

Involving patients and their carers from Culturally and Linguistically Diverse backgrounds in recognising and escalating care for clinical deterioration: A scoping review protocol.

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Abstract

Introduction: Early recognition of clinical deterioration and escalation of care is a key safety initiative within health service delivery. Involving patients in these initiatives has widely been advocated to enhance early identification of, and response to, clinical deterioration. Patient and carer-activated escalation of care programs have been developed to facilitate this involvement. How these programs support patients and carers from Culturally and Linguistically Diverse (CALD) backgrounds remains unclear.

Aim: 1) To synthesise the current evidence on hospital programs aimed at involving patients and their carers in recognising and escalating care for clinical deterioration, with a focus on CALD populations. 2) To identify considerations made within these programs to involve patients and carers from CALD backgrounds.

Methods: The 6-stage Joanna Briggs Institute methodology for scoping reviews will guide this review, with reporting following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews guidance. Five online databases (Medline, Joanna Briggs Institute, ProQuest, Cumulative Index of Nursing and Allied Health Literature and Informit) will be searched for published literature related to research, policy and practice. Grey literature will be included. Titles and abstracts will be screened first, then full text followed by reference list and grey literature screening. Literature available in full text will be included ranging from 1 January 2005 until 31 March 2024. Endnote and Covidence will be used to support source selection, data extraction and management. Findings will be presented in both narrative and tabulated form.

Discussion: The purpose of this scoping review is to map existing research evidence regarding initiatives to involve patients and carers in the recognition and escalation of care for clinical deterioration within acute hospitals and examine considerations for people from CALD backgrounds within these initiatives. Synthesis of the evidence may yield valuable insights that could inform future patient and carer-activated escalation program design and delivery to support a more inclusive approach.

Keywords/terms: deterioration, patient, carer, escalation, CALD, patient safety, engagement

Introduction

Background:

Clinical deterioration continues to be a significant risk for patients who are admitted to hospital, despite the implementation of rapid response systems in healthcare services internationally over the past 20 years.¹ As many as 71 patients/1000 hospital admissions experience clinical deterioration requiring an emergency response,² with 10-25% resulting in admission to an intensive care unit (ICU).³ Physiological signs of clinical deterioration, including vital sign changes, may be exhibited by patients for 8 to 20 hours before an adverse event.⁴ Therefore, it is well understood that early recognition of acute physiological deterioration, timely response and subsequent treatment improve patient outcomes and reduce adverse events or patient harm.⁵

Initially reported in the United States of America,¹ the move to involve patients, families and carers in recognising clinical deterioration and escalating care was driven in part by many highly publicised coronial inquiries into patient deaths, particularly in the paediatric population.⁶ These inquiries found insufficient healthcare provider response to family concerns in the hospital, resulting in delays to appropriate treatment, contributing to patient deaths.⁷ In response, processes have been developed to support patients and their carers to activate an escalation of care for clinical deterioration. Although a myriad of terms are used to refer to these processes, Patient and Carer Activated Escalation (Pcae) will be used here.

In Australia, since 2012, health services have been guided to implement programs to support Pcae through the National Safety and Quality Health Service Standards.⁸ These programs aim to improve early recognition and response to the deteriorating patient as well as facilitate partnering between healthcare staff and patients.^{9, 10} They enable patients or carers to activate an independent process, to seek urgent expert clinical assistance when concerned about clinical deterioration.¹¹ This usually involves a phone call for assistance from clinicians who are skilled at assessing and initiating required interventions or further escalating care as needed.¹¹

Evaluations of Pcae programs have indicated added value to patients and carers in terms of improved patient satisfaction, quality of care, feelings of empowerment¹² and safety,¹³ but introducing and implementing these programs is complex.¹⁴ Recent studies have identified several assumptions underpinning these programs and barriers impacting system utility,¹⁵⁻¹⁷ including the ability and willingness of patients to monitor their health, recognise changes, and escalate care.^{15, 16} The influence population diversity has on program utility is poorly understood. It is unclear if the experience patients and carers from CALD backgrounds have within Pcae programs has been considered.¹⁵

Australia has a culturally and linguistically diverse population that continues to grow with over 7.6 million people are born overseas.¹⁸ One in five people speak a language other than English with Mandarin being the most common language other than English spoken at home here in Western Australia.¹⁹ Seventy four percent of these people experience low health literacy.²⁰ Migrants and refugees often experience barriers to access and engaging with healthcare services and understanding health information. A recent systematic review of 45 studies from nine countries, including Australia, found that people from CALD backgrounds had a higher risk of experiencing a patient safety incident than the general population.²¹ They were more

likely to experience adverse events, such as hospital-acquired complications or medication dosing errors,^{21, 22} longer hospital stays and higher readmission rates.²³ Low health literacy, limited English language proficiency and care that is perceived as not culturally competent are commonly identified barriers contributing to poor access and utilisation of healthcare services amongst people from CALD backgrounds.^{24, 25}

Rationale

PCAE program development has been accepted as an important patient safety mechanism, but there appears to be little consideration in the literature for the needs of people from diverse backgrounds who experience low health literacy and limited English proficiency.¹⁵ Little is understood of the challenges these patients and their carers face to engage or participate in these programs.

A scoping review will be conducted as this supports a broader search to assess the literature scope and synthesis of evidence. This will enable the mapping of evidence, including identifying main themes, theories, and gaps in knowledge, thus informing the scope and methods for future research.²⁶

Aim

1) To synthesise the current evidence on hospital programs aimed at involving patients and their carers in recognising and escalating care for clinical deterioration, with a focus on CALD populations. 2) To identify considerations made within these programs to involve patients and carers from CALD backgrounds.

Objectives

1. To summarise programs in the acute hospital setting that involve patients and carers in recognising and escalating care for clinical deterioration.
2. To synthesise effectiveness of these programs.
3. To describe the considerations made in these programs to involve patients and carers from CALD backgrounds in recognising and escalating care for clinical deterioration.

Scoping review question:

1. What considerations have been made to support patients and carers from CALD backgrounds to participate in PCAE programs?

Methods

The scoping review will be guided by the Joanna Briggs institute (JBI) guidance document for conducting scoping reviews, based on Arksey and O'Malley's framework (2005)²⁷ with further advancements by Levac et al. (2010).²⁸ This involves six stages including: 1) identifying the research question, 2) identifying the relevant literature, 3) selecting the relevant studies, 4) mapping out the data, 5) summarising, synthesising, and reporting the results, and 6) expert consultation.²⁹ To ensure transparency in reporting, the PRISMA-ScR checklist will be utilised.³⁰

Protocol and registration

A review protocol relevant to the research objectives was not found in a search of Medline, CINAHL, JBI and Open Science Framework. The scoping review protocol is registered through Open Science Framework.

Eligibility criteria

Population

This review will focus on people (patients or consumers) admitted to hospital. Of particular interest are those who identify as coming from a CALD background. Although the term CALD is commonly used in Australia, the acronym may be replaced by other terms in an international context.³¹ Terms such as global majority, ethnic, minority, migrants, refugees, multicultural, non-English speaking, low English proficiency and low health literacy will be relevant. No age limit will be placed on this population. Families or carers (as defined by the patient) of patients experiencing an admission, and healthcare professionals working in a hospital setting are also included in the population of interest.

Concept

The central concept for the review is PCAE for clinical deterioration programs. Patient and Carer Activated Escalation encompasses a program that can be activated by hospitalised patients or carers to bring assistance to their bedside, when their concerns about clinical deterioration are perceived to not being met.¹¹ This assistance is independent of their primary care team.

Context

The review will consider any studies carried out in an inpatient acute healthcare setting that has a PCAE program. Private healthcare organisations will be included. Primary healthcare settings are not included. Articles from all countries will be considered. There will be no limitation on the perspective of the sources, including patients, carers, family and healthcare professionals. See Table 1.

Table 1. Population, Concept and Context

Population	Hospitalised patients and their carers (families or caregivers as defined by the patient), people who identify as CALD, and healthcare professionals
Concept	PCAE for clinical deterioration - initiatives to involve patients and carers in recognition and escalation of care for clinical deterioration
Context	Acute inpatient healthcare setting

Information Sources

The date range for source searching will be from 1 January 2005 to 31 March 2024. The start date was selected as the first consensus conference on medical emergency teams was held in 2005.³² All peer-reviewed sources of research will be considered for inclusion as well as grey literature such as government or institutional reports/websites and thesis repositories. There will be no restrictions on study design. Studies not available in full text will be excluded. A hand search of reference lists of relevant studies, literature and systematic reviews will also be performed to identify further inclusion records.

Search strategy

The search strategy was developed by the research team, who include experts in subject matter and scoping review methodology. A four-step search strategy will be used to identify relevant literature. This includes (a) an initial limited search in Medline (Ovid), and Cumulative Index of Nursing and Allied Health Literature (CINAHL) to identify articles on the topic. Text words contained in the title, abstract and index terms will be analysed to identify relevant Medical Subject Headings (MeSH), terms and keywords, see table 2, (b) after refining the search strategy with the research team and research librarian the strategy will be applied to all included databases; Medline (Ovid), JBI EBP (Ovid), ProQuest, CINAHL and Informit, (c) reference lists of relevant published literature will be hand searched, and (e) sources of unpublished studies and grey literature will be searched through ProQuest Dissertations and Theses, Google Scholar (first 100 results) and Google Advanced (first 50 results).

Table 2. Proposed Medline Search Strategy

#	Search terms
1.	"clinical deterioration" or "patient deterioration" or "deteriorating patient" [<i>deteriorat*</i>]
2.	patient* or famil* or parent* or consumer* or relative* or carer* or visitor* or partner* or advocate*
3.	escalat* OR activat* OR initiat* OR response OR call
4.	team or teams OR help OR system*
5.	hospital* OR acute
6.	#1 and #2 and #3 and #4 and #5

Selection of sources of evidence

Following the search, all identified records will be collated and uploaded into EndNote, duplicates removed then imported to Covidence for data management. A research team will conduct the review, with two reviewers independently assessing 10% of records, against the inclusion criteria. Titles and abstracts of retrieved articles will be assessed for relevance. This will be streamlined through Covidence machine learning, to predict relevance of studies, placing all unscreened studies in that order.³³ After this initial assessment, full-text versions of all potentially eligible articles will be retrieved and assessed for eligibility against the inclusion criteria, by two reviewers. Any uncertainties will be resolved by a second or third member of the research team as necessary until consensus is reached. Full-text source exclusion rationale will be documented and the search process presented using the PRISMA 2020 flow chart.³⁴

Data extraction

Data will be charted using an iterative data charting form, developed by the research team. The JBI Manual will guide descriptive analysis of characteristics of the included studies for evidence synthesis. The data charting form will be piloted on two studies to ensure it works as intended and discrepancies are resolved.

Key data may include:

1. Author, date of publication, context - country, city, type of hospital, setting for implementation, pilot site, number of beds, adult or paediatric setting.
2. For research evidence, study design, aim/s, instruments and outcome measures.
3. Demographics of participants (including linguistic background if different to the dominant language in the country of study).

4. Program model (direct activation, triaged response).
5. Key findings relevant to the review question.

The JBI Critical Appraisal Tools will guide the assessment of trustworthiness, relevance and results of sources of evidence.³⁵

Data synthesis and presentation

A cross-study analysis will compare the similarities and differences between studies. Existing knowledge gaps will be considered. Data will be presented using tables, figures and narrative summary³⁶ of the synthesised results. Quantitative data extracted from included articles will be summarised in numerical counts while qualitative data will be summarised through thematic analysis. See Table 3 for an example of the tabular presentation of data, which will be refined throughout the data extraction.

Table 3. Example tabular data presentation³⁶

Parameter	Results
Number of publications	<ol style="list-style-type: none"> 1. Total number of sources of evidence 2. Year of publication
Source	All types
Population/participants identified	<ol style="list-style-type: none"> 1. Age (Children <18 years OR Adult 18+) 2. Patient 3. Carer/family 4. Healthcare professional 5. Patient/carer demographic (ethnicity, country of birth; language spoken at home; highest education (Literacy))
Culture and/or language considerations	<ol style="list-style-type: none"> 1. Language 2. Communication 3. Health literacy 4. Cultural competency 5. Accessibility for CALD community 6. Acceptability for CALD community 7. Co-design
Program model	<ol style="list-style-type: none"> 1. Direct activation 2. Indirect activation
Usage	<ol style="list-style-type: none"> 1. Number of calls 2. Activator (patient/carer)
Activation reason	<ol style="list-style-type: none"> 1. Clinical deterioration 2. Communication 3. Complaint 4. Clinical concern
Level of Effectiveness	<ol style="list-style-type: none"> 1. Level 1 - 5

Consultation with stakeholders

Experts in both topic and search strategy have been consulted in the development of this protocol. This includes a research librarian and a PhD supervisory team with significant research experience in clinical escalation processes.

Discussion

The purpose of the proposed scoping review is to map the existing research evidence regarding initiatives to involve patients and carers in the recognition and escalation of care for clinical deterioration within acute hospitals, with a focus on how the needs of people from CALD backgrounds have been considered within these initiatives. Studies related to these initiatives have been reported from several different countries but due to varying underlying factors such as health service, population, policy and guidelines, the features of initiatives may be different. An overview of the study characteristics, demographics, initiative model, and outcomes will be provided in this review. Second, this review will identify how the needs of the CALD community have been considered within these initiatives. Third, the review will map out strategies that have been used to engage CALD communities to participate in PCAE initiatives. It is intended that this synthesis of literature will inform further research and intervention strategy development to enhance the engagement and participation of patients and carers from CALD backgrounds in the recognition and escalation of care for clinical deterioration.

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