (72%), while others live in inner regional areas (18%) and outer regional areas (8.1%).<sup>10</sup> In 2021, people living in inner regional or outer regional areas had a mortality rate 1.1 times higher than their counterparts in major cities.<sup>10</sup> The regional health service in this study is classified as a large rural town as per the Modified Monash Model (2024) and carries an Australian Statistical Geography Standard – Remoteness Area (ASGS-RA) score of RA Code 2 (Outer Regional). Nurse-led paracentesis clinics have been successfully established in other global settings.<sup>11-15</sup> The existing evidence for safety and feasibility of nurse-led paracentesis, the projected rates of liver disease and the disparate health outcomes for people living in regional areas in Australia supports the rationale for establishing a nurse-led paracentesis clinic at a regional health service.

**METHODS****STUDY DESIGN**

A retrospective analysis of abdominal paracentesis procedures that were attempted by the APN over an 8-month period between July 2022 and March 2023 was conducted. This study was based at a single site at a regional public hospital.

**PARTICIPANTS**

Participants of this study included adults (18 years or older) who required abdominal paracentesis for symptomatic relief of ascites. Although this study was focussed on a hepatology-related cohort, oncology participants were assessed for skills and training purposes, with consent and in conjunction with the patient and the patient's treating team. All patients consented to the procedure in conjunction with a relevant medical officer.

**CREDENTIALING**

The Advanced Practice Nurse (APN) identified to lead this service had ten years of post-graduate nursing experience, six of which included specialised hepatology training in a role as a Hepatology Clinical Nurse Consultant. The APN was enrolled in a postgraduate nurse practitioner course, which fostered clinical leadership and decision-making skills. A review of the literature on nurse-led abdominal paracentesis was conducted by the APN in preparation for the implementation of this model of care. The APN observed the procedure being performed on five different occasions, by four different clinicians: two medical officers and two

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interventional radiologists. The interventional radiologists used ultrasound-guided techniques, in comparison to the medical officers who used abdominal ultrasound to mark the insertion site, then a sterile technique to guide the catheter into position without the use of ultrasound. The APN was supervised by a senior medical registrar on five different occasions before attending the procedure independently. Self-assessment and debriefing with the senior medical registrar and a Gastroenterologist were attended after each supervised procedure.

### PATIENT SELECTION

Abdominal paracentesis procedures were attended by the APN during their in-patient admission or in an Ambulatory Care Unit. The Ambulatory Care Unit facilitates a weekly or bi-weekly abdominal paracentesis clinic, with the capacity to facilitate between one and four abdominal paracenteses on a single occasion. This intervention was established to reduce hospital readmission rates for people presenting with recurrent ascites.

Referral pathways for abdominal paracentesis varied. Some patients were referred to the outpatient liver clinic by primary care or other health services, whilst others were identified during a hospital admission. Patients were selected based on the following key criteria: perceived volume of ascites; perceived location of ascites; severity of liver disease and the patient's experience of previous attempts at paracentesis. Patients who did not satisfy the minimum requirements of the APN prior to attempt, were referred to the Radiology department.

### PROCEDURE

The APN was involved in pre-procedure work-up to ensure consent for the procedure by a medical officer; engagement with the patient by the APN; the coordination of any follow-up appointments with specialists. The patient does not need to fast from food prior to the procedure but may be required to withhold diuretic medication on the day of the paracentesis to reduce the risk of symptomatic hypotension.

Patients were admitted to the Ambulatory Care Unit, which is equipped with a crash cart and resuscitation equipment. Pathology and radiology results were interpreted by the APN prior to the procedure date or at the time of admission. Any abnormal or concerning results were discussed with the designated medical officer or treating specialist. Platelet counts less than  $50 \times 10^9/L$  required a platelet infusion prior to the procedure. An International Normalized Ratio (INR) of  $>2$  was not a contraindication to procedure but discussed whether intervention prior to the procedure was required. The patient's blood pressure, oxygen saturation, respiratory rate, heart rate and temperature are assessed by the Ambulatory Care Unit nurse. The APN attended a physical and general assessment of the patient. Other issues such as medication adherence, disease symptoms, weight

fluctuations, psychosocial and mental health factors that may influence clinical presentation were also discussed with the patient.

The patient is assisted into a supine position on the bed. An abdominal ultrasound machine is used to locate ascites and to estimate the depth at which ascites can be obtained, i.e. from the insertion point at the abdominal tissue to the parietal peritoneum. An appropriate insertion point is marked. The advanced practice nurse dons a sterile gown and gloves. A sterile field is prepared using chlorhexidine (chlorhexidine gluconate 2% w/v and ethanol 70% v/v) then a sterile drape is applied. Lignocaine 1% is injected into the intended insertion site using a 21-gauge needle. A 19-gauge needle is inserted into the abdomen perpendicular to the abdomen, creating a track for easier insertion of the Safe-T-Centesis catheter. The Safe-T-Centesis catheter is advanced into peritoneal cavity until it reaches ascitic fluid. The syringe is drawn back to assess for fluid. Once the catheter is in the correct position, the pigtail is advanced over the introducer, then the introducer is withdrawn. The catheter is secured to the patient's abdomen using gauze and a clear dressing film. Ascitic fluid samples are taken, as necessary. To reduce the risk of hypotension due to fluid shift, one vial of 20% albumin is administered intravenously, for every two litres of ascitic fluid drained. The catheter is removed when the recommended maximum amount of fluid has been removed, when flow slows to less than 100mls/hour, when the tube goes cold or at six hours from the insertion time. The patient is reassessed once the catheter is removed and if medically stable, discharged home.

### RESULTS

There were 66 presentations of ascites among 18 different patients, who were assessed by the APN for paracentesis. Fifty-nine (59) attempts at paracentesis were made by the advanced practice nurse. Seven (7) paracentesis procedures were deferred due to minimal or loculated ascites on clinical examination and on abdominal ultrasound. Two failed attempts were due to loculated ascites.

The primary aetiologies among the study participants were alcohol-related cirrhosis (39%), MASLD-cirrhosis (33%), hepatitis C (11%), primary biliary cholangitis (6%), and cancer (bowel and ovarian (11%)). Over half of the study participants were male (67%). The average age of study participants was 65 years old (range 49-87), with 66% of study participants aged 61 years or older. The clinical results recorded were the most recent results taken prior to the abdominal paracentesis. Renal impairment was classified as an eGFR of  $<40 \text{ mL/min/1.73m}^2$ ; only a third (33%) of study participants showed a marked reduction in renal function at baseline. The average INR for study participations was 1.3 (range, 1.0 – 2.4). The Child-Pugh score for patients with liver disease varied from Child-Pugh B to Child-Pugh C (range, 7-11).

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**TABLE 1. BASELINE CHARACTERISTICS OF PATIENTS UNDERGOING ABDOMINAL PARACENTESIS**

Characteristics	Value
Number of patients	18
Average age (years)	65.61
Age range (years)	49–87
<b>Age group (years)</b>	<b>n (%)</b>
≤40	0 (0)
41–50	1 (5.56)
51–60	5 (27.78)
61–70	4 (22.22)
71–80	8 (44.44)
<b>Sex (M/F)</b>	<b>n (%)</b>
Male	12 (66.67)
Female	6 (33.33)
<b>Aetiology of Ascites</b>	<b>n (%)</b>
Alcohol-related liver disease	7 (38.89)
MASLD – cirrhosis	6 (33.33)
Hepatitis C infection (HCV)	2 (11.11)
Primary biliary cholangitis (PBC)	1 (5.55)
Bowel cancer	1 (5.55)
Ovarian cancer	1 (5.55)
<b>Child Pugh score (ex. oncology diagnoses)</b>	<b>n (%)</b>
<b>Class A</b>	<b>0 (0)</b>
<b>Class B</b>	<b>12 (75.00)</b>
7	2 (12.50)
8	3 (18.75)
9	7 (43.75)
<b>Class C</b>	<b>4 (18.75)</b>
10	3 (18.75)
11	1 (6.25)
<b>Coagulation</b>	
Average International Normalized Ratio (INR)	1.3
(INR) range	1.0 – 2.4
<b>Renal function</b>	
>90	6 (33.33)
60–89	5 (27.78)
30–59	4 (22.22)
15–29	2 (11.11)
<15 or dialysis	1 (5.55)

The average amount of ascitic fluid drained among the study participants was 7.57 litres (range 0.8 – 16 litres). The average time spent for study participants who attended the day procedure was 5.75 hours (range 2.46 hrs – 24.27 hrs). The overall success rate for abdominal paracentesis was 97%, which was calculated as insertion successful drainage over the number of attempted insertions. There were no episodes

of infection post-paracentesis as indicated by ascitic fluid biochemistry and ascitic fluid microscopy samples. There was 1 episode (1.69%) of hypotension resulting in transfer to a short stay ward, however the patient was asymptomatic. There was 1 episode of excessive leakage at insertion site (1.69%), 1 episode of pain at insertion site (1.69%) and 1 episode (1.69%) of localised erythema to the insertion site. One patient with cirrhosis received a liver transplant within six months of the completion of the study period.

## DISCUSSION

The most significant aspect of safety identified within this study was the capacity of the APN to select patients for abdominal paracentesis. The APN's scope of practice was informed by the complexity of the patient's symptoms, the severity of their liver disease, and their overall treatment goals. This activity allowed for the APN to consolidate their hypothetic-deductive approach to clinical decision-making.<sup>16</sup> Self-assessment and de-briefing were an important aspect for overall practice. Although the minimum number of supervised procedures in this study was 5, this was specific to the experience and confidence of the individual APN. Practicing within a tiered framework such as Miller's Pyramid allows the learner to develop a deeper understanding of the clinical picture and further enhance clinical assessment skills.<sup>17</sup> The Bondy Scale was used throughout the APN's course to assess clinical competence.<sup>18</sup> This tool could be modified to the context of nurse-led paracentesis to help evaluate skill and clinical competence in this technique.

The APN had been working in a clinical nursing role for six years and received clinical supervision over that period. A senior medical registrar taught the APN the technical skill of abdominal paracentesis. The hospital supported the APN to increase her scope of practice by supporting her nurse practitioner candidacy. The use of checklists in paracenteses improve rates of informed consent, appropriate documentation, and protocol adherence.<sup>19</sup> The APN reviewed the current abdominal paracentesis protocol and developed a pre-procedure checklist in conjunction with interventional radiology staff and the ambulatory care nursing staff to further support patient safety. McGibbon (2007) suggests a simple approach to streamlining referrals for paracentesis addressing some key points about selection criteria.<sup>20</sup> An adaptation of this approach could include questions such as:

1. Does the patient have ascites?
2. Do they require paracentesis and what is the preferred timeline?
3. What are the risks and complications for his patient?
4. What will happen if you don't perform paracentesis?
5. Who will perform the procedure, and in what setting?
6. What other diagnostic information is required and what is the interpretation of these results?

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Other factors that influenced whether patients were selected for nurse-led paracentesis included degree of symptoms of ascites (breathlessness and coughing), and the perceived volume, location and loculation status of the ascites. The use of ultrasound enables practitioners to identify the most appropriate location for the insertion of the catheter.<sup>21-28</sup> Varying research suggests different locations for performing abdominal paracentesis.<sup>29-33</sup> The left lower quadrant (LLQ) is preferable to the infraumbilical midline (ML) due to the thinner abdominal wall and greater depth of ascites in this area.<sup>34</sup> This area is also referred to as the contralateral (left) McBurney's point.<sup>35</sup> Additional margin of safety was attained by selecting the deepest pocket of ascites using a curvilinear probe during ultrasound assessment.

The most common haemorrhagic complications in abdominal paracentesis include pseudoaneurysm, hemoperitoneum and abdominal wall haematoma with the latter suggested as the most common.<sup>36-37</sup> Mild and moderate abnormalities in clotting and platelet function are not associated with increased haemorrhagic complications in these patients with no clinical evidence of bleeding at the time of the procedure.<sup>38-39</sup> In this study, mild to moderate INR did not affect the decision to attend or withhold paracentesis; none of the paracenteses attended were complicated by abdominal wall haematoma, hemoperitoneum or intraperitoneal haemorrhage.

The aetiology of the presentations reflects the type of patients who accessed the service. Patients with alcohol-related liver disease reaccumulated large-volume ascites more frequently. There were seven occasions where an attempt at paracentesis were withheld; five patients were assessed and did not have enough fluid to drain, while on the two other occasions, a low volume of fluid, estimated to be <2 litres, excluded those patients from nurse-led paracentesis. The first failed attempt was due to loculated ascites, and the second failed attempt occurred in a patient who had abdominal tissue >30mm, and therefore local anaesthetic could not be delivered effectively without access to the correct equipment.

Developing a relationship with the radiology department was an important step in establishing this service. Initially, all patients requiring abdominal paracentesis assessment, were booked in with radiology as a contingency plan in the event of unplanned leave or procedure difficulty. Clear communication between the APN and the radiology department is paramount to the efficiency of the service. Medical officers were available to prescribe local anaesthetic, intravenous albumin and any other medication alterations required during the admission. Studies show that early paracentesis is associated with reduce mortality in patients hospitalised with cirrhosis and ascites, and delays can result in multiple-day admissions.<sup>40</sup> The time taken to complete the procedure from admission to discharge was 5.75 hours which is important when considering ambulatory care unit service hours.

The barriers in providing this service were more apparent in the initial stages of implementation. The first major hurdle was having timely access to an abdominal ultrasound. The ambulatory care service did not have its own designated ultrasound machine, causing delays in assessment and the procedure. This issue was brought to the attention of the hospital and was rectified by purchasing an ultrasound machine for the unit.

## LIMITATIONS

The main limitation to our study is the retrospective and heterogeneous nature of the data collected. There were limited cases numbers for each aetiology of liver disease, and hence the implementation of this service may not be applicable to all aetiologies. It was a single site study, with limited numbers of study participants. The timeframe analysed was a short period. A cost-benefit analysis comparing this model of care to usual care was not included but future similar studies would benefit from this analysis. The data presented is from a regional population and hence, may not extrapolate to more unwell patient cohorts in more subspecialised liver units.

## CONCLUSION

Given the current disparity in medical workforce distribution, the need to bridge the gap in delivery of care to regional and remote patients is crucial. This study describes a nurse-led model of care that is safe and feasible in an ambulatory care setting in a regional hospital that is equipped with suitable resources. Establishing patient selection criteria for nurse-led abdominal paracentesis is a crucial step in ensuring patient safety. We suggest that abdominal paracentesis can be attempted by advanced practice nurses if they have the appropriate level of post-graduate training and credentialing within their scope of practice. We conclude that there is no single minimum number of supervised procedures that deems competence in abdominal paracentesis, rather, that clinical competence should be based on individual competence in the procedure.

This model of care may need to be appraised in different settings, to provide understanding of the safety and feasibility profile in other patient cohorts. In future studies, the implementation of patient feedback surveys could provide information about the patient's experience of the procedure and prove that early engagement of an APN with a patient can hasten care coordination, education and reduce emergency presentations related to ascites; this was a key theme throughout the study but was not formally evaluated.

In areas where resources are limited, such as in regional, rural and remote areas, nurse-led paracentesis may offer an option of care that can reduce hospital presentations and enhance the care of patients with decompensated cirrhosis.

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# Examining the impact of rapid response team nursing models on patient outcomes: A single-centre retrospective observational study

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## ABSTRACT

**Objectives:** To determine whether rapid response team (RRT) end-of-call patient outcomes differ between a dual-role intensive care unit (ICU)/RRT nursing model and a partially dedicated RRT nursing model, to report any associations between ICU adverse events and RRT calls, and to describe RRT call characteristics.

**Background:** ICU nurses commonly staff RRTs but juggling simultaneous ICU and RRT duties may compromise patient safety and care.

**Methods:** A single-centre retrospective cohort study compared all ward-based RRT calls during two equivalent eight-month periods at a large Australian adult teaching hospital: January–August 2017 (non-dedicated model) and January–August 2018 (partially dedicated model). Data was obtained primarily from the RRT database. Descriptive statistics and binomial proportion tests compared call characteristics.

Unadjusted logistic regression examined associations between nurse role (dual or dedicated) and end-of-call outcomes: remained on ward, transferred, or died (primary outcome = death; secondary = transfer).

**Results:** Of the 6,955 RRT calls analysed, the proportion attended by dual-role ICU/RRT nurses fell markedly after two dedicated nurses were introduced, down from 39.4% (1366/3466) in 2017 to 11.6% (403/3489) in 2018 ( $\chi^2(2) = 838.4$ ,  $p < 0.001$ ). Across both periods, dual-role nurses still managed 1,769 calls (25%). RRT calls attended by dual nurses carried more than threefold higher odds of death (odds ratio [OR]: 3.015 [95% CI: 1.796–5.061],  $p < 0.001$ ), double the odds of any transfer off the ward (OR: 2.027 [95% CI: 1.756–2.340],  $p < 0.001$ ), and 43% higher odds of ICU transfer specifically (OR: 1.428 [95% CI: 1.148–1.776],  $p = 0.001$ ). The pattern of RRT trigger reasons changed significantly between 2017 and 2018, with fewer calls for cardiac

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arrest or low oxygen saturation and more calls initiated because staff were "worried," among other shifts ( $\chi^2 (15) = 61.95, p < 0.001$ ). No statistically significant associations could be demonstrated between ICU-recorded adverse events and RRT call characteristics; nevertheless, exploratory trends in the data suggest possible links that require further research.

**Conclusions:** The dual ICU/RRT nursing model was associated with poorer patient outcomes, including higher mortality and more frequent transfers. In contrast, the partially dedicated RRT nursing model was associated with more favourable outcomes.

**Implications for Clinical Practice:** The findings suggest that dedicated RRT nursing staff may improve patient outcomes by reducing the dual nurses' workload, highlighting the importance of workload management in RRT staffing. Further studies are warranted to explore these results in other settings.

### What is already known about the topic?

- Rapid response teams often rely on ICU nurses, who bring expertise in advanced assessment to support acutely deteriorating patients in general hospital wards.
- In some hospitals, nurses undertake dual roles, providing both patient care in the ICU and attending RRT calls.

### What this paper adds

- A focused comparison of RRT patient outcomes between dedicated RRT nurses and dual ICU/RRT nurses.
- Dedicated RRT nurses were associated with a significant reduction in in-hospital arrests and RRT patient mortality, compared with the dual ICU/RRT model, highlighting how nursing can contribute to potential improvements in patient outcomes.

**Key words:** Critical Care Nursing; Health Care Rationing; Hospital Rapid Response Team; Intensive Care Units; Workforce.

## INTRODUCTION

Rapid response teams (RRTs) are now an established element of acute-care hospitals and form the efferent limb of a broader rapid-response system that encompasses physiological detection and escalation processes (afferent limb), institutional patient-safety governance, and an oversight committee.<sup>1</sup> The principal mandate of the RRT is to deliver immediate, specialist care to ward patients who manifest early signs of clinical deterioration. Landmark observational studies have shown that physiological derangement frequently precedes in-hospital cardiac arrest, indicating that timely activation of an RRT can avert preventable deaths.<sup>2-4</sup>

RRTs are usually multidisciplinary and, in larger institutions, routinely include intensive care unit (ICU) clinicians, particularly nurses.<sup>5</sup> Many of the earliest teams evolved from traditional cardiac-arrest services and were introduced with minimal additional resources.<sup>5</sup> Consequently, ICU nurses are often required to interrupt bedside responsibilities to attend RRT activations (hereafter "RRT calls", also termed medical-emergency-team (MET) calls in some jurisdictions). Such redeployment has several potential ramifications.<sup>6</sup> First, it may compromise the mandated 1:1 ICU nurse-to-patient ratio, thereby increasing workload and the likelihood of missed care.<sup>7-8</sup> Second, accumulating evidence links frequent work interruptions to a higher incidence of medication and procedural errors among ICU nurses.<sup>9</sup> Insufficiently resourced RRTs may therefore jeopardise both ward-level and ICU-level patient safety, leading to issues such as medication delays, ventilator weaning delays, and unplanned ICU transfers.<sup>6</sup>

The present study compares two nursing configurations for RRT coverage at a large metropolitan teaching hospital: a non-dedicated model in 2017 and a partially dedicated model introduced in 2018 (Figure 1). In both years, four ICU nurses were assigned to the RRT service; however, in 2017, all four nurses balanced routine ICU duties or equipment management with RRT attendance, whereas in 2018, two nurses were rostered exclusively to the RRT around the clock, supported by two on-shift ICU nurses for overlapping calls. The number of medical staffing attending was unchanged (Supplementary Material). Using routinely collected RRT database records, we examine whether reallocating nursing resources in this manner influenced RRT call characteristics, end-of-call patient outcomes, and ICU adverse-event rates.

## AIM

To evaluate whether end-of-call patient outcomes differ between rapid response activations covered by dual-role ICU/RRT nurses and those managed by dedicated RRT nurses.

## OBJECTIVES

1. Compare patient outcomes: death during the call, transfer to higher-acuity care, or ward retention between the two nursing models.
2. Characterise RRT activations by trigger, timing, responder mix, and scene-time metrics.
3. Examine associations between ICU-level adverse events and the frequency of RRT calls.

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## METHODS

## STUDY DESIGN AND SETTINGS

This single-centre retrospective cohort study examined ward-based patients who experienced deterioration events requiring RRT attendance. The study took place at a large adult metropolitan teaching hospital in Australia, using data from 1 January to 31 August 2017 and from 1 January to 31 August 2018 (inclusive). The age of the data is unavoidable, due to delays resulting from the study's unfunded nature and the COVID-19-related clinical redeployment of author one, although the study captures key insights into the transition to a dedicated RRT nursing service. To minimise seasonal variation in hospital presentations, two eight-month periods (January–August) were compared using an Interrupted Time Series (ITS) design. Time-series analysis was selected for three principal reasons. First, because the staffing redesign occurred at a single, well-defined moment, treating the hospital as its own control strengthens causal inference in the absence of randomisation. Second, by modelling both the baseline level and the underlying trajectory before the intervention, the method disentangles the intervention's impact from secular and seasonal patterns that would otherwise blur a simple pre-versus-post comparison. Third, the technique leverages the data's fine-grained chronological detail, capturing every monthly observation, thereby increasing statistical power and enabling detection of both abrupt (level) and progressive (slope) changes. The September–December period, which aligned with the implementation of the new RRT nursing model, was excluded to maintain focus on trends within comparable seasonal windows, ensuring consistency in hospital activity patterns across both periods.

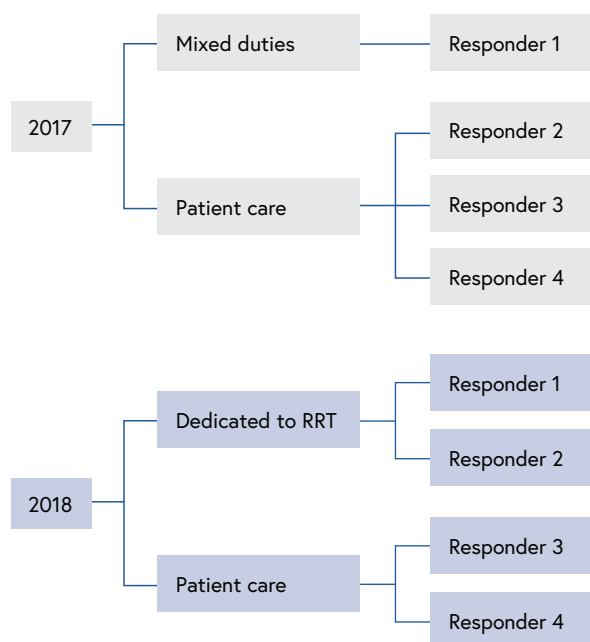


FIGURE 1. RRT NURSING MODEL IN 2017 AND 2018

## PARTICIPANTS

All ward-based hospital inpatients who experienced at least one RRT call within the previously specified timeframe were included. The unit of analysis was the individual RRT call, which was matched to its patient episode through a unique database identifier and timestamp, enabling the retrieval of patient demographics, end of call outcomes, and the nursing staff assigned to the call.

## SAMPLE SIZE

A total of 6,955 RRT calls were analysed (2017: 3,466; 2018: 3,489).

## DATA COLLECTION AND MANAGEMENT

Three routinely collected hospital databases were queried with permission from the respective data custodians: (1) the local COMET (core outcome measurement and evaluation tool) ICU activity database; (2) the SA Health safety learning system (SLS) database, which captures staff reported adverse events; (3) the RRT database, where all RRT calls are transcribed from paper forms (written by nurses) into the database (by an administrative officer).

The ICU admissions database was used to obtain activity data for the study periods, totalling 4,792 admissions ( $n = 2,398$  in 2017;  $n = 2,394$  in 2018). The SLS database showed that ICU staff recorded 811 adverse events during the study ( $n = 342$  in 2017;  $n = 469$  in 2018). An adverse event was defined as any occurrence during healthcare that could have, or did, result in unintended psychological or physical harm to a patient or staff member.<sup>10</sup> After COMET data extraction, the data were viewed in Microsoft® Excel® spreadsheets, then manually reviewed, screened, cleaned, and coded.<sup>11</sup> Errors or outliers identified during the review were addressed with the data custodian. Due to missing data from the RRT database, 264 of 6,955 RRT calls had an unknown nurse responder status. These calls were still included in the analysis. Data were coded (scale, ordinal, nominal) and entered into IBM SPSS Statistics for Windows (Version 28) for analysis.<sup>12</sup>

## STATISTICAL ANALYSIS

Descriptive statistics were conducted on the demographic data to summarise key characteristics of the study population. Demographic characteristics and reasons for RRT calls were compared between the two years using a binomial proportions test. Statistical significance was defined as a  $p$ -value  $< .05$ . Patient RRT call outcomes (either: (1) remained in the ward, (2) transferred to another location, or (3) death during the RRT call) were analysed using logistic regression, with dual ICU/RRT nurse status as the dependent variable. Both significant and insignificant outcomes were included in the individual binomial logistic regression analysis for transparency. Given the exploratory nature of the analysis and the limited available data, the analysis was unadjusted for factors such as age or severity of illness. The exposure of

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interest was the nursing model, dual-role nurses compared with coverage by partially dedicated RRT nurses. The primary outcome was death during the RRT episode; secondary outcomes were transfer to any higher-acuity location and scene-time duration.

## ETHICS STATEMENT

This study was classified as low and negligible risk. Ethical and governance approval was granted by the local health network (#13893). To protect confidentiality and minimise potential biases, identifiable data related to staff and/or patients were not extracted, ensuring privacy and maintaining objectivity in the analysis.

## RESULTS

## CHARACTERISTICS: RRT CALLS

Over the 16-month study window, the RRT attended 6,955 calls, 3,466 in January–August 2017, and 3,489 in the corresponding months of 2018, equating to 1.45 and 1.46 calls per ICU admission, respectively. Introduction of two partially dedicated RRT nurses in 2018 sharply reduced dual-role coverage: dual ICU/RRT nurses attended 1,366 calls (39.4%) in 2017 but only 403 calls (11.6%) in 2018, a 71% fall that was highly significant ( $X^2(2) = 838.4$ ,  $p < .001$ ). Overall, dual-role nurses still managed one-quarter of all activations (25.4%) during the study. Patient ages ranged from 3 to 104 years, with a mean age of 67 years (SD 19) and a median age of 71 years (IQR 57–82). Occasionally, the team must treat a visiting child, so a few database records show an age of three years, even though we are an adult hospital. The incidence of RRT in-hospital arrests (cardiac and respiratory arrests) decreased significantly from 57 (1.6%) in 2017 to 33 (0.9%) in 2018 ( $X^2(1) = 6.65$ ,  $p = .01$ ).

Furthermore, in-hospital mortality among patients who received an RRT call fell from 44 deaths (1.3%) in 2017 to 20 deaths (0.6%) in 2018 ( $X^2(1) = 9.245$ ,  $p = .002$ ) (Table 1).

## TRIGGERS FOR RRT ACTIVATION

Systolic blood pressure (SBP) <90 millimetres of mercury (mmHg) remained the most frequent cause of RRT calls in both years, accounting for 25.8% of calls in 2017 and 25% in 2018. Between 2017 and 2018, significant differences were observed in the frequency of RRT calls for the following reasons: “cardiac arrest” ( $p = 0.048$ ), “O<sub>2</sub> saturations <89%” ( $p = 0.001$ ), “unexpected or uncontrolled seizure” ( $p = 0.032$ ), and “worried” ( $p < 0.001$ ) (Table 2).

## RRT CALL DURATION

From 2017 to 2018, both the mean and variability of RRT scene times increased. This rise in mean scene time, coupled with a broader range and greater variance, indicates that RRT calls were longer and more variable in 2018 (Table 3). Dedicated RRT nurses exhibited shorter and less variable call times, with a narrower range and fewer extreme values, compared to dual ICU/RRT nurses. Dual nurses had slightly longer calls on average, with greater variability and more frequent outliers, as indicated by higher skewness and kurtosis values (Table 4).

## RRT TIME AND ADVERSE EVENTS

Monthly interrupted time-series plots suggested that periods of intense dual-role activity coincided with more ICU adverse events, whereas lighter dual-role workloads aligned with fewer events (Figure 2). However, the correlation between the two series ( $r = -0.483$ ) was not statistically significant ( $p = 0.58$ ), precluding firm inferences about temporal coupling.

TABLE 1. DEMOGRAPHIC INFORMATION: PATIENT CHARACTERISTICS AND RRT ACTIVITY

Variable	Overall 2017 & 2018	2017	2018	Test statistic (df)	p
<b>Patient characteristics</b>					
Median patient age, years (IQR)	71 (57–82)	72 (57–83)	69 (56–81)		
Mean patient age, years (SD)	67 (19)	68 (18)	66 (19)		
<b>ICU activity</b>					
Total admissions to the ICU, n	4792	2398	2394		
<b>RRT activity</b>					
Total RRT calls, n	6955	3466	3489		
RRT calls attended by ICU nurses, n (%) <sup>a</sup>	1769 (25.4)	1366 (39.4)	403 (11.6)	$X^2(2) = 838.4$	< .001
RRT calls triggering ICU/HDU admission, n (%) <sup>b</sup>	418 (8.7)	213 (8.9)	205 (8.6)	$X^2(1) = 0.15$	.70
RRT calls for in-hospital cardiac arrest outside ICU, n (%) <sup>a</sup>	90 (1.3)	57 (1.6)	33 (0.9)	$X^2(1) = 6.65$	.01
RRT calls in which death was recorded, n (%) <sup>a</sup>	64 (0.9)	44 (1.3)	20 (0.6)	$X^2(1) = 9.245$	.002

a) Percentage of all RRT calls in the given study period, 2017 or 2018.

b) Percentage of all ICU/HDU admissions in the given study period.

Note (1): significance level: .05

Note (2): The data for 2017 and 2018 includes only the period of study Jan–Aug, inclusive, of each year.

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**TABLE 2. THE DISTRIBUTION OF REASONS FOR RRT CALLS, WITH A COMPARISON OF COLUMN PROPORTIONS**

Reason for RRT call	2017		2018	
	n	n %	n	n %
Respiratory Arrest	10	0.3	3	0.1
Cardiac Arrest	47 <sup>(.048)</sup>	1.4	30	0.9
Threatened Airway	38	1.1	31	0.9
Significant Bleeding	20	0.6	29	0.8
Respiratory Rate <7	13	0.4	17	0.5
Respiratory Rate >30	375	10.8	339	9.7
O <sub>2</sub> Saturation <89%	486 <sup>(.001)</sup>	14.0	397	11.4
Pulse Rate <40	59	1.7	60	1.7
Pulse Rate >140	326	9.4	377	10.8
SBP >200 mmHg	255	7.4	275	7.9
SBP <90 mmHg	893	25.8	873	25.0
Level of Consciousness / Sedation	467	13.5	453	13.0
Unexpected or Uncontrolled Seizure	105 <sup>(.032)</sup>	3.0	77	2.2
Worried	347	10.0	502 <sup>(.001)</sup>	14.4
Unattended MDT Review	10	0.3	17	0.5
≥3 Observations in Red Zone	15	0.4	9	0.3

Note (1): significance level: .05

Note (2): Pearson  $\chi^2(15) = 61.95$ ,  $p < .001$ , indicating the pattern of RRT triggers changed between 2017 and 2018.

p-values represent two-sided tests comparing 2017 and 2018.

The value is placed beside the year with the larger column proportion, with the p-value show in brackets.

**TABLE 3. DESCRIPTIVE STATISTICS OF RRT SCENE TIME (MINUTES) IN 2017 AND 2018**

	2017	2018
Sum all RRT call time	122433	134438
Mean (Std. Error)	35.32 (.439)	38.53 (.508)
95% Confidence Interval for Mean		
• Lower Bound	34.46	37.54
• Upper Bound	36.18	39.53
Median	30	30
Standard Deviation	25.824	30.006
Interquartile Range	24	28
Range (min–max)	265 (0–265)	278 (2–280)
Variance	666.885	900.38
Skewness (Std. Error)	2.308 (.042)	2.432 (.041)
Kurtosis (Std. Error)	8.771 (.083)	9.101 (.083)

**TABLE 4. DESCRIPTIVE STATISTICS OF RRT SCENE TIME (MINUTES) IN 2017 AND 2018, SEPARATED BY NURSE RESPONDER ROLE**

	2017		2018	
	Mixed duties	Dual ICU/RRT	Dedicated RRT	Dual ICU/RRT
Total minutes at RRT calls, minutes (%) <sup>a</sup>	67,792 (53.4)	48,026 (39.2)	115,043 (85.6)	16,404 (12.2)
Mean (Std. Error)	35.61 (.592)	35.16 (.705)	38.12 (.535)	40.70 (1.587)
Median	30	30	30	32
Standard Deviation	25.84	26.06	29.382	31.863
Interquartile Range	23	23	27	29
Range (min–max)	236 (2–238)	265 (0–265)	246 (2–248)	247 (4–251)
Variance	667.719	679.132	863.301	1015.263
Skewness (Std. Error)	2.145 (.056)	2.589 (.066)	2.259 (.045)	3.073 (.122)
Kurtosis (Std. Error)	6.818 (.112)	11.851 (.132)	7.395 (.089)	14.340 (.243)

a) Percentage of all time (minutes) spent at RRT calls in the given study period (total 2017 = 122433; 2018 = 134438), acknowledging missing data.

**TABLE 5. LOGISTIC REGRESSION FOR DUAL ICU/RRT NURSES (NURSES ON PATIENT CARE) AND RRT CALL OUTCOMES**

RRT Patient Outcome	p-value	Odds ratio*	95% CI for Exp(B)	
(Variable)	(Sig.)	[Exp(B)]	Lower	Upper
Left in the ward	<.001	0.472	0.41	0.543
Transferred out of the ward	<.001	2.027	1.756	2.34
Transferred to the ICU/HDU	0.001	1.428	1.148	1.776
Died during the RRT call	<.001	3.015	1.796	5.061

\*Odds ratios are unadjusted.  
CI = confidence interval

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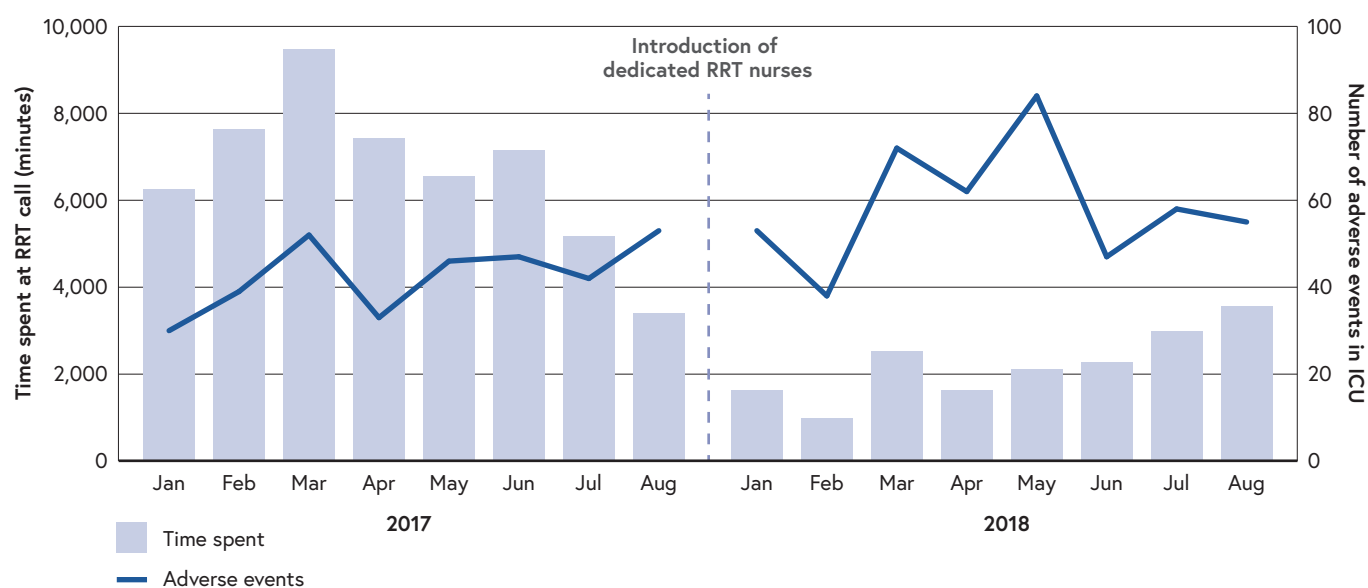


FIGURE 2. INTERRUPTED TIME-SERIES GRAPH OF ADVERSE EVENTS AND DUAL ICU/RRT NURSE ACTIVITY AT RRT CALLS

### PATIENT RRT CALL OUTCOMES

After each RRT call, the nurse documented one of the three available patient outcomes on the medical record form: (1) remained in the ward, (2) transferred to another location, or (3) death during the RRT call. Unadjusted population-averaged logistic regression showed that dual-role coverage was associated with substantially poorer end-of-call outcomes, compared with calls handled by dedicated nurses (Table 5). RRT calls attended by dual nurses carried more than threefold higher odds of death (odds ratio [OR]: 3.015 [95% CI: 1.796–5.061],  $p < 0.001$ ), double the odds of any transfer off the ward (OR: 2.027 [95% CI: 1.756–2.340],  $p < 0.001$ ), and 43% higher odds of ICU transfer specifically (OR: 1.428 [95% CI: 1.148–1.776],  $p = 0.001$ ). Calls that resulted in transfer lasted longer (mean 50 minutes) than those that did not (mean 35 minutes); whereas, calls ending in death were shorter (mean 30 minutes, compared to mean 37 min for non-fatal outcomes) and occurred predominantly after hours (66% between 20:00–08:00 hours).

### DISCUSSION

This retrospective, single-centre study demonstrates that reallocating two ICU nurses to a partially dedicated RRT was associated with clinically meaningful improvements in ward patient outcomes, possibly due to improved nurse workloads. Compared with calls attended by dedicated RRT nurses, those covered by dual-role ICU/RRT nurses carried more than threefold higher odds of death during the call and around double the odds of transfer to another care area, including the ICU. In parallel, the incidence of non-ICU in-hospital arrests fell from 1.6% to 0.9% and RRT-recorded deaths halved after the staffing change. Although causal

inference is limited by the study's observational design, the magnitude and direction of these associations are consistent with a large body of international evidence linking excessive nurse workload to excess mortality and longer length of stay.<sup>13-15</sup>

High nurse workload, as seen in the dual ICU/RRT nursing model, is a well-established risk factor for adverse patient outcomes. Recent studies across multiple countries have consistently shown that increased nurse workload is linked to higher patient mortality and unfavourable outcomes.<sup>13-15</sup> Aiken et al., examined the relationship between nurse staffing and patient outcomes in Chile, and Lasater and Aiken et al., explored the impact of high nurse workloads on patient outcomes and length of stay in Illinois, United States.<sup>13,14</sup> In another study, Lasater and Sloane et al. focused on the effects of nurse staffing and sepsis bundles on patient outcomes in New York, United States.<sup>15</sup> Despite differences in research focus, these studies highlight the critical role of nurse staffing and workload in determining patient outcomes. Similarly, the dual ICU/RRT nursing model, which often involves a heavier workload and competing responsibilities for nurses, may contribute to poorer patient outcomes by limiting the ability to provide timely, specialised care during RRT calls, and is not reflective of staffing practices in top-performing hospitals, where dedicated RRT teams are associated with better patient outcomes and improved safety.<sup>16,17</sup> Building on Aiken et al.'s recommendations, improving nurse staffing levels could enhance patient outcomes, with the costs of additional nurses potentially offset by these benefits.<sup>13</sup> Similarly, Lasater, Sloane et al., demonstrated that adequate nurse staffing positively impacts patient outcomes, reinforcing the need for minimum safe staffing standards.<sup>15</sup>

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### INTERPRETATION IN THE CONTEXT OF PREVIOUS WORK

High-performing hospitals typically deploy dedicated, multidisciplinary RRTs with protected staffing, a practice associated with rapid scene arrival, shorter intervention times and lower cardiac-arrest rates.<sup>16,17</sup> By contrast, the dual-role model studied here forced ICU nurses to suspend 1:1 ICU assignments each time an RRT call arose, breaching Australian and United Kingdom ICU safe-staffing recommendations and potentially exposing both ICU and ward patients to harm.<sup>7,8,18</sup> The observed reduction in arrests and RRT deaths following implementation of the dedicated nursing model is plausible; nurses relieved of conflicting demands can respond more promptly, remain for the full duration of deterioration management, and avoid cognitive overload that predisposes to error.

Two significant improvements in patient outcomes were observed following the introduction of dedicated RRT nurses: a reduction in non-ICU in-hospital arrests (IHAs) and a decrease in deaths during RRT calls. These findings align with previous literature that identifies nurse workload as a key determinant of patient outcomes.<sup>13-15</sup> For instance, Lasater, Sloane et al., demonstrated that nurse workloads significantly impact mortality rates, with each additional patient per nurse associated with a 12% increase in in-hospital mortality odds compared to other factors.<sup>15</sup> In our study, the reduction in IHAs and deaths in 2018 could be attributed to the introduction of dedicated RRT nurses, who focused solely on RRT duties, without the added responsibility of ICU patient care. This model likely facilitated more comprehensive investigations into patient deterioration and enabled timely, proactive interventions, potentially improving patient outcomes. Scene-time analyses support this explanation.

### MECHANISTIC CONSIDERATIONS

Calls involving dual-role nurses, in 2018, were usually longer and displayed greater variance than those managed by dedicated staff, suggesting that task switching and competing priorities impeded efficient care delivery. Moreover, most RRT deaths occurred during off-hours, precisely when ICU staffing reservoirs are thinnest, underscoring the vulnerability of dual-role systems to diurnal workload variations. Building on recent findings by Griffiths et al., the use of temporary staff to mitigate low nurse staffing numbers and having appropriately qualified, senior nursing staff was shown to only partially address the associated risks, highlighting the need for sustainable, long-term solutions to ensure patient safety.<sup>19</sup> This further underscores the importance of establishing comprehensive workforce standards and guidelines for RRT nurses in Australia, informed by ongoing research and expert consultation, to ensure sufficient staffing and mitigate the risks associated with high nurse workload.

### RRT CASELOAD VS ICU DEMAND

In 2018, dedicated nurses responded to 88% of RRT calls and dedicated more time per call compared to 2017. Despite the longer call durations in the 2018 data, there was no increase in ICU admissions, suggesting that the increased focus on RRT duties did not result in greater ICU demand. The ratio of RRT calls to ICU admissions we calculated were nearly double those reported in an earlier Australasian multi-centre study (0.73), highlighting the notably high RRT caseload in relation to ICU admissions and the increasing demand for RRT services over time.<sup>5</sup> Elliott et al., (similar RRT, tertiary hospital) likewise stressed that maintaining a multi-tier RRT requires recurrent funding and that dedicated RRT personnel cannot be double-rostered to ICU duties, noting that the associated RRT staffing costs are 'not insignificant'.<sup>20</sup> However, evidence shows that investing in the nursing workforce both improves patient outcomes and reduces overall costs.<sup>13</sup> Our study suggests a similar trend, where investment in RRT nursing resources may have helped optimise ICU bed management, reduce unplanned admissions, and improve patient outcomes.

### SAFETY AND QUALITY IMPLICATIONS OF DUAL ICU/RRT STAFFING

In terms of the relationship between dual ICU/RRT nurse activity and adverse ICU events, Figure 2 visually suggested that periods of increased dual nurse activity coincided with a rise in adverse ICU events. While this correlation was not statistically significant in our study, it may still hold clinical relevance. One possible explanation is that the increased use of dual ICU/RRT nurses reduces the staffing levels in the ICU, potentially compromising the quality of care. This is consistent with concerns raised in the Australasian RRT guidelines, which caution that inadequate resourcing of the rapid-response system may have adverse effects on ICU care by preventing proper clinical handovers or removing necessary staff from direct ICU patient care.<sup>21</sup> By comparison, the United Kingdom's guidelines for the provision of intensive care services, developed for a public health system similar to Australia's, are less prescriptive about RRT staffing resourcing but emphasise core elements such as having a rapid-response capability (i.e. arrive quickly to the ward area), robust track-and-trigger systems, and a patient-safety culture.<sup>18</sup>

During peaks in RRT demand, dual-role ICU/RRT nurses were pulled from their 1:1 ICU assignments for extended periods, up to 251 minutes. These long interruptions risk eroding ICU care quality; Santomauro et al., found that ICU nurses who experienced increased interruptions during medication administration were more prone to errors.<sup>9</sup> Other studies likewise show that understaffing compromises patient outcomes.<sup>13-15</sup> Taken together with our data, the evidence suggests that adequate, dedicated staffing, for both the RRT and ICU, is important to safeguard patients and minimise risk.

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### STRENGTHS AND LIMITATIONS

Key strengths include the natural “step-change” in staffing that created a quasi-experimental comparison, a large consecutive sample of 6,955 calls, and an interrupted time-series approach that minimised seasonal bias. Nevertheless, several limitations temper interpretation. First, as a retrospective, observational cohort study, it cannot establish absolute causal relationships between dual ICU/RRT nurse roles and RRT call outcomes. Second, the RRT database contained no patient-level covariates; thus, illness severity, comorbidity, and end-of-life decisions could not be adjusted for. Third, the single-hospital setting and eight-month windows constrain generalisability and preclude assessment of long-term sustainability; additionally, there was missing data, and the age of the data is acknowledged as a limitation. Finally, exploratory correlations between dual-nurse workload and ICU adverse events did not reach statistical significance ( $r = -0.48$ ,  $p = 0.58$ ), highlighting the need for larger, multicentre evaluations.

### IMPLICATIONS FOR POLICY AND PRACTICE

Despite these caveats, the data adds to a growing consensus that diverting on-shift ICU nurses to ward emergencies jeopardises patient safety. Health-service managers should weigh the downstream costs of adverse events against the comparatively modest expense of rostering dedicated RRT nurses; economic analyses elsewhere suggest the investment is likely to be cost-neutral or cost-saving.<sup>13-15</sup>

### FUTURE RESEARCH

Prospective, multisite studies with risk-adjusted outcomes are warranted to confirm these findings and to delineate the optimal skill-mix, seniority and training requirements for dedicated RRT nurses. Incorporating patient-reported outcome measures and economic endpoints would further inform policy decisions. Establishing national workforce standards for RRTs analogous to ICU staffing guidelines could provide a pragmatic framework for resource allocation.

### CONCLUSION

Within the constraints of an unadjusted, single-centre analysis, the transition from a dual-role to a partially dedicated RRT nursing model coincided with fewer in-hospital arrests, fewer RRT deaths and markedly lower odds of adverse end-of-call outcomes. These results reinforce international evidence that excessive nurse workload compromises patient safety and support the adoption of protected, dedicated nursing roles within rapid-response systems. Hospitals with similar RRT demands in Australia, Canada, and the United Kingdom, and other comparable health systems, may benefit from investing in dedicated RRT nursing staff to alleviate the burden on ICU nurses and improve patient care.

**Data availability statement:** Restrictions apply to the availability of the data which were used for this study. The data that supports the findings of this study were taken from three different government departmental databases and are not publicly available.

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# Decreasing the length of stay for term babies requiring respiratory support: A quality improvement project

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## ABSTRACT

**Objective:** To decrease the mean length of stay in the neonatal intensive care unit (NICU) for term infants requiring less than 24 hours of continuous positive airway pressure (CPAP).

**Background:** Term infants with respiratory distress are frequently admitted to the NICU for non-invasive respiratory support with CPAP. The most common cause of respiratory distress in term babies is transient tachypnoea of the newborn (TTN). In term infants with mild to moderate cases of TTN, symptoms typically resolve within 24 hours. However, we observed that many term infants who were admitted with respiratory distress had prolonged admissions to NICU, even after their respiratory distress had resolved.

**Study design and methods:** Quality improvement methodology was used to undertake this study. We used the Evidence-Based Practice for Improving Quality (EPIQ) framework to conduct a single plan-do-study-act (PDSA) cycle. The principal change idea was developing and implementing a new guideline incorporating a nurse-led decision-making model

of care. We chose outcome, process, and balancing measures to determine the risks and benefits of implementing this guideline. Periods pre- and post-implementation of the guideline were selected for comparison.

**Results:** A total of 69 term infants who required less than 24 hours of CPAP were included in the study (30 pre- and 39 post-). The mean length of stay in NICU significantly decreased from 21.4 to 14.0 hours ( $p < 0.001$ ). There were statistically significant decreases in the commencement of intravenous glucose infusions (83.3% to 23.1%,  $p < 0.001$ ), the time to enteral milk feed (8.0 to 2.4 hours,  $p < 0.001$ ), and the time to first suck feed (13.1 to 9.7 hours,  $p = 0.003$ ). No differences in other project measures were found.

**Conclusions:** This quality improvement project implemented a guideline that enabled nurse-led decision-making, significantly decreasing the length of stay in the NICU and the use of intravenous glucose infusions. There was no evidence of any adverse outcomes with this approach.

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**Implications for research, policy and practice:**

This quality improvement project demonstrated significant benefits after introducing a new guideline that facilitated a nurse-led decision-making model to assist in caring for term babies with respiratory distress treated with CPAP. More research is required to determine whether the observed benefits are maintained over time and if additional PDSA cycles would lead to further improvements. Future studies should consider additional outcome measures such as parental satisfaction and financial costs.

**What is already known about this topic**

- Term babies with respiratory distress are commonly managed in the neonatal intensive care unit (NICU) with continuous positive airway pressure (CPAP).
- The most common cause of respiratory distress in term babies is transient tachypnoea of the newborn (TTN). Most term babies with mild to moderate TTN require less than 24 hours of CPAP before their respiratory distress resolves.

- NICU admission causes parental stress, may negatively impact parental bonding, and can delay breastfeeding initiation.

**What this paper adds**

- Nurse-led decision-making guidelines can decrease the length of stay in neonatal intensive care for term babies requiring less than 24 hours of CPAP.
- Nurse-led decision-making guidelines can decrease the time to first enteral feed, decrease the time to first suck feed, and reduce the administration of intravenous glucose infusions for term babies requiring less than 24 hours of CPAP.
- Undertaking a quality improvement project using the EPIQ 10-step framework can significantly improve patient and family outcomes within the NICU.

**Keywords:** Quality improvement, Term infant, Respiratory distress, Nurse-led

**OBJECTIVE**

To decrease the mean length of stay in the neonatal intensive care unit (NICU) for term infants requiring less than 24 hours of continuous positive airway pressure (CPAP).

**BACKGROUND**

Respiratory distress occurs in up to seven per cent of infants born at term.<sup>1</sup> There is an extensive list of possible causes of respiratory distress, including transient tachypnoea of the newborn (TTN), surfactant deficiency, air leak syndromes, infection, aspiration syndromes, congenital anomalies of the lungs/airways/heart, genetic abnormalities, metabolic conditions, and neurological conditions.<sup>1,2</sup> The most common cause of respiratory distress is TTN, which is caused by the delayed reabsorption and clearance of alveolar fluid, making the lung less compliant.<sup>3</sup> Most infants with mild to moderate TTN have a resolution of their symptoms within 12 to 24 hours.<sup>3</sup> Continuous positive airway pressure (CPAP) is often used to treat TTN; the proposed benefit is that it helps to overcome poor lung compliance by holding the airway open, maintaining functional residual capacity. CPAP may also promote the reabsorption of alveolar lung fluid.<sup>4</sup> Anecdotally, we observed that many term infants who were treated with CPAP for TTN had prolonged lengths of stay in our Neonatal Intensive Care Unit (NICU). A preliminary audit of 10 consecutive admissions of term infants who were commenced on CPAP revealed that the mean length of stay in our NICU was 20.6 hours. Neonatal Intensive Care admission causes considerable stress for parents, may negatively impact parental attachment and can delay breastfeeding initiation.<sup>5</sup>

The Mater Mothers' Hospital NICU is a 79-bed (47 intensive care, 32 special care) quaternary neonatal unit located in South Brisbane, Queensland, Australia. In our neonatal unit, the standard practice for term infants with mild to moderate respiratory distress is to commence CPAP at a pressure of eight cm of water. Before undertaking this project, if the bedside nurse assessed that the respiratory distress had resolved, they would need to contact a medical officer or nurse practitioner to review the patient and decide if the CPAP could be ceased. Our preliminary audit noted variations in how clinicians ordered the CPAP to be ceased. Some clinicians would first decrease the CPAP to a lower level (e.g., five to six cm), whereas others preferred to stop treatment at eight cm. Variations in the initiation of intravenous (IV) glucose infusions, the commencement of enteral feeds, the choice of expressed breast milk (EBM)/ or formula (after parental consent), and the duration of observation in the NICU post-cessation of CPAP were also noted. Some clinicians would defer the transfer of an infant back to their mother in the postnatal ward until two successive suck feeds had been successful. Unit policy for infants admitted with respiratory distress requires six-hourly blood glucose monitoring for the first 24 hours. The unit policy does not allow any infant on CPAP to attempt breast or bottle feeding; however, gastric tube feeding with either EBM or formula can be commenced in babies with respiratory distress. Many clinicians routinely ordered intravenous glucose infusions and did not start enteral nutrition until signs and symptoms of respiratory distress resolved. Some clinicians would start early enteral feeding via a gastric tube and only commence intravenous fluids if the infant

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was hypoglycaemic. After the preliminary audit, variation in clinical practices was most likely the predominant contributing factor to the prolonged length of stay.

Quality improvement (QI) has been suggested as one of the leading reasons for improved outcomes in Neonatal Intensive Care.<sup>6</sup> There is no universal definition of QI.<sup>7</sup> One definition is “A deliberate, systematic activity that engages people in planning, implementing change and measuring outcomes”.<sup>8</sup> Quality improvement has its own distinct science and methodology that incorporates cycles of information gathering, collaboration in determining and implementing suggestions for improvement, and monitoring the results of the implemented changes. The Evidence-based Practice for Improving Quality (EPIQ) workshop was developed by the Canadian Neonatal Network and incorporates plan-do-study-act (PDSA) cycles and numerous other accepted educational concepts and tools into its QI methodology.<sup>8</sup> The EPIQ workshop is a four to six-hour course that uses an easy-to-follow 10-step program, enabling participants to work in teams whilst acquiring the basic skills and knowledge in QI.<sup>8</sup> The project team included one master EPIQ facilitator and two accredited EPIQ facilitators. Therefore, a QI project was undertaken using the EPIQ methodology to decrease the length of NICU stay by four hours (approximately 20%) for term infants with respiratory distress who require less than 24 hours of CPAP. The aim was to achieve this reduction within six months.

## STUDY DESIGN AND METHODS

A single PDSA cycle was conducted using the tools and processes taught in the Evidenced-based Practice for Improving Quality (EPIQ) workshop.<sup>8</sup> The SQUIRE 2.0 guidelines for reporting quality improvement projects were utilised for this study, and the relevant components of their 18-point checklist were incorporated into this QI project.<sup>9</sup>

The underlying problem was the perceived unnecessary duration of NICU admission for a term infant with respiratory distress who required less than 24 hours of CPAP. The project team comprised neonatal nurses, clinical nurse consultants, nurse educators, managers, and neonatologists. The team first met to discuss this project in March 2021.

The team developed a process map to outline the current admission and discharge processes for term infants commenced on CPAP for respiratory distress. Possible factors

contributing to increased length of stay were brainstormed and change ideas addressing the identified factors were incorporated into a Driver diagram (see Figure 1).

Three potential change ideas most likely to have the highest impact were discussed using the EPIQ feasibility tool.<sup>8</sup> The project team ultimately chose “Develop guideline which facilitates nurse-led decision-making” (highlighted in Figure 1) as the principal change idea to implement. This change would predominantly remove the bedside nurse needing the baby reviewed by a medical officer or neonatal nurse practitioner before CPAP could be ceased. The guideline was intended to provide a straightforward decision-making algorithm that would empower bedside nurses to make clinical decisions in the best interest of their patients. Before deciding on the change idea, the team worked through the guidelines’ components, focusing on steps to facilitate nurse-led decision-making. The guideline underwent several revisions by the project team. Attempts were initially made to incorporate a feeding pathway; ultimately, these attempts were dropped, and we referred to our existing hypoglycaemia and enteral nutrition guidelines. The project team’s final version was sent for wider review by NICU staff and approval per the standard hospital policy. After review, the gestational age to which the guideline would be applied was lowered from 37 to 35 weeks to ensure consistency with other pre-existing hospital guidelines. Despite this change to the guideline, the project team elected to continue with their pre-determined 37-week cut-off for data collection to exclude the possible confounder of prematurity increasing the length of stay. The approved guideline is provided in Appendix 1.

Determining how to measure the effectiveness of a QI project is an essential step in the project.<sup>8</sup> The outcome, balancing, and process measures to assess the benefits, risks, and compliance with the implemented change idea (see Table 1) were pre-determined before introducing the guideline into clinical care. Several team members expressed concerns that not starting IV glucose infusions may increase the number of infants experiencing an episode of hypoglycaemia; therefore, a decision was made to include this as a balancing measure. Another concern was that following our existing hypoglycaemia pathway would increase the amount of formula use and inadvertently lead to a decrease in breastfeeding rates because there would be less need for breast milk. Therefore, we also included the number of infants exclusively formula feeding at discharge as a balancing measure. We thought early infant discharge from

**TABLE 1. PRE-DETERMINED OUTCOME, PROCESS AND BALANCING MEASURES**

Outcome measures	Process measures	Balancing measures
Total time in NICU (hours)	Number (percentage) of infants receiving IV glucose infusions	Number (percentage) of infants with hypoglycaemia (blood glucose level <2.6 mmol/L) during NICU admission
Time in NICU on CPAP (hours)	Time to first enteral feed (hours)	Maternal length of stay (hours)
Time in NICU post-cessation of CPAP (hours)	Time to first suck feed (hours)	Number (percentage) of infants exclusively formula feeding on discharge from hospital

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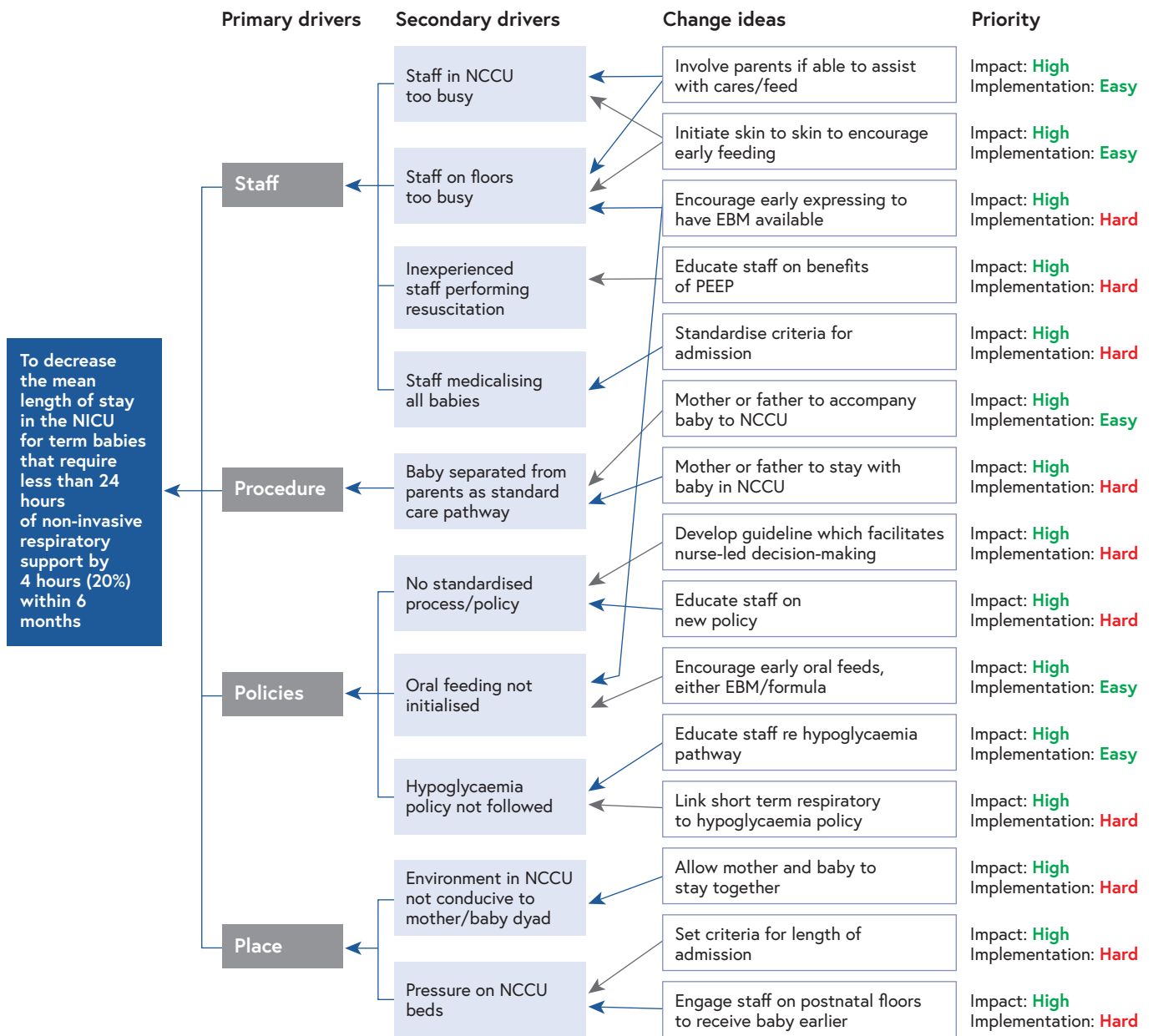


FIGURE 1. DRIVER DIAGRAM

the NICU may also facilitate earlier maternal discharge from the hospital and included this as a balancing measure.

Other collected demographic data included gestational age at birth, mode of delivery, birth weight, and gender. We planned to compare results for two cohorts (pre- and post-implementation of the guideline). All term infants admitted to the NICU who had respiratory distress and were commenced on CPAP were eligible for inclusion. Subsequently, we excluded term infants who received more than 24 hours of CPAP because of the increased likelihood that they might have had another cause of respiratory distress other than TTN. Data were extracted from our neonatal database. Missing data were obtained by directly searching individual patient records. Critical milestones for the project are summarised in Table 2.

TABLE 2. PROJECT MILESTONES

Milestone	Date
First meeting	17/03/2021
Process Mapping completed	28/04/21
Driver Diagram completed	11/05/2021
Change idea determined	26/05/21
Guideline developed and sent for approval	27/10/2021
Guideline approved	03/11/2021
"Non-invasive respiratory support (short term) for babies born greater than 35 weeks – work instruction" released.	15/11/2021

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This study met the requirements of the National Health and Medical Research Council's Ethical Considerations in Quality Assurance and Evaluation Activities 2014.<sup>10</sup> This study was reviewed by the Mater Human Research Ethics Committee (HREC) and given an exemption. Informed consent was not required.

## STATISTICAL METHODS

Summary statistics for normally distributed data are reported as means and standard deviation (SD). Summary statistics for categorical data are reported as numbers and percentages. Paired Student t-tests assessed comparisons between groups for normally distributed data. The Mann-Whitney U test was used to assess comparisons between groups for non-parametric data. Categorical data were compared for statistically significant differences using the Kruskal-Wallis test. All statistical tests were done using Addinsoft (2023) XLSTAT statistical and data analysis solution Boston, USA.<sup>11</sup> We chose to present the primary outcome (length of stay in NICU) in a control chart. A control chart is a graphical display of individual results over time; it is essentially a run chart that incorporates statistical measures, such as control limits, to identify data variability visually. We defined our upper and lower control limits as three standard deviations above or below the mean. The control chart was developed using QI Macros for Excel (2023).<sup>12</sup>

## RESULTS

Pre-implementation data were retrospectively collected on consecutive patients from January 1st to February 22nd, 2021. Post-implementation data were retrospectively collected on consecutive patients from November 22nd, 2021, to February 6th, 2022. Patient demographics for each cohort were similar, with no statistically significant differences found between groups (see Table 3).

The primary outcome measure was the total length of stay in NICU; this significantly decreased from a mean of 21.4 hours to 14.0 hours ( $p < 0.001$ ) (see Table 4). The total length of stay in the NICU was divided into the time spent on CPAP and the time off CPAP. As demonstrated in Table 4, there was no statistical difference in how long an infant needed CPAP, with the reduced length of stay being due to a significant decrease in the time spent post-cessation of CPAP in the NICU. A control chart for the total length of NICU stay pre- and post-implementation of the guideline is presented in Figure 2.

After implementing the guideline, the mean length of stay decreased, and the control chart's upper and lower control limits narrowed. The narrowing of the control limits signifies less variability in the individual data points and implies more consistent management practices in the post-implementation period.

TABLE 3. PATIENT DEMOGRAPHICS

Demographic	Measurement	Pre-implementation (N = 30)	Post-implementation (N = 39)	p-value
Gestational age at birth (weeks)	Mean (SD)	39.3 (1.3)	38.8 (1.09)	0.20 <sup>†</sup>
Birth weight (grams)	Mean (SD)	3437 (466)	3379 (376)	0.57*
Spontaneous vaginal delivery	N (%)	13 (43.3%)	23 (59.0%)	0.20 <sup>#</sup>
Male gender	N (%)	11 (36.7%)	16 (41.0%)	0.72 <sup>#</sup>

N = number, % = percentage, SD = Standard Deviation, † = Mann-Whitney U, \* = Student's t-test, # = Kruskal-Wallis

TABLE 4. PROJECT MEASURES RESULTS

Project measure	Measurement	Pre-implementation (N = 30)	Post-implementation (N = 39)	p-value
Total time in NICU (hours)	Mean (SD)	21.4 (10.6)	14.0 (12.6)	<0.001 <sup>†</sup>
Time in NICU on CPAP (hours)	Mean (SD)	8.5 (6.1)	6.7 (5.3)	0.17 <sup>†</sup>
Time in NICU post-cessation of CPAP (hours)	Mean (SD)	12.9 (9.5)	7.3 (11.6)	<0.001 <sup>†</sup>
Received IV glucose	N (%)	25 (83.3%)	9 (23.1%)	<0.001 <sup>#</sup>
Time to first enteral feed (hours)	Mean (SD)	8.0 (7.1)	2.4 (2.3)	<0.001 <sup>†</sup>
Time to first suck feed (hours)	Mean (SD)	13.1 (8.5)	9.7 (11.9)	0.003 <sup>†</sup>
Hypoglycaemia	N (%)	4 (13.3%)	2 (5.1%)	0.23 <sup>#</sup>
Formula only on discharge	N (%)	2 (6.7%)	3 (7.7)	0.87 <sup>#</sup>
Maternal length of stay (hours)	Mean (SD)	73.3 (25.3)	72.4 (37.4)	0.33 <sup>†</sup>

N = number, NICU = Neonatal Intensive Care Unit, CPAP = Continuous Positive Airway Pressure, SD = Standard Deviation, IV = intravenous, † = Mann-Whitney U, \* = Student's t-test, # = Kruskal-Wallis

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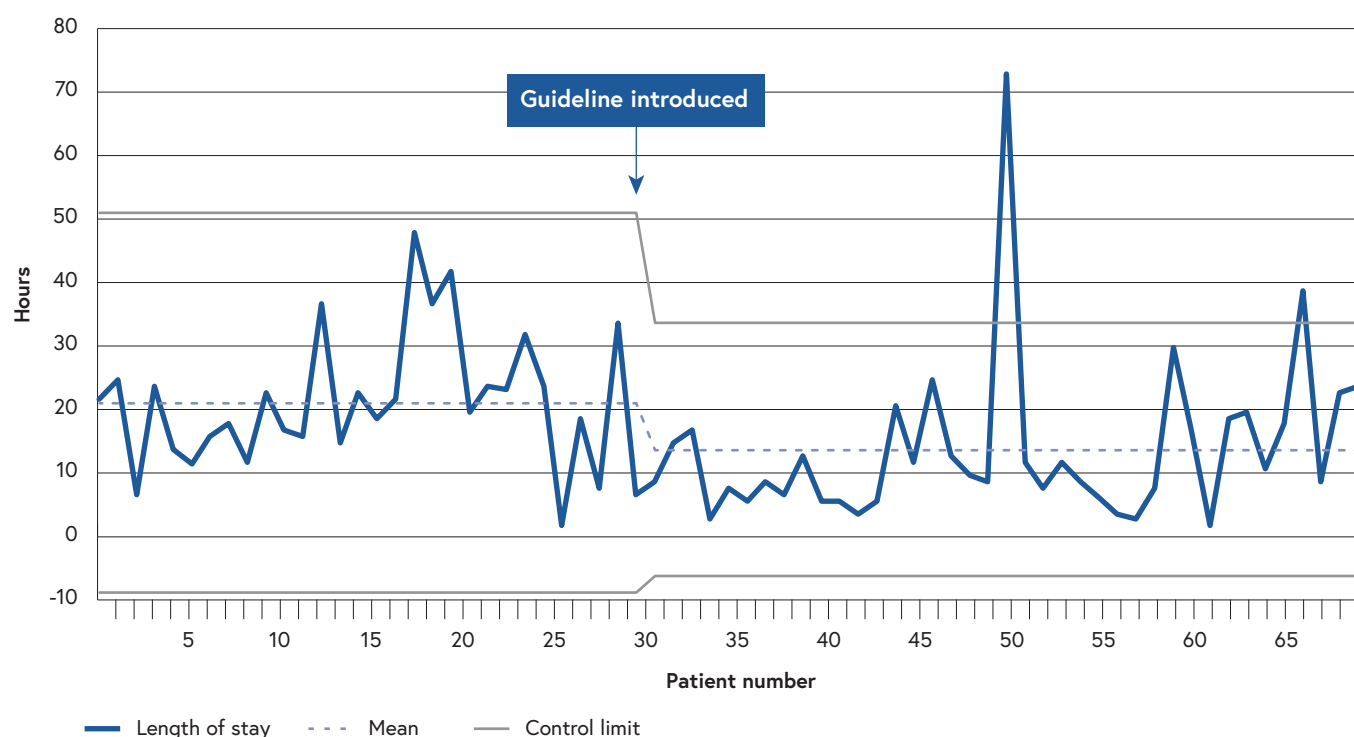


FIGURE 2. CONTROL CHART: LENGTH OF STAY IN NEONATAL INTENSIVE CARE UNIT

The control chart clearly demonstrates an outlier above the upper control limit in the post-implementation guideline group (see Figure 2). This patient stayed for an additional 73 hours in the NICU after their CPAP was ceased. Excluding this patient from analysis (assuming there was another reason for the prolonged length of stay besides respiratory distress) further reduces the mean total length of stay in NICU to 12.5 hours (a decrease of almost 9 hours).

In the pre-implementation period, 83.3% of infants were commenced on IV glucose infusions, as opposed to a statistically significant reduction of 23.1% in the post-implementation period ( $p < 0.001$ ) (see Table 4). The new guideline advised clinicians to follow the pre-existing hypoglycaemia policy (see Appendix 1). The hypoglycaemia policy incorporates several measures that should be attempted (e.g. breastfeeding, glucose gel, complementary feed with formula) before recommending that an IV glucose infusion be commenced. Statistically significant reductions were found in the number of infants receiving IV glucose infusions ( $p < 0.001$ ) as well as the time to first enteral feed ( $p < 0.001$ ) and the time to first suck feed ( $p = 0.003$ ) in the post-implementation group (see Table 4). Reassuringly, no significant differences in the number of babies having hypoglycaemic episodes or being discharged on exclusive formula feeding were observed between the groups (see Table 4). Another potential benefit identified was a possible decrease in the maternal length of stay; however, no significant change was observed (see Table 4).

## DISCUSSION

This single-cycle QI project demonstrated that the introduction of a guideline which facilitated nurse-led decision-making led to a significant reduction in the NICU length of stay post-cessation of CPAP for term infants who required less than 24 hours of non-invasive respiratory support. Nurse-led, protocolised decision-making for adjusting mechanical ventilation has been reported in paediatric and adult intensive care; however, we could not identify comparable studies conducted in NICU to compare our findings with.<sup>13-15</sup> Nurse-led decision making for cessation of CPAP within the NICU has not been reported. However, there are several other clinical scenarios in which Nurse-led decision making can be successful, including newborn resuscitation, breastfeeding, infant follow-up, and pain management.<sup>16-19</sup> There is growing evidence for using QI projects to improve patient outcomes within NICU.<sup>20-25</sup> We aimed to reduce the mean length of stay by four hours but achieved a seven-hour reduction. The guideline (see Appendix 1) stated that patients could be discharged to the postnatal ward if they remained stable off respiratory support for at least one hour. However, the mean duration of stay post-cessation of CPAP was still 7.3 hours, and there was a wide variation (standard deviation of 11.6 hours). A limitation of this study is that individual cases were not audited to determine why infants stayed in the NICU after the cessation of their respiratory support. The underlying causes of the respiratory distress and/or additional co-morbidities could increase the length of stay. In an attempt

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to control the underlying cause of the respiratory distress and target those babies with presumed TTN, we chose to only include term infants who needed less than 24 hours of CPAP in our study. However, other causes of respiratory distress may resolve within 24 hours, and it is known that in severe cases of TTN, symptoms can take up to 72 hours to resolve.<sup>3</sup> Arguably, this may also be a strength of the study in that the implementation of this guideline resulted in a decreased length of stay, irrespective of the underlying cause of respiratory distress. Unfortunately, data were not collected on how many term infants were tried off CPAP but subsequently failed, or on the total number of attempts at ceasing CPAP on each baby.

Whilst the length of stay post-cessation of CPAP was significantly shorter ( $p < 0.001$ ), the overall maternal length of stay was similar between the groups. The standard deviation for the maternal length of stay in both pre- and post-implementation groups is large (see Table 4). A limitation of this project is that the mothers' charts were not audited to examine factors that may have contributed to their overall length of stay. There was a notable difference in spontaneous vaginal delivery (SVD) rate between groups (43.3% in the pre-implementation versus 59% in the post-); however, this did not reach statistical significance. It would be expected that mother's post-caesarean section would require a more extended stay; therefore, the pre-implementation group would have a longer mean length of stay. Despite not impacting the maternal length of stay, implementation of this guideline resulted in a significantly shorter total duration of NICU admission ( $p < 0.001$ ). This may have the additional benefit of improving parental-infant bonding and parent satisfaction; however, no attempt was made to collect data on these critical outcomes. While a cost-benefit analysis was not undertaken, the decreased overall length of stay of the infant in the NICU may have implications for nursing workforce-related expenditure in the future.

The initial aim was to complete this project within six months; however, it took approximately eight months from the first meeting to the final version of the guideline being released (see Table 2). Despite not meeting the original timeline, this was a notable achievement given the COVID-19 pandemic, which compromised the NICU workforce and ability to undertake research during that time.

Due to the study design incorporating pre- and post-implementation cohorts, a limitation of this study is that it is impossible to determine if any other practice changes (apart from the implemented guideline) may have impacted upon the results. Another limitation of this project is that only one PDSA cycle was completed. Due to the success of this single cycle and other clinical priorities, quality improvement work within the unit changed focus. There is a plan to re-audit in the future to see if the benefits have been maintained and determine if further change ideas and PDSA cycles need implementation (see Figure 1).

A particular strength of the study was the collaboration of a motivated multidisciplinary team that consisted of clinicians, educators, and administrators. Using a structured and systematic approach incorporating the ten steps taught in the EPIQ course developed a change idea that was explicitly targeted towards our environment. It has previously been demonstrated that using change guidelines from another unit is ineffective for improving outcomes compared to undertaking a quality improvement project within that particular service.<sup>26</sup> Undertaking the same QI project in a different clinical environment may result in entirely different change ideas, project measures and results. This is one of the significant benefits of this methodology, resulting in solutions considered most appropriate for the setting undertaking the QI project. However, it is also one of the limitations in that the results of our project will not be generalisable to other settings.

## CONCLUSIONS

This quality improvement project led to a significantly decreased length of stay in the NICU ( $p < 0.001$ ). Additionally, there were significant decreases in the number of babies being commenced on intravenous glucose infusions ( $p < 0.001$ ), the time to initiation of first enteral feed ( $p < 0.001$ ), and the time to first suck feed ( $p = 0.003$ ). Notably, there was no associated increase in the incidence of infants having episodes of hypoglycaemia and no increase in the number of infants being exclusively formula-fed on discharge. Implementing this guideline has increased the opportunity for infant-parent bonding by enabling earlier discharge from the NICU.

## IMPLICATIONS FOR RESEARCH, POLICY AND PRACTICE

This project highlights the significant benefits of nurse-led decision-making models of care. More research is required to determine whether the observed benefits are maintained over time and if further PDSA cycles would lead to further improvements. Future studies should consider outcome measures such as parental satisfaction and financial costs.

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# Patients' perspectives on promoting tracheostoma self-care: A qualitative study

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## ABSTRACT

**Objective:** To explore patients' perspective about promoting tracheostoma self-care.

**Background:** Promoting self-care is one of the main areas of intervention for nurses who care for patients undergoing tracheotomy/total laryngectomy. Self-care can improve autonomy, quality of life and reduce tracheostoma complications. To achieve this, interventions need to be evidence-based and sensitive to the patients' needs and preferences. However, little is known about patients' experiences of learning to care for their tracheostoma and their preferences.

**Study design and methods:** A qualitative descriptive study was carried out through semi-structured, individual, and face-to-face interviews with patients who had undergone tracheotomy/total laryngectomy (n = 17). Purposive sampling was performed with maximum variation. All interviews were audio-recorded and transcribed verbatim, and data were analysed using qualitative content analysis. The study complied with the Consolidated Criteria for Reporting Qualitative Research (COREQ).

**Results:** This study identified two main themes. The first was the experience of living with a tracheostoma. Participants recognised the implications of the tracheostoma in everyday life, the importance of tracheostoma awareness, critical moments, possible response patterns, and the personal, social, and health-related factors that can affect this experience. The second theme identified was the promotion of tracheostoma self-care. The participants mentioned the rebuilding of autonomy as the main objective, the thematic content that should be addressed by nurses before and after the surgery, the different strategies and resources that can be used, and what determines the appropriate time to intervene.

**Conclusion:** Despite the challenges of living with a tracheostoma, participants acknowledged the promotion of self-care as crucial for regaining autonomy. Nursing interventions that incorporate contents, methodologies, and implementation moments sensitive to the preferences, needs, and characteristics of each patient, which are maintained over time, appear to be the desired approach according to the participants.

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**Implications for research, policy, and practice:**

This study's findings can help to design and implement nursing interventions to promote tracheostoma self-care that leads to better health outcomes.

**What is already known about the topic?**

- Undergoing a tracheotomy/total laryngectomy requires adapting to a new condition of life. Promoting self-care in these patients enhance autonomy, and adaptation to the tracheostoma.
- Nursing care for tracheostoma patients is poorly systematised. So, interventions to promote tracheostoma self-care should be created and tested, to improve clinical practice.
- Nursing interventions tailored to the specificities, needs, and preferences of the target population are more likely to be accepted and effective. Therefore, it is important to understand patients' perception and involve them in identifying appropriate interventions.

**What this paper adds**

- This study can help nurses to understand the complexities faced by people living with a tracheostoma. Recognising the implications, critical events, response patterns, and factors that influence this experience can assist nurses in anticipating care needs over time.
- The study participants emphasised the relevance of self-care for maintaining autonomy. They identified the issues, strategies and resources, and significant moments for promoting self-care for people with a tracheostoma.
- The results of this study can contribute to defining more coordinated, timely, and tailored nursing care models that meet the needs of individuals and improve health outcomes.

**Keywords**

Content analysis; nursing; patients' perception; qualitative research; self-care; tracheostomy

**BACKGROUND**

A stoma can be defined as an artificial mouth or opening to the outside of the body, created for therapeutic reasons.<sup>1</sup> In this article, the term tracheostoma will be used to describe an opening to the trachea through the neck to allow breathing, regardless of indication, the technique used (percutaneous/surgical tracheotomy or total laryngectomy) or its duration (temporary/permanent). A tracheostoma may be performed for several reasons: airway obstruction, airway protection or maintenance, airway cleansing, prolonged mechanical ventilation and to facilitate weaning.<sup>2</sup> It is one of the oldest surgical procedures in the history of medicine and is frequently performed in hospitals around the world.<sup>3</sup>

For individuals with a stoma, the promotion of self-care is essential.<sup>4</sup> Stoma self-care can be described as a decision-making process that influences actions related to maintaining the stoma and peristomal skin (the skin right around the stoma), identifying problems and complications, and ways to effectively manage them.<sup>5</sup> Self-care competence in patients with a tracheostoma appears to enhance autonomy, acceptance, and adaptation to the stoma,<sup>6</sup> reducing the incidence of complications, and decreasing healthcare costs.<sup>7</sup>

Despite the recognition of the importance of teaching people how to care for and manage their tracheostoma,<sup>8</sup> there is still no robust evidence to guide and systematise how this should be done. A review of the literature on nursing interventions to promote self-care in tracheostoma patients highlighted the need to develop and test nursing interventions to promote self-care.<sup>9</sup>

In addition to being evidence-based, nursing interventions should be tailored to the characteristics, needs, and preferences of the target population. This means interventions are appropriate to individuals and encourages active engagement and participation in self-care.<sup>10</sup> To date, no study has focused on patients' perceptions of the promotion of tracheostoma self-care. Understanding the individual's perspective can help to build a better understanding of living with a tracheostoma, leading to more sensitive and satisfactory care that meets individual needs.<sup>11,12</sup> Furthermore, it will allow for reporting of experiences, identification of difficulties, service failures, desired topics/subjects to be addressed, appropriate timing, and the intended educational methodology,<sup>12</sup> which could be useful for redirecting care toward more effective, person-centred, and high-quality care.

**OBJECTIVE**

The objective of this study is to explore patient perceptions regarding the promotion of tracheostoma self-care. It is part of a broader project that aims to develop a nursing intervention programme for the promotion of self-care in individuals with a tracheostoma in Portugal.

**STUDY DESIGN AND METHODS**

A qualitative descriptive study was conducted. The COREQ checklist for reporting qualitative studies was followed.<sup>13</sup>

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## STUDY PARTICIPANTS

The study was conducted in the Otorhinolaryngology (ORL) inpatient and outpatient departments of two hospitals in Portugal: a central general hospital and an oncology hospital. These two hospitals were chosen because they serve populations in geographically diverse areas. One hospital has a structured follow-up care model for tracheostoma patients.

To be included in the study patients needed to be 18 years of age or older, to have had a tracheostoma (following tracheotomy or total laryngectomy) less than 2 years ago and be autonomous with self-care or have the potential for this. Purposive sampling with maximum variation was used. Participants with different sociodemographic characteristics (such as gender, age, level of education, area of residence)

TABLE 1. CHARACTERISATION OF THE PARTICIPANTS

Demographic and clinical characteristics (n = 17)	% (n) or Mean (range; SD)
Age (years)	58.4 (38–74; 10.37)
30–40	5.88% (1)
41–50	17.65% (3)
51–60	23.53% (4)
61–70	47.06% (8)
71–80	5.88% (1)
<b>Gender</b>	
Female	11.76% (2)
Male	88.24% (15)
Years of education	7.76 (4–12; 2.49)
<b>Type of surgery</b>	
Scheduled Total Laryngectomy (TL)	41.18% (7)
Tracheotomy	47.06% (8)
Emergency Tracheotomy and scheduled TL later	11.76% (2)
<b>Purpose of Surgery</b>	
Neoplasm	82.35% (14)
Laryngeal trauma	5.88% (1)
Subglottic stenosis	11.76% (2)
<b>Stoma duration</b>	
Permanent	52.94% (9)
Temporary	47.06% (8)
Time elapsed since surgery (days)	328.82 (9–683; 259.12)
<b>Interview setting</b>	
Inpatient department of the central general hospital	29.41% (5)
Outpatient department of the central general hospital	11.76% (2)
Inpatient department of the oncology hospital	5.89% (1)
Outpatient department of the oncology hospital	52.94% (9)

and clinical characteristics (such as surgical indication, technique/procedure performed, and tracheostoma duration) were included.

The sociodemographic and clinical characteristics of study participants are shown in Table 1.

## DATA COLLECTION

The data were collected through a semi-structured, individual, and face-to-face interview. All interviews were conducted by the main researcher. The main researcher received specific training and guidance on conducting interviews during doctoral studies and from the research co-authors (third and fourth author), who have experience in conducting research interviews. The interviews took place between November 2020 and December 2021 and lasted between 15 and 40 minutes.

An interview script was developed based on the defined objective (see Table 2). The interview script was tested prior to the study to ensure that the questions were clear and unambiguous. As no changes were made to the script, the data obtained in the test were included in this study.

TABLE 2. SEMI-STRUCTURED INTERVIEW SCRIPT FOR PARTICIPANTS

Interview questions
1. What has it been like caring for/learning to care for your tracheostoma?
2. Tell me about the cursing care you received before undergoing the tracheotomy/total laryngectomy. *
3. Describe how you were prepared/are being prepared for caring for your tracheostoma during your hospital stay.
4. What was it like caring for your tracheostoma like when you returned home? *
5. Tell me about the follow-up nursing care after you were discharged from hospital. *
6. What needs and/or difficulties have you experienced over time in caring for your tracheostoma over time?
7. What factors have made it easier for you to learn to live with and care for your tracheostoma?
8. What factors have made it more difficult to learn to live with and care for your tracheostoma?

\* Questions may not have been asked, given the participant's perioperative stage or clinical context.

Interviews continued until no more relevant information was obtained, i.e. until the research team considered that data saturation had been reached. The study therefore had a total of 17 participants.

## DATA ANALYSIS

Interviews were audio recorded. Six participants had aphonia (due to damage to the vocal cords or because they were not yet able to communicate with the voice prosthesis). In these cases, lip reading was carried out by

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the main researcher (who, as an ORL nurse, has extensive experience of caring for and communicating with these patients) and repeated aloud to the participant to confirm that the lip reading had been correctly interpreted and to enable the audio recording. Field notes were also taken of the participants' non-verbal communication during the interviews. Qualitative content analysis of the interviews was then carried out using the technique of categorical analysis.<sup>14</sup> Interviews were transcribed verbatim. The pre-analysis phase began immediately after the transcription of the first interview. Two researchers (first and second author) carried out an overall reading of the transcriptions and field notes simultaneously. The content deemed significant in each interview was extracted and organised into coding units by the two researchers. The emerging categories were then defined. The coding and categorisation carried out by the two researchers were then reviewed by the entire research team, comparing the coding structure with the transcriptions. The coding, final naming of categories, and themes, were discussed among the team until a consensus was reached. The data analysis was facilitated using NVivo 12 software.

## ETHICAL CONSIDERATIONS

This study was approved by the two participating hospitals ethics committees (approval number 436-19) and the Universidade Católica Portuguesa (approval number 166). All participants were informed of the scope of the study, its objectives, the voluntary nature of their participation, and the possibility of withdrawing at any time during the interview. Written informed consent to take part in and record the interviews was obtained from the participants.

## RESULTS

Two main themes emerged from the data analysis: *the experience of living with a tracheostoma* and *the promotion of tracheostoma self-care*. Participants' quotations supporting each category identified are presented throughout the text. Each quote is referenced by the letter P (participant) and a unique identification number ranging from 1 to 17.

## THEME: THE EXPERIENCE OF LIVING WITH A TRACHEOSTOMA

*The experience of living with a tracheostoma*, identified the following categories: *implications of living with a tracheostoma*, *tracheostoma awareness*, *critical moments*, *response patterns*, and *conditioning factors*, as presented in Table 3 and expanded upon below.

## Implications of living with a tracheostoma

Participants said that living with a tracheostoma has '*multiple and challenging consequences*' for breathing, communication, appearance, swallowing, smell, taste and activity tolerance. These physical and functional consequences of the

TABLE 3. THEME: THE EXPERIENCE OF LIVING WITH A TRACHEOSTOMA

Categories	Subcategories
Implications of living with a tracheostoma	Multiple and challenging consequences that make them different
	New and complex care
Tracheostoma awareness	
Critical moments	Returning home
	Confronting the change in self-image
	Confronting difficulties or complications
Response patterns	Autonomy in tracheostoma care
	Becoming a habit/routine
	Building confidence
	Returning to usual/previous life
	Self-acceptance
	Forgetting the difference
	Negative emotions: fear, shame, complex, anger, saturation, frustration, hopelessness
Conditioning factors	Related to the person
	Related to family, community, and society
	Related to healthcare resources

tracheostoma '*make them different*' from who they were before the surgery. "*We become different* [following the creation of the tracheostoma], *don't we? The way we speak changes (...)* speaking is different now. (...) *I have to chew my food properly* [to make it easier to swallow]. *At first I had no flavour* [referring to the loss of taste after surgery], *now I do. I also have no sense of smell. (...)* *I had to stop working...*" (P12, underwent total laryngectomy in January 2020)

Participants also found that living with a tracheostoma requires '*new and complex care*'. For example, the person must learn to care for the tracheostoma and its devices. "*... it's all very new and complicated. If it were in a leg or an arm. But here* [pointing to the neck], *everything scares us, cleaning, changing, whatever it may be, we get anxious, short of breath.*" (P4, underwent tracheotomy in July 2019)

## Tracheostoma awareness

Participants mentioned the significance of the day-to-day experience of living with a tracheostoma and the implications. They must learn what the tracheostoma is and what it means in their lives. Even if the person is prepared for what is to come, it is only through experience and trial that they can understand what the tracheostoma means in their life. "*They explained to me very well what would happen after the operation. But I wasn't fully aware, I had never seen it before, and I couldn't imagine what they were telling me. (...)* *It was only after the surgery that I found out what it was. (...)* *Now that I have been through it, I understand, it makes sense to me (...)*" (P12, underwent total laryngectomy in January 2020)

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### Critical moments

Participants highlighted the significant and challenging events of the experience of living with a tracheostoma. 'Confronting the change in self-image' was described as a critical moment in the experience of living with a tracheostoma. "Confronting myself with that image in the mirror, seeing that hole in the mirror, and having to insert a tube in there...it really affected me, I felt very nervous, I couldn't do it." (P11, underwent tracheotomy in January 2021)

'Returning home' was identified as another critical moment, as participants no longer had the support of professionals to care for the tracheostoma. "Especially because when you go home, you have to do everything yourself, there's no support." (P2, underwent tracheotomy in August 2020)

'Facing difficulties or problems/complications' was also described as a significant moment. "Once, when I was taking a shower, a drop of water got in and I was very distressed. My wife helped me. It was terrible. Now I'm very careful." (P8, underwent tracheotomy in February 2020)

### Response patterns

'Autonomy as a result of self-care' was identified as a positive response to the experience of living with a stoma, as participants were able to manage their tracheostoma independently. Caring for the tracheostoma as a 'habit or routine' was also suggested as a positive response to living with a tracheostoma. 'Gaining confidence' in stoma care was also mentioned as a positive response pattern. "And of course, as time went on and I gained confidence, there was no longer a need to have someone there." (P11, underwent tracheotomy in January 2021)

Participants suggested that 'accepting' the tracheostoma was a positive response to the experience, as they came to understand that the stoma was necessary and that they needed to integrate it into their lives. 'Resuming life', especially daily activities and adapting to the constraints of the tracheostoma, was another possible positive response to living with a tracheostoma. "I'm going out, I'm living my life, I'm spending time with my friends, no problem at all... I'm carrying on, within the bounds of what's possible." (P7, underwent total laryngectomy in April 2020)

Other participants suggested that 'forgetting about the difference' was a positive response to living with a tracheostoma. In some cases, the selection and suitability of stoma devices to meet participants' needs was the driving factor behind this outcome. "It's totally different now with the speaking valve, sometimes I even forget [about the tracheostoma]." (P14, underwent tracheotomy in February 2021)

Finally, the participants emphasised another possible pattern of response to the experience of living with a tracheostoma: the presence of 'negative emotions'. Some highlighted feeling

ashamed or self-conscious about having a tracheostoma, especially at an early stage after the surgery. "Then, gradually, I freed myself from that complex. I feel calmer, psychologically I feel better. (...) But the adaptation was difficult." (P9, underwent total laryngectomy in October 2019) Others expressed fear of not being able to care for the tracheostoma or fear for the future. "There was also the fear that it would get worse [the disease may get worse]." (P14, underwent tracheotomy in February 2021)

Other negative emotions such as anger, frustration, and tiredness were mentioned, both because to the constant need for tracheostoma care and because of having to deal with the consequences of having a tracheostoma, particularly the change in communication. A sense of hopelessness about the consequences of living with a tracheostoma was also suggested. "I'm tired of dealing with this... Psychologically, it is not easy at all. It's hard to explain...I feel like I ripping it out [referring to the tracheostoma tube]." (P4, underwent tracheotomy in July 2019)

### Conditioning factors

In the category of 'conditioning factors', the participants identified factors related to the individual, the family, the community, and society, as well as factors related to healthcare resources that can affect the experience of living with a tracheostoma.

In the factors 'related to the person', having faith/hope, motivation/willpower, staying calm, having high self-efficacy, and a leisure activity/hobby as therapy were identified as factors that can improve the experience of living with and caring for a tracheostoma. "The best part of this process was me, what I did for myself. We have to fight [referring to the illness], face its consequences and have the strength to deal with it. The willpower and joy of living cannot be lost, this is where it comes from [points to the head]." (P7, underwent total laryngectomy in April 2020) "Finding a therapy, a leisure activity is important." (P9, underwent total laryngectomy in October 2019)

Having a temporary tracheostoma, living far away from the hospital, undergoing stoma surgery due to an oncological condition, experiencing a recurrence of the oncological disease, facing complications, undergoing other adjuvant therapies, and having a voice prosthesis located in a difficult-to-see and care for position were identified as challenging factors in the experience of having a tracheostoma. "If I knew it was permanent, my attitude and way of dealing with it might be different. I would have already defined an adapted life plan for it. As it is, I'm always waiting." (P5, underwent tracheotomy in May 2019) "The person is already weakened by the situation, and the complications are demotivating." (P9, underwent total laryngectomy in October 2019)

In the conditioning factors 'related to family, community, and society', the presence of supportive family and friends, as well as sharing experiences with individuals who have gone through the same situation, were stated as facilitators.

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*“Family support is crucial to overcome this situation.”*  
(P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

Social stigma was mentioned as a hindrance, as individuals feel excluded and discriminated against by society. *“People who don’t have [health] problems, or maybe even have more serious ones, discriminate against us. On buses they move away.”* (P4, underwent tracheotomy in July 2019)

Regarding the conditioning factors ‘*related to healthcare resources*’, the reimbursement for stoma devices, support from healthcare professionals, and the existence of a multiprofessional model of care for individuals with a stoma were suggested as facilitators of a better experience. *“The health professionals who treat us are very important in helping, teaching, and supporting us.”* (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019) *“This system [referring to the hospital’s multi-professional clinical circuit/pathway for patients with tracheostoma] works well as a whole, with a system and circuit in place. I go to one office, then move to another, and everything is taken care of at the same time. Everyone is working towards the same goal. This was not how it worked in the other hospital.”* (P14, underwent tracheotomy in 2013 and again in February 2021)

Finally, the lack of experience of community healthcare staff, the lack of systematisation in the care of individuals with a tracheostoma, and the short length of hospital stay were identified as challenging factors in the experience of living with a tracheostoma. *“The nurses at the community health centre mentioned that they didn’t receive any training to deal with it [referring to tracheostoma and tracheostoma devices], and it was always here [in the outpatient department] that they would see how things were going.”* (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

### THEME: PROMOTION OF TRACHEOSTOMA SELF-CARE

‘*Promotion of tracheostoma self-care*’ identified the following categories: objective of self-care promotion, desired contents, strategies and resources, and the appropriate timing for intervention, as presented in Table 4.

#### Objective of self-care promotion

‘*Rebuilding autonomy*’ was identified as an objective in promoting self-care for individuals with a tracheostoma. This autonomy enables the person to take care of themselves independently and maintain their routine. *“...I think it’s important for me to be able to do everything by myself... Wherever I am, at any time, I can take care of whatever is necessary...”* (P12, underwent total laryngectomy in January 2020)

**TABLE 4. THEME: PROMOTION OF TRACHEOSTOMA SELF-CARE**

Categories	Subcategories
Objective of self-care promotion	Rebuilding autonomy
Desired contents	The surgery and its consequences
	Caring for the tracheostoma and the devices
	Prevention, detection, and management of complications
	Encouraging care participation
	Improving self-efficacy perception
	Involving and empowering the family for care
	Device selection and availability
	Stoma assessment
Strategies and resources for tracheostoma self-care	Surveillance and follow-up support
	Face to face
	Written information
	Telephone
	Video
	Materials and devices
Proper intervention moment	Spotlight
	Pain free
	Airway clearance
	Initiated awareness

#### Desired contents

In the category of ‘*desired contents*’, the participants identified the topics that should be addressed when promoting self-care for individuals with a tracheostoma.

Firstly, the participants emphasised the importance of individuals being prepared for ‘*the surgery and its consequences*’. *“Before the operation, they explained to me what the surgery was about...and they explained to me exactly how I would become, what condition I was going to be in... Of course, this issue has to be clear, it has to be explained well...”* (P9, underwent total laryngectomy in October 2019)

The person should also be able to ‘*care for the tracheostoma and the tracheostoma devices*’. *“The nurses taught me how to remove the tube, clean it, clean the skin, and put the tube back in place.”* (P9, underwent total laryngectomy in October 2019)

‘*Prevention, detection, and management of complications*’ related to the tracheostoma, peristomal skin, and phonatory prosthesis, if applicable, were stated as another element to be addressed in promoting self-care. *“Regarding complications, they explained things in a more general way, but then they’d explain things to me as they arose, either by coming here or by explaining how I should resolve them.”* (P9, underwent total laryngectomy in October 2019)

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Participants also mentioned the need for ‘*encouraging care participation*’, so that the person is supported to take the initiative in caring for their tracheostoma. “*At first, it was the nurse who did it. And then, he'd say, “You have got to start doing it too. Remember, there won't be anybody else at home.” So, I started doing it with him in front of the mirror. There was no choice; I had to learn.*” (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

‘*Improving self-efficacy*’ by repeating procedures, as well as the nurse praising the person’s performance, was mentioned as necessary to promote self-care. “*Training and time are important. The more we repeat these procedures, the better we get at them. Standing in front of the mirror, and repeating, practising.*” (P2, underwent tracheotomy in August 2020)

‘*Involving and empowering the family in care*’ was recognised as essential in promoting self-care for individuals with a tracheostoma. “*It's important to have someone in the family who is familiar with the issue. Knowing that we have someone at home who knows how to help, who can provide support and assistance if, for example, the tube comes out or the tape comes off, is very reassuring.*” (P5, underwent tracheotomy in May 2019)

Another element identified as indispensable in promoting self-care was the ‘*selection and availability of tracheostoma devices*’. It is important to provide guidance to the person in choosing the most appropriate device for their characteristics and tracheostoma. “*...And it is important to inform people that there are alternatives to devices. They need to be told what options are available for their condition.*” (P5, underwent tracheotomy in May 2019)

‘*Tracheostoma assessment*’ by nurses was identified as necessary to avoid potential complications as the condition of the stoma and peristomal skin can affect self-care and the selection of devices.

Finally, the importance of ‘*ongoing surveillance and follow-up support*’ was identified. This ensures reinforcement of information previously provided, provides reassurance, and motivates the person to maintain tracheostoma care and offers support in solving problems and difficulties that arise over time. “*It is good to be accompanied [by nurses] here, especially at the beginning, to feel supported and reassured.*” (P11, underwent tracheotomy in January 2021)

### Strategies and resources for tracheostoma self-care

In this category, participants identified the approaches nurses used to promote patient self-care.

The ‘*face-to-face*’ strategy employed by nurses was reported by all participants as the most significant for acquiring skills in tracheostoma care and device change. “*They [nurses] would do it, teach us, and then my wife and I would repeat... I think the most important part is the practical aspect, doing it, the more the better, with the help of the nurses.*” (P9, underwent total laryngectomy in October 2019)

‘*Written information*’ was suggested as a useful complementary method, particularly information about what changes with the surgery and the sequence of activities to perform in tracheostoma care. “*It is indeed helpful to have written information to follow the steps in case something goes wrong. I think it is always useful to have information on paper.*” (P4, underwent tracheotomy in July 2019)

Another strategy identified was the ‘*telephone service*’, especially for problem solving and addressing difficulties when individuals are at home. The possibility of using the telephone as a planned method in the first few days after returning home was also suggested. “*Whenever I have a problem or doubt, I call. I ask to speak to the outpatient department, and they either solve the problem on the phone or ask me to come in person.*” (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

The use of instructional ‘*videos*’ about the tracheostoma and tracheostoma care was another possible strategy suggested by participants. “*Perhaps a video of a patient caring for themselves would be a good idea. It would allow people to see how it's done, overcome fear, and understand that they can learn to do it themselves...*” (P4, underwent tracheotomy in July 2019)

For ‘*resources*’, participants identified the importance of having a ‘*spotlight*’ near the mirror to help visualise the phonatory prosthesis, if it exists. They also stated the importance of having different ‘*devices for tracheostoma*’ available in the health unit so that people know about them, can experiment and choose the ones they prefer.

### Proper intervention moment

In the category of ‘*proper intervention moment*’, participants described the ideal circumstances for promoting self-care in individuals with a tracheostoma. For this, the person should be ‘*pain free*’ allowing them to be receptive to learning new information. “*In the first few days I was very unwell. I had a lot of pain...no, I couldn't do it... (...) Only later, when I felt better, did the nurse start to teach me...*” (P17, underwent total laryngectomy in November 2021)

Patients should have an effective cough so they can clear secretions and manage ‘*airway clearance*’. “*...I had a lot of coughing and a lot of mucus. It was only when I started to improve with the coughing that I was able to learn...*” (P1, underwent tracheotomy in October 2020 and total laryngectomy in November 2020)

Participants also mentioned the importance of individuals feeling ready to cope with the change, that is, showing signs of ‘*becoming aware*’ of the new life circumstances and willingness to engage. It was “*Only after two or three days that I started to feel ready to deal with this. At first, I was confused and overwhelmed by it all.*” (P6, underwent tracheotomy in August 2019 and total laryngectomy in September 2019)

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## DISCUSSION

Living with a stoma means that the person needs to become aware of and adapt to the changes and restrictions that the stoma brings to daily life.<sup>15</sup> The multiple and challenging effects that make people different from who they were, together with the daily care of the tracheostoma, were identified by the participants as the main consequences of living with a tracheostoma. Previous studies suggest that the functional consequences of living with a tracheostoma are often the most valued in the early stages.<sup>16</sup> As their functional status gradually improves, the desire to return to social activities increases. It is at this time that the consequences related to communication and changes in appearance become more challenging to manage.<sup>16</sup> Individuals with a tracheostoma often experience periods of aphonia or are unable to vocalise audibly and quickly. Responses to these challenges vary significantly between individuals.<sup>17</sup> As a result of, or in response to the tracheostoma it is common for people to show impatience, irritability, resentment, frustration, and anxiety due to their inability to communicate effectively with others.<sup>16,18</sup> These findings underline the importance of individuals being prepared for what is to come and receiving ongoing professional support as their needs and difficulties change over time. It also highlights the need for more studies focusing on understanding and managing emotions in people with a tracheotomy/total laryngectomy.<sup>17</sup>

On the other hand, participants identified the factors that influenced their experience of living with a tracheostoma. Having a temporary tracheostoma and undergoing a tracheotomy/laryngectomy due to an oncological disease were identified as personal hindering factors. People with a temporary stoma focus on the temporary nature of their condition, choosing to put their lives on hold until it is resolved.<sup>19</sup> The same authors also recognised that a cancer diagnosis can affect a person's experience due to uncertainty about their future. In terms of family and community factors, participants mentioned the perception of stigma or social exclusion due to having a tracheostoma as an additional challenge. A tracheostoma is cosmetically unattractive and is sometimes seen as intimidating by the community.<sup>20</sup> People with a tracheostoma feel that they can be labelled, discriminated against, and not understood because they look different.<sup>16</sup> These findings highlight the need for community awareness interventions to promote social inclusion in the face of differences.

Regarding factors related to healthcare resources, the lack of standardised care, shorter hospital stays, and lack of experience among community healthcare providers were identified as barriers to the experience of living with a tracheostoma. Due to the lack of formalisation of knowledge and standardisation of care for individuals with a tracheostoma, educational interventions are often inconsistent between professionals.<sup>21</sup> It is, therefore,

important to improve the systematisation of care for individuals with a tracheostoma and the coordination of different healthcare resources.

Thus, identifying factors that negatively influence the experience of living with a tracheostoma may indicate greater vulnerability and therefore require a more tailored and personalised response from nurses.

In terms of promoting tracheostoma self-care, participants recognised its importance for maintaining autonomy. Self-care is a key concept in the life of a person with a stoma. Improving the self-care skills helps to increase self-confidence and self-esteem.<sup>16</sup> Tracheostoma patients need to develop self-care skills and a sense of wellbeing to adapt to changes in living conditions and to carry out activities of daily living.<sup>22</sup> Study participants identified the topics that should be addressed when promoting self-care of their tracheostoma. Encouraging self-care performance was recognised as crucial for individual engagement. For this reason, health professionals should encourage individuals to actively participate in self-care.<sup>16</sup>

Education about the surgery, its consequences, how to care for the tracheostoma, and how to prevent and manage potential complications was identified as crucial. In fact, information, training, time, and successful experience in stoma care can increase autonomy.<sup>23</sup> That's why nurses spend a lot of time with tracheostomy patients and their families, teaching, assessing and helping them to manage and deal with difficult situations that may arise at home.<sup>22</sup>

The importance of ongoing surveillance and follow-up by healthcare professionals to maintain motivation, the desired levels of self-care competence, and early detection of complications has also been highlighted.

Other studies suggest that continuity of care after discharge allows for patient education and self-care supervision. This improves self-care competence, satisfaction with health care, and quality of life.<sup>24</sup> Therefore, it is important to ensure access to specialised care and to improve the health care response when they return home.

Finally, this study identified several strategies to promote self-care in tracheostoma patients. Verbal education alone (conventional care) tends to be forgotten and misinterpreted over time, which can lead to inadequate care.<sup>24</sup> Therefore, it is important for nurses to consider the variety of strategies available and to select, combine, and adapt them to the needs and preferences of each individual.

## STRENGTHS AND LIMITATIONS

To the authors' knowledge, this is the first study on the promotion of tracheostoma self-care based on patients' perceptions. Understanding individuals' perceptions helps to understand how nursing interventions to promote self-care can be improved in response to patients' needs and

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preferences. However, this study has limitations. Participants were selected from a single country, with a specific socio-cultural context. The study was limited to only two different care settings, which may have influenced the results obtained. Furthermore, the differences in results between the two care settings were not explored. Therefore, further qualitative research with individuals with tracheostomas from different clinical and geographical contexts in Portugal should be conducted to corroborate these findings or to identify potentially different outcomes.

## CONCLUSION

Having a stoma means adapting to a new way of life. For this reason, healthcare professionals should help individuals to understand and accept the changes resulting from the surgery. They should also empower individuals to manage their stoma, as autonomy helps to improve adjustment and quality of life.<sup>25</sup>

The results of this study have helped to understand the complexity of living with a tracheostoma. Recognising the implications, critical events, response patterns, and factors that influence this experience can help nurses to anticipate care needs over time.

On the other hand, the participants in this study emphasised the importance of self-care in maintaining an autonomous life. They identified the issues, strategies and resources, and key moments to promote tracheostoma self-care. Indeed, understanding individuals' perspectives can help to design nursing interventions that are sensitive to their expectations, preferences, and specific needs.

## IMPLICATIONS FOR RESEARCH, POLICY, AND PRACTICE

This study provides a unique insight into patients' perspectives on learning to live with and care for a tracheostoma and adds a new dimension to the existing knowledge on this topic. The findings of this study have several implications. Firstly, it provides an opportunity to explore available interventions for nurses to promote tracheostoma self-care. Therefore, the findings may be useful for nurses to provide better and more tailored support to tracheostoma patients and to reflect on current practice in healthcare settings. Secondly, it highlights the existence of personal, social, and health-related factors that negatively affect the experience of living with a tracheostoma. These factors may indicate greater risk or vulnerability. Therefore, they need to be assessed in all patients with a tracheostoma and once identified, these patients need to receive more attention, time, and support from nurses. Thirdly, this study helps nurses to understand the experience of transitioning to life with a tracheostoma. On the one hand, it identifies the potentially most difficult moments, which therefore deserve

greater attention from nurses. On the other hand, it lists the possible responses to this experience, which will indicate whether patients are going in a negative or positive direction in the process of adapting to their new condition. Finally, the findings could inform future interventions to promote tracheostoma self-care. The results of this study, which reflect people's preferences and experiences, should inform the definition of interventions to promote tracheostoma self-care. Indeed, the design of such interventions should take into account the results of existing descriptive studies collected from all the stakeholders (patients, families, and nurses) and the best available evidence. Future studies from other cultures and ethnicities are also recommended to improve the current understanding of tracheostoma self-care experiences.

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# Unleashing the full potential of midwifery: Victorian midwives' motivation and ability to contribute to maternity service reform

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## ABSTRACT

**Objective:** To explore the motivation and ability of midwives in Victoria to contribute to maternity service reform recommendations, specifically expansion and promotion of midwifery continuity of care models.

**Background:** Since the inception of the National Maternity Services Plan in Australia in 2010, midwifery continuity of care has been a key priority area for maternity service reform. It is known that midwifery continuity of care models improves outcomes for mothers and babies, and that midwives' value and support working in these models. What is not known, is the motivating factors and ability of midwives in Victoria to contribute to Maternity Services Reform, through promotion of the initiation and expansion of midwifery continuity models.

**Study design and methods:** A cross-sectional, qualitative descriptive design was used. Ten midwives participated, resulting in six semi-structured individual interviews and one focus group of four midwives. Interview and focus group data was analysed using thematic analysis.

**Results:** Midwives in this study were generally supportive of maternity service reform, especially midwifery continuity of care models, but many felt powerless to contribute to reform agenda. Midwives described limited knowledge of maternity service reform and lack of exposure to midwifery continuity of care models. Systemic issues like medical dominance and lack of institutional support further hindered midwives' ability to enact change. Despite these challenges, many midwives expressed a desire to work to their full scope, suggesting that with adequate education, mentorship, and leadership, they could become more active agents of reform.

**Conclusion:** Midwives within this study are motivated to contribute to Maternity Services Reform and support greater access to midwifery continuity of care models, however, the majority felt unable to make an appreciable contribution to the expansion and promotion of these models. Strategies identified to improve midwives' contribution to reform included: education on transforming maternity care, having access to supportive midwifery leaders, successful interdisciplinary collaboration, and fostering a strong midwifery professional identity.

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**Implications for research, policy, and practice:**

Participants in this study were motivated to contribute to maternity service reform and practice in midwifery continuity of care models. However, there were many aspects of their role as a midwife and the current maternity care system that did not enable them to contribute. Recommendations to improve midwives' ability to contribute include education programs that focus on continuity of care experiences, successful and respectful interdisciplinary collaboration, identifying midwifery leaders with a strong vision for reform agenda, and strengthening midwifery as a profession.

**What is already known about the topic?**

- Widespread implementation of midwifery continuity of care models remains slow in Australia.
- Midwives' ability and motivation to contribute to these models is unknown.

- Australia's maternity service reviews have recommended expansion of midwifery continuity of care models.

**What this paper adds**

To contribute to reform recommendations around midwifery continuity of care models, midwives require:

- education on transforming maternity care.
- supportive midwifery leaders & interdisciplinary collaboration.
- a strong midwifery professional identity.

**Keywords:** Caseload midwifery, maternity health services, maternity service reform, midwifery continuity of care, midwifery.

**OBJECTIVE**

The aim of this study is to explore the motivating factors and ability of midwives in Victoria to contribute to Maternity Services Reform, through promotion, initiation, and expansion of midwifery continuity models. Recommendations for midwifery practice that may lead to greater implementation of midwifery continuity of care models in Victoria, and across Australia will be outlined based on the findings of this study.

**BACKGROUND**

In the last three decades there have been over 15 government reviews of maternity services in Australia. Each of these reviews generate Maternity Service Reform (MSR) recommendations that aim to improve access to quality maternity services for women in Australia.<sup>1</sup> Midwifery Continuity of Care (MCoC), also known as caseload or Midwifery Group Practice (MGP), is a model of care that aligns with recommendations from multiple maternity service reviews over the past decade.<sup>2</sup> These models are defined by Australian Institute of Health and Welfare (AIHW) as where the same midwife, or small group of midwives, provides care and support to a woman during the antenatal, intrapartum and postnatal period.<sup>10</sup> There is high quality evidence to support the safety and efficacy of MCoC models. Women who have care from a known midwife during their childbearing journey are more likely to have a spontaneous vaginal birth, and less likely to experience interventions such as epidural analgesia, episiotomy, and instrumental birth.<sup>3</sup> Additionally, MCoC has been found to improve maternal mental health outcomes when compared to other models of care.<sup>4</sup>

There are also many known benefits for midwives working in MCoC models. Midwives experience greater role satisfaction, and are less likely to experience burnout.<sup>5,6</sup> The perceived professional identity and autonomy for midwives working in continuity models is higher compared with midwives working in shift-work centric, fragmented models.<sup>6</sup> Whilst there is evidence that change is occurring in some states with more midwives working in models where they provide MCoC,<sup>7</sup> most midwives in Australia are currently employed within a hospital setting and provide care under a medical model of care.<sup>8</sup>

Despite national campaigns promoting widespread implementation of MCoC models, and the known benefits to women, babies and midwives', a significant increase in access to MCoC models for women has not been realised.<sup>9</sup> In 2024, the AIHW outlined in their review of maternity care models that only 11.4% of Victoria's maternity care models involved MCoC, compared to 24.1% in Queensland, 21.4% in South Australia and 16% in the Australian Capital Territory.<sup>10</sup> Victoria is one of the most populous childbearing states in Australia and providing maternity services in line with reform recommendations is essential.

Over the past 5 years, Victorian health services have arguably been the most impacted by the COVID-19 pandemic, and the midwifery workforce is no exception. This is due to extensive restrictions and prolonged lockdowns that led to a "transformative shock", which involved abrupt and extensive changes across Victorian healthcare services.<sup>11</sup> A recent Victorian study revealed that 76% of midwifery managers have inadequate staff levels, with increasing difficulty recruiting midwives since the COVID-19 pandemic.<sup>12</sup>

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The study identified an urgent need for recruitment and retention of midwives in Victoria. Expanding and upscaling MCoC models may be a way to do this. A scoping review identifying reasons why midwives stay in the profession found themes that are synonymous to working in MCoC – such as building relationships with women, protecting normality in pregnancy and birth, and working autonomously.<sup>13</sup> Upscaling of MCoC models will not only improve access and outcomes for women and babies but may also provide more appealing job prospects for midwives in Victoria.

A barrier to upscaling MCoC models is midwives who are unwilling, unsupported or feel unable to work in this way.<sup>14,15</sup> Therefore, to support successful transition to wide scale implementation of MCoC in Victoria it is vital to explore the views of midwives working in Victoria.

## STUDY DESIGN AND METHODS

### DESIGN

A qualitative descriptive methodology was used. Qualitative descriptive methods stay close to the data on a surface level and provide a comprehensive description.<sup>16</sup> This approach is particularly useful where little is currently known about the issue under investigation.<sup>17</sup>

### PARTICIPANTS, RECRUITMENT, AND SETTING

This cross-sectional study was conducted within the state of Victoria, Australia between December 2018 and September 2019. Midwives working in any maternity setting (public, private, or MCoC), were invited to participate. Multiple recruitment strategies were employed. A combination of purposeful, convenience, and snowballing sampling was employed as a recruitment method. These methods are frequently employed in qualitative research to gather insights from a specific population – in this case, midwives in Victoria – who possess relevant knowledge or experience regarding the phenomenon of interest.<sup>18</sup> Purposeful sampling occurred through the use of social media advertising and email outreach through local midwifery networks, the Endorsed Midwives Facebook page, and an Australian University Midwifery Programs' social media page. These pages were chosen to gain interest from midwives working in private midwifery practice, as well as midwives working in the hospital setting. Six participants were recruited through the use of social media, and one was recruited via convenience sampling, through emailing of midwives who were known to the researcher to have worked in a specific area of practice for an extended period of time. This recruitment strategy was employed to add diversity to the participants, as many recruited to this point were relatively new to the profession or currently working in MCoC models. Three participants were gained through snowball sampling, which occurred through word of mouth

from a colleague. Participants emailed the researcher to register their interest and receive more information to inform their decision to participate. Demographic data was collected from participants, and included age, educational pathways into midwifery, tertiary qualifications, practice setting, model of care working in, and years of experience.

### DATA COLLECTION

Six one-on-one semi-structured interviews were used to collect data. In addition, one small focus group interview of four participants was conducted to elicit shared views of these midwives working in private practice. All participants were offered one-on-one interviews at the location and time of their choosing, and the participants working in private practice chose a group interview for convenience. All interviews took place face-to-face, except for one phone interview with a rural midwife. Interviews lasted on average 60 minutes. A semi structured interview guide (Appendix 1) was used, which enabled open ended discussions and flexibility depending on the participant's direction and experience. The interview questions explored participant's working context, current knowledge about MSR and perceptions around their role, motivation, and ability to contribute to MSR and MCoC in Victoria. To ensure the interviews were comprehensive and focused on the research objectives a pilot interview was conducted. The pilot interview guide was developed and reviewed by three PhD qualified, experienced researchers. Interviews were recorded and transcribed verbatim using a transcription service. All interview data was de-identified to protect the privacy of participants. In addition, handwritten field notes and memos were taken in each individual interview to add depth to the data collected.

### ETHICAL CONSIDERATION

Ethics approval was obtained through Griffith University Human Research Ethics Committee (GU Ref No: 2018/812). Participants were invited to participate following informed written consent. Responses were de-identified throughout the transcription and data analysis process by using pseudonyms to ensure anonymity. Participants were informed of their right to withdraw at any point without penalty, however no participant employed this right.

### DATA ANALYSIS

Thematic analysis was conducted according to Braun and Clarke's steps to thematic analysis.<sup>19</sup> These steps involved immersing in the data, generating codes, identifying and reviewing themes, defining and naming the themes, and producing the story. Following initial data analysis by the primary researcher, the three co-researchers then discussed and made recommendations until consensus was reached. The final themes and sub-themes are represented in Table 2.

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TABLE 1. PARTICIPANT DEMOGRAPHICS

Pseudonym	Age	Years of experience	Midwifery qualification	Current Practice setting	Model of care working in as per MaCCs** taxonomy
Kylie	20–29	1 year	Bachelor of Nursing/ Midwifery	Urban Public Hospital	Public Hospital Maternity Care
Hayley	20–29	6 years	Bachelor of Midwifery	Urban Agency Work (public and private casual work)	Public Hospital Maternity Care & Private Hospital (Obstetrician Care)
Jessica	40–49	3 years	Bachelor of Midwifery	Urban Public Hospital	Team Midwifery Care
Karley	40–49	17 years	Bachelor of Midwifery	Rural public hospital Rural private hospital Rural midwifery private practice	Public Hospital Maternity Care, Private Hospital (Obstetrician Care) & Private MCoC
Tegan	20–29	1 year	Bachelor of Nursing/ Midwifery	Urban Public Hospital	Public Hospital Maternity Care
Caitlyn*	60+	30+ years	Graduate Certificate of Midwifery (hospital trained)	Urban midwifery private practice	Private MCoC
Ariana*	40–49	23 years	Graduate Certificate of Midwifery (hospital trained)	Rural public hospital Rural midwifery private practice	Public Hospital Maternity Care & Private MCoC
Stephanie*	40–49	6 years	Bachelor of Midwifery	Urban public hospital Urban midwifery private practice	Public Hospital Maternity Care & Private MCoC
Kelly*	60+	30+ years	Bachelor of Midwifery (UK)	Urban public hospital Urban midwifery private practice	Public Hospital Maternity Care & Private MCoC
Michelle	60+	30+ years	Graduate Certificate of Midwifery (hospital trained)	Urban Public hospital	Public Hospital Maternity Care

\*Focus Group Participant \*\*Maternity Models of Care in Australia (AIWH, 2024).

## RESULTS

Participants age ranged from 20 years old -60+ years years old (Table 1). Participant years of midwifery experience ranged from one year to 30+ years. Half of the participants held an additional midwifery prescribing qualifications and worked within private MCoC models. All other participants worked within public or private maternity settings, except for one who worked in a Team Midwifery model (a midwifery-led model of care where a small team of rostered midwives provide antenatal, intrapartum, and postnatal care). Four participants who worked in private MCoC were also employed in a public hospital maternity care model. Only two participants worked in rural areas of Victoria, with others working in metropolitan Melbourne and urban surrounds.

Data analysis identified four themes related to how able and motivated participants felt they could contribute to the MSR agenda and MCoC. These themes and sub-themes are outlined in Table 2.

## I'M TRYING, BUT IT'S SO HARD

The first theme explores how despite midwives being motivated and willing to contribute to MSR, at times it was beyond their ability to do so. There are two sub-themes, 'Supporting maternity service reform' and 'Feeling powerless'.

## Supporting maternity service reform

There was an overwhelming level of support from midwives for MSR agenda, specifically regarding MCoC models.

TABLE 2. THEMES AND SUBTHEMES

Theme	Sub-theme
I'm trying, but it's so hard	Supporting maternity service reform
	Feeling powerless
I don't know how to contribute to maternity service reform agenda	Maternity Service Reform is invisible
	University didn't prepare me
	I'm just a grad
This is bigger than me	Lack of systemic and political support
	More support is needed for midwives to contribute to MSR
	It's not my job
Unleashing the full potential of midwifery	Claiming midwifery identity
	Enable midwives to work to their full potential
	Midwives finding their political voice

Support for reform from the entire midwifery profession was determined essential by all participants. As Kylie explained, to bring about change, "You'd really need support from the whole profession ... because ideally caseload would be – or every woman would have caseload basically".

There was also a strong call for midwives to take initiative, as Jessica described: "... a willingness of people to take that on, a willingness of us midwives on an individual level to go yeah, we'll give it a go. We'll try it. We'll see how we go."

Those currently working in a MCoC model explained how their passion for these models fuelled their continuing desire to contribute to MSR. Karley, a midwife working in

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private practice stated that “...everything else looks inferior”. Midwives who had experience working in MCoC models were more familiar with the benefits and wanted to share their passion with their colleagues and encourage more midwives to work that way.

### Feeling powerless

Despite all participants demonstrating support for the widescale implementation of MCoC models, a narrative of feeling powerless to contribute to the reform agenda emerged. Many midwives, like Kelly, felt unheard: “I don’t think anybody is particularly listening to midwives.” There was a lack of confidence that their opinion “...would be heard by anyone that needs to hear it, I suppose.” (Kylie). Many participants also shared a cautionary tale involving fear of speaking out about MSR. Karley commented that: “...there’s that fear of speaking up loudly and making ourselves vulnerable.” Ariana, a midwife in private practice, experienced resistance within the public maternity system and commented: “We are bullied severely for standing up for women.” This feeling of being persecuted and stigmatised resonated through many of the participant’s stories when they advocated for MSR.

Some participants who described being willing and able to contribute to MSR also described that burnout often prevented their contribution. Maintaining mandatory training, workplace changes, and a lack of paid or personal time to participate in professional development related to the MSR agenda all contributed to their feelings of burnout. Contributing to MSR was seen as another role that the already overworked midwife had to perform, with Hayley commenting: “We’re – just as a profession, we’re burnt-out – totally burnt-out”.

### I DON'T KNOW HOW TO CONTRIBUTE TO MSR AGENDA

The second theme to emerge was around the midwife’s lack of awareness and ability to contribute to the MSR agenda. There are three subthemes, *MSR is invisible*, *University didn’t prepare me* and *I’m just a grad*.

#### MSR is invisible

While a small number of participants were well versed in the National Maternity Services Plan (NMSP) – being the most recent maternity service review at the time of interviews – the majority acknowledged that their first discussion around reform agenda was in these interviews. Jessica described the NMSP “...wasn’t something I’d heard of, which is strange given that I work in this area, but we aren’t aware.” When asked if they felt MSR was visible, all participants answered “no”. Hayley described MSR as:

“Totally invisible. I think that you have to dig to find that sort of information. You have to know somebody who’s informed you. It’s not out there in the public, at all.”

A lack of promotion around the NMSP as well as a lack of MCoC models in Victoria were seen as contributing to the invisibility of MSR recommendations. Some acknowledged the government’s role in MSR but criticised the lack of dissemination of information.

“It’s too slow. Is it happening at all? Who’s looking at it? There’s just no information getting out to anybody. We’re working on the ground here at the level that we need to know what’s going to happen and how it’s going to happen and which direction it’s going to go in, so we can be prepared as well.” (Michelle).

#### University didn’t prepare me

Many participants could not recall learning about MSR during their university studies. Only one participant who had completed their studies in the last 10 years recalled discussing maternity reform plans. Tegan, a newly qualified midwife, recalled, that there was a focus on “numbers” and “the practical skills a midwife needed to do” rather than the preparation to work across the full scope of midwifery practice.

Many participants believed that Victorian university programs did not provide adequate exposure to MCoC models. This resulted in a lack of confidence to work in MCoC, as Tegan said,

“...I think I need a couple of more years’ experience with more support around, but having said that, if I was trained differently, I could come into that better prepared to do continuity.”

Additionally, none of the participants described working in MCoC models as a student or a newly qualified midwife.

Midwives working in MCoC models, and those with more experience, also felt that graduating midwifery students were not ready to contribute to MSR. Kelly, stated “They’re not training midwives to be confident to actually do a caseload.”

#### I'm just a grad

Despite a lack of in-depth knowledge around MSR, the newly qualified and early career midwives (5), who had between 1-6 years’ experience, described a desire to work in MCoC models and contribute to the reform agenda. However, they also described feeling apprehensive in their ability to contribute, with Kylie, a newly qualified midwife, stating:

“...it’s hard, I would support anything that was sort of presented in terms of things like caseload, but I wouldn’t know how I, individually right now, could do anything about it...”.

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### THIS IS BIGGER THAN ME

The third theme captures the perceived external factors that can influence an individual midwife's ability to contribute to MSR. There are three themes exploring these factors; *'Lack of systemic and political support'*, *'More support is needed for midwives to contribute to MSR'* and *'It's not my job'*.

#### Lack of systemic and political support

Most participants described a medically dominated maternity care system that did not align with MSR recommendations and MCoC models. Hayley explained that the system did not support her philosophy, having been warned during midwifery studies about the conflicting ideology in practice,

“there's going to be a very medical model that you'll be placed into – try not to conform. Try to stick to your own philosophy. ...I feel so grateful, that that was my education, because... I've never lost that. Whereas I can see there's many other midwives who completely conformed to the medical model because that's what there is and it's exhausting to attempt to do anything other.”

In addition to medicalisation of the midwife's role, many participants discussed a lack of knowledge by women regarding care options and women would receive fragmented care by default,

“...unless they're cluey and they get on and they go to somewhere like the state government's website where it does list all of your options.... and go and see that they actually do have lots of options. But most of them don't, they just go to the GP and off they go on the trolley.”  
(Caitlyn).

It was also acknowledged that despite the government's MSR recommendations, midwives working in private practice were not supported by government policy. This included lack of insurance options, inadequate Medicare rebates for women, and the need for collaborative agreements. Ariana, who works rurally, described the public hospital in her area having an embargo on referrals to private midwives.

“So, in the area in which I work, the hospital will have nothing to do with independent midwives. .... all their doctors have got a contract that says they will not refer to independent midwives.”

Regardless of personal motivation to contribute to reform, all participants felt the government should be doing more to contribute to MSR. Many felt there was not enough government funding, and this was beyond the role of the midwife to contribute in that way.

“Without funding you can't – I suppose that's state as well, but you can't do anything if you're not supported. In public hospitals ... things like caseload and stuff can't

run if you haven't got government support in the public hospital, and funding because it's obviously less cost orientated.” (Kylie).

#### More support is needed for midwives to contribute to MSR

Midwifery leaders were seen to positively or negatively influence participant's ability to contribute to maternity reform. Many participants spoke of the need for leadership support as role modelling.

“... I really think the management have to want it. Because if you've got management, like say you have management that didn't care about caseload...that weren't thinking about how that was going to benefit the women using the service. Then you've got no one behind you...” (Kylie).

Some participants described that the Australian College of Midwives (ACM), Australia's peak professional body for midwives, could be doing more to encourage midwives to participate in and promote MSR. Ariana explains: “Our insurance needs to be through the Australian College of Midwives, and we need to be supported by them.” Midwives interviewed felt that it was more difficult to be politically active without this support from professional bodies.

All participants acknowledged that effective interprofessional collaboration was a key component to successful reform. Hayley gave a positive example of collaboration in establishing a MCoC model in a tertiary centre:

“... it started with a really good relationship between midwives and obstetrics. The head of obstetrics and the head of the midwifery unit were on the same page and the midwife was absolutely for the idea of a continuity program. She had a couple of midwives under her who were very passionate about it. As a multi-disciplinary strategy, they made it happen.”

This successful collaboration was not widely reported amongst participants, and few could provide examples of where they had seen collaborative practice resulting in successful service re-orientation.

#### It's not my job

There were a select few participants who were happy to leave contributions to the reform agenda to others. Although a supporter of the reform agenda, Michelle explains: “I have time issues. It's not a priority for me.” Karley acknowledged her lack of skillset to lead reform changes, stating: “It would require quite a massive effort and motivation to shift things, and I'm not the one to do that, so that probably won't happen then.”

There was also a small number of participants who felt that women needed to take more responsibility for changing the maternity care. Jessica described:

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“Most of the women that I’ve come across the majority of them are pretty naïve when it comes to their maternity care. They haven’t really researched anything, be that the model of care or any of the tests or investigations or anything that you kind of offer them. They’re just quite happy to be led, in which case it comes back really to the midwives to say this is the options.”

### UNLEASHING THE FULL POTENTIAL OF MIDWIFERY

The fourth theme encompasses the growth and realisations that participants discussed over the course of the interviews around their role in MSR. This theme describes what midwives require to unleash the full potential of their role and their ability to contribute to MSR. There are three sub-themes: ‘*Claiming a midwifery identity*’, ‘*Enable midwives to work to their full potential*’ and ‘*Midwives finding their political voice*’.

#### Claiming midwifery identity

Midwives felt they needed respect from their colleagues and medical professionals to feel confident and able to contribute to MSR. Hayley detailed:

“I think we just need to be taken seriously. We need to have a level of respect that we’re professionals who are very skilled in what we do and that we’re not just hippies and witches and we’re not here just to preach feminist views...”

Many participants, like Stephanie, felt that due to the medicalisation of childbirth, those direct entry midwives without a nursing background were struggling to assimilate to hospital practice due to the vast difference in philosophies around childbirth.

“But if you haven’t done the nursing degree beforehand and you’re doing the direct entry, which is much more focused on supposed midwifery care and midwifery values and midwifery philosophies, God help you, mate. Most of them don’t survive.” (Stephanie).

However, midwives working in private practice had a particular interest in cultivating awareness and enabling placements for midwifery students in MCoC models.

#### Enable midwives to work to their full potential

Although midwives were seen to have the potential to work in MCoC models as per reform recommendations, the current system did not enable midwives to work in that way. Medical dominance of maternity care, the fragmented shift-work style rosters that most hospitals employed for midwifery staff, and a lack of willingness of some midwives to rotate across all areas of maternity care prevented this way of working. “Upskilling” was a term used often and was promoted as a strategy to enhance midwives’ scope of practice and ability to contribute to MSR. Jessica explained:

“...some midwives will have worked in certain roles for many years. That might be a barrier to them to coming into caseload. They might feel I haven’t done clinic in so many years or I haven’t worked in labour suites for so many years... Whereas, if they were given the correct training and cross-skilling and investment to come back into those areas, they’d be willing to do that.”

When speaking of scope of practice, many participants felt that working in private practice was a way to work to their full scope of midwifery practice and directly contribute to MSR. Those working in private practice already, also expressed a desire to mentor and support more midwives to contribute in that way.

#### Midwives finding their political voice

Throughout the course of each interview, the narrative around MSR grew from uncertain to positive and empowered. The final question from the interviews invited participants to consider what they required to contribute to MSR in an ideal world. Most participants, like Jessica, discussed the need for midwives to be equipped with the knowledge to contribute to MSR:

“... ideally as well going back to the education of midwives, from the start and teaching them about maternity services and where the deficits are at the moment and what we want to achieve. Giving them that information at the beginning so they’re enthusiastic and they come out with a voice. They know how to fight.”

Participants also discovered midwives needed to be political when finding their role in MSR. Many participants initially struggled to identify the political role of the midwife in MSR, however throughout the interviews many identified that calling for reform action within their own profession was a political role that they could assume.

## DISCUSSION

### SUPPORT FOR MCoC MODELS

Like participants in this study, midwives across Australia support and wish to work in MCoC models. Midwives working in MCoC describe a way of working that is both fulfilling, and challenging.<sup>20</sup> Additionally, many midwives not working in MCoC in Australia describe a willingness to work in the model in the future.<sup>5</sup> There is, however, a feeling of powerlessness by midwives in Australia to work in and contribute to MCoC due to medically-dominated work environments.<sup>21</sup>

This sense of “powerlessness” has been described by others within the Australian context.<sup>22-24</sup> In a study exploring midwifery workplace culture, midwives described feeling fatigued and powerless to change the culture of their workplace towards MCoC and a less medically dominated

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system.<sup>22</sup> Additionally, in an appreciative inquiry study conducted in Queensland, midwives felt powerless to contribute to MSR and demonstrated passive acceptance of the medicalised culture at their workplace.<sup>23</sup>

Whilst not a subtheme, the concept of burnout was also mentioned multiple times by participants in this study. Working within MCoC has been found to be a protective factor against burnout, where burnout is more likely in midwives working in standard care.<sup>6,25</sup> Within the literature, factors associated with feelings of work-related burnout in midwives included a sense of powerlessness to change the medicalised maternity culture and working in rotational work patterns.<sup>6,26</sup>

### MIDWIVES IN VICTORIA FELT MORE KNOWLEDGE WAS REQUIRED TO CONTRIBUTE TO MSR

For many participants, involvement in the research interview was the first time they had considered and discussed MSR agenda. Another Australian study exploring midwives working in fragmented models of care and their knowledge around MSR discovered that there was a vast knowledge gap around reform recommendations,<sup>26</sup> confirming this lack of visibility. When considering gaps in midwifery knowledge around MSR, it is essential to explore how university programs are preparing midwives to transform maternity services. There has been a vast amount of literature that outlines the importance of Continuity of Care Experiences (CoCE) for both midwifery students and women.<sup>27-30</sup> These experiences prepare the midwife to work in and understand the value of MCoC. Although a mandated national requirement for all midwifery students, the number and structure of CoCE differs vastly among states and university programs.<sup>31</sup> With inconsistencies between midwifery university program requirements and content, it is unsurprising that there are varying reports from early career midwives on their ability to contribute to MCoC.

Contrast to the participants within this study, when exploring the experiences of midwifery students and early career midwives from across Australia, midwives and students from other states, such as Queensland, South Australia and New South Wales, described feeling prepared and motivated to work within MCoC models both as students and upon graduation.<sup>27,32,15,33</sup> These findings may indicate Victorian midwifery programs should increase opportunities for experience and exposure to MCoC for midwifery students, as this enables midwives to feel more motivated and prepared to work in these models upon graduation.<sup>30</sup>

### MIDWIVES REQUIRE SUPPORT TO CONTRIBUTE TO MSR

Respectful interprofessional collaboration is widely documented as essential in providing safe and effective maternity care to women around the world.<sup>34,35</sup> Despite this, midwives from many countries and maternity settings have

described tensions and conflict providing woman-centred care in a medically dominated setting.<sup>36,37</sup> These feelings of subordinacy to medical colleagues has been present for Australian midwives since the 1900s.<sup>38</sup> With increasing rates of medical interventions documented and described on a global scale,<sup>39</sup> it is unsurprising participants described a lack of support to step away from obstetric-led models of care that a majority of participants worked within.

In many recent international studies exploring the implementation of MCoC models, supportive midwifery leaders were found to be essential to lead reform.<sup>40-44</sup> In an exploration into the attributes required of midwifery leaders', vision, passion, courage, a realistic view of maternity services, feminist values, and a sense of social justice were identified.<sup>45</sup> Participants in this study who named a midwifery leader with experience and passion for MCoC models described feeling more able to contribute to MSR and described these leaders as having many of these attributes described in this exploratory study.<sup>45</sup>

In a recent international review of the literature exploring barriers and facilitators to MCoC, it was found that barriers were mainly systematic in nature, and included hierarchical power dynamics, inadequate healthcare infrastructure, and inadequate policy support.<sup>44</sup> This further bolsters the need for systemic, interprofessional, and leadership support to achieve widespread MCoC models.

### STRENGTHENING THE MIDWIFERY PROFESSIONAL IDENTITY

Professional recognition is known to contribute to job satisfaction for midwives and allows midwives to work to the full potential of their role.<sup>46,47</sup> Despite the midwifery profession in Australia undergoing many changes in the last 25 years, midwives are still required to be political and take action to strengthen profession recognition, scope of practice, and midwifery ways of working.<sup>48</sup>

An exploration into the views of both women and midwives around the role of the midwife identified many barriers to midwives working to their full scope of practice.<sup>49</sup> Barriers included a lack of opportunity for midwives to work within MCoC models, medical dominance, and an invisibility of midwifery as a profession in the wider community.<sup>49</sup> In another study, midwives in Australia have described ambiguity around the scope of practice of the midwife as a barrier to working to their full potential.<sup>50</sup> Reasons for this ambiguity were found to be due to the competing role expectations of midwives and obstetricians and the medical setting in which they practised<sup>50</sup> and those reasons were mirrored by this study's participants. In a systematic review exploring experiences of midwives providing CoCE, professional autonomy was the most common benefit of working in a continuity model.<sup>20</sup> This sense of professional autonomy was not described by participants in this study.

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A further barrier to practicing autonomously in MCoC models are restrictions incurred by Medicare funding and insurance arrangements for midwives working in private MCoC. Despite recent changes that removed the need for collaborative arrangements for midwives in private practice and increased Medicare rebates for women accessing private MCoC, this model of care still out of reach for many women in Australia. With only 2.2% of women in Australia accessing private midwifery care,<sup>10</sup> barriers still include the cost of private midwifery care and insurance related restrictions on midwives when providing care for women with complex pregnancies.<sup>51</sup> In addition, the funding model used for Australian maternity services actively restricts women's access to MCoC models despite these models costing the healthcare institution less.<sup>45</sup> With a health care system that is financed via public and private sources, a large proportion of public maternal health resources are expended into private funding (through medical benefits scheme to obstetricians) and pooling of funding, rather than on publicly funded MGP programs.<sup>52</sup> In New Zealand, where women allocate the funding for their maternity care to their chosen model of care, over 90% of women have a known midwife for their pregnancy care.<sup>53</sup> Increased Medicare rebates for private midwifery services have recently been implemented in Australia<sup>54</sup>, however, cost is still a large barrier with only 41.6% of women accessing a known midwife for their maternity care.<sup>10</sup>

### STRENGTHS AND LIMITATIONS

There have been other studies conducted in Australia examining midwives' views of MSR agenda, and perceptions of how MSR impacts the role of the midwife.<sup>23,26</sup> However, this is the first study that examines the motivation and ability of midwives in Victoria, Australia, to contribute to MSR, and the development of MCoC models. Midwives from Victoria were of particular interest due to the small number of MCoC models available to women<sup>8</sup> and growing concerns around recruitment and retention of midwives in Victoria.<sup>12</sup> Gaining an in-depth understanding of the barriers and enablers to the midwife's motivation and ability to contribute to MSR has produced an understanding and generated recommendations that will foster the implementation MCoC models by midwives. Although there was a diverse sample in this study who worked across a range of maternity care models with varying entry programs to practice, and years of experience, the sample size was small and only from one state in Australia. Additionally, there were many midwife participants who were already working in MCoC models, creating a potential bias. However, due to the findings, there may be an even more demonstrable difference in knowledge and interest in MSR for the wider population of midwives with most not working in MCoC.

This study was conducted prior to 2020 and the COVID pandemic which has a significant impact on maternity care. The COVID-19 pandemic has had major implications for midwives and ways of working in Australia. Arguably, midwives and women in Victoria were affected by strict lockdowns and service reforms to meet these requirements more than any other state. Changes to maternity services occurred quickly to align with lockdown requirements, and many services, including MCoC models, have not returned to pre-pandemic capacity.<sup>52</sup> Anecdotal reports indicate that some MCoC models have not been reestablished following COVID, further restricting midwives' ability to work and contribute to MCoC models.

### CONCLUSION

Reorientation of services toward greater implementation of MCoC models in Victoria requires numerous strategies to facilitate midwives to effectively contribute to MSR. Among these is a maternity care culture that promotes effective implementation of MCoC models. This cultural change can be bolstered by supportive midwifery leadership, development of collaborative interprofessional relationships and encouragement from healthcare organisations to support MCoC models. Fostering a strong midwifery identity by enabling midwives to work across the full scope of midwifery practice and appropriate government funding of MCoC models were also identified to facilitate MSR recommendations. Other important measures include university preparation that fosters a strong midwifery identity, including opportunities to provide MCoC for future workforce capacitation.

Enabling midwives to feel able to contribute to MSR and work in MCoC models will improve satisfaction in the workforce, ensuring greater implementation of evidence-based, sustainable models of care for women and ways of working for midwives.

### IMPLICATIONS FOR RESEARCH, POLICY, AND PRACTICE

The following recommendations outline factors that will enable midwives in Victoria, and potentially midwives from around Australia, to contribute to MSR reform and MCoC models. Preparing midwives to contribute to MSR by strengthening the undergraduate education regarding reform agenda, with a focus on CoCE to build confidence in MCoC models is required. Furthermore, interdisciplinary education that focuses on maternity reform would strengthen relationships with a focused goal of improving outcomes for women at a systemic level. Providing midwifery leaders with access to postgraduate midwifery qualifications that focus on change management strategies and advocacy to promote and facilitate midwives' ability to reform maternity services will facilitate the implementation and expansion of

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MCoC models. Finally, midwives who work to their full scope of practice feel empowered and have a strong midwifery identity. Professional development programs that inform and encourage midwives already practising to extend their scope of practice and highlight the benefits of MCoC models is also required. Additionally, a change in maternity care funding to allow great access to both public and private MCoC is required.

Further studies exploring the ability and motivation of midwives from different states and settings with a larger, more diverse sample size in Australia to help further identify strategies that enable midwives to feel prepared, confident and motivated to contribute to MSR is also recommended. Finally, an appreciative inquiry research project exploring how midwives develop a strong professional identity would have indirect positive influence on MSR.

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# REVIEW AND DISCUSSION PAPERS

## The origin, evolution and definition of comprehensive care: A discussion paper

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### ABSTRACT

**Objective:** To synthesise the origin, evolution, and definition of comprehensive care.

**Background:** Understanding comprehensive care is of great importance for rapidly evolving modern healthcare systems to adapt to a more holistic approach to care delivery. However, its concept remains poorly defined and inconsistently applied.

**Study design and methods:** We searched literature via PubMed, Scopus, and CINAHL as well as Google Scholar, supplemented by our prior review and empirical research. Findings were synthesised narratively to support a critical discussion of the origin, evolution, and definition of comprehensive care.

**Results:** Comprehensive care emerged in the 1950s-1960s. Its concept has evolved significantly since its inception. Different interpretations and applications emerged as this term became more widely referenced. We identified three defining characteristics of comprehensive care (person-centredness, multidisciplinary collaboration, and care coordination), and proposed an operational definition grounded in these principles.

**Conclusion:** This paper proposes an operational definition of comprehensive care to support consistent understanding and practice. Aligning policy with comprehensive care principles is essential for translating the concept into practice.

#### Implications for research, policy, and practice:

This paper contributes to the theoretical development of comprehensive care by clarifying its fundamental characteristics, which can support a more consistent understanding that can inform future standards, research, and implementation efforts.

#### What is already known about the topic?

- The traditional disease-specific approach to care delivery cannot meet the complex needs of patients.
- Comprehensive care is increasingly recognised not only for its potential to improve care quality but also for its cost-effectiveness.
- The concept of comprehensive care remains poorly defined and inconsistently applied.

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### What this paper adds:

- Comprehensive care emerged in the 1950s-1960s, and different interpretations and applications emerged as this term became popular.
- This paper clarified the conceptual foundations of comprehensive care and proposed an operational definition to guide implementation and policy development.

- To embed comprehensive care meaningfully into health systems, greater alignment is needed between definitions, workforce roles, and regulatory frameworks.

**Keywords:** comprehensive health care; patient-centred care; coordinated care; history

## OBJECTIVE

Modern healthcare recognises that patients are an entity that have not only medical needs but also social and psychological needs. Gaps in patient safety and quality are often recognised as failures to address these needs holistically. The concept of comprehensive care was introduced to promote care that considers the full spectrum of patient needs.

However, its concept remains poorly defined and inconsistently applied in the literature. The objective of this paper was to synthesise the origin, evolution, and definition of comprehensive care, and to develop a clearer, more operational understanding to inform future implementation, research, and policy.

## BACKGROUND

The traditional disease-specific approach to care delivery is often unable to meet the complex and multidimensional needs of patients. When care is fragmented across several care providers, it often results in inefficiencies, poor clinical outcomes, and unsatisfactory care experiences.<sup>1,2</sup> To address these challenges, the concept of **comprehensive care** has received growing attention in policy and practice.<sup>3</sup> In 2017, the Australian Commission on Safety and Quality in Health Care (ACSQHC) released and mandated the Comprehensive Care Standard to ensure patients receive comprehensive care that meets their needs and preferences.<sup>4</sup>

Comprehensive care is increasingly recognised not only for its potential to improve care quality but also for its cost-effectiveness for both care providers and patients.<sup>3,5,6</sup> A rapid review identifying 16 articles on the effectiveness of comprehensive care found that comprehensive care can improve health service delivery and positively impact both patient-centred care and clinical outcomes in acute care settings, including increased patient satisfaction, reduced length of stay, lower cost of care, few readmissions, and improved shared decision making and goals setting.<sup>3</sup>

However, the concept of comprehensive care is poorly defined and inconsistently applied in the literature. There is no universally accepted definition of comprehensive care, and its definition varies widely.<sup>7,8</sup> Many existing definitions

are either outdated, failing to consider changes in its scope, or too obscure to provide clinical guidance to care providers. For example, the term “comprehensive care” is often used to refer to complete care from a multidisciplinary team,<sup>9</sup> which lacks explicit emphasis on patient-centeredness. Additionally, the term is often used interchangeably with other concepts, such as multidisciplinary care, holistic care, and integrated care, further complicating its understanding and application.

This lack of definitional clarity remains a barrier to the effective implementation of comprehensive care.<sup>10</sup> Without a clear understanding of its key characteristics, healthcare providers and systems may struggle to apply the concept meaningfully or evaluate its outcomes. There is, therefore, a pressing need to examine how comprehensive care has been historically conceptualised, how its scope has evolved across different settings, and how it should be defined and understood in future policy and practice.

In this paper, we aimed to explore the **origins, evolution, and definitions** of comprehensive care. It contributes to the theoretical development of comprehensive care by clarifying its fundamental characteristics, which can support a more consistent understanding that can inform future standards, research, and implementation efforts.

The Research Questions are

- When was comprehensive care developed (origin)?
- How has comprehensive care evolved?
- What is the definition of comprehensive care?

To inform discussion, we searched literature in PubMed, Scopus, CINAHL, and Google Scholar on 10<sup>th</sup> January 2024 (See Supplementary Files 1 and 2), reviewed reference lists of the included papers, and applied pre-specified inclusion and exclusion criteria. Data extraction was conducted using a structured charting method. In addition to the literature identified through this search, our discussion draws on findings from our previous research on the implementation and impacts of the Comprehensive Care Standard.<sup>6,10-16</sup>

This paper does not aim to comprehensively map the literature, but rather to synthesise and discuss the historical development, evolutions, and conceptual foundations of comprehensive care.

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### THE ORIGINS OF COMPREHENSIVE CARE

The term “comprehensive care” began to appear in the early 1950s, during a period of immense growth and change in medicine, with increasing interest in the social and psychological aspects of medicine.<sup>17</sup> It was recognised that existing models of care often treated physiological pathology while neglecting patients’ psychological, social, and economic situations.<sup>18</sup> This aligned with the classic purpose of medicine, which is “to help sick people find their way back to the integrity of body, mind, and spirit”.<sup>19(p1177)</sup> Fragmentation in care delivery became a growing concern, driving the adoption of a more holistic approach.

Medical professionals stressed the importance of caring for patients as individuals rather than as demonstrations of disease entities or examples of anatomical abnormalities.<sup>20,21</sup> Comprehensive care emerged as a response to this need, guided by the conviction that improved care can be achieved by integrating and applying existing knowledge and skills from psychiatric, behavioural, and social sciences into medical practices.<sup>22</sup> Central to this shift in thinking was the recognition that the patient should not be defined by the specific illness they have, but as a person experiencing illness in a broader context.<sup>22</sup>

Early literature on comprehensive care included a range of interpretations.<sup>23</sup> For example, some authors referred to the “person behind the disease” and “the whole person” as central ideas, though these phrases were often seen as too imprecise to guide clinical practice.<sup>22</sup> To emphasise that it addressed the social and psychological aspects, comprehensive care was defined as “an integrated, aggressive approach to the physical, emotional and social health problems of people”.<sup>24(p371)</sup> While this definition acknowledged broader dimensions of care, it remained simplistic and lacked detail on how such care should be delivered or by whom.

Others worked to define the concept more clearly. Over time, comprehensive care came to be described as an “intelligent and disciplined appreciation of the patient as a person whose pathology may be somatic, psychic, environmental, or any combination thereof, including consideration and treatment of the patient’s structural and physiological pathology together with and in the context of his psychological, social and economic adjustment”.<sup>18(p353)</sup> This definition introduced more nuance and attempted to capture the complexity of real-world care, but its language was abstract and remained grounded in physician-led models of care.

From the perspective of care professionals, comprehensive care was also framed in terms of attributes and competencies: “scientific knowledge, intellectual curiosity, conscientious attention to detail, and constant stimulation of research” combined with “an awareness of the psychological and social factors affecting the patient’s total health”, “the value of preventive techniques,” and “the ability and willingness to bring to bear on the patient’s problem . . . whatever

specialised knowledge and advice”.<sup>25(p198)</sup> This perspective highlighted the breadth of knowledge and attitude expected of professionals, but again did not define the structural components of care delivery.

In paediatrics, comprehensive care was defined as “the systematic inclusion and addition of psychosocial dynamics and personality development to the practice of paediatrics, within a family and community context”.<sup>23(p1099)</sup> While this was one of the earliest recognitions of family-centred care, this definition was specific to one discipline and setting, limiting its generalisability.

In summary, these early definitions established a foundation for comprehensive care but revealed several limitations. They were either too simplistic or too abstract and rarely addressed how comprehensive care should be operationalised in clinical practice. The most significant feature of comprehensive care, as consistently highlighted even in its early formulations, is that it is patient-oriented as opposed to disease-oriented.<sup>22</sup>

### THE EVOLUTION OF COMPREHENSIVE CARE OVER TIME

Following its emergence in the 1950s, comprehensive care gradually expanded in scope. What began as a call to consider the patient as a whole person, addressing not only physical illness but also psychological and social needs, evolved into broader models that integrated team-based approaches, service coordination, continuity of care, and patient-centeredness.<sup>26,27</sup>

In the early decades, the focus of comprehensive care remained on individualised, patient-oriented approach.<sup>22</sup> By the 1960s, the concept began to incorporate multidisciplinary collaboration. A multidisciplinary team (MDT), consisting of associate professionals such as nurses, therapists, social workers, and counsellors,<sup>19</sup> were recognised as essential for delivering comprehensive care. This reflected the growing understanding that no single professional could meet the full range of patient needs. As Worthingham (1957) noted, securing and coordinating the services of associate professionals was a challenge for many physicians,<sup>21</sup> underscoring the importance of structured coordination in comprehensive care.

In the 1970s, the scope of comprehensive care also shifted geographically and institutionally, from hospital care to primary care in the community, with an emphasis on the integration of various services.<sup>28,29</sup> The role of case coordinator or advocate emerged, previously undertaken by physicians. This role needed to have knowledge of available resources, medical understanding, and counselling skills and to act as a coordinator of the team of professionals who worked together to develop a comprehensive care plan for the patient.<sup>28</sup>

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Falk (1972) further advanced the idea by introducing the principle of continuity of care, defining it as “the organised provision of health services to the entire family, including a full spectrum of services from prevention through rehabilitation, continuity of care for the individual, emphasis upon the social and personal aspects of disease and its management, use of the health team concept with personal physician responsibility, and coordination of the diverse elements of modern scientific medical practice”.<sup>30(p472)</sup>

While Falk’s definition broadened the scope of care and acknowledged team-based delivery, the emphasis on personal physician responsibility reflects a hierarchical model that may limit true interdisciplinary collaboration.

Formicola (2008) noted that the comprehensive care movement contributed to the development of patient-centred clinics focused on efficient, quality patient care.<sup>31</sup> Later interpretations increasingly emphasised patient-centredness. Family-centred and person-centred care became closely associated with the comprehensive care model in fields such as paediatrics and primary care,<sup>32</sup> reflecting a growing emphasis on shared decision-making and responsiveness to patient preferences.

In recent decades, comprehensive care often relates both to the scope of services offered and to a whole-person clinical approach.<sup>33</sup> Therefore, it may be defined in terms of either the breadth or depth of services offered, with generalist physicians capable of addressing most of their patients’ healthcare needs.<sup>34</sup>

Overall, the scope of comprehensive care has broadened significantly over time. While this evolution reflects the growing intent of the concept, it has also introduced complexity. Clarifying what comprehensive care fundamentally involves, beyond its practical adaptations, remains essential for its consistent application and evaluation.

### NOT COMPREHENSIVE CARE – THE TERM IS USED LOOSELY

As the term “comprehensive care” became more widely referenced, different interpretations and applications emerged.<sup>35</sup> Many publications included the term in their titles, but without defining it in the main text.<sup>9,36</sup> In some studies, comprehensive care refers simply to a multidisciplinary approach to care.<sup>9,37</sup> In others, it refers to “better care” with extra care (e.g. patient education, psychological comfort) added to routine care, without any multidisciplinary involvement.<sup>38</sup> Some researchers used the term to refer to “comprehensiveness of care”, focusing on the breadth or depth of services offered.<sup>39</sup> Other studies focused on the coordination of care or continuity of care across services and time.<sup>27,40</sup> The US Institute of Medicine, for example, associated comprehensive care with the management of “any health problem at any given stage of a

patient’s life cycle”.<sup>35(p522)</sup> In other cases, this term has been applied to specific patient groups, such as those with all but very uncommon or unusual conditions or multiple chronic conditions.<sup>35-37</sup>

In recent decades, the definition of comprehensive care has also varied considerably across disease contexts, further highlighting its conceptual ambiguity. For instance, in multiple sclerosis, comprehensive care typically involves a neurologist supported by at least two types of extra-neurologic services, such as physical therapy, occupational therapy, speech therapy, and psychological services.<sup>41</sup> In haemophilia, the concept emerged in the 1960s and has since been defined as the continuous supervision of all medical and psychosocial factors affecting the patient and their family.<sup>42-45</sup> For Dravet syndrome (genetic paediatric epilepsy), comprehensive care includes a multidisciplinary, physician-guided approach centred on the patient and caregivers through diagnosis, treatments, and ongoing management.<sup>46</sup> These examples illustrate how the meaning and scope of comprehensive care were shaped by clinical contexts, but also underscore the lack of a unified definition applicable across conditions.

Comprehensive care also has different interpretations in different countries. In Canada, family physicians defined comprehensive care as “the type of care family physicians provide (either on their own or with a team) to a defined population of patients across the life cycle in multiple clinical settings, addressing a spectrum of clinical issues”.<sup>35(p522)</sup> In China, it is most often understood as a patient-centred nursing mode.<sup>47-50</sup> For example, Pan (2021) defined comprehensive care as a nursing method organised based on the framework of nursing procedure, delivered by a group of nursing staff who contribute together in working for a group of patients.<sup>47</sup> In Australia, ACSQHC defined comprehensive care as “the coordinated delivery of total health care required or requested by a patient”.<sup>4(p44)</sup>

These variations, across both clinical contexts and national health systems, reflect the conceptual ambiguity surrounding comprehensive care and reinforce the need for definitional clarity. Without a clear and consistent definition, the term is used loosely in the literature, making it difficult to compare studies, implement interventions, or evaluate outcomes consistently across settings and populations.

### DEFINING COMPREHENSIVE CARE

Although there is no consistent definition of comprehensive care, we propose that the concept generally consists of three key characteristics. First, patients must be involved in decision-making and care planning, and care must be guided by the needs of patients along with their families and/or carers.<sup>4,18,51</sup> This characteristic reflects the principle that comprehensive care addresses all aspects of a patient’s needs rather than solely medical issues. Second, it requires

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professionals from multiple disciplines to work together to deliver care that addresses the patient's needs and preferences.<sup>18,19,52</sup> This highlights the recognition that no single professional is equipped to meet the full spectrum of patient needs. Third, a coordinated and proactive approach to health and social care needs is necessary to address the fragmentation of care.<sup>20,51</sup> This reflects the need for continuity across settings and providers, ensuring that care remains connected and responsive throughout the patient journey. Together, these elements form a foundation for the operationalisation of comprehensive care in practice.

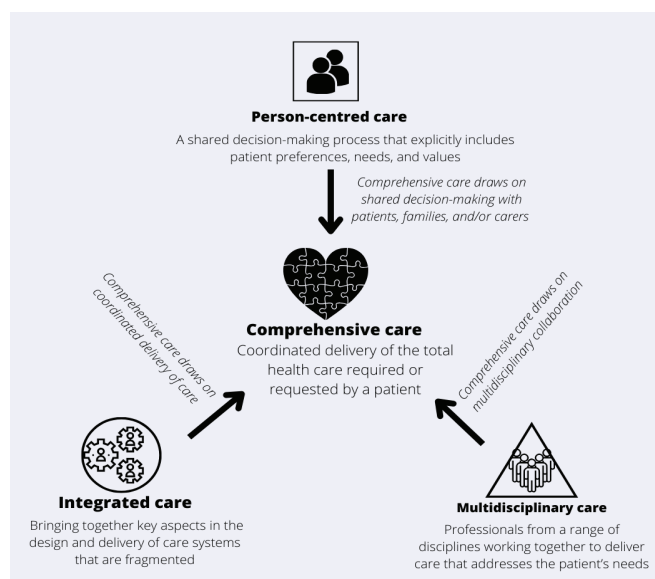
Building upon the three key characteristics and ACSQHC's definition, we suggest that the operational definition of comprehensive care is "the coordinated delivery of the total health care required or requested by a patient through multidisciplinary collaboration after shared decision-making with the patient, family and/or carers". This definition emphasises the fundamental philosophy of patient-centred comprehensive care by explicitly incorporating shared decision-making, coordination, and interdisciplinary input.

Many different terms are being applied to refer to the concept of "comprehensive care", including "holistic care", "person-centred care", "integrated care", "integrated comprehensive care", "coordinated care", "multidisciplinary care", and "primary care" or "family medicine".<sup>51,53,54</sup> While these terms overlap with comprehensive care, they each emphasise different elements. For example, "Integrated care" or "coordinated care" focuses on bringing together fragmented services, particularly at the systems level.<sup>55,56</sup> "Person-centred care" (or "patient-centred care") focuses on a shared decision-making process that explicitly includes patient needs, preferences, and values in goal setting and development.<sup>57,58</sup> "Holistic care" emphasises addressing physical, mental, emotional, spiritual, social and economic aspects of the patient but often neglects the role of patient in their care.<sup>53</sup> "Multidisciplinary care" focuses on multidisciplinary collaboration,<sup>59</sup> while "primary care" uses a generalist approach that considers common conditions in community settings exclusively.<sup>60</sup>

We developed a concept map<sup>12</sup> to illustrate the concept of comprehensive care and its relationship with commonly used terms – person-centred care, multidisciplinary care, and integrated care (Figure 1).

### THE IMPLEMENTATION OF COMPREHENSIVE CARE IN PRACTICE

Over the past several decades, various attempts have been made to implement comprehensive care in both education and practice. Early efforts to operationalise the concept through medical education provide insights into the challenges of translating philosophy into practice. In the 1950s and 1960s, comprehensive care was introduced into medical education through programs such as the University



Adapted from Xiong B, Stirling C, Martin-Khan M. *The implementation and impacts of national standards for comprehensive care in acute care hospitals: An integrative review. International Journal of Nursing Sciences.* 2023;10:425–34.

**FIGURE 1. COMPREHENSIVE CARE CONCEPT MAP**

of Colorado experiment and the Cornell Comprehensive Care and Teaching Program.<sup>20,25,29,61-63</sup> These initiatives aimed to familiarise students with the whole-person approach in care in the outpatient settings, but their long-term impact was limited. Reader (1976) found while most medical educators expressed a strong desire to teach and practice comprehensive care, they often viewed their programs as inadequate.<sup>29</sup> The effectiveness of these programs depended heavily on factors such as the setting, including the presence of a multidisciplinary team and a compassionate, friendly environment and appropriate patient selection for teaching. A hectic environment and heavy workloads were seen as barriers to fostering the desired attitudes and teamwork.

Efforts to implement comprehensive care in clinical settings have also faced significant challenges. In the 1960s-1970s, a series of hospital-based projects were initiated, attempting to apply comprehensive care to larger patient groups.<sup>61</sup> However, many were eventually terminated due to a lack of financial and faculty support, infrastructure limitations, and staff shortage.<sup>29,61</sup> Goodrich et al. (1972) highlighted limitations in hospital settings for implementing comprehensive care and recommended a community-based approach with coordination provided by community agencies such as the health department.<sup>61</sup>

Since the 1970s, the comprehensive care model has shifted toward the community, changing the perspective from hospitals 'reaching out' to the patients, to communities 'reaching in' to hospitals for specialised services.<sup>61(p. 367)</sup> This shift responded to both the limitations of hospital-focused implementation and the growing emphasis on community-based care and integrated service delivery across settings.

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As a result, comprehensive care became increasingly associated with the principles of primary care, particularly in relation to continuity of care and the integration of services. Falk (1972) noted, “primary care is the cornerstone of comprehensive care upon which all other components can readily be built”.<sup>30(p.473)</sup> While some consider comprehensive care synonymous with family medicine or general practice, the two are not interchangeable. Unlike comprehensive care, which encompasses a broad spectrum of care, family medicine typically emphasises common illnesses within its scope of practice.<sup>60</sup>

Comprehensive care has since been implemented in various healthcare settings, with a primary focus on acute care settings. It has taken various forms, such as comprehensive care clinics or departments within hospitals, standalone comprehensive care centres, or even national standards embedded in health policy.<sup>64</sup> In some systems, comprehensive care has been formalised through national frameworks, for example, the Australian Comprehensive Care Standard,<sup>4</sup> which mandates comprehensive care across hospitals, day procedure services, and public dental services and actively promote its adoption in other care settings.<sup>12</sup>

Despite policy mandates and national guidelines, implementing comprehensive care remains challenging. Common barriers include staff shortages, high turnover, heavy workloads, and limited training. Organisational and clinical challenges such as poorly integrated documentation systems, excessive paperwork, lack of standardised care plans, nursing dependency, and weak multidisciplinary collaboration also impede adoption.<sup>10,65</sup> Difficulties in governance processes further complicate implementation.<sup>66,67</sup> Key facilitators include strong leadership, integrated electronic documentation tools such as care plan templates, access to training, a culture of patient-centredness, and active engagement from both staff and patients in planning and delivery.<sup>10</sup>

## DISCUSSION

This review provided an overview of the origin, evolution, and definition of comprehensive care. Historically, comprehensive care emerged as a response to fragmented, disease-focused models by promoting a patient-oriented approach that considers patients’ social and psychological aspects. Over time, the scope of comprehensive care has evolved to incorporate multidisciplinary teamwork, integration of services, care coordination, continuity of care, and person-centredness. Building on this historical perspective, we proposed an operational definition that captures the key characteristics of comprehensive care and offers a clearer and more actionable basis for implementation.

A clearer understanding of the key characteristics of comprehensive care is essential for improving implementation. Person-centredness emphasises responsiveness to patients’ needs and preferences in shared decision-making processes across all aspects of care.<sup>31,68</sup> Multidisciplinary collaboration enables the integration of diverse professional perspectives to address the complex and long-term needs of patients. Care coordination, the third key element, ensures continuity and integration across services and providers.<sup>30,69</sup> Comprehensive care plans are a practical tool that can support all three elements by guiding care planning, clarifying roles, facilitating care delivery, and enabling regular review.<sup>70-72</sup> However, the effective use of care plans is often hindered by governance issues, time constraints, limited accessibility, limited ownership and participation among care team members, and logistical barriers.<sup>73,74,75</sup> The need for dynamic, electronic care plans that are easily accessible to all providers is frequently highlighted, alongside the importance of actively involving patients and families in developing and updating the plans.<sup>72,75,76</sup>

## SCOPE OF PRACTICE AND REGULATORY ENVIRONMENT

The evolution of comprehensive care from hospitals to communities reflects a shift toward decentralised and accessible healthcare services. While this shift aligns with modern health policy priorities, translating it into practice remains difficult. Real-world implementation remains constrained not only by workforce and financial pressure, but also by the scope of practice regulations that define what health professionals are permitted to do. For instance, nurses, allied health professionals, and other team members may be restricted from initiating care plans or leading coordination efforts (e.g. make referrals) due to licensure or institutional policies, which can restrict the flexibility needed for collaborative, team-based care. Regulatory frameworks often reinforce physician-led models, making it difficult to achieve shared leadership or fully collaborative care.<sup>29,61</sup> Addressing these challenges requires supportive policy frameworks and sustainable funding models that allow all professionals to contribute meaningfully to comprehensive care.

## IMPLICATIONS FOR PRACTICE, POLICY, AND RESEARCH

Standardising definitions and guidelines for comprehensive care in clinical practice can reduce confusion and promote consistent implementation. Early educational programs and clinical practice offered valuable insights but were often not sustained or systematised. To support the implementation of comprehensive care, policy and practice must shift from broad conceptual endorsement to system-wide operational support. This includes clarifying definitions and expectations for comprehensive care, promoting continuous professional development, supporting interdisciplinary collaboration,

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and leveraging technology to develop dynamic, accessible care plans that facilitate team coordination. Engaging patients, families, and carers as active participants in care planning is crucial for enhancing the relevance and effectiveness of comprehensive care, thereby improving patient and provider experiences.

Future research could refine and validate the operational definition and examine the application of comprehensive care across various healthcare settings such as acute care, home care and nursing homes. Studies are also needed to identify barriers and facilitators to implementing comprehensive care, assess its impacts on patient outcomes, and evaluate effects on healthcare staff performance and costs. Longitudinal research could provide insights into the evolution of comprehensive care initiatives and their sustained impacts on care quality. Additionally, exploring the influence of regulatory factors and policies will help inform both practice improvements and policy development, ensuring that comprehensive care becomes a standard component of clinical practice.

### LIMITATIONS

This study has some limitations. Due to the lack of a clear definition and standardised terminology for comprehensive care in the existing literature, some relevant publications may have been missed. Furthermore, the studies included in this review were mostly narrative reviews. While narrative reviews provide valuable insights, they are inherently subjective and may lack the rigorous methodology of systematic reviews or meta-analyses. This reliance on narrative reviews may have impacted the comprehensiveness and objectivity of our findings. Another limitation of this review is the reliance on older references, as much of the foundational literature on comprehensive care was established in earlier decades, and recent publications often use the term without providing clear definitions, limiting their inclusion in this analysis.

Despite these limitations, this paper offers a structured synthesis of the conceptual fundamentals of comprehensive care, with a level of rigour that includes at least two researchers involved in each step of the data screening and extraction process. This approach enhances the reliability and validity of our findings, providing a foundation for future research and practice in comprehensive care.

### CONCLUSION

This review examined the origins, evolution, and definitions of comprehensive care. By synthesising historical perspectives and contemporary usage, we proposed a clearer operational definition grounded in person-centredness, multidisciplinary collaboration, and care coordination. While comprehensive care is widely endorsed, its definition and implementation remain inconsistent. To embed

comprehensive care meaningfully into health systems, greater alignment is needed between definitions, workforce roles, and regulatory frameworks. Future research should focus on evaluating implementation strategies, barriers and facilitators, and impacts across diverse care settings. Understanding how comprehensive care functions in real-world hospital, community, and primary care contexts will be essential to building sustainable, patient-oriented models that translate policy into practice.

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