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The care of older people with dementia in rural Australian hospitals – a case study

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KEY WORDS

Empathy; Health Resources; length of stay; risk management; workload

ABSTRACT

Objective

Investigate how nurses in rural hospitals care for people with dementia.

Design

A case study research design.

Setting

Three rural hospitals in one region of the state of New South Wales, Australia.

Subjects

A purposive sample of 21 nurses who were employed at the study sites.

Main outcome measure

Description of how nurses working in rural hospitals care for people with dementia.

Results

Nurses drew upon their community connectedness to creatively use limited resources to provide person-centred care for people with dementia. The physical environment of the hospital influenced rural nurses' practice, with chemical and physical restraint occasionally used when nurses' were concerned about workload and safety.

Conclusion

Rural nurses used their community connectedness to help them provide person-centred care for people with dementia, but at times, this care was limited by overriding concerns about risk management and patient safety.

INTRODUCTION

In 2015 it was estimated that, worldwide 46.8 million people had dementia and this number would double every 20 years, to 74.7 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International 2015). Against this background, increasing recognition is being given to the needs of people who have dementia by governments and non-government organisations internationally (Alzheimer's Disease International 2015). Rural areas are becoming increasingly populated by older people due to a combination of declining fertility rates, out-migration of younger people and in-migration of older people to these areas (Smailes et al 2014). As rural areas age, it is likely that the numbers of people with dementia will rise. An international systematic literature review reported the need for increased formal dementia services for people who live in rural areas (Morgan et al 2011). In Australia, rural hospitals are used for sub-acute care, including dementia care (Alzheimer's Australia 2007).

People with dementia are most commonly admitted to hospital for conditions unrelated to their dementia (Zuliani et al 2012). Hospitalised people with dementia have longer hospital stays than those who do not have dementia (Draper et al 2011; Mukadam and Sampson 2011). In hospital, people with dementia have higher rates of hospital-acquired complications of delirium, pressure injuries, urinary tract infection and pneumonia (Bail et al 2013), with significant costs to the health service (Bail et al 2015).

The hospital environment can increase confusion for people who have dementia (Dewing and Dijk 2016) leading to distress. Qualitative studies based in metropolitan hospital settings suggest that nurses may lack the skills necessary to care for people with dementia (Cowdell 2010), may be unclear on what constitutes a person-centred approach for people with dementia (Clisset et al 2013), and/or may be focussed on risk management rather than on the person (Moyle et al 2011). A person-centred approach encompasses respectful relationships between staff, the people they are caring for and those who are important to them and is enabled in workplaces where staff are empowered to develop their practice (McCormack and McCance 2016). The calm presence of staff has been found to have a positive impact on wellbeing for people who have dementia and are in hospital (Edvardsson et al 2012).

Working in a rural hospital is unique. Nurses are generalists rather than specialists (Mills et al 2010) and may care for people with different diseases or concerns, often on a single shift. The lack of specialist knowledge may negatively impact the way rural nurses are able to provide care for people with dementia (Robinson et al 2010). There are strong interconnections in rural communities, with many overlapping interactions between personal and professional lives, including nurses' lives (Baernholdt et al 2010; Robinson et al 2010). The nature of generalist practice and strong community interconnections are potential challenges for nurses to provide care for people with dementia in rural hospital settings. This study aimed to explore how nurses in rural hospitals cared for people with dementia.

METHOD/METHODOLOGY

In order to study events that were contemporary and outside the control of the researcher, an exploratory case study research design was selected (Yin 2009).

Setting

A purposive sample of three rural hospitals, each with 50 beds or less, was selected in one rural region of New South Wales. Rural hospitals of this size typically have a mix of acute services, as well as dedicated long-term aged care beds (New South Wales Health 2009).

Participants

Nurses who worked at one of the three hospitals were invited to participate in the study. Patient participants were included if they had a diagnosis of dementia and were in a general ward (exclude those in the emergency department or high dependency unit).

Ethical considerations

For the people with dementia, capacity to consent to have their care observed was not assumed. The nurses, who agreed to be observed, initially approached the patients and if necessary, their legal guardians, about the study. If they expressed interest, the researcher (first author) provided a participant information sheet and discussed the study with the patient and the legal guardian. The researcher included the patient in the process of consent however the legal guardian provided final consent for observation.

Ethical approval for the study was secured from the University of Canberra Committee for Ethics in Human Research (Project number 10-156) and the Greater Western NSW Area Health Service Human Research Ethics Committee (HREC/10/GWAHS/41).

Data collection

Two sources of data were collected. Observations of nurses caring for people with dementia were undertaken. Nurses were also invited to participate in a semi-structured interview. Additionally, a reflective journal was maintained to monitor the researcher's thoughts, impressions and feelings regarding the data throughout the data collection phase. Data were collected between June and August 2011. The details of data collected by site is described table 1.

Table 1: Data collection by site

| Hospital | A | B | C | Total |
|--|---|---|---|-------|
| Number of nurses interviewed | 8 | 7 | 4 | 19 |
| Number of nurses observed providing care | 0 | 7 | 6 | 13 |
| Number of patients whose care was observed | 0 | 1 | 2 | 3 |

The first author observed nurses caring for three patients with dementia at two of the study sites. No observations were conducted at the first site visited, because there were no patients with dementia in the hospital at the times scheduled for data collection. At each of the other two sites, observation of practice took place over two days. At the second site the care of one patient participant was observed for seven hours in three periods ranging from 90 minutes to 210 minutes. At the third site the care of two patient participants was observed for five hours in one-hour periods. A total of twelve hours was spent observing care, with the researcher seated in day rooms or ward areas of the hospitals. Intimate care was not observed.

The semi-structured interviews were conducted using an interview guide. Questions focussed on ways of caring for people with dementia in their settings that worked well or didn't work well, important aspects of care for people with dementia, and the impact of rurality on the ways that care was enacted in their facilities. The first author conducted all interviews at the nurses' workplace with one exception, conducted by telephone. Interviews were recorded using a digital voice recorder. In one case, at the nurse participant's request, the interviewer did not record the interview and made detailed notes as soon as the interview was concluded. Interviews lasted between thirty and sixty minutes.

Data analysis

The nurse participant interview recordings, observation recordings and personal field notes were transcribed into word documents. The word documents were read and re-read, with immersion in the data, maintaining

notes of recurring concepts and constructs. Data analysis was an iterative process, carried out by the first author with validation provided by the second author. Concepts were inductively grouped into a hierarchy of categories and then themes, with the aim to capture the most important themes in the data (Franzosi 2004). Study credibility was ensured through data triangulation (Yin 2009). The three sources of evidence, participant interviews, participant observation and reflective field notes were constantly compared to arrive at the final themes.

FINDINGS

Twenty-one nurses participated in the study, with eight participating in the interviews only, eleven in interviews and observations and two in observations only. All of the nurses were female, with half in the 50 to 70 year age range. Basic demographic information of the 19 interviewed nurse participants is provided in table 2. Nurse participants have been given pseudonym names in order to protect their identities.

Table 2: Demographic profile of nurse participants

| Qualifications | | Age range | | | | | Average years of experience |
|----------------|----|-----------|-------|-------|-------|-------|-----------------------------|
| | | 21-30 | 31-40 | 41-50 | 51-60 | 61-70 | |
| RN | 13 | 1 | 2 | 2 | 7 | 1 | 22.5 |
| EN | 5 | 1 | 2 | - | 1 | 1 | 18.4 |
| AIN | 1 | - | - | - | 1 | - | 2 |

aRegistered Nurse; bEnrolled Nurse; cAssistant in Nursing

Analysis of the data led to the development of three themes, entitled 'watchful wandering', 'risk versus restraint', and 'keeping people close to home'.

Watchful wandering

Wandering within a calm atmosphere was valued to decrease distress for people with dementia. Nurses valued ensuring people were safe, distress was minimised and people were cared for in ways that were respectful of their dignity and personhood. They found creative and simple ways of using the existing resources to safely care for people.

'Watchful wandering' consisted allowing people with dementia to move around the ward, while providing continuous supervision. Nurses were observed to invite people with dementia to accompany them to clean cupboards, prepare notes and write notes. Nurse participants acknowledged the ward environment was not ideal for wandering:

"We try and take them with us when we are working but you can't take them into every room, it depends on whether the other patients are happy for us to do that" (Margaret, EN).

To enhance continual observation during wandering, nurses would accommodate people with dementia in rooms near the nurses' station and put them in shared rooms:

"... if they're [person with dementia] wandering we try to put them in with someone else [who] might notify or ring the bell ... so they can say "that patient's gone out the door or something" (Ellen, RN).

Observational data confirmed people with dementia were in rooms close to the nurse's station or in a communal sitting room, where staff could easily observe their movements.

Working collaboratively with family members was valued by nurse participants and often nurses would invite family members to stay with the person:

“...We like to have that relationship with the family where we can ring them and they’ll come and sit with them and things like that” (Margaret, EN).

Nurses valued keeping the overall ward atmosphere calm and quiet. The interactions between nurses and people with dementia were observed to be calm and respectful. At one site in particular, nurses were observed to speak and act calmly, even during an emergency situation. Several nurses voiced the value of routine:

“Just to keep things routine is so important, basically” (Penny, RN).

“Once [people with dementia] are agitated, it becomes much more difficult to look after them, so if you can maintain calm throughout your shift it makes life much easier” (Mary, RN).

In summary, watchful wandering was achieved through continuous observation. Nurses were focussed on the person and their dignity, maintaining a calm atmosphere in the ward through routines and supporting the people with dementia to wander as much as possible.

Risk and restraint

Nurse participants in this study were very concerned with keeping patients safe and they were particularly concerned patients would fall or go outside the building.

“The layout of the hospital is difficult because of the stairs [leading outside] and you don’t have the staffing to supervise them [in the way] you’d like to; it only seems to take a second and they’re gone” (Liz, RN).

At each of the sites visited, nurses described the use of restraint, either physical or chemical, to keep people with dementia safe. The use of physical restraints appeared to be limited to those times when the person with dementia exhibited behavioural and psychological symptoms of dementia. The use of physical restraints was confirmed by observational data at one site. The use of restraint was described as being necessary when workloads were heavy and when the physical environment made keeping patients safe difficult. Nurse participants acknowledged these practices could lead to adverse outcomes for people with dementia.

“If we’re short staffed or overworked, we have to chemically restrain [people with dementia]...very rarely physically unless it’s just with a chair lockup... most people don’t like doing that because it just aggravates some people” (Rachel, EN).

Nurses recognised it was preferable to use other ways of managing behaviours, such as trying to keep people with dementia busy with 'helping' tasks, because restraint increases the person’s distress.

“If you keep her [person with dementia] occupied, she’s quite amenable but [if] you try and restrain her and stop her from wandering, it makes it quite difficult... she gets quite [distressed]” (Ann, RN).

Another form of restraint was used at times, known in Australia as ‘specialling’. This is the close supervision, usually confined to the patient room, to prevent wandering. Some nurses described the use of security staff to ‘special’ people with dementia who were likely to wander when they were busy due to increased workload:

“We get security if we’re short staffed; they’re very helpful and they’ll watch [the person with dementia], especially through the night” (Carol, RN).

However, some nurses saw the use of security staff for close observation as exacerbating distress for the person with dementia. Having family members sit with the person was the preferred option, if this was possible:

“...and then you get the security, so you’re bringing another frightening thing at them” (Karen, RN).

“Sometimes you have to get the family to come and sit with [the person with dementia] because you haven’t got the time to [stay] and you’re very reluctant to use chemical restraint” (Christine, RN).

In a busy ward, nurses may see physical restraint as necessary, but the safe management of restraint also required extra resources:

“Because we have other higher level care [patients]... it is very difficult because you can’t go back and take [the person with dementia] out of their restraints every so often, it does make it very difficult” (Emma, EN).

Nurses spoke of the tension between their desire to care for people with dementia in ways that are more person-centred, for example allowing them to wander in order to ‘use up’ energy, and the need to ensure their safety in older hospital buildings that are not designed for people who are cognitively impaired. Observational data confirmed the physical environments at each site were not safe for unsupervised wandering, with exit doors opening to busy and dangerous roads or, in higher floors of the hospital, to stairwells where dangerous falls were possible:

“The door as you come out of the ward onto the main stairwell [cannot] be locked...if [people with dementia] are wanderers...you can’t lock them in their room and it’s very difficult ...because we are an acute [hospital setting], and people [with dementia] need to be able to wander...to use up their energy, but we can’t actually keep them safe all day and that’s my biggest dilemma” (Denise, RN).

Nurses justified the use of restraint on the grounds of potential injury:

“Restraints are probably a very interesting topic to get into, because you say that people have the right to choose, but busted bones [sic] are frowned upon” (Val, RN).

The same nurse participant spoke of the need for a balance between providing idealised care that facilitates freedom for the individual and managing the use of restraint safely:

“So it’s always a toss-up... I know the idealists will say you know we shouldn’t... restrain them, but the other thing is managing the restraint making sure that you’re there to release it and making sure that they go for their walks and all that sort of stuff” (Val, RN).

In summary, nurses occasionally used physical and chemical restraint, as well as ‘specialling’ of people with dementia to manage perceived risks of injury.

Keeping people close to home

The local hospitals were an extension of the respective communities. The nurses often drew upon their personal knowledge of people with dementia from their local communities for application to their clinical practice. The nurses knew the histories of people with dementia in the community because they had been in hospital previously or were users of services affiliated with the hospital. The nurses also knew about people with dementia through personal networks in their communities. For example:

“...we’ve been aware of her [person with dementia] for the last couple of weeks. The husband’s [has] got to the crisis point where he needs emergency respite” (Mary, RN).

The nurses recognised the importance of connections with family and community for people with dementia, with an established volunteer visiting program in one of the study sites. The local volunteers were observed informally visiting all of the long-term patients in the ward.

Older people with dementia can access government funded care services, either in their own homes or within residential aged care facilities, but must first have their level of care needs assessed by a multidisciplinary Aged Care Assessment Team (ACAT). However, given the rural setting, geographical distance was challenging. For example, one person with dementia lived around 80 kilometres from town, was considered too far for community based aged care services:

“We could have kept her at home a bit longer but you see [her town] is so isolated, there [are very few] services out there.” (Ann, RN).

If the ACAT recommends an aged care facility placement, people with dementia would wait in the hospital for a placement. Often families preferred local aged care facility placement, although that was not always possible:

“We always go for their first choice and if that’s not available, [we’ll aim for] a bed as close as possible” (Rachel, EN).

“Sometimes the family put on a bit of pressure that they only want them to come into the local aged care facility, but if there’s a bed [outside of town], they should be taking the bed and then when one comes available in the local facility, they can transfer across. I don’t think the family understand that because [the distance is] difficult for family too” (Denise, RN).

As indicated in the previous theme, nurses sometimes know patients as members of their local communities, and can use this knowledge to support the person with dementia in hospital. Where possible nurses endeavoured to keep people with dementia in their local hospitals while they waited for an aged care service or placement and aimed to place people in aged care facilities located in the local community.

Limitations

The data from the three study sites were analysed and reported as a single case, due to concerns about participants and study sites being recognisable. However, this could be a limitation of the study because multiple case study design is acknowledged as a stronger design than single case study design (Yin 2009). The timeframe available for observations, the fact one site had no eligible patients at the time of the site visit, and the small sample size, are potential limitations of the study. The results of the study cannot be generalised to the wider population due to the small sample size and the study being conducted in one region in rural New South Wales.

DISCUSSION

Three themes emerged to describe how rural nurses work with people with dementia in hospital. In describing their practices, the physical hospital environment had an impact on the way that care was provided.

'Watchful wandering' was the preferred way that nurses maintained a calm environment, encouraging people with dementia to engage with their environment. However, like nurses in a metropolitan hospital study (Nilsson et al 2013), rural nurses were frustrated that increased workloads meant they could not provide this care. Keeping the ward atmosphere calm, speaking calmly, not using raised voices and not rushing, in order to avoid worsening confusion or agitation for people with dementia, is also consistent with metropolitan hospital practice (Hynninen et al 2015). However, keeping the atmosphere calm was sometimes challenging within the ambience of a hospital environment.

Nurses in the current study described the simple ways they occupied people when they have time. These interventions can prevent boredom, social isolation and associated agitation (Cohen-Mansfield et al 2010). The nurses were creative in their strategies to engage people with dementia. Other authors have recommended interventions such as art therapy (Peisah et al 2011), exercise such as walking with volunteers (Bateman 2010) and animal-assisted therapies (Bernabei et al 2013) for keeping hospital people who have dementia socially and cognitively engaged.

The majority of nurse participants spoke of patient safety being one of their main concerns when they are nursing people who have dementia. Considerations about the environment influenced nurses' focus on patient safety. Previous researchers have also found that nurses are concerned safety of people with dementia in hospital settings (Dewing and Dijk 2016; Moyle et al 2011). In this study, the nurses used close supervision or 'specials' and physical and chemical restraint when they judged this was necessary to enhance patient safety. The use of 'specials' for supervision of people who are cognitively impaired is well established in hospitals (Kerr et al 2013; Moyle et al 2011; Wilkes et al 2010).

While they preferred continued observation, restraint was used when the ward was busy and continuous observation could not be sustained. The nurses who discussed restraint use did not clearly state an ethical dilemma but this was implied in their descriptions of practice. The use of restraint was justified on the grounds of inadequate resources (staff time) for watchful wandering and the dangers inherent in the hospital environment. While nurse participants in the current study recognised restraint had adverse consequences for patients, they chose the risks associated with restraint over the risks of injury related to falls or absconding.

This finding is disturbing in that restraint reduces mobility and can lead to preventable complications such as urinary tract infection, pressure injuries and pneumonia (Bail and Grealish, 2016). There is also emerging evidence that for people with cognitive impairment, reduced use of restraint is associated with reduced length of stay (Gerace et al 2013; Kwok et al 2012). How rural communities access and enact evidence-based practice in the area of restraint requires urgent attention.

People who live and work in rural communities are often connected in overlapping ways. Lauder et al (2006) use the term "community embeddedness" to describe this interconnectedness (p.75-76). The nurses valued their relationships in the local community; it was easy for them to invite family members to assist with a person with dementia who was distressed in the hospital environment. In contrast a study in a large metropolitan hospital found that the nurses infrequently requested family members be involved in the care of people with dementia in hospital (Moyle et al 2011). The interconnectedness in rural communities can enhance the ability of nurses to provide high quality care (Baernholdt et al 2010), with relationships enhanced and patient care improved (Pesut et al 2012).

Nurses in this study recognised older people needed to remain in their local communities to enable the continuation of lifelong connections. Having to move outside of their own communities to accept an aged care bed has been likened by older rural people to being exiled (Bernoth et al 2012). Nurses in this study worked to reduce separation of the older person with dementia from their community.

CONCLUSIONS

This study has found that despite unsuitable physical environments and multiple competing demands on the time of the nurses, rural nurses found simple ways to maintain person-centred care. Maintaining a calm atmosphere required creativity and thoughtfulness, and drew upon the nurses' personal connections with their rural community. However, when the ward was busier and resources were scarce, there was an increased focus on risk management, often with significant clinical implications for the person with dementia. There is a need for further discussion and clarification between nurses and health care managers about the meaning of risk, and clarifying whose interests are being protected when chemical and physical restraint are used. Contesting the idea of risk of injury for people with dementia in the rural hospital contexts is worthy of further research.

The nurses recognised the value of the community-based relationships with the family members of people with dementia and with other service providers and used the information gathered through these relationships to provide better care for people with dementia. Working collaboratively with family members is a strategy that could be adopted by nurses in urban and rural hospitals in Australia and globally in order to improve care for people with dementia who are hospitalised.

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Does studying postgraduate palliative care have an impact on student's ability to effect change in practice?

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KEY WORDS

Alumni, survey, higher education, impact of learning, practice change

ABSTRACT

Objective

To find out from alumni whether their postgraduate course in palliative care had an impact on their ability to change practice

Setting

Palliative & Supportive Services, Flinders University has delivered postgraduate palliative care courses via the online learning mode of delivery since 2004

Subjects

An online survey was administered to alumni asking about such issues as: the impact of learning for practice, and their ability to influence change (Flinders University ethics no: 7154). Seventy-six alumni responded to the survey, and were mostly older female nurses, which is not only a reflection of our student cohort but also of clinical practice.

Primary argument

In this study, we are examining the relevance of our courses to practice, specifically how alumni report the impact of postgraduate study on both their individual clinical practice and organisational systems. Evidence based practice is the cornerstone of nursing and of education programs globally and while our students are learning best practice they report that they cannot easily translate their new knowledge into practice.

Conclusion

Clinicians with postgraduate qualifications can be empowered to expand their clinical skills and more, for example, their leadership capabilities, to critically challenge health care systems and act as a role model for others. However, if we are to truly build the capacity of our students and alumni to implement changes in the workplace then we need to also engage them in evidence to practice strategies and change management theory and practice.

INTRODUCTION

Palliative care has been described as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness” (World Health Organization, 2015). Ongoing changes in palliative care that include both service delivery and an increasingly competitive education marketplace (Lockett et al 2014) demand that higher education providers take proactive approaches to the future with strategic plans for education provision.

Palliative care higher education providers need to equip clinicians with the knowledge and ability to become life-long learners and critical thinkers in a rapidly changing environment, via the delivery of a wide range of clinically significant topics (Jones et al 2018). At the interface between education and the workplace, each individual is expected to acquire the knowledge, skills and competencies to become an effective employee (Alias et al 2013), which includes the ability to mobilise knowledge (Jones et al 2018). These are the skills students are expected to acquire and demonstrate when studying; envisaging that this then translates into the work environment.

We decided to investigate whether the courses we offer are building the capacity of those who study palliative care at Flinders University. To do this we turned to our alumni, who Johnson et al (2014) describe as being important to evaluation in higher education as they can provide, from their unique perspective, context specific information on whether their learning has had an impact on their practice. In this paper, we will focus on this latter aspect in relation to practice change.

BACKGROUND

Palliative & Supportive Services at Flinders University, South Australia, offers post-graduate courses in Palliative Care and Palliative Care in Aged Care, both of which have been offered by distance education since 1995, converting to eLearning in 2004. Students work mainly as healthcare clinicians, often with the expectation they will study at Masters Level particularly when working in specialist palliative care (Kember et al 2014). Courses leverage from the multidisciplinary studentship by directing students to work together virtually and collaboratively as they would in practice (Head et al 2016).

Within our teaching program we have been aware over the last few years of a change in our student cohort, which increasingly includes those who are younger and are working in much more diverse areas. This includes aged care, acute hospitals, chronic disease and areas where end of life care issues arise and a palliative approach (Mitchell et al 2013) is deemed appropriate. The changing nature of our student cohort also reflects the slowly changing nature of the health care workforce with older staff reducing their hours or retiring (Sherman et al 2013).

Students may be working in lead clinical positions (eg, as a physician or specialist palliative care nurse), they may be working in generalist health care settings, or they may be looking to bring the principles of good palliative care to their own practice in oncology, aged care or in renal units. International students study either internally or online, and will take what they have learned and adapt the principles, implementing changes in their own country.

Despite both internal and external regulatory processes to ensure quality in our courses, it was felt that to add rigour we should look to the relevance of our courses to practice, and to their impact, not only at the individual level but potentially at the organisational level as well. In their study of alumni, Johnson et al (2014) found participants reporting positive impacts of two certificate programs (human performance technology and online instructional development) not only on their professional career but also on their own self-improvement. In

particular, there was an improvement in knowledge, skills and confidence, so we have taken these concepts as a starting point to see if our courses are equally having an effect.

METHODS

Survey Administration

Criterion sampling (Palinkas et al 2015) was used to administer a one-time online survey to alumni who had the experience of studying postgraduate palliative care within the department. The survey was informed by work undertaken on dementia courses by Innes et al (2012). It was thought a retrospective survey would also elicit longer-term effects that may only have become evident years later (Rogers 2009). The University alumni office provided a list of 721 alumni from their records of students who had studied with us (although in hindsight this did not include an earlier Master of Public Health, Palliative Care pathway). An administration assistant de-duplicated those who had studied more than one course and checked how many had provided an email address.

The survey was subsequently administered to 426 alumni. In order to increase response rates, information regarding the surveys was also provided via e-newsletters relevant to the sector, and which were distributed by: Palliative Care Nurses Australia, CareSearch (a palliative care website that administers four newsletters), the Australian and New Zealand Society of Palliative Medicine and Australian Allied Health in Palliative Care. The survey was open for an eleven-week period (01/02/2016 to 21/04/2016) allowing dissemination of the survey via the newsletters and therefore as we had multiple avenues by which to invite alumni to participate, calculating a response rate was problematic.

An email was sent from an administrative email address with an invitation to participate in the online survey. Once the students clicked on the link they had access to the participant information sheet, and consent was implied by clicking into the survey, which was held on a password protected research data management platform not dissimilar to survey monkey (CareSearch 2017). No staff member is aware of who completed the survey and who did not. Ethics approval was received from Flinders University Social and Behavioural Research Ethics Committee (Project: 7154).

RESULTS

A total of 76 responses were received. Only 15.8% of respondents (n=12) were under the age of 40, with the majority (71.1%) falling between the ages of 40 and 59 (n=54). A further 13.2% (n=10) were over the age of 60. Of 76 respondents 94.7% (n=72) identified as female and 5.3% (n=4) as male.

Course taken and when

Respondents provided information on what they studied and were able to provide more than one answer as some will have progressed through from a Graduate Certificate to Masters and will have recorded each. Results show that 35 studied a Graduate Certificate, 21 a Graduate Diploma, 29 a Masters and 1 a PhD. Time since they studied (n=72) also varied, with the majority (76.4%) studying in the past 5 years, which may speak to the accuracy of our contact details or that the course is still fresh in their mind. Sixty-three respondents gave the time since their undergraduate studies, with the earliest studying initially in 1973, and the rest in the 43 years since. Of 74 respondents, the time taken to complete their course with us ranged from 10 months to 11 years. Of 73 respondents, 34 (46.6%) worked part-time while studying and 39 (53.4%) full-time, indicating a huge commitment to ongoing professional development on the part of the students.

Changing practice

Respondents were asked the question: Do you think that the course you studied has had a long-term impact on your practice and your ability to affect change? Of 76 respondents: 86.8% (n=66) agreed yes and 13.2% (n=10) said no.

To the question, “Which areas of your practice have changed the most since your study?” respondents were able to tick all statements that applied and included here are the three items that relate to changing practice. Table 1 highlights that 92% (n=68) agree or somewhat agree that their course has provided them with the confidence to disseminate knowledge to others, with 93% (n=71) having developed, influenced or participated in decision making within their team and 80% (n=61) having developed, influenced or participated in decision making within their workplace or organisation.

Table 1: Impact of Learning for Practice

| | Agree | Somewhat Agree | Neither Agree nor Disagree | Somewhat Disagree | Disagree | Don't Know or Not Sure |
|---|------------|----------------|----------------------------|-------------------|----------|------------------------|
| My course/study has helped me to recognise areas for improvement or change at my workplace (n=72) | 44 (61.1%) | 21 (29.2%) | 7 (9.7%) | | | |
| My course/study has helped me to effect changes in my work environment (n=74) | 32 (43.2%) | 24 (32.4%) | 12 (16.2%) | 3 (4.1%) | 1 (1.3%) | 2 (2.7%) |
| My course/study has provided me with the confidence to disseminate knowledge to others (n=74) | 50 (67.6%) | 18 (24.3%) | 6 (8.1%) | | | |

In our small study, relative to practice change (n=55) we see that even though they hold postgraduate qualifications in palliative care, nine respondents (16%) feel they are not in a position to propose changes and 18 (33%) do not feel they have a voice in the organisation. We also found that 23 respondents (42%) feel the organisational culture is not receptive to change. The result of this is that 50 former students (91%) do not feel enabled to go ahead and implement change as a result of further studies.

Motivation to implement change following study

It is important to consider whether the length of time the respondents studied with us (such as very part-time study or the difference in undertaking a Graduate Certificate or Masters) has an impact on this as well, with longer time in study shown as having more transfer (into practice) potential (Parsons et al 2012).

Does the time since you undertook your studies have an effect on your motivation to change practice? Seventy-six respondents provided answers with a demonstrable decline in motivation the further away they were from study (table 2).

Table 2: Motivation to implement change following study

| | Agree | Somewhat Agree | Neither Agree nor Disagree | Somewhat Disagree | Disagree |
|--|------------|----------------|----------------------------|-------------------|----------|
| I felt motivated to implement practice changes while I was studying (n=76) | 43 (56.6%) | 27 (35.5%) | 2 (2.6%) | 4 (5.26%) | |
| I felt motivated to implement practice changes immediately following my study (n=76) | 41 (53.9%) | 27 (35.5%) | 6 (7.9%) | 2 (2.6%) | |
| I felt motivated to implement practice changes much later after my study (n=75) | 28 (37.3%) | 20 (26.7%) | 13 (17.3%) | 11 (14.7%) | 3 (4.0%) |

Respondents were asked the following question: Do you think that the course you studied has had a long-term impact on your practice and your ability to affect change? All respondents (n=76) answered yes (n=66) or no (n=10), and the following comments are representative of views provided. Comments are often quite positive despite participants finding barriers in the workplace:

“It has clarified many practice issues for me, meaning I can see where opportunities to improve exist.”

“Despite the organisations unwillingness to change practices and its culture of disciplinary towers, I am more confident in my communication skills and feel I have the credibility with a masters degree to speak out more across the disciplines.”

“I am now in a position to influence organisational change as a result of my study. As a result I am more confident and my opinions are valued by peers, colleagues & my employer.”

“developing knowledge and skills assisted in building assertiveness to speak to those in a position to assist with change and provided me with skills to support an argument (sic) and provide evidence for best practice.”

“Change is a long term goal that may be years away!”

“It allowed me to progress to a CNC position where I can and do affect change.”

“The course provides a platform to increase my critical thinking skill and confidence to voice my opinion though my opinion has not always been seriously listened to. It is important not to give up and keep trying.”

“have the confidence to persevere with trying to affect change.”

DISCUSSION

Impact of course

A cohort of Flemish researchers involved in important research with teachers on the effectiveness of faculty training courses (Stes et al 2007) found individual learning and behavioural changes, as well as a willingness to take on more responsibility and our study supports this. It was also interesting to note that respondents felt empowered to participate more in discussions with colleagues, and attempted to exert influence at the organisational level, with many of these changes impacting long-term. We do often read examples of student reported practice changes in the topics as a result of what has been read in the literature or learned from tutors and colleagues. These results are encouraging even with the small number of participants, in that the courses they are studying are having an impact at the individual, service and organisational level and ultimately helping to improve end of life care in Australia and overseas.

Ability to Change Practice

One of the central questions of this survey was whether our alumni perceive their studies increased their ability to change practice – either the way in which they themselves work, or by influencing organisational changes. Despite our findings that individuals report a significant increase in knowledge, a similar increase in ability to change practice is not evidenced. When looking to change practice in the workplace, in what context dissemination of knowledge occurs and whether the students were actually influencing decision-making or participating remains unclear.

Change has been acknowledged as complex and multifaceted, and there is much to take into account such as personal, cultural, organisational, social, financial and structural factors any of which could be barriers or enablers to the process. Rogers (1983) diffusion of innovation theory has been articulated in this context by Zhang et al (2015) in considering whether changes are adopted. This includes the complexity and nature of the change or required behaviour required, the communication style adopted (face to face is more effective), the social context (such as hierarchical structures or a culture of creativity and innovation) and how decisions are made (Alvarez 2016). Change at the organisational level requires the support of management and the commitment of workers, but can be hindered by constraints (resource, organisational structure) (Kogan et al 2017).

Motivation to change practice and ability to change practice are closely interwoven (Gegenfurtner 2011) and we found that motivation to implement change dropped slightly as time passes and the student or alumni is further removed from their course/study. Further, Gegenfurtner (2011) looked at the various factors that can influence whether a student is motivated to implement change following study. This author cited the culture of the organisation (whereby responsiveness to suggestions in the organisation may mean the student is not motivated to change practice even before they start study); the students personal attributes (the student is not in a position to propose changes or doesn't feel they have a voice); their opinions of the courses (again speaks to the design of the course); and in the midst of study they feel inspired to change but this does not carry forward to practice (Gegenfurtner 2011). We could look at distance from study and cross reference with the students change ability but there are many confounding factors that we would also need to consider, such as whether this is actually influenced by who they are in the organisation or the level of study they undertook.

Students' learn about evidence-based practice, but it is not sufficient to simply notify colleagues or managers of exemplary practice that could or should be introduced into the workplace. The ability to know how to decide if changing current practice is appropriate, possible or even welcome requires a different skillset. (Shaffer et al 2013). Individual students or alumni will not necessarily be drivers of change, but can become empowered through postgraduate study to identify areas where practice is not based on evidence or where it can be improved and highlighted within the team.

The further that alumni are from graduating from their course is an indication of their motivation to change practice, and the impetus lessens, as they are immersed back in the workplace and not formally studying. This demonstrates the need for good quality evidence based continuing professional development activities (Ross et al 2013) that build on the foundations of their learning. We see this in some people who are life-long learners and proceed from a Graduate Certificate to a PhD over a number of years. We can look at whether there are implications for us in these findings and consider building on previous work in the discipline on supporting service change in relation to evidence to practice (Tieman et al, 2014).

The Way Forward

The discipline has a commitment to strategically plan to ensure future students receive appropriate and quality higher education. We can help to empower students in delivering care at the end of life and to hopefully foster a desire to influence their colleagues to go ahead with postgraduate study by acting as role models (Mannix et al 2013). However, from this study we see there is also the imperative to look to the knowledge translation and implementation literature (such as Scott and Glaszlou 2012) to ensure students are also equipped with the knowledge and skills to translate evidence into their palliative care practice (van Riet Paap et al 2015).

This study is timely in that our inquiry has provided information on how to improve the experience and learning of students. This has required a degree of critical reflection: examining our previous assumptions; ensuring engagement and participation of alumni; and made us think of how we initiate change, based on good pedagogy (Le Fevre 2014). Instigating a feedback loop will ensure that alumni view us as responsive and proactive, (Manswell Butty et al 2015) and the results of this study will be disseminated in much the same way the survey was. It will also inform policy, contribute to course reviews, potentially drive future topic development and contribute to marketing (Rogers 2009). Teaching and learning in the discipline has a focus on enhancing the students' learning experience (Stes et al 2007), which arguably is something that we have been doing for some while and will strive to continue.

This context-specific impact evaluation aimed to provide a more comprehensive picture of the usefulness of our courses in real world settings (Onwuegbuzie and Hitchcock 2017). It is an imperative that we offer courses that are uncommonly taught in the mainstream, not just in Australia, but across the world. In this context, impact can be far reaching, and arguably, from studying with us, students' changes in knowledge and skills will impact on those requiring end of life care (Song et al 2015; El-Nagar and Lawend 2013).

Strengths and Limitations

Numbers are relatively low in this study as we were unable to reach the entire alumni, so our ability to draw conclusions is somewhat inhibited. Representativeness is also a consideration in all surveys and we must consider that non-respondents will be different from responders, those that do not receive the survey and those who choose not to respond.

CONCLUSION

Many of those working in palliative care or related areas will pursue higher education to further their knowledge and skills. Despite further study, often to Masters level, students encounter personal, institutional or systems barriers in implementing what they have learned into the clinical setting. The need to critically reflect in multiple ways is crucial to maintain and improve quality higher education, and in incorporating study findings, we need to incorporate change management theory and practice to continue to improve systematic practice change of end of life and palliative care in our health care sector.

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Factor analysis to validate a survey evaluating cultural competence in maternity care for Indigenous women

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ABSTRACT

Objective

This research set out to develop and validate a tool to assess the self-reported progress of Australian publicly funded maternity services towards the goal of culturally competent maternity care for Indigenous women. The tool aimed to measure the degree to which these services had incorporated actions towards achieving 14 identified characteristics into the current fabric of their organisation.

Design

An online exploratory survey was distributed to consenting respondents nationally.

Setting

Public maternity services in each State and Territory of Australia.

Subjects

The survey was distributed to 149 public maternity organisations, with 85 organisational consents and 44 respondents completing the survey.

Main outcome measure

Construct validity of a survey designed to describe progress in working towards organisational cultural competence in maternity services was assessed by principal factor analysis and varimax with Kaiser rotation.

Results

The results support the two subscales identified as appropriate groups of questions to address 1) assessment of cultural competence and 2) assessment of the survey. Reliability was assessed by Cronbach's reliability and results established evidence of a reliable survey.

Conclusion

The results of this study show that the survey assessing and identifying organisational cultural competence in public maternity care for Indigenous women demonstrated acceptable reliability and validity for a newly developed instrument. Responses to the survey provided participants of this study with a baseline for assessing further progress. Upon further testing and refinement, the survey can provide a validated tool to guide both national and local activity to improve the maternity experiences of Indigenous women.

INTRODUCTION

Aboriginal and Torres Strait Islander mothers and babies experience higher rates of mortality and morbidity compared to non-Indigenous women and babies. In 2010, the Australian Health Minister's Advisory Council (AHMAC) commissioned research to identify the characteristics of culturally competent maternity care for Aboriginal and Torres Strait Islander people (Kruske, 2012) as an action under the National Maternity Services Plan (NMSP) (AHMAC 2011). Using a literature review and stakeholder consultations, Kruske identified 14 characteristics of effective culturally competent care in maternity services including:

1. Physical environment and infrastructure
2. Specific Aboriginal and/or Torres Strait Islander programs
3. Aboriginal and Torres Strait Islander workforce
4. Continuity of care and carer
5. Collaborating with Aboriginal Community Controlled Health Organisations and other agencies
6. Communication, information technology and transfer of care
7. Staff attitudes and respect
8. Cultural education programs
9. Relationships
10. Informed choice and right of refusal
11. Tools to measure cultural competence
12. Culture specific guidelines
13. Culturally appropriate and effective health promotion and behaviour change activities
14. Engaging consumers and clinical governance.

Kruske's (2012) research emphasised that the indicators identified were preliminary in nature, requiring future development and testing in line with 'middle year' activities of the five year NMSP. Developing a tool based on the 14 identified characteristics and using this tool to conduct a national survey to assess organisational cultural competency was subsequently endorsed by AHMAC for fulfilling the middle years activity of conducting a national stocktake of access to culturally competent maternity care for Aboriginal and Torres Strait Islander women.

Although population data identifies that the highest concentration of Indigenous people is in urban eastern Australia, the percentage of Aboriginal and Torres Strait Islander people within individual populations rises with increasing remoteness. With the highest proportion of people within its population who identify as Aboriginal and Torres Strait Islander people (30% compared to 1 – 3% in other Australian jurisdictions), improving the experiences of Aboriginal women is a key priority for the Northern Territory Department of Health. This jurisdiction volunteered to facilitate the research on behalf of all AHMAC members. The approach taken to tool development recognised that examining the systems that underpin organisational cultural competence is an essential component of improving the provision of health care to Aboriginal women. At the same time it was recognised that such a tool can only be successfully applied and reliably used if it has validity for the intended purpose.

Literature

The 14 characteristics of culturally competent maternity care identified by Kruske (2012) were not provided as measurable indicators, nor did Kruske recommend a tool for assessing organisational cultural competency. Although there is much written about individual health practitioner competency and patient experiences of health care, there are however, limited data available for measuring the incidence of institutional racism (Paradies et al 2014; Paradies and Cunningham 2009) or evaluating cultural competence of health services (Suarez-Balcazar et al 2011). More generally, such tools are valuable for enhancing organisational accountability for workplace practices, and to act as a driver to improve the quality of health service provision (Australian Council of Safety and Quality Standards in Health Care, ACSQHC 2017). When used specifically to assess organisational performance in relation to cultural competence, Trenerry et al (2010) argue that auditing and assessment approaches are of significant value for supporting resource development, role-modelling, adoption of positive behaviours and reducing discrimination.

A number of approaches and tools to assess cultural competence have been developed in the last decade; most draw upon earlier work from the United States of America; and most have opted for the self-assessment mode of audit (Kruske 2012; Multicultural Mental Health Australia (MMHA) 2010; Axelby and Rigney 2006a; 2006b). Areas that are audited in these tools include: the presence or absence of a policy framework that acknowledges and recognises cultural diversity and the need for cultural competence, access to tailored and specific services, engagement with culturally diverse populations, employment of people from within a culturally specific population, recognition of cultural diversity within policies, services, recruitment and staff training, and consumer input into services (Bainbridge et al 2015; Cherner et al 2014).

Organisational level self-assessment tools developed for the Australian context include:

1. National Cultural Competency Tool (NCCT) for Mental Health Services, developed for culturally and linguistically diverse (CALD) backgrounds (MMHA 2010);
2. Aboriginal Cultural Competency Self-Assessment Instrument developed for South Australian public sector agencies (Axelby et al 2006a and 2006b);
3. Cultural Competence Assessment Tool Kit developed to measure access/ utilisation of antenatal services by Western Australian Indigenous women (Walker 2010; 2011);
4. Aboriginal Cultural Inclusion Checklist for New South Wales Maternity Services (Office of Kids and Families NSW Health 2016).

Although these cultural competency tools provide an excellent basis for tool development, they are either for contexts broader than the maternity service context (1 and 2), or do not entirely capture the 14 characteristics of organisational cultural competency (3 and 4). Nor has information on interventions to address cultural competency in maternity services been captured at a national level.

Norbeck (1985) suggested that developing a new tool should assess at least one type of content validity, one type of construct validity and two types of reliability. Other researchers (Johnson et al 2014) have used retrospective validation and previous literature as a basis for developing a tool that can be used by clinicians. One study (Mbuagbaw et al 2014) used content validity, construct validity and test-retest reliability in development of a tool to assess health competence as a measurement of the public's health and recommends further validation of their tool by using the tool in many populations and settings.

METHODS

The tool developed in this study for assessing organisational cultural competence set out to address each of the criteria identified by Norbeck (1985), and incorporated the experiences of Johnson et al (2014) and Mbuagbaw et al (2014). This process was guided by an expert reference group of midwives and Aboriginal and Torres Strait Islander spokespersons respected in each Australian jurisdiction for their ability to contribute an Indigenous voice to health policy. This group provided professional and Indigenous governance respectively for the entire project providing input into tool development, advising on data collection, and reviewing and advising on the interpretation and reporting of results.

The survey was structured in three sections. Section one was designed to obtain demographic information to describe the population and settings where the tool was used and also as potential variables influencing progress towards achieving the identified characteristics. Section two included questions relating to a self-assessment of the degree to which health service delivery reflects the characteristics of culturally competent maternity care. Section three consisted of questions relating to the length, format and perceived consistency, clarity, and benefit of the self-assessment tool.

Section two development began with formulating questions that measured practical progress against the 14 characteristics that Kruske (2012) had suggested were suitable for future use within a cyclical tool for assessing organisational cultural competence. The research also took the approach that cultural competence, along with its contributory elements of cultural security and cultural responsiveness are one way to create a culturally safe environment for Aboriginal and Torres Strait Islander women and that cultural competence is a developmental process that evolves over an extended period. Accordingly, it was hypothesized that organisations would be at various levels of awareness, knowledge and skills along the cultural competence continuum. Survey questions were framed with this continuum in mind, using a four point Likert scale for participants to record responses that included: no progress or yet to begin achieving this goal; some progress towards this goal; almost fully achieving this goal; successful in achieving this goal. Five open ended questions were also included to probe more deeply the criteria organisations used for identifying cultural competence of actual and potential employees; the engagement, employment, and support for Aboriginal and Torres Strait Islander people in their workforce overall and cultural competence training and service design and delivery specifically.

Four options were used in section three to evaluate usability of the tool; asking respondents to rate design elements as extremely good, good, adequate, and less than adequate.

The tool was piloted to test reliability in two maternity services (one in Northern Australia and one in Southern Australia) that were not eligible to participate in the national sample. As the survey was newly developed for this particular project, reliability was assessed using test-retest reliability and Cronbach's alpha. With a correlation of 1.0 and statistically significant ($p < 0.01$) for test-retest and Cronbach's reliability being a coefficient alpha of 0.94, the pilot scores showed good reliability. Face validity was verified by distribution to expert stakeholders from three states of Australia including a specific Aboriginal Health and Wellbeing unit.

The research was approved by multiple Human Research Ethics Committees with shared and individual authorities under the national network covering all Australian States and Territories. Also included in this network were Aboriginal and Torres Strait Islander sub-committees, research governance committees at health network and health service levels, and site specific assessments. This process did not result in any further amendments to the survey. Likert tool items for sections two and three suitable for statistical validation are presented in tables 1 and 2. Open ended questions are not discussed in this paper.

Table 1: Cultural competency subscale

| Cultural Competence | No progress | Some progress | Almost fully achieving | Successful |
|--|-------------|-------------------------------|----------------------------------|---------------------|
| 1. Does your organisation actively recruit Aboriginal and / or Torres Strait Islander employees? | | | | |
| 2. Does your organisation specify cultural competence and compliance with cultural competence / policy guidelines as selection criteria for employee recruitment? | | | | |
| 3. Does your organisation have guidelines and policies specific to Aboriginal and / or Torres Strait Islander maternity care and / or support culturally competent care for Aboriginal and / or Torres Strait Islander people? | | | | |
| 4. Does your organisation provide educational resources designed specifically for Aboriginal and Torres Strait Islander women? | | | | |
| 5. Does your organisation display the Aboriginal or Torres Strait Islander artwork and / or flags? | | | | |
| 6. Does your organisation provide antenatal records through to discharge summaries to all relevant stakeholders including Aboriginal and / or Torres Strait Islander women? | | | | |
| 7. Does your organisation collect data on which services Aboriginal and /or Torres Strait Islander women use within your maternity services? | | | | |
| 8. Does your organisation report on evaluation of maternity outcomes for Aboriginal and / or Torres Strait Islander women as a specific cohort? | | | | |
| 9. Overall, how culturally competent would you rate your maternity services in relation to Aboriginal and / or Torres Strait Islander people? | | | | |
| 10. Does your service encourage family members to accompany and support Aboriginal and / or Torres Strait Islander women? | Never | Proportion of staff sometimes | Proportion of staff all times | All staff all times |
| 11. Does your organisation involve Aboriginal and / or Torres Strait Islander women in design and implementation of health promotion activities and programs, for example, cessation or reduction of smoking in pregnancy? | No progress | Some progress | Almost fully achieving this goal | Successful |

Table 2: Assessment of survey subscale

| Assessment of tool | Extremely good | Good | Adequate | Less than adequate |
|--|----------------|------|----------|--------------------|
| 12. How would you rate the format of this survey in terms of ease of use? | | | | |
| 13. How would you rate the clarity of these questions in this survey? | | | | |
| 14. How would you rate the consistency of the questions posed in this survey with the aim of this project? | | | | |
| 15. How would you rate the benefit of completing this survey as a self-assessment tool? | | | | |

Maternity services were defined for this project as services that provide care including any or all elements across the continuum of antenatal, intrapartum (birthing) and postnatal periods. Public sector maternity services for populations greater than 1,000 people were eligible to participate. Excluding services providing care to populations less than 1,000 people was based on minimizing the possibility of identification of an individual service and the likelihood that the number of Aboriginal and Torres Strait Islander women receiving care in these services is low and intermittent. Such a profile was considered likely to negatively affect the validity and reliability of self-assessment.

Recruitment of participants was a three step process. Without a national database of maternity services, a convenience sample of 149 eligible organisations and relevant executive contact persons were identified by senior government midwifery advisors in each jurisdiction. Executives provided organisational consent and delegated responsibility to complete the survey to a person best equipped to respond on behalf of the health service. Consenting organisational representatives were emailed a web link to access, complete and submit the survey anonymously. The survey could also be downloaded immediately after completion and used internally as feedback on progress and as a tool to guide immediate initiatives for service improvement.

Analysis was a stepped process that was calculated in Statistical Package for Social Sciences (SPSS), Version 24. The Bartlett test was used to determine if factor analysis is an appropriate analysis for this specific sample. The Kaiser-Meyer Olkin method and communalities determined the adequacy of the sample size.

Principal component analysis to extract factors was used in the first instance. Principal component analysis is related to the sample collected. Generally speaking, generalisation of results can only be achieved if using different samples that reveal the same factor structure. Principal component analysis is at best a common factor analysis that decomposes an original data set into a set of linear variates that are less complex than factor analysis that composes a mathematical model (Field 2013). Principal component scores are actual scores whereas factor scores are estimates of underlying latent constructs (Suhr 2005). Factor loadings are identified by groupings of the questions relating to a particular theme. The final decision about what questions belong to which group or theme is made by the researcher, being guided by this factor loading output of principal component analysis.

As factors were deemed independent, orthogonal varimax with Kaiser rotation was used to improve interpretability of the factors and further refine the groupings of questions. The final step revealed the eigenvalues that identify those factors that are most substantially important. Factor analysis enables identification of common underlying dimensions and in this way common variance is established and factors explain this variance by using eigenvalues (Field 2013).

FINDINGS

Organisational consent to participate in the study was received from 85 of the 149 eligible health services, representing a response rate of 57%, and included representation from all jurisdictions. Of the 85 maternity services who agreed to participate, 44 surveys were completed by nominated representatives, representing a response rate of 51.8% compared to organisational consent, and an overall response rate of 29.5%.

In the main study, principal component analysis was conducted to assess construct validity of specific questions for the two subscales (cultural competence and assessment of survey) to determine the appropriate domains and constructs so that the survey can be used for future cyclical use. Means and standard deviations are presented in table 3. The mean scores report a composite score for each individual on a particular factor and one of the simplest ways to estimate factor scores for each respondent involves totalling raw scores corresponding to all questions loading on a factor and additionally, summed factor scores preserve variation in the original data (DiStefano et al 2009).

Table 3: Survey Item Means and Standard Deviations

| Survey Item Means and Standard Deviations | | | | |
|---|--|----------|----------|-----------|
| No. | Question | <i>n</i> | <i>M</i> | <i>SD</i> |
| 1 | Recruitment of Aboriginal and / or Torres Strait Islander employees | 42 | 2.31 | .95 |
| 2 | Specification of cultural competence in policies as selection criteria for employee recruitment | 42 | 2.33 | 1.1 |
| 3 | Guidelines and policies specific to Aboriginal and / or Torres Strait Islander maternity care and / or support culturally competent care | 42 | 2.26 | 1.1 |
| 4 | Providing educational resources | 42 | 2.55 | .97 |
| 5 | Display Aboriginal and/or Torres Strait Islander artwork and / or flags | 42 | 3.36 | .98 |
| 6 | Provide antenatal records through to discharge summaries to all relevant stakeholders | 42 | 3.36 | .85 |
| 7 | Encourage family members to accompany and support Aboriginal and / or Torres Strait Islander women | 42 | 3.6 | .63 |
| 8 | Involve Aboriginal and / or Torres Strait Islander women in design and implementation of health promotion activities and programs | 42 | 2.02 | 1.1 |
| 9 | Collect data on which services Aboriginal and /or Torres Strait Islander women use within your maternity services | 42 | 2.38 | 1.2 |
| 10 | Report on evaluation of maternity outcomes for Aboriginal and /or Torres Strait Islander women as a specific cohort | 42 | 2.45 | 1.2 |
| 11 | Rating of cultural competence of maternity service | 42 | 2.43 | .70 |
| 12 | Rating of format of survey | 43 | 2.28 | .59 |
| 13 | Clarity of questions in survey | 43 | 2.33 | .61 |
| 14 | Consistency of questions in survey | 43 | 2.23 | .53 |
| 15 | Benefit of questions in survey | 44 | 2.07 | .66 |

Factor analysis can only work if there are some relationships between variables and the Bartlett method was used to assess this (Field 2013). A significant Bartlett test ($p < 0.05$) demonstrates that factor analysis is therefore appropriate (Field 2013), and this was demonstrated by the two subscales in the survey, respectively, 190.16, 59.97, $p < 0.001$. The Bartlett test also assesses sampling adequacy (Field, 2013), and demonstrated further evidence of sufficient sampling for this study. Communalities were assessed for the first subscale with all communalities being above 0.6, for this small sample (less than 100) and measured as adequate for sample size (see table 4).

Measures of sampling adequacy (MSA's) were evaluated for the second subscale, with values being greater than 0.7, indicating adequacy and suitability for retaining items in the analysis (see table 5). Using the Kaiser-Meyer-Olkin method of assessment, the sample was deemed adequate for sample size, both subscales measuring 0.79 and 0.75 overall respectively (Field 2013).

Table 4: Communalities for Cultural Competency subscale

| No | Question | Extraction |
|----|--|------------|
| 1 | Recruitment of Aboriginal and / or Torres Strait Islander employees | .754 |
| 2 | Specification of cultural competence in policies as selection criteria for employee recruitment | .752 |
| 3 | Guidelines and policies specific to Aboriginal and / or Torres Strait Islander maternity care and / or support culturally competent care | .728 |
| 4 | Providing educational resources | .714 |
| 5 | Display Aboriginal and/or Torres Strait Islander artwork and / or flags | .775 |
| 6 | Provide antenatal records through to discharge summaries to all relevant stakeholders | .828 |
| 7 | Encourage family members to accompany and support Aboriginal and / or Torres Strait Islander women | .803 |
| 8 | Involve Aboriginal and / or Torres Strait Islander women in design and implementation of health promotion activities and programs | .660 |
| 9 | Collect data on which services Aboriginal and /or Torres Strait Islander women use within your maternity services | .780 |
| 10 | Report on evaluation of maternity outcomes for Aboriginal and /or Torres Strait Islander women as a specific cohort | .803 |
| 11 | Rating of cultural competence of maternity service | .843 |

Table 5: Measure of sampling adequacy factor loadings for assessment of survey subscale

| No | Question | MSA |
|----|------------------------------------|------|
| 12 | Rating of format of survey | .736 |
| 13 | Clarity of questions in survey | .718 |
| 14 | Consistency of questions in survey | .768 |
| 15 | Benefit of questions in survey | .794 |

A Likert scale assessed the level of progress made in working towards achieving cultural competence and assessment of the tool was provided as four options with rating the clarity, benefit, consistency and format. The majority of respondents answered that they believed the survey was good in all of these areas, with remaining respondents answering adequate and extremely good. Of significance, approximately 80% of respondents ranked the benefit of the survey as good or extremely good. Minimal respondents ranked the survey as less than adequate. These results highlight that organisations value the need for future work in this area. Almost two-thirds (61.4%) of respondents completed the survey between 15 to 30 minutes, almost a quarter (22.7%) in less than 15 minutes and a small proportion (15.9%) took longer than 30 minutes to complete.

Principal component analysis to extract factors was used in the first instance (table 6). The majority of the questions loaded onto the first factor that promoted cultural competence. The second factor identified two questions related to actively acknowledging women's Aboriginal and Torres Strait Islander heritage / identity. The third factor specifically identified questions relating to supporting Aboriginal and Torres Strait Islander women during their childbearing journey. The fourth factor identified two questions that related to reporting and collecting data on Aboriginal women's outcomes, with one question on recruitment.

Table 6: Factor loadings for subscales for Principle Component Analysis for all questions

| Cultural competence Questions | Factor 1 Promotion of cultural competence | Factor 2 Actively acknowledging heritage / identity | Factor 3 Supporting women | Factor 4 Development and reporting about Aboriginal women |
|--------------------------------------|--|--|--------------------------------------|--|
| 1 | .502 | | | .630 |
| 2 | .694 | -.491 | | |
| 3 | .794 | | | |
| 4 | .794 | | | |
| 5 | .424 | .691 | | |
| 6 | | | .812 | |
| 7 | | | .815 | |
| 8 | .729 | | | |
| 9 | .677 | | | -.563 |
| 10 | .613 | .446 | | -.477 |
| 11 | .874 | | | |
| Assessment Questions | Factor 1 | | | |
| 12 | .818 | | | |
| 13 | .846 | | | |
| 14 | .805 | | | |
| 15 | .770 | | | |

Orthogonal varimax with Kaiser rotation was used to improve interpretability of the factors and further refined the groupings of questions (table 7). The first factor only identified six questions related to cultural competence as compared with the previous table that identified nine questions. The second subscale identified only one question from the previous table with two new questions specifically acknowledging women's identity as Aboriginal and / or Torres Strait Islander people, as opposed to the other two questions which were broader and related to reporting and selection criteria. Therefore, rotation has further refined this factor and the relevance of the questions. The third factor identified the same factor, only the loadings were higher in this rotation. The fourth factor identified two of the same questions from the previous table related to development and reporting, and one new question, relating to liaising with Aboriginal and / or Torres Strait islander stakeholders about the effectiveness of services. The factor loadings were also higher than those in the previous table, confirming greater suitability of this factor. As the second subscale revealed only one factor, this could not be rotated.

Eigenvalues exceeding a value of one identify those factors that are most substantially important (Field 2013). The first subscale revealed a factor solution of four factors with eigenvalues of over one. The first factor explains 40.6% of variance, the second, 14.3% of variance, the third, 11.5% and the fourth, 10.3% (76.7% total variance). The second subscale identified only one factor with an eigenvalue over one and for this reason, could not be rotated. This factor explains 65.6% of the variance. Eigenvalues are displayed in table 8.

Table 7: Factor loadings for subscale Cultural Competence for Orthogonal Varimax with Kaiser Rotation

| Cultural competence Questions | Factor 1 Promotion of cultural competence | Factor 2 Actively targeting Aboriginal and Torres Strait Islander people | Factor 3 Supporting women | Factor 4 Development and reporting cultural competence |
|-------------------------------|--|---|------------------------------|---|
| 1 | | .742 | | |
| 2 | .854 | | | |
| 3 | .767 | | | |
| 4 | .758 | | | |
| 5 | | .741 | | .416 |
| 6 | | | .899 | |
| 7 | | | .858 | |
| 8 | .447 | .562 | | |
| 9 | .427 | | | .753 |
| 10 | | | | .846 |
| 11 | .856 | | | |

Table 8: Eigenvalues for both subscales

| Cultural competence subscale | Factor 1 Promotion of cultural competence | Factor 2 Displaying artwork or flags | Factor 3 Supporting women | Factor 4 Development and reporting cultural competence |
|------------------------------|---|--------------------------------------|---------------------------|--|
| | 4.47 | 1.57 | 1.26 | 1.13 |
| Assessment subscale | | | | |
| Factor 1 | 2.62 | | | |

Internal consistency for the scales was evaluated by Cronbach's alpha reliability with a coefficient alpha of 0.70 being acceptable for a new survey (DeVon et al 2007). A Cronbach's alpha reliability of 0.835 was achieved for the cultural competence subscale and 0.750 for the assessment subscale, establishing evidence of a reliable survey. These results demonstrate construct validity and reliability and the capability of the tool being used for cyclical use, not only in maternity care organisations but for other health professions' assessment of cultural competence in the work place.

DISCUSSION

The statistical analysis of the responses from respondents confirms validity and reliability. The results strongly suggest that with some minor revision to the tool, the research aim of developing an instrument suitable for cyclic use has been achieved. These findings concur with other researchers (Mbuagbaw et al 2014) who also used content validity, construct validity and test-retest reliability in development of their tool, and who suggest that further distribution to different populations in different settings could provide further validation. In this case, both distribution to different populations and further refinement within the existing populations surveyed is recommended in order to achieve the research aim of evaluating organisational cultural competence to improve the experiences of Aboriginal women. This could be achieved through using the tool as a component of mandatory reporting requirements in all public maternity services. Such use would both provide the opportunity for greater refinement and obtain a more accurate assessment of progress towards adopting organisational characteristics of cultural competence than was achieved with only a small number of services participating in this research.

There is also current momentum for such work more broadly than within maternity services. West et al (2017) have validated a survey to measure midwifery student's capability against the Aboriginal and Torres Strait Islander Health Curriculum Framework (Department of Health 2014). Culturally safe and respectful practice is included in the updated Nursing and Midwifery Board of Australia Code of Conduct for Nurses and Midwives (NMBA 2018). The Australian Council of Safety and Quality Standards in Health Care (ACSQHC 2017) have included six specific actions in their requirements for health services to meet the needs of Aboriginal and Torres Strait Islander people. Together these initiatives support expanding the application of this current research to the broader health care population to develop appropriate tools for a cycle of evidence informed initiatives and evaluation in health services nationally. Adapting the validated questions from this tool for incorporation in patient experience questionnaires would also contribute to this endeavour.

LIMITATIONS

The small sample size may have contributed to the reliability of the survey, and repeating the research to include a larger number and wider range of maternity services will assist in further refining the tool, and greater generalizability of findings.

Another limitation is that employees were not asked to identify their Indigenous status. Therefore, the results may not reflect the views of Aboriginal and/or Torres Strait Islander staff. Moreover, research by McBain-Rigg and Veitch (2011) identifies that the perceptions of non-Indigenous staff and Indigenous patients differed in what they considered culturally sensitive care. Accordingly, as suggested above, considering how this survey may be developed to also gain the perspective of Aboriginal and Torres Strait Islander women is indicated.

Such development and any further refinement of the tool would benefit from a more decolonizing approach than was used to develop the current survey. Although Aboriginal and Torres Strait Islander people participated in the reference group the limited Indigenous knowledge and governance this offered could be improved upon by incorporating local governance by First Nations people in the future to refine the national tool for local level application. Work by West et al (2017) provides one such model.

CONCLUSION

This research has presented a snapshot of how organisations are working to improve access to culturally competent maternity care in public maternity services, and that with further development, following distribution over some years and inclusion of community governance and community validation measures, the tool used for this research will provide a mechanism for ongoing evaluation of progress. This research also suggests that with further work, the tool may be suitable for adaptation for use beyond maternity services and across a wider range of health service areas.

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An integrative review: adherence barriers to a low-salt diet in culturally diverse heart failure adults

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KEY WORDS

heart-failure, salt, diet, CALD, health behaviour

ABSTRACT

Objective

A sodium restricted diet (SRD) is generally included in chronic heart failure (HF) management. The objective of this review is to explore and synthesise the research findings of the adherence barriers to a SRD in adults from culturally and linguistically diverse (CALD) backgrounds with HF.

Setting

The principle research question addressed in this review is:

what are the adherence barriers to a SRD for chronic heart failure management in adults from CALD backgrounds?

Primary argument

Patient education plays an important role in health decision-making but it is only one of the many factors in dietary sodium restriction adherence. In order to promote the adherence behaviours among the adults with HF, nurses should develop a tailored approach to overcome individuals' perceived barriers and circumstances especially adults from CALD backgrounds.

Results

The literature search was undertaken in PubMed, CINAHL and MEDLINE. After eliminating duplicates and applying the selection criteria, eleven titles were included in the review.

Conclusion

This review found three major perceived barriers for adults living with HF to adhere to a SRD from CALD backgrounds: 1) lack of sufficient, appropriate provision of patient education; 2) the levels of interference with social and family life; and 3) the availability and affordability of healthier food alternatives. These barriers are critical to the design of nursing interventions for promoting adherence behaviours. Lack of published research in adults from CALD ethnic minority groups living with HF in Western countries limited the ability to explore all of the barriers identified in this review.

INTRODUCTION

Heart failure (HF) is defined as a clinical syndrome that results from structural or functional abnormalities causing the heart to be unable to maintain adequate cardiac output to meet metabolic needs (National Heart Foundation of Australia and The Cardiac Society of Australia and New Zealand 2011). It is a chronic and irreversible medical condition that affects more than 23 million around the globe and 5.8 million people in the United States of America (USA) (Moe and Tu 2010; Lip et al 2004). It is estimated the total spending on HF management in the USA will increase from \$20.9 billion in 2015 to \$53.1 billion by 2030 (Ziaei and Fonarow 2016). In Australia, approximately 480,000 people are living with HF (Atherton et al 2018) and more than 173,000 hospitalisations were associated with heart failure in 2015-2016 (Atherton et al 2018). From a public health point of view, chronic HF can be managed through a combination of medical and surgical treatments, promoting self-care behaviours, education and counselling (National Heart Foundation of Australia and The Cardiac Society of Australia and New Zealand 2011). In general, a sodium restricted diet (SRD) is one of the popular chronic HF management strategies.

The role of dietary sodium restriction in HF management

Dietary sodium restriction is a common self-care strategy for HF management (Wessler et al 2014; Welsh et al 2013; Hummel et al 2009). Evidence shows that following a SRD may prevent fluid retention and associated symptoms in adults living with chronic HF (Welsh et al 2013). However high sodium (salt) intake is a worldwide health problem in this century. According to the World Health Organization (2016), many people in the world routinely consume 9 to 12 grams of salt every day. This is almost two to three times higher than the recommended amount of salt intake (5 grams per day) (World Health Organization 2012). In general, high dietary sodium intake does not only increase the risk of fluid retention and exacerbate the associated symptoms in adults with chronic HF, but it also reduces the therapeutic effects of angiotensin-converting-enzyme inhibitors (Suckling and Swift 2015). Angiotensin-converting-enzyme inhibitors are medications which are commonly prescribed for HF treatment. Therefore, adults with HF are often advised to restrict their sodium intake to 2 to 3 grams a day (World Health Organization 2012; National Heart Foundation of Australia and The Cardiac Society of Australia and New Zealand 2011; Neily et al 2002).

Potential barriers to follow a sodium restricted diet

Salt (sodium) plays an important role in the sensory properties of foods (Liem et al 2011). It enhances the food flavour by increasing the sense of saltiness and sweetness, and suppresses bitterness (Liem et al 2011). Therefore, a reduction of salt in foods would reduce the overall appetitive responses to foods, thus increasing the perceived intensity of a bitter taste. As a consequence, following a SRD is often difficult to maintain in many culturally and linguistically diverse (CALD) adults especially older ones who may also suffer from taste disorders (dysgeusias) (Syed et al 2016). Overall, the adherence rate of a SRD among adults with chronic HF is approximately 25 to 28% (Lennie et al 2008; Chung et al 2006).

We know that dietary practices often represent an individual's cultural background and ethnic identity (Kenny 2015). This creates a challenge to the nurses in the delivery of care to the adults living with HF from different CALD backgrounds. Each individual may have their own cultural belief and expectations to their health. In most cases, adults are likely to sustain a health behavioural change if they perceive the health benefits are greater than the barriers and are capable of making the change (Rosenstock et al 1988). A CALD adult's perception of the barriers plays an important role in health-related behaviour changes. Therefore, there is a need to gain a better understanding of their perceived barriers to dietary sodium restriction adherence so that nurses can ensure the recommended interventional strategies are clinically and culturally appropriate to them.

This review will explore and synthesise the current available research findings of the barriers to adherence to a SRD in adults from CALD backgrounds with HF.

METHODS

Review method

The integrative review method was selected to conduct this review. This facilitates combining experimental and non-experimental studies into integrated results and conclusions to summarise known factors across cultures and studies to synthesise a fresh perspective (Whittemore and Knafl 2005). This review uses the steps outlined by Whittemore and Knafl (2005) as a framework to guide the review process.

Problem identification

Changing an adult's health-related behaviour is a complex process and there are many barriers influencing the adherence behaviours for a medical condition. This review examined the evidence from studies focusing on the perceived barriers to adherence of a recommended SRD for HF management in CALD adults around the globe, including the role of culture and ethnic origin in SRD adherence. It aimed to answer the question, "what are the barriers to adherence of a sodium restricted diet for chronic heart failure management in adults from CALD backgrounds?"

Literature search

The search was undertaken in three electronic databases; PubMed, CINAHL and MEDLINE using the years 2006 to 2017 as limiters. This time frame was chosen to ensure the literature review reflects the most recent clinical practice in this area. The combinations of search terms, culturally and linguistically diverse people, CALD, minority populations, immigrants, refugees, cardiac failure, heart failure, congestive heart failure, salt, sodium, salt restriction, sodium restriction and barrier(s) aimed to capture the articles in relation to the barriers to adults who were advised to restrict their dietary sodium intake for the management of heart failure around the world (table 1).

Table 1: Article search results

| As at 14 January 2017 | The number of articles | | |
|--|------------------------|---------|---------|
| | CINAHL | MEDLINE | PubMed |
| Keywords used: | | | |
| Group 1- populations: | | | |
| 1a: (CALD OR Culturally and linguistically diverse people OR minority populations OR immigrants OR refugees) | 15,539 | 17,457 | 26,227 |
| 1b: (heart failure OR cardiac failure OR congestive heart failure) | 32,613 | 89,045 | 111,673 |
| Groups 1a AND 1b | 36 | 54 | 142 |
| AND | | | |
| Group 2 – Sodium restriction (Salt OR Sodium OR Salt restriction OR Sodium restriction) | 19,896 | 201,027 | 599,167 |
| Group 3 – Barriers (barrier*) | 37,094 | 139,528 | 141,773 |
| Results: | | | |
| Groups 1a AND 1b AND 2 | 0 | 0 | 2 |
| Groups 1b AND 2 AND 3 | 17 | 37 | 43 |

Study selection

Studies (articles) to be included in the literature review had to meet all the inclusion criteria and did not fall under the exclusion criteria. The inclusion and exclusion criteria for this review are detailed in table 2. These criteria were set to ensure:

1. the same approach was taken in the study selection; and
2. only the current primary studies in adults living with HF and the barriers that they experienced were included in the review.

It is important to note, non-English language publications and postgraduate theses were not excluded in the search. Articles exclusively exploring the barriers of dietary sodium restriction in hypertension and renal failure management were excluded.

Table 2: Inclusion and exclusion criteria

| Inclusion criteria |
|--|
| <ul style="list-style-type: none"> • Peered reviewed, • primary research studies/empirical studies, • published in between 2006 and 2017, • the participants were at least 18 years of age with a confirmed diagnosis of HF, and • provided a discussion of the barriers to a SRD in chronic HF management. |
| Exclusion criteria |
| <ul style="list-style-type: none"> • Articles were not related to dietary sodium restriction in chronic HF management, • grey literature, • government reports, and • clinical guidelines and position statement. |

Data evaluation

The Crowe critical appraisal tool (CCAT) was used to evaluate the quality of the selected studies. CCAT was selected because it can be used to appraise all research designs in health science research. Intraclass correlation coefficient is a common statistical test to measure reliability and consistency of the measurements between different types of research. The intraclass correlation coefficient of CCAT in appraising the descriptive, exploratory and observational research ranges from 0.91 to 0.64 (Crowe et al 2012). The absolute agreement value is 1.0 therefore a higher total or total percentage score indicates a higher level of credibility (Crowe and Sheppard 2011). The CCAT has a high level of consistency and reliability across a wide range of research designs. None of the included studies were excluded based on the results of this data evaluation rating system. Overall, the quality scores of the included studies ranged from 70 to 88% that indicated acceptable level of credibility. The scores of the included studies are presented in table 3.

Data analysis

The data analysis consisted of two phases. In phase 1, each article's content was analysed to identify and summarise the (1) HF stages, (2) sample size and location, (3) research designs, (4) tools used, (5) major findings and (6) limitations. In phase 2, the summarised major findings were categorised using the frequency distribution to identify three key barriers to SRD adherence for HF management in adults from CALD backgrounds.

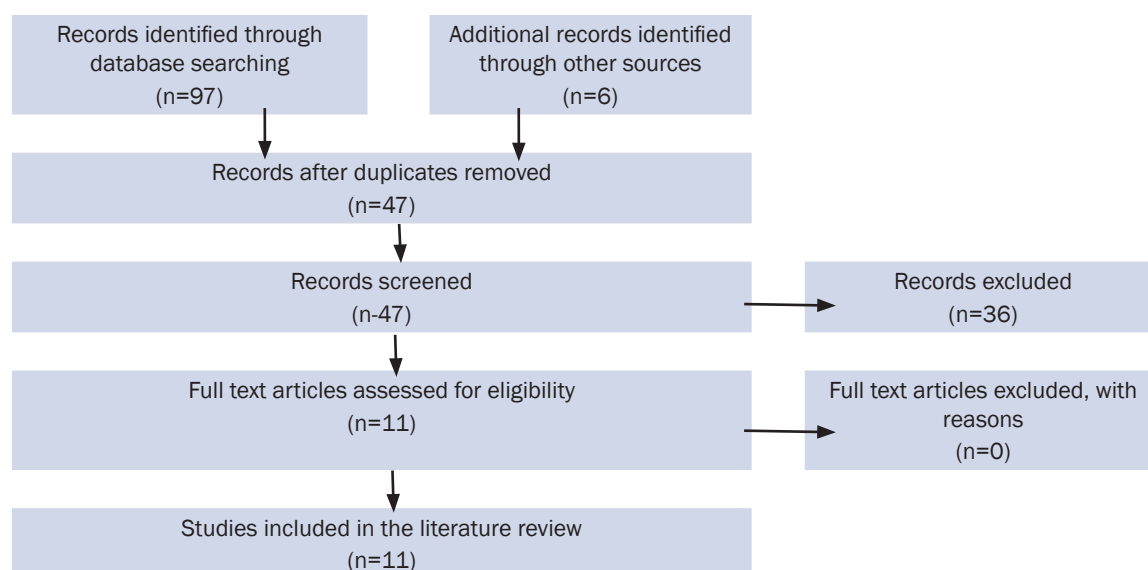
Table 3: CCAT appraisal results

| Assessment of studies included in the review | Discipline | Country | Score (%) |
|--|---------------|-----------------|-----------|
| Hoe et al (2015) | Nursing | USA | 88% |
| Sethares et al (2014) | Nursing | USA | 80% |
| Jiang et al (2013) | Nursing | Taiwan | 75% |
| Pretorius et al (2012) | Medical | South Africa | 80% |
| van der Wal et al (2010) | Nursing | The Netherlands | 87% |
| Lennie et al (2008) | Nursing | USA & Australia | 80% |
| Sheahan and Fields (2008) | Nursing | USA | 88% |
| van der Wal et al (2007) | Nursing | The Netherlands | 88% |
| Bentley et al (2006) | Nursing | USA | 88% |
| Chung et al (2006) | Nursing | USA & Australia | 73% |
| Kollipara et al (2006) | Allied health | USA | 83% |

RESULTS

The search results showed there were 142 articles available in PubMed, 54 in MEDLINE and 36 in CINAHL databases when the authors combined the keywords in the population groups – people from CALD backgrounds (1a) and heart failure (1b). The number of articles reduced to 2 in PubMed and 0 in MEDLINE and CINAHL (table 1, result-A) when the authors combined the population groups (1a and 1b) with the search keywords related to salt or sodium restriction (group 2). Consequently, as a result of the limited availability of the articles (n=2) on the people from CALD backgrounds, therefore this literature review placed more focus on the heart failure, sodium restriction and barriers (groups 1b, 2 and 3).

The search using the search terms related to heart failure, sodium restriction and barriers led to a total of 97 titles; 43 titles from PubMed, 17 from CINAHL and 37 from MEDLINE (table 1, result-B). A further 6 titles retrieved were from the reference list of the reviewed papers. After eliminating duplicates and applying the inclusion and exclusion criteria, 11 titles met the selection criteria and were included in the review (figure 1).

Figure 1: Flow chart of identified records

Of the 11 included articles, four used the qualitative approach and seven used the quantitative approach. Of these, four studies used the same data collection tool, the Dietary Sodium Restriction Questionnaire (DSRO) that was developed based on the Theory of Planned Behaviour. Additionally, the research design of the other three studies were based on the health belief model. Convenience sampling was used in all included studies.

Phase 1 Analysis

Most participants were diagnosed with New York Heart Association (NYHA) functional classes II, III and IV [NYHA functional class is a subjective estimate of a HF patient's functional capacity (American Heart Association 2015)] in the included studies. The studies conducted by Sheahan and Fields (2008) and Jiang et al (2013) did not include a cardiac function requirement in their sample recruitment criteria. The sample size varied according to the research design, it ranged from 12 to 33 in the included qualitative studies and 60 to 954 in the quantitative studies. The ethnocultural groups included American (n = 4), African American (n = 1), American and Australian (n = 2), Dutch (n = 2), South African (n = 1) and Taiwanese (n = 1). The methodology of the included studies are presented in table 4.

Table 4: The methodology of the included studies

| Author/Date | HF stages | Sample | Design |
|---------------------------|---|------------------------------|------------------------------------|
| Hoe et al (2015) | NYHA Classes I to IV | N = 232 USA | Quantitative; convenience sampling |
| Sethares et al (2014) | NYHA Classes II to IV | N = 78 USA | Quantitative; convenience sampling |
| Jiang et al (2013) | Medical records | N = 12 Taiwan | Qualitative; convenience sampling |
| Pretorius et al (2012) | NYHA Classes II, III & IV | N = 50 South Africa | Quantitative; convenience sampling |
| van der Wal et al (2010) | Hospitalised for symptomatic HF with structural changes | N = 15 The Netherlands | Qualitative; convenience sampling |
| Lennie et al (2008) | NYHA Classes II, III & IV | N = 246 Australia and USA | Quantitative; convenience sampling |
| Sheahan and Fields (2008) | Self-reported HT or HF | N = 33 USA | Qualitative; convenience sampling |
| van der Wal et al (2007) | NYHA Classes II to IV | N = 954 The Netherlands | Quantitative; convenience sampling |
| Bentley (2006) | NYHA Classes I, II & III | N = 20 USA | Qualitative; convenience sampling |
| Chung et al (2006) | NYHA Classes II, III & IV | N = 68 USA & Australia | Quantitative; convenience sampling |
| Kollipara et al (2006) | NYHA Classes III & IV | N = 219 USA | Quantitative; convenience sampling |

Phase 2 Barriers of following a SRD

Two authors (A.C., M.K.) reviewed the summarised findings of the included studies and used the categorical frequency distribution method to identify three key barrier categories. They were:

1. lack of patient education (Jiang et al 2013; Pretorius et al 2012; van der Wal et al 2010; Lennie et al 2008; Sheahan and Fields 2008; van der Wal et al 2007; Bentley 2006; Chung et al 2006);
2. interference with socialisation (Pretorius et al 2012; Lennie et al 2008; Sheahan and Fields 2008; Bentley 2006; Chung et al 2006); and
3. food preferences and non-affordability of a low sodium diet (Sethares et al 2014; Jiang et al 2013; Pretorius et al 2012; van der Wal et al 2010; Sheahan and Fields 2008; van der Wal et al 2007; Bentley 2006).

More specific details will be discussed in the following section.

DISCUSSION

This review identifies three key perceived barriers of adherence to the recommended SRD (adherence behaviours) for HF management. Adults are likely to change their dietary practices (a health-related behaviour) if they perceive the benefits are greater than the barriers and are capable of making the change (Rosenstock et al 1988). So in order to minimise nonadherence to a SRD, nurses and other health care providers should take their clients' perceived barriers to the changes of dietary practice into account when providing care and treatment to this population group (Bentley et al 2005). More specific studies that explore the barriers to dietary modifications in adults from CALD backgrounds are needed. Based on the above results in phase 2, the three key barrier categories are used as a context for this review.

Lack of patient education

Evidence shows that patient education not only improves adults' knowledge about heart failure and their recommended regimens, but also promotes self-management and adherence to the recommended SRD (Lennie et al 2008; Sheahan and Fields 2008; Bentley 2006; van der Wal et al 2007; Chung et al 2006). A semi-structured interview approach was utilised in these studies. Overall, participants' attitudes, barriers and knowledge in relation to SRD in heart failure management were measured in the data collection. Four included studies (Heo et al 2015; Lennie et al 2008; Bentley 2006; Chung et al 2006;) utilised the dietary sodium restriction questionnaire (DSRQ) that was initially developed by Bentley et al (2009) based on the Theory of Planned Behaviour in the interviews.

Accordingly, adults with HF prefer to receive both verbal and written SRD information from their health care providers (Bentley 2006). However not all adults with HF received the same level of education from their health care providers. Sheahan and Fields (2008) found that 58% of the participants received medical advice to restrict their dietary sodium intake but of those, only 24% received written information or instructions about SDR. Another study conducted in the USA and Australia also found that 20% of the participants did not receive formal medical advice to follow a SRD (Lennie et al 2008). Lack of sufficient patient education and formal advice by the health care providers may have a negative impact on the adherence. In addition, adults with less than adequate health literacy skills in acute care settings are often less prepared for self-management of the associated chronic conditions and therefore have poorer health outcomes (Lennie et al 2008). They are more at risk of misinterpreting the health-related information and may have ineffective communication with their health care providers. In most cases, low level of health literacy is often associated with poor information retention and SRD knowledge (Jiang et al 2013).

In many cases, adults with HF are told to avoid adding salt to the cooking and to remove salt from the dining table (Lennie et al 2008). The focus of the SRD education is often on identifying the high-sodium (salt) foods. As a result, many adults may not be aware of foods that contain low sodium when they shop in stores or order their meals in restaurants (Lennie et al 2008; Bentley 2006; Chung et al 2006). Further, this generic high sodium food information may mislead adults from CALD backgrounds because they may believe their cultural foods are low in sodium. Due to the possibility of language, age and/or cultural practices, these adults often have low functional health literacy skills, poor knowledge about the hidden salt in processed foods and the healthy affordable alternatives (Jiang et al 2013; Pretorius et al 2012). Jiang et al (2013) and van der Wal et al (2010) found their participants diluted the salty foods with water and perceived that to be an effective strategy in controlling sodium intake. This could be associated with low literacy skills resulting in lack of knowledge about or misunderstanding of SRD. For instance, none of the participants in the Taiwanese study could read and understand the food labels written in their own language (Jiang et al 2013). They relied purely on their sense of taste to control the sodium intake. Although the potential benefit of patient education about SRD in HF management is well established, health disparities do exist and result in adults from ethnic minority groups not receiving the culturally appropriate patient education. The study conducted by Kollipara et al (2006) found that four out of the eight frequently consumed high sodium foods by urban African Americans were not the core foods in Caucasian Americans and this cultural variation was not considered in the HF education in Dallas, USA. So, the minority ethnic populations may not accept and adapt to the SRD education designed for the mainstream population leading to a low adherence to the recommended health behaviour change (sodium restriction). Of note, adults with less experience/knowledge about the HF management often perceived more barriers and negative beliefs to the adherence of a SRD (van der Wal et al 2007). This will have a significant impact on the nurses when educating their clients from ethnic minority groups about sodium restriction.

Interference with socialisation

The interference of socialisation with family and friends is another key barrier to adherence of a SRD in all communities regardless of the ethnic, cultural and socio-economic backgrounds (Chung et al 2006; Lennie et al 2008; Pretorius et al 2012; Sheahan and Fields 2008; Bentley 2006). Food is not only the basic human need for growth, but also an important social tool/media across all cultures (Cotugna and Wolpert 2011). Many adults on a SRD experience being excluded from family and friends' gatherings or perceived that their special dietary requirements limited their social opportunities. It is because they cannot share the same type of foods with friends resulting in less conversation topics in the event (Lennie et al 2008; Bentley 2006). Also, this may have a significant impact on the cultural value and food practices among adults from CALD backgrounds (Wu and Barker 2008). On the other hand, some family members may not understand and respect their medical needs. As a consequence, adults may feel alone or that they are being excluded from their immediate family members who continue to eat high sodium foods in the same household (Bentley 2006). This will have a significant impact on their health behaviours and adherence to a SRD in the long term. For this reason, nurses should encourage the immediate family members to participate in the care planning process. This does not only increase the self-efficacy of the adults, but also assists the family members to notice the barriers their loved ones are experiencing in dietary behavioural changes for HF management.

Further, lack of social interaction and loneliness during mealtimes may affect the adherence behaviours in adults with HF. Sheahan and Fields (2008) found that single older participants resided in group homes and had a lack of motivation to cook meals for themselves. Only two out of the 33 participants had the desire to cook. They tended to consume commercial or meals provided by the group homes, which were often high in sodium. Overall, very few studies have been undertaken to investigate the effects of social interference on

dietary behavioural changes. Study on the SRD among elderly or older adults living with HF in the communities or institutional facilities is a less explored topic and the current available literature may not fully reflect on their dietary practices.

Food preferences and non-affordability of a low sodium diet

The perceptions of health/illness and adherence to the recommended SRD treatment for HF are often affected by individuals' food routines, cultural food practices, and beliefs about what makes foods look good and tasty. The study conducted by Sheahan and Fields (2008) found that both African American and Caucasian American participants who were raised with highly salted foods such as bacon and sausage in the south-eastern USA continued to consume high sodium foods even though they were given medical advice to follow a SRD regimen. Possibly, some adults may perceive meals without salt are tasteless and therefore this is a barrier to maintaining the sodium restrictions (Pretorius et al 2012; Sheahan and Fields 2008; van der Wal et al 2007). Their health decision-making about the dietary sodium restriction may not be based on the education or the social/family support they have received. In fact, their decision-making process may incorporate their daily routine, cultural food practices and life experience including the HF symptoms they are suffering. In a Dutch study conducted by van der Wal et al (2010) it was found there was a close relationship between the adults' daily routine and their adherence to a SRD. In other words, if the adults can establish a daily routine in restricting the amount of sodium in their diet, they are more likely to adhere to the sodium restriction. In practice, nurses may encourage adults to set up a series of small manageable goals in their care plan (Sheahan and Fields 2008). This may assist them to establish their routines that incorporate their own cultural food practices and beliefs in order to promote their adherence to the regime.

In most cases, dining out is often a challenge to the adults who are on a SRD. This is because the commercial foods in restaurants are mostly prepared and cooked with excessive salt and seasonings to enhance the taste and appeal of foods. It is estimated over 70% of adults' dietary sodium intake is from commercial foods, so-called hidden salt (Lennie et al 2008). This results in a lack of food choices for the adults living with HF when dining out (Sethares et al 2014; van der Wal et al 2007). Apart from the reduced food selections, the affordability of healthy foods such as fresh fruits and vegetables is another key barrier to the adherence of SRD (Pretorius et al 2012; van der Wal et al 2010). This is a particularly important issue to the adults living in developing countries or from the low socioeconomic backgrounds. The high prices of healthier foods may further limit some adults' food selections. For example, evidence showed that adults with HF in Soweto would have to spend approximately 40% of their social security/disability benefits on foods if they adhered to the recommended SRD in 2008 (Pretorius et al 2012). Given these points, nurses should assess and tailor the health interventional designs according to individuals' food affordability and financial circumstances.

Further, eating a meal is not only essential for humans to maintain their lives, individuals' food selections and practices may also "reflect their attitudes toward health, spiritual beliefs, cultural norms and life experiences" (Kenny 2015). Therefore, the effects of food selections and practices on personal identity and group membership should not be overlooked or underestimated. This is particularly important to some members of ethnic and racial minorities. Giving up their cultural food patterns and food choices may be considered the same as losing their own identity (Parasecoli 2014). In addition, hidden salt in the traditional foods such as salt-cured meats and pickled vegetables is a health concern (Jiang et al 2013). In most cases, the influence of culture on dietary practices may not be adequately addressed in the educational interventions for the mainstream populations. Therefore, if possible, nurses must incorporate the cultural contexts of individuals' dietary practice in order to create culturally appropriate measures. An infusion of culturally appropriate healthier alternatives in their traditional dietary patterns may enhance the adherence behaviours in adults from CALD backgrounds (Mukherjea et al 2013).

CONCLUSIONS AND RECOMMENDATIONS

This review revealed the key barriers to adherence of a sodium restricted diet (SRD) for chronic heart failure (HF) management in CALD adults including: 1) lack of sufficient appropriate patient education; 2) the levels of interference with social and family life; and 3) the availability and affordability of healthier food alternatives. In general, the adults' health decision-making about restricting sodium intake and changing their health behaviours may not be solely based on the education that they have received and their levels of understanding. Although patient education plays an important role in health decision-making, it is only one of the key factors in dietary sodium restriction adherence. In order to promote the adherence behaviours among the CALD adults with HF, nurses should routinely assess their individual needs and perceived barriers to sustain the dietary change for their medical conditions. Lack of sufficient appropriate education may result in adults being less prepared for self-management of their conditions and non-adherence to the SRD. This is a particularly important factor in dietary sodium restriction adherence among the adults from CALD backgrounds living with HF. These adults may not adhere to the recommended diet if the education and interventions are not culturally appropriate to their social and cultural life or incorporate into their traditional dietary patterns. Therefore, nurses should:

- tailor the SRD education that is designed for the mainstream population to adapt to meet the needs of adults from CALD backgrounds;
- encourage the adults and their immediate family members to participate in the care planning process in order to increase their self-efficacy in adhering to a recommended SRD at home; and
- provide culturally appropriate healthier food alternatives to promote their adherence behaviours.

Published research in adults from ethnic minority groups living with HF in western countries is scarce (table 1). Future research is needed to explore and address how to tailor the nursing interventions to meet the individual's needs, health literacy level, cultural practice and lifestyle in order to improve the adherence behaviours regarding SRD in these population groups.

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Complexities of the Australian perioperative nurse entrepreneur

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nurse entrepreneur, nurse practitioner, surgical assistant

ABSTRACT

Objective

This paper articulates a need for the nurse entrepreneur working as a surgical assistant. Negatively impacting on the role are the complex factors of:

- lack of professional support from the Nursing and Midwifery Board of Australia;
- lack of a process for remuneration through the Medical Benefits Schedule; and a
- lack of guidance to navigate the bureaucratic system.

Setting

Australian healthcare system.

Subjects

Clinicians who are a registered nurse or nurse practitioner surgical assistant in the Australian healthcare system private sector.

Primary Arguments

- A need exists for the perioperative nurse entrepreneur working in the private sector for specialty surgical assisting skills; adding a dimension of cost saving; and enhancing patient safety.
- The same mechanism for remuneration to medical practitioners, as surgical assistants, via the Medical Benefits Schedule is not available to nurse surgical assistants undertaking the same role. A contributor to this is the lack of support by the Nursing Midwifery Board of Australia.
- Lack of remuneration through Medicare exposes the patient to out of pocket expenses.

Conclusion

Absence of recognition of nurses (including Nurse Practitioners) as surgical assistants by the Nursing and Midwifery Board of Australia is not conducive to recognition of these roles by other government entities such as Medicare. Specialty advanced practice roles like that of the nurse surgical assistant enhance patient safety. While support for these specialty roles from the medical profession is applauded, it is an indictment on the peak Australian regulatory body for the nursing profession that support for the nurse surgical assistant including the nurse practitioner surgical assistant is not yet evident.

INTRODUCTION

Nurse entrepreneur role in the Australian healthcare system

A nurse entrepreneur is a business owner offering nursing services in the context of preventative care, rehabilitation, education, research, administration or clinical specialty direct patient care (International Council of Nurses 2004). The progression of nurses' roles into private practice serves to address gaps and unmet needs in the healthcare sector (Hong 2017). In Australia, this diversified role has generated debate within the nursing profession; the wider healthcare community; and the political and economic facets of the administration of healthcare (Lowe et al 2016; Wilson and Jarman 2002).

The role of nurse entrepreneur requires more complex knowledge and skills to that of the employed nurse. The nurse entrepreneur utilises a mixture of advanced nursing practice and corporate skills to meet client needs (Wilson 2003). These nurses are not salaried and must navigate the lack of a Medicare remuneration pathway and lack of recognition by consumers and stakeholders (Adams et al 2017). Other constraints on practice include varying levels of regulation through professional nursing bodies and clinical site accreditation issues that exist within the often inflexible bureaucracy of the healthcare system to provide their services. Motivation for nurses undertaking the nurse entrepreneur role include professional evolution, job satisfaction, regaining a sense of autonomy regarding work/life balance while filling areas of deficit within the healthcare system (Hong 2017; Wilson 2003).

In the Australian perioperative setting, clinical specialty direct patient care is delivered by the nurse entrepreneur working as a nurse practitioner surgical assistant or perioperative nurse surgeon's assistant (PNSA). These roles are under the umbrella of the internationally described non-medical surgical assistant (NMSA) (Hains et al 2017c). These clinicians may provide care in the pre-operative, intra-operative and post-operative phases of the perioperative journey (Hains et al 2016).

From a practice audit survey administered in 2015, 32% of nurse surgical assistants in Australia were working as employees of a surgeon or surgical practice, 16% were not working and the remaining 52% were working as perioperative nurse entrepreneurs either invoicing predominately the patient; or the surgeon or the healthcare facility for their services. Overall 76% of perioperative nurse entrepreneurs' workload was in the private healthcare sector. Nurse practitioner surgical assistants accounted for 14% of respondents (Hains et al 2016). From the practice audit survey it is noted that task divergence exists between nurse surgical assistants and nurse practitioner surgical assistants. This is related to the inability of the nurse surgical assistant to prescribe medications (or fluids), order investigations and refer to other healthcare professionals.

In addition to the Nursing Midwifery Board of Australia (NMBA), the peak professional body for nurse practitioner surgical assistants is the Australian College of Nurse Practitioners (ACNP). The peak professional body representing the perioperative nurse entrepreneur (including nurse practitioners and registered nurses) in Australia is the Australian Association of Nurse Surgical Assistants (AANSA).

DISCUSSION

Nurse surgical assistant or medical surgical assistant

Medical surgical assistants are medical practitioners who assist surgeons during surgical procedures. They may undertake this role as their only form of professional work or they may work in the role on a part-time basis undertaking other professional tasks as a medical practitioner.

It is not always possible for a surgeon to obtain a medical surgical assistant for procedures in the private healthcare sector. This is not the case in the public healthcare sector as surgeons have access to training medical personnel requiring learning experiences.

A survey of Australian surgeons was conducted by the authors in 2015-2016. A total of 445 surveys were submitted, not all respondents answered all questions. (Hains et al 2018) From this survey 27.5% (n=85) of surgeons revealed they had postponed or cancelled cases as an appropriate surgical assistant could not be found. Of the surgeons who responded to this question, 22.71% (n=62) expressed it was difficult or very difficult to secure a surgical assistant for urgent/emergent private sector cases. In the private healthcare sector, when a medical surgical assistant is not available, the instrument nurse may be required to simultaneously act as the surgical assistant in addition to performing their own role which requires completion of surgical counts. From the surgeon survey it was revealed that 22.22% (n=70) operate; once a month or more frequently; without a surgical assistant or, use hospital employed scrub/scout staff; without formal training for the surgical assistant role; to assist for cases that would routinely require a dedicated assistant.

Some surgeons may choose to use a perioperative nurse entrepreneur due to the specialised nature of certain surgery. Some examples of this are robotic surgery, cardiac surgery or surgery requiring operating through a microscope all which requires the surgical assistant to have highly developed specialty skills (Hains et al 2016). In these types of surgeries, if an appropriately skilled surgical assistant cannot be located, surgery may be postponed or cancelled.

It is important to highlight here that use of a perioperative nurse entrepreneur does not translate to duplication of services or payments. A surgeon uses the skills of a medical surgical assistant OR a perioperative nurse entrepreneur, not both.

Lack of professional support from the Nursing and Midwifery Board of Australia

Advanced Practice Nursing (APN) is described by the NMBA as follows:-

“APN is a continuum along which nurses develop their professional knowledge, clinical reasoning and judgement, skills and behaviours to higher levels of capability. Nurses practising at an advanced level incorporate professional leadership, education and research into their clinically based practice” (Nursing and Midwifery Board of Australia 2016).

The competencies in this statement align with the strong model of advanced practice that includes direct comprehensive care, support of systems, education, research and professional leadership (Mick and Ackerman 2000, Norsen et al 1997).

In an Australian paper, Gardner et al (2016) expand on the domains of the strong model of advanced practice highlighting tasks such as:

“focusing on specific needs, including procedures, provision of physical care, promoting innovative patient care, activities that involve enhancement of students, activities that support a culture of practice that challenges the norm and activities that allow for sharing and dissemination of knowledge beyond the individual’s institutional setting” (Gardner et al 2016).

A practice audit of nurse surgical assistants in Australia revealed that all of the activities listed above are currently carried out by the perioperative nurse entrepreneur. AANSA also supports the research component of APN by offering an annual research award. Many perioperative nurse entrepreneurs are experienced theatre nurses and are able to add a dimension of education and supervision to medical/nursing students and novice nurses working in the perioperative environment. The Perioperative nurse entrepreneur also adds valuable experience during urgent and emergency situations (Hains et al 2016).

Lack of a process for remuneration via the Medical Benefits Schedule

While the Medical Benefits Schedule (MBS) provides remuneration for medical surgical assistants under

the “Assistance at Operations” TN.9.1 Item Numbers 51300-51318, these numbers are only available to medical practitioners (Australian Government 2018). As the MBS does not recognise the perioperative nurse entrepreneur for remuneration of surgical assisting services, neither do other healthcare entities such as the Department of Veteran’s Affairs and the private health funds. Nurse practitioner surgical assistants have access to the MBS for consultation with patients but are unable to access “Assistance at Operations” TN.9.1 Item Numbers 51300-51318. The lack of an MBS mechanism for remuneration of the perioperative nurse entrepreneur exposes private patients to an out of pocket expense when a perioperative nurse entrepreneur assists for their surgical procedure. Since their inception AANSA has been proactive in a resolution for the out of pocket expenses patients incur through the use of a perioperative nurse entrepreneur.

In 2013 AANSA brokered an agreement with WorkCover Queensland to gain a WorkCover Queensland provider number and access to payment through WorkCover Queensland for surgical services for the nurse surgical assistant related to WorkCover Queensland patients. This resulted in a cost saving for WorkCover Queensland as the agreement for remuneration of the nurse surgical assistant was 15% of the surgeon’s fee compared to 20% of the surgeon’s fee for Medical surgical assistants (Hains et al 2017d)

AANSA is currently on a pathway to formal credentialing of the nurse surgical assistant role in Australia. The credentialing process aims to standardise educational and professional requirements for roles which aspire to be recognised as APN. Nurse Practitioners already have a mechanism for standardised competencies/ education and professional requirements administered by the NMBA. There is a robust body of literature that the nurse practitioner improves patient outcomes, is acknowledged by patients as an alternative healthcare professional and increases access to healthcare (Adams et al 2017) yet the nurse practitioner as an APN role endorsed by the NMBA is not able to access Medical Benefits Schedule remuneration for surgical assisting services. Given this, it is hard to imagine that credentialing which is not sanctioned by the NMBA will attract access to the MBS for non-nurse practitioner nurse surgical assistants.

Lack of guidance from government agencies to navigate the bureaucratic system

In 2012 AANSA submitted an application to the Medical Services Advisory Committee (MSAC) to gain access to the MBS for the perioperative nurse entrepreneur for surgical assisting services. This application failed to proceed past the Health Technology Assessment (HTA) group as it was identified that the perioperative nurse entrepreneur was not a new service but a new group providing existing surgical assisting services. No further guidance was given to the AANSA on how to progress the application to access the MBS.

In 2015 AANSA executive met with MBS Representatives from the Medicare Finance and Listings Branch and the Medicare Reviews Unit. AANSA was set three tasks:

1. obtain endorsement for the Nurse surgical assistant role from the Nursing and Midwifery Board of Australia;
2. obtain a letter of support from Royal Australasian College of Surgeons (RACS); and
3. demonstrate the need for the Nurse surgical assistant role.

In 2016 AANSA submitted an application to the MBS Taskforce Review for access to MBS remuneration for surgical assisting services. The MBS Taskforce Review is tasked with aligning the MBS with contemporary clinical evidence and practice (Australian Government 2015). The MBS has not been reviewed since its inception approximately 43 years ago. AANSA’s application included a submission to the Principles and Rules Committee of the MBS Taskforce to change the rule limiting access to ‘Assisting at Operation’ item numbers to medical practitioner. On 27 March 2018 AANSA received correspondence from the Australian Government - Department of Health outlining:

“The MSAC pathway is the most appropriate pathway to gain access to the MBS.”

In July 2018, in a teleconference between an MSAC representative and the president of AANSA, it was outlined by the MSAC representative that MSAC was not the correct pathway.

Tasks from the MBS representatives meeting in 2015

1. Obtain endorsement for the nurse surgical assistant role from the Nursing and Midwifery Board of Australia.

In 2010 the NMBA considered the endorsement of a range of nursing specialties in preparation for the transition to the National Registration and Accreditation Scheme (NRAS). It was identified that:

- *“A variety of mechanisms are employed internationally to recognise and regulate specialty practice, including licensure, endorsement, credentialing, validation and certification*
- *Formally regulating specialty groups for purpose of registration did not reduce the risk to the public*
- *There was lack of significant evidence that regulation of specialty practice improves patient/client outcomes” (Nursing and Midwifery Board of Australia 2016).*

In a recent survey of perioperative staff in Australia 124 surveys was submitted. Of the respondents 22% indicated that the instrument nurses in their healthcare facility were required to simultaneously perform the role of surgical assistant and instrument nurse on a daily basis when a designated surgical assistant could not be located. (Hains et al 2017a) This is in breach of the Australian College of Perioperative Nurses (ACORN) standards which state the instrument nurse may not perform a dual role as the surgical assistant. In this situation patient safety is compromised. In addition to compromising patient safety, untrained operating theatre staff acting as an impromptu surgical assistant expose themselves to organisational and medico-legal ramifications should complications arise in the intra-operative or post-operative period.(Hains et al 2017a)

Aside from compromising patient safety; other factors such as role evolution within the nursing platform should be considered. (Hains et al 2017b) In a recent Australian surgeon survey an equal number of surgeons thought governance of the nurse surgical assistant role should be by the Nursing and Midwifery Board of Australia 43% (n=140) or via the Medical Board of Australia 41% (n=133) (Hains et al 2017d).

While the NMBA resists the calls from many advanced specialty practice nursing groups to recognise and assist with sanctioned regulation, support for the Perioperative nurse entrepreneur continues from the medical profession.

2. Obtain a letter of support from Royal Australasian College of Surgeons (RACS).

AANSA has corresponded with the RACS and has received a letter of support for the role of the nurse surgical assistant. This letter states that RACS is supportive, of the role within the MBS definition of T.9.1. Assistance at Operations - (Items 51300 TO 51318) provided the clinician meet minimum entry requirements. These are:

- “1. Must obtain an appropriate qualification*
- 2. Must continue to be credentialed at each hospital in which they work*
- 3. Must continue to have a surgeon mentor at each hospital in which they work*
- 4. Must hold the appropriate indemnity insurance” (Perry 2017)*

3. Demonstrate the need for the nurse surgical assistant role.

A need has been demonstrated as the perioperative nurse entrepreneur fills a deficit in the private sector which alleviates the instrument nurse from performing a dual role and impacting on patient safety. The perioperative nurse entrepreneur additionally helps avoid surgical procedures being cancelled or postponed when a surgical assistant with appropriate skills is not available.

The perioperative nurse entrepreneur also enhances the surgical process. Some nurse surgical assistants work with patients in the pre-operative period so they have in-depth knowledge of the equipment needed for the patient's surgical procedure. The most common reasons for delays in operating lists relate to 'In Theatre Preparation Time' where inadequate staffing/planning issues impact on theatre utilisation (Orchard et al 2010) The tasks undertaken by the Perioperative nurse entrepreneur correlate to 'In Theatre Preparation Time'. By contributing to these tasks, the Perioperative nurse entrepreneur supports cost saving by avoiding cancellations and delayed theatre lists. Additionally, skilled surgical assistance can also support a reduction in operative time. (Hains et al 2016, McWinnie 2005)

The perioperative nurse entrepreneur role although not (as yet) fully evaluated, has shown a trend towards a cost benefit within the Australian healthcare system (Hains et al 2017d; Hains et al 2016) This is illustrated by:

- the perioperative nurse entrepreneur undertakes intra-operative tasks directly related to 'In Theatre Preparation Time' that facilitates the operating list, therefore avoiding delays and cancellation of procedures;
- WorkCover Queensland remunerates the perioperative nurse entrepreneur at a rate of 15% of the surgeon's fee compared with a 20% rate for the medical assistant for 'Assisting at Operation' on WorkCover Queensland patients (Hains et al 2017d); and
- a contract between a corporate healthcare provider and Queensland Health contracts the Perioperative nurse entrepreneur to operate on public patients in the private sector. This agreement has been in place since 2013. In this case the perioperative nurse entrepreneur better suited the needs of the contract (Smith et al 2016).

If the perioperative nurse entrepreneur role attracted remuneration from the MBS there is the prospect of further cost saving within the Australian healthcare system.

Out of pocket expenses

Highly topical at the moment is the high out of pocket expenses private patients incur for which there have been recent senate enquiries. Out of pocket expenses are cost shifting from the private health funds to the private patient. Out of pocket expenses coupled with the private health insurance costs increasing by 3.95% on average in 2018 is forcing the population into the public sector thus increasing the workload on an already struggling public healthcare system (Graham 2018).

A remuneration option for the perioperative nurse entrepreneur through the MBS would assist to alleviate the burden the patient incurs with out of pocket expenses. This out of pocket expense may come directly from the perioperative nurse entrepreneur, or it may come from the surgeon who pays the perioperative nurse entrepreneur. Surgeons should have the choice of working with the surgical assistant they are most comfortable with and who possess the necessary specialty surgical skills, without the patient being financially disadvantaged.

CONCLUSION

As has been clearly demonstrated here, there is a need in the Australian healthcare system for the perioperative nurse entrepreneur.

It is more than eight years since the investigation into regulation of advanced specialty nursing roles was undertaken by the NMBA. During this time unsanctioned evolution of these roles has continued with specialty nursing organisations resorting to self-credentialing of their members to validate their roles. While this maintains a minimum standard of education and professional development, there is no mediation or unification across the different nursing specialties.

As is evident by the fact the perioperative nurse entrepreneur has a significant caseload, there is a deficit of medical surgical assistants in the private sector. The perioperative nurse entrepreneur fills this deficit. However, with the current lack of formal remuneration through the MBS, and as a follow on the private health funds and DVA, the role of the perioperative nurse entrepreneur is unsustainable to many clinicians. Lack of formal remuneration is partly due to the lack of input by the NMBA. As demonstrated by WorkCover Queensland, payment to the perioperative nurse entrepreneur could translate a cost saving to the Australian healthcare system.

The role of the Perioperative nurse entrepreneur has a positive effect on patient safety. Is it time to re-visit the necessity for recognition of other advanced practice nursing roles beside the midwife and nurse practitioner? If the NMBA does not wish to regulate APN roles other than the midwife and nurse practitioner then support of the nurse practitioner role to receive remuneration for surgical assisting services would incentivise perioperative nurse entrepreneurs to obtain this qualification.

At present there is no enticement to become a nurse practitioner as this qualification does not attract remuneration for surgical assisting clinical services.

It is a condemnation on the nursing profession that the most significant professional support given to the Perioperative nurse entrepreneur comes from the medical profession.

RECOMMENDATIONS

- Formal regulation/governance of specialty advanced practice nursing roles by the Nursing and Midwifery Board of Australia would assist with validation by other government agencies. In the absence of this, support for the nurse practitioner surgical assistant from the Nursing Midwifery Board of Australia.
- A mechanism for remuneration through the Medical Benefits Schedule for the perioperative nurse entrepreneur would facilitate savings to the Australian healthcare system.
- Assistance from government agencies to negotiate the bureaucratic system would help the Perioperative nurse entrepreneur gain access to remuneration.

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Preserving families psychological and psychosocial health in PICU: a review on the health professionals role

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KEYWORDS

psychological, psychosocial, family unit, paediatric intensive care unit.

ABSTRACT

Objective

The aim of this review was to examine the health professional's role in preserving the psychological and psychosocial health of family units of paediatric intensive care patients, and to identify strategies used to reduce this risk long term.

Setting

Paediatric Intensive Care Units.

Subjects

Family units of paediatric intensive care unit patients.

Primary Argument

For the family of a child admitted to the paediatric intensive care setting, the psychological and psychosocial impacts are varied, and in many cases detrimental to the family unit itself. Health professionals, in particular nurses, perform a vital role in identifying the risks posed to these families.

Conclusion

The family unit becomes at great risk of poor psychological and psychosocial health when a child member is admitted to an intensive care unit. Nurses play a pivotal role in promoting and implementing strategies to reduce the negative impacts often experienced by these family units. Health professionals must have a thorough understanding of this risk, to be able to adequately screen and assist in preserving the health of these family units.

INTRODUCTION

“Friends and relatives could never come close to understanding what we were going through” (Koenig 2009). At the age of 12 years, Cheryl Koenig’s talented son Jonathan was involved in a horrific car accident leaving him clinging to life. After months in a paediatric intensive care unit (PICU) doctors predicted he would never walk, talk or eat again. Cheryl refused to accept this prognosis and set out on a relentless quest to save her son.

Very few health professionals can truly understand the disruption a child’s admission to an intensive care unit can have on a family unit’s health. If friends and relatives can’t come close to understanding, to what extent can health professionals? Cheryl Koenig’s (2009) book *Paper Cranes* demonstrates the enormity and longevity of psychological and psychosocial unrest parents face whilst having a child in intensive care. This book is a must read for nurses who care for critically ill children and their families. As health care professionals looking after these families for sometimes months on end, it is imperative that health professionals acknowledge the psychological and psychosocial impacts on the family unit. Once acknowledgement is made, health professionals can help identify at risk families. Furthermore, health professionals can promote and implement interventions and strategies to protect and support the personal health of the family unit, and their journey back to optimal health.

DISCUSSION

The Paediatric Intensive Care Unit is a specialist section in a hospital where the highest level of medical care can be given (Torres 2015). PICU is where children go who require intensive therapies such as intubation, ventilation and drugs such as inotropes that can only be given under close medical and nursing supervision. These children are usually critically unwell or are at greater risk of becoming critically unwell (Torres 2015). The PICU can be a very intimidating and frightening environment for families. Most parents feel a loss of control and ‘feelings of utter helplessness’ whilst having a child in PICU (Merk and Merk 2013).

Acknowledgement of parental helplessness can allow health professionals; in particular, paediatric nurses to implement and promote strategies to assist in the rebalancing of the wellness state of the family (Malik 2013). Strategies such as empowerment and information sharing can improve patient and family outcomes, short term and long term (Bronner et al 2009).

The wellness of a family unit often deteriorates whilst a child is in an intensive care unit (Hardacre 2003). The psychological and psychosocial effects are often worse and longer lasting than their physical counterparts (Balluffi et al 2004). Four themes of nonphysical health have been identified by a number of studies in the area of emotional unrest in families while in the ‘waiting room’ of intensive care units. These themes were described as shock, fear, loneliness and helplessness (McKiernan and McCarthy 2010).

Shock and trying to make sense of what is happening is one of the largest and most intense emotions families describe initially when a child is admitted to an intensive care unit (McKiernan and McCarthy 2010). Usually the admission happens quickly and families don’t always have time to comprehend what, and why, this is happening to their loved one. Keeping the family informed is one of the most important roles a nurse can play at this time to decrease feelings of shock (Bronner et al 2009). Another vital role the paediatric intensive care nurse can play to improve long term health outcomes of patients and their families, is to improve the detection of poor mental health and raise awareness of mental health issues (Bronner et al 2009). The risk of mental health compromise in children and their carers is increased after a paediatric intensive care unit admission (Balluffi et al 2004). Furthermore, parental post-traumatic stress disorder is associated with poorer psychological recovery in the child (Gledhill et al 2014). Early detection and support during this time can help protect the family unit’s mental health and preserve their competence as caregivers. This in turn can

improve the health of the sick child (Gledhill et al 2014). Therefore, it is imperative that health professionals are able to identify family units at risk and provide psychological support from an early stage to minimise poor long-term health outcomes. A formal family assessment is a great strategy to reduce poor health outcomes (Rausch 2002).

Family coping styles have been proved to be a great predictor of psychological and behavioural outcomes rather than amount of/and long-term exposure to stress when caring for a child with a chronic condition (Rausch 2002). Some studies suggest that follow up contact from the intensive care unit staff to families following an admission may decrease long term distress in traumatised families (Coleville 2010).

Fear and loneliness are two other intense emotions felt by families while a child is in an intensive care unit (McKiernan and McCarthy 2010). These emotions can manifest and impact greatly on the family unit's health. Paediatric nurses care for children, however according to the family systems theory, this care directly affects the whole family (Malik 2013). To reduce the manifestation and enormity of these emotions on families and reduce the risk of poor personal health long term, nurses need to focus on holistic, family centred and developmentally supportive care (Obeidat et al 2009). For example, an interactive formal assessment of the family to create an appropriate plan of care can also assist in decreasing feelings of fear in the family unit (McKiernan and McCarthy 2010).

Paediatric intensive care nurses are highly skilled in meeting 'highly technological' and 'unstable physical' health needs of their paediatric clients (McKiernan and McCarthy 2010). The time allocated to meeting these needs often means time spent with families is greatly reduced (McKiernan and McCarthy 2010). Interventions that promote timely information sharing and open communication channels will greatly benefit the nurse and the family (Malik 2013). By improving nurses' understanding of the family's experience in the 'waiting room,' paediatric nurses are more likely to play a greater role in empowering and interacting with families (Malik 2013). This will assist in reducing the burden of stress that these emotions have on the family and improve the family unit's overall wellness (Malik 2013, Plowfield 1999).

The physical health of the caregiver is often thought of by paediatric nurses, however it is most often overlooked by family units engulfed by crisis. Paediatric nurses know that sleep deprivation and shock reduces one's ability to be involved in appropriate decision making and adequate care giving (Keilty et al 2015). The most common physical themes identified by families in the waiting room include, eating and sleeping difficulties, tears and the inability to speak (McKiernan and McCarthy 2010).

In stressful situations such as having a child admitted to PICU, the hypothalamus in the brain is activated (Marieb and Hoehn 2010). It initiates an adrenaline response which in turn heightens some responses such as the release of glucose and dampens other responses such as digestive activity (Marieb and Hoehn 2010). The frontal lobe plays a large role in decision making and is very sensitive to these stress induced changes caused by the adrenalin response (Starcke and Brand 2012). This in turn impacts on decision making during times of acute stress (Starcke and Brand 2012). Sleep deprivation also threatens competent decision making by varying the activation of certain brain regions such as nucleus accumbens and insula, both associated with risky decision making and emotional processing (Venkatraman et al 2007).

Nursing staff play a key role in maintaining the physical health of the family unit (Høye and Severinsson 2010). Paediatric nurses cannot force parents to sleep and eat, however, can promote interventions and support strategies that give parents time, space and environments to make smart decisions for their physical health (Kutash and Northop 2007). Some 'helpful' strategies and interventions as reported by families of intensive care unit patients include; reducing the physical distance from patient to family, physically seeing staff

provide 'caring behaviours' towards their loved ones, having a comfortable environment to wait in and most commonly reported as of greatest importance was receiving timely information (Kutash and Northop 2007).

Multicultural families report slightly different themes whilst having a child in the intensive care unit, whether short term, long term or on multiple occasions (Høye and Severinsson 2010). These themes were reported as specifically impacting on their overall struggle to preserve their cultural belonging within the modern health care system (Høye and Severinsson 2010). According to Høye and Severinsson (2010), these non-western ethnic background families identified the following themes that negatively affecting their psychological and psychosocial health:

- Having information 'filtered'.
- Language barriers.
- Lack of acknowledgement of cultural traditions.
- Poor communication of roles, rules and expectations.

These themes were specifically in regards to their experience of encounters with nursing staff (Høye and Severinsson 2010). Nurses need to be sensitive to cultural customs and incorporate customs where possible into care plan to help promote optimal health in these families (Høye and Severinsson 2010).

It is, however, important to note that health professionals generally expect higher degrees of distress in families than what manifests (Myhren et al 2004). Families report that generally they are satisfied with the support and communication given in the intensive care unit environment despite the enormity of stress they face (Myhren et al 2004). A longitudinal study from 2011-2014 showed a significant improvement in patient/customer satisfaction associated with nursing and medical competency (Sarode et al 2015).

In conclusion, from the themes reviewed above it is evident that health professionals, in particular nursing staff, would benefit from further training in assessing, screening and addressing distress in family units within the paediatric intensive care setting. Provoking insightful thought processes through education, will improve patient and family satisfaction.

Please note that although the topic reviewed in this literature review is very current and relevant to all health professionals working in the PICU, there is very little current literature available on this topic. It would be recommended that current research into this area in needed.

CONCLUSION

The family unit becomes at great risk of poor psychological and psychosocial health when a child member is admitted to an intensive care unit. The paediatric nurse plays a vital role in detecting 'at risk' family units. Once these families are identified, health professionals can engage and promote services and strategies to preserve the health of the family unit. However, further education and training for these health professional is needed to increase insightfulness and improve clinical practice. It is imperative that health professionals acknowledge the disruption to wellness families face when a child is admitted to an intensive care unit. Without this fundamental acknowledgement, adequate screening and preservation of health cannot be effectively achieved. This increases the risk of negative, long term, psychological and psychosocial outcomes for the family unit.

List of interesting articles related to this topic

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