Separation of conjoined twins: experiences of perioperative nurses and their recommendations

K. Martin-McDonald¹ PhD, MEd, BAppSc, RN, P. McIntyre² BN, GDN, RN & D. Hegney³ PhD, BA (Hons), DNE, COHN, CNNN

- 1 Senior Lecturer, Department of Nursing, University of Southern Queensland, Toowoomba,
- 2 Nurse Unit Manager, Operating Room Suite, Royal Children's Hospital, Brisbane,
- **3** Director, Centre for Rural and Remote Area Health, University of Southern Queensland; University of Queenslandand; Queensland Health; Queensland, Australia

MARTIN-MCDONALD K., MCINTYRE P. & HEGNEY D. (2005) Separation of conjoined twins: experiences of perioperative nurses and their recommendations. *International Nursing Review* **52**, 52–59

Background: Within an 8-month period, an unprecedented and historical first in Queensland, Australia, the perioperative nurses were members of teams involved in the surgical separation of two sets of conjoined twins. Little is known about the (dis)stress that some of these perioperative nurses experienced nor how best to support them during such experiences.

Aim: The aim of this paper is to report on the qualitative study that explored the experiences of those perioperative nurses involved in the surgical separation of cojoined twins and from their stories propose recommendations to support perioperative nurses who are confronted with such workplace experiences.

Methods: Using a narrative methodology, nine perioperative nurses shared their stories of being involved in the surgical separation of conjoined twins in Australia. Narrative and thematic analyses were conducted and recommendations to support perioperative nurses through workplace (dis)stress were identified. Participants validated the findings and recommendations.

Findings: The analyses revealed the themes of professionalism, teamwork, 'them vs. us' and emotional loads.

Discussion: The sensationalism around the rarity of conjoined twins brought an intensive intrusiveness from the world media. As a result, secrecy within the hospital about the conjoined twin cases created divisions between those perioperative nurses on the teams and those not. The processes and outcomes of the two surgical cases were in contrast to each other. For some perioperative nurses this caused distress. It is essential that professional support is offered in a way in which the perioperative nurse can take it up without fear of negative judgement.

Keywords: Conjoined Twins, Narrative, Perioperative Nurses, Workplace Stress

Introduction

Conjoined twins occur as a result of an incomplete separation of the developing monozygotic embryo. Most are stillborn, and many that are born do not survive more than a few hours postbirth (Wallis & Doman 1996). The birth of conjoined twins is a rare and unique occurance globally, with the incidence in North America cited as about

1:50 000 (Harper et al. 1980). The degree of fusion varies enormously as does the area(s) shared. Points of fusion can be entire torsos, the top or side of the cranium, hips, buttocks and chests.

Within an 8-month period, an unprecedented and historical first in Australia, Queensland's perioperative nurses (PNs) were members of the teams involved in the surgical separation of two sets of conjoined twins. The recent Australian sets of twins were joined at the head, which adds to the significance of the event internationally, as it is estimated that such fusions occur only one in every five million births (CNN 2001). The focal point of global attention that surrounds the surgical separation of conjoined twins includes the outcome for the twins, the parents' traumatic experience, and the procedural concerns of the surgeons and anaesthetists.

In the midst of the emotions surrounding the birth of such twins, especially if surgery is indicated, invisible to the public, are the PNs who will be part of the surgical team should a decision be made to separate the twins. The experiences of the PNs through the surgical separation are somewhat 'invisible'. Thus the aim of this study was to explore the experiences of those PNs who have been involved in the surgical separation of conjoined twins and from their stories propose recommendations to assist in supporting the PNs who are confronted with this type of workplace stress.

Background

Caring for conjoined twins places PNs in the midst of contentious debates, especially when separation is considered. Is it medically achievable? Is it right to do so? Is the expense justifiable in emotional and financial terms? Who should make the decisions? Within this debate are also the roles and reactions of health care professionals and the contextual issues that influence these responses.

Ethical issues

There has been extensive ethical debate over whether parents and/or health professionals have the right to separate conjoined twins, particularly if one twin may die during this separation (London 2001a, 2001b; MacLeod 2000; Wallis & Doman 1996). The ethical problems are complicated as they are socially regulated, culturally constituted and historically determined (Thomasma & Muraskas 1996). The problems that are referred to with regard to ethical issues are often emotional and words such as 'killing' (Easterbrook 2001; Gillon 2001; MacLeod 2000) 'sacrificing' one child (London 2001a) and/or 'murder' by health professionals (English et al. 2001) are used.

There are several ethical and moral arguments within the literature with regard to separation of conjoined twins (Thomasma & Muraskas 1996). The right of any person to decide that one child should die so that another can live is the most emotive argument in the literature. There are three distinct discourses surrounding the ethics of surgical separation. The first, states that killing one twin to save the other is justified (Batiu & Singer 2001; Easterbrook 2001; Gillon 2001; MacLeod 2000) to prevent both children from dying (Dowling 2000; London 2001a, 2001b). The second discourse relates to how the separation (and subsequent death of one child) of the twins allows one twin to live 'normally' (Wallis & Doman 1996). Whilst the third articulates that there is no ethical

or moral dilemma in the case of emergency separations when one twin is already dead or dying (Mackenzie 2000).

Those who argue that surgical separation is never justified if there is a chance of one twin dying, state that separations that result in the death of one child is never justified (London 2001b; Wallis & Doman 1996) as no human being should be made to give up their life for another, nor does any person have the right to hasten the death of another (London 2001a). In contrast, others argue that if the twins were old enough to give informed consent, would they agree to the death of one so the other could live (Batiu & Singer 2001)?

The emotional and economic cost of separation surgery

Within the conjoined twins and organ donation literature is the issue of the economic cost of these operations to society (Batiu & Singer 2001; Pearson et al. 2001), particularly in an atmosphere of cost containment. Some authors hold the view that in a world of limited public medical resources the exorbitantly costly procedure of separating conjoined twins would be better redirected elsewhere. For example, it should be used to maximize health benefits for as many people as possible rather than just one set of conjoined twins (Batiu & Singer 2001).

Separation of conjoined twins has enormous emotional costs, particularly to the parents. These emotions can also be complicated by religious beliefs. For example, in the case of separated conjoined twins in Britain, who were separated by a court order, the operation was against the religious beliefs of the parents. Further, the children were from a developing country and it was unlikely that they would be able to access the type of health care required for the surviving twin. In this case, the separation caused considerable emotional costs to these parents (Easterbrook 2001; English et al. 2001; Gillon 2001).

Whatever circumstance brings conjoin twins to the point of surgical separation the deep and profound impact on those directly involved is poignantly captured in the following quotes from surgeons: One of the surgeons said that when the blood vessels connecting Amy with Angela were severed, cutting off the blood flow and causing her death, 'nothing was said, but I know everybody felt it' (Thomasma & Muraskas 1996, p. 3). 'This was the hardest day of my professional life but only because of what I had to do, not for moral reasons . . . the morals of the situation were clear. We had to choose between two deaths or one death and one life. We chose life.' (Easterbrook 2001, p. 2)

Perioperative nurses

The PN is 'the link between what are often stressful, complicated, technical procedures associated with the diseased condition and mental functions which are so critical to the patient's comfort and important to him [sic] as a person . . . The theatre nurse aims to give vital care and support throughout this vulnerable time' (Jones 1990, p. 1094). Within the hidden social processes and emerging drama of the operating theatre the nurses within that environment may be subjected to stresses that have the potential to lead to moral distress. PNs will inevitably face critical events, which if left undealt with will potentiate attrition to that environment and possibly to the discipline of nursing itself (Michael &

Jenkins 2001).

Thus this study will redress the invisibility of the PNs exposing their experiences of workplace stress related to the separation of conjoined twins with the goal of proposing recommendations that might assist other nurses in similar situations.

Methods

The narrative mode of thought (Bruner 1986) leads to stories that convey living the experience. Bruner (1986, p. 11) convincingly argued 'that narrative knowledge is more than emotive expression; rather it is a legitimate form of reasoned knowing'. The *Epistemology* is transactional and subjectivist, which embeds the meanings in a structured story. The ontology is relativist, which encompasses the dialogues and interchange of stories that convey living the experience. The criterion that is fundamental to the core of quality narrative research is verisimilitude or 'truth-like' (Denzin 1989, p. 28) where the goal is the building of shareable understandings of the life experiences of another.

Research design

This is a descriptive study at the factor isolation level.

Research questions

What is the experience of PNs involved in the surgical separation of conjoined twins?

What recommendations do PNs propose to support them when they experience a workplace stress?

Population/sample

The sample includes nine PNs who were members of the surgical teams that separated one or both sets of conjoined twins in Brisbane, Australia in 2000 and 2001. The participants' experiences of being a PN ranged from 6 months to 19 years (the mean being 10 years). Two nurses had been involved in three cases of separation of conjoined twins in total, four nurses had experience in two cases and three nurses were involved in one case. The participants represented the three different areas of responsibilities within the theatre: scrub nurse, scout nurse and anaesthetic nurse.

Data collection

The interview was framed as a narrative production by addressing the requests: 'Tell me your story of how you came to be on one or both of the surgical teams that separated conjoined twins?' and 'What was your experience of being involved with the surgical separation of conjoined twins?' and 'From your experience, what recommendations would you propose that would support nurses faced with workplace stress?' The interviews lasted from 1 to 2 hours, the length of which was determined by the participants when they believed they had completed the narration of their story. The place, time and location of the interviews was determined by each participant. Every interview was tape-recorded with the participants' permissions and transcribed verbatim.

Then each participant's story was returned to them through the post in order for them to validate the story's accuracy. This also gave the opportunity for the participant to add, refine, or alter their story, in any way they saw fit.

Data analysis

To draw the transcripts into meaningful stories the processes of Emden (1998) were adhered to. Each story was thematically categorized before looking for similarities, differences and patterns across the different stories. 'Thick' descriptions are incorporated in the 'Findings' section of this paper for the reader to decide on the transferability and relevance of the data, as well as to establish the confirmability that there is an internal congruity between interpretations and actual evidence.

Ethical issues

The National Health & Medical Research Council (2000) guidelines were adhered to with regards to fully informed, voluntary consent, participants' right to withdraw from the study at any time without consequence to them, confidentiality procedures to protect the identity of the participants and data storage for 5 years with disposal by shredding at that time. The Ethics Committee of the Hospital in which the PNs are employed gave ethical approval.

Findings

These two experiences of surgical separation of conjoined twins in this project were vastly different from each other for several reasons. The first case was elective surgery giving advanced preparation time, and both twins survived. The media portrayed the parents as self-focused, seeking financially gain from the rarity of the case and lacking in parental skills. In contrast, the second case was an emergency, one twin died during surgery and the media portrayed the parents as the ideal, loving couple. Despite these differences both experiences revealed similar themes of professionalism, teamwork, 'them vs. us' and the emotional load felt by the PNs.

Professionalism

The participants answered the call for PNs to volunteer for these cases as they perceived it as an opportunity to be involved in something relatively rare and, because of this rarity, it was also perceived to be challenging and exciting. In some of their comments that follow the reader becomes aware of their enthusiasm:

I was absolutely enthusiastic about doing that . . . and basically because I realized that this only comes up once in a lifetime . . . (and) that would enhance my career and provide me with learning experiences.

It's an opportunity. It's rare to see one set of Siamese twins let alone two. So I had my hand up straight away.

I enjoy doing the big cases . . . so I do grab them when I can.

It was such an unusual situation, I put my name down.

The participants took on the roles and responsibilities of being on the team in a professional manner. Activities included preparation for the procedure by reading the literature (much of this was done in their off-duty time); extensive planning and practice sessions that identified what would need to be specific roles; and anticipation of difficult aspects that they could then practise. The following comments illuminate this aspect:

We did literature reviews . . . we didn't find many at all and a lot of them were in different languages . . . The anaesthetic team and medical teams provided us with information that they had actually received . . . had to look at it from a nursing perspective and then what the doctors will need as well. So we had to assess the actual operating theatre and how we were going to do it that way and just using our knowledge from everyday nursing practice . . . It was partly in hospital time and quite a lot in our own time as well.

There was a lot of planning. They had the resus (resuscitation) dolls joined together. We had the surgeon come to theatre a week before with the dolls to work out the turns together. . . . So that was good, we had a few 'oh what about if we do this?' or 'why don't we do that?' and so we all had input into that and take notes.

The well-planned and rehearsed preparation of the first conjoined twin case was in stark contrast to need for emergency operation to separate the second case, which is indicated by the nurses statements below:

It was different for the second set of twins. It was an emergency for a start.

The second set I think was much more upsetting I think because it was in the middle of the night and you were out of your comfort zone anyway.

The nurse who co-led the first elective surgery nurse team had returned from a 7-day outreach programme in remote Australia. She was contacted immediately on her return, late at night, and was asked to organize a surgical team of nurses for the emergency separation early the next morning. Here is how she retells some of what went on to organize this:

Between 10 PM and midnight, there were so many phone calls between the Nurse Manager and I, ringing back and saying, 'I've tried that person, no they're away. I've tried this person, no they're on-call' or 'I've tried this person, they said if you can't get anyone else we'll do it'. I was starting to panic because I had a very small team. Thankfully I knew the other senior nurse had said yes. Gradually in that 2 hours I think we ended up with maybe five or six people. That was only just enough to start the operation. There was a team to cover transplants and a team to cover emergencies and that was all that I could get at that time.

Despite these difficulties the professionalism of all involved came to the fore as the same senior nurse spoke of the attitude of all the nurses when they arrived in the theatre the next morning:

Everyone just sort of switched automatically into, right we'll get ready for the twins and we'll do everything exactly the same. . . . so based on that, with no surgeons around and no anaesthetists, the nurses all just worked out how they were going to set up the room, how they were going to do everything and we just made our own little plan in a really short space of time, based on the first set of twins because thankfully most of us had been there.

The experiential knowledge gained by these surgical teams has been shared with many other professionals at conference presentations, staff developments and in published journal articles.

Teamwork

The participants declared the strength of the surgical teams, which they identified as the nurses, anaesthetists, surgeons and wardsman. The rarity of the occasion brought them together in a cohesive way where 'teams within teams' were multidisciplinary and supportive.

Sharing of journal articles, extensive joint planning and discussions prior to the surgery and the work during the surgery led to a bonding and 'probably made us a bit closer as a team and (this) worked better'. Some comments in this regard are listed below:

We were really close knit . . . we had to be there trusting each other and communicating with each other, so that we all knew what was happening at each stage, otherwise we would've put their (twins) lives in jeopardy.

Everyone was enthusiastic and wanted it to be right and to be perfect. It was really nice to be a part of a team of people that I trusted completely.

That was one thing that will stick in my mind is the fact how everyone sort of pulled together and we were just trying to resuscitate the babies.

We achieved something. We were a team.

All participants agreed that it was their like-mindedness that resulted in a unique bonding as a team member. This, they believed, was the result of volunteering to be a part of the team:

I think it was the like-minded people choosing to be involved that made it work so well . . . I think that was the key that people wanted to be there and wanted to be involved.

Them vs. us

The perioperative team for the conjoined twins cases sensed and overheard comments by nurses not in the team that indicated a tension and strain between the two groups. Some participants believed that the secrecy demanded of them, because of the 'prowling media'; the high profile and subsequent attention given to the team members after the success of the first twin separation; the bond between the team members and the perceived nepotism of team member selection were the causes of this tension:

The thing that stood out in my mind was the secrets. The way we were told nothing until the last minute or we were told not to tell others not involved in the twin cases. That was the worse.

Because of the media, they kept the date of the operation and everything so quiet. It was all hush-hush . . . There were rumours. 'You can't say this, you can't say that, you can't let anyone know you're doing this . . .' When you have so much secrecy around it makes the tension in the theatre . . . Because they're so secretive other girls got a bit bitchy . . . because the other people felt like they weren't trusted.

I was disappointed by some people's responses . . . like the attitude of some of your colleagues. I don't know whether they were jealous that they weren't involved . . . Like you came to work and you looked tired and there were a lot of innuendoes made like . . . 'I didn't get any special treatment'.

Everything was so secretive, even amongst the staff. I don't like that. Amongst a lot of staff, people were perceived to have been favourites and that's why they were on the team.

Emotional loads

The experiences of the PNs involved in the surgical separation of the conjoined twins were emotionally demanding. The success of separation and life for both twins in the first case distinctly separates the emotional load from the second case. Even though the first case required resuscitation of one of the twins, the final outcome of separation with both twins alive is the emotional dominant feature. One participant tells it this way:

When the second twin (first case) was sent off to recovery there was absolute joy I think and relief and just success, achievement of what we'd set out to do . . . We did the whole big group hug and were really excited and just happy that it was all over . . .

Everybody was overwhelmed with feeling of pride or just excitement.

The experiences of the nurses involved in the surgery for the second set of conjoined twins were dramatically different, calling on the personal resources of the nurses to move through it. Some nurses were vulnerable to being emotionally overburdened. This occurred through fatigue from a heavy workload immediately prior to the second conjoined case. For others their focus on successful surgical outcomes exposed their vulnerability to the highly probable outcome of death for one twin who lacked several

vital organs. Vulnerability also arose through the absence of personal support networks, or an inability to access professional support to facilitate the grieving process. One nurse stated:

I guess the day was hugely stressful . . . We just worked and worked and worked and kept going at an extraordinary pace and there was lots and lots of stressful moment where there was bleeding . . . when the healthy baby arrested I think it just shook everyone . . . everyone was kind of standing, that weren't doing the resuscitation part, willing the babies on . . . as soon as they were separated the second twin died . . . I just wanted to make her pretty . . . was trying to fight back the tears while I cleaned her all up . . .

The media influenced the participants' perceptions of the twins' families to various degrees thereby having an effect on the emotional load of the participants. One participant openly shared the following:

The first set (parents of the first set of conjoined twins) probably weren't portrayed in the media as nicely as what the second set were because they came from different backgrounds . . . so you sort of got a lot more attached to the second set. I know that sounds an awful thing to say, but I know I did . . . So it felt a little bit more emotional about the second set.

Some participants spoke of the parents of the second conjoined twins in the following ways:

When you walked into the room, you were sort of overwhelmed by the parents and the fact that this was crunch time for them . . . they had been there and known that the babies were deteriorating.

The mother was crying (when twins were collected for surgery by nurses and anaesthetists) because she knew what might happen and said 'I'm so sad, watch out for them'. Oh even thinking about it I get sad still . . . I think I've got worse as I've gotten older (crying).

This empathy was also extended to other team members, as one participant disclosed both her empathy and a feeling of being torn between what she wanted to do and what she needed to do as a professional:

I felt really bad because I wanted to be with the other nurse to help her look after this child (dead twin) but I had to go back in and just leave her (the nurse was crying). Just go and help the other people to try and save the other one. That was a bit hard.

Adding to the emotional burden was the lack of formal, institutional support needed by some PNs. One of the two senior PNs expressed a deep ongoing sorrow over the death of one twin in the second case.

I knew that I wasn't coping, but as one of the senior people there I felt like I should have been. I'd never seen a baby die before. In all my nursing years I'd never seen a baby die before and I didn't know how I was suppose to behave . . . following that my whole world fell . . . I couldn't sleep . . . it was on the front page of the newspaper . . . I didn't know who I could tell . . . so I didn't tell anyone.

Dealing with the grief took varied forms, all of them drawing on personal networks rather than professional ones at the time because of the negative way in which professional counselling was offered. Additionally, some participants noted that as a nurse, it was expected that they would cope with anything. For example:

Sometimes in nursing there's this mental (attitude) that you have to be tough and just stick it out.

So support has to be made available in a way 'That's not thought of in terms of being weak' if you use it.

Discussion

Technology now allows medical and surgical intervention previously unavailable to take place and therefore consideration is given to surgery previously not possible (Pearson et al. 2001). In both cases of conjoined twins, the PNs professionally prepared themselves for the separation cases. This preparation included searching and reviewing the literature, practising the positioning and turning of the patients using life-sized dolls and drawing on their extensive experience. Despite the level of knowledge and skills required to be a competent PN there is evidence in the literature that the PN's knowledge, skills and experience is defined and controlled by the medical profession (Cunningham 1998; Leinonen & Leino-Kilpi 1999; McGarvey et al. 2000). PNs are 'commonly perceived, by those who are not theatre nurses, to be technical, focusing on assisting the surgeon and anaesthetist, rather than focusing on the care of the patient' (Montgomery 1997, cited in Arndt 1998, p. 3). It is apparent from this study, that Montgomery's perception of the PN is not correct. Rather, it is apparent that PNs must be competent and abreast of technology but the central and primary focus is the patients and their care.

Secrecy was thrust upon the PNs in this study reportedly because of the hospital administration's attempt to manage the public profile and sensationalism that the media might provoke over such a rare and controversial surgical procedure as that of the separation of conjoined twins. From a health professional institutional viewpoint, it was noted that the institutions benefited from the publicity. It has been documented in the USA that in one case, the intensive media interest influenced the parents' decision regarding the medical treatment of their conjoined twins (Thomasma & Muraskas 1996).

Whilst the secrecy could have been seen to have benefited the health service, it also created several difficulties within the PNs' environment. First, it created a division between those 'in the know' and those 'out of the loop' as some nurses were chosen to be

involved in the separations and others were not. Second, it is apparent that the PNs perceived they were not viewed as trustworthy or as professionals who would protect the privacy of the patients and family, which led to resentment on behalf of the PNs towards the hospital management. Third, the secrecy forced circuitous routes for preparation for surgery to be taken and a restriction of normal debriefing mechanisms and support measures. Perhaps the most negative consequence, for the discipline of nursing and in particular, the speciality of perioperative nursing, was how secrecy worked to ensure the removal of the importance of the PNs from the view of the public. Arndt (1998, p. 2) confers that 'one of the greatest hindrances to the recruitment of perioperative nurses is the fact that low visibility has gained the specialty an unrealistic reputation'. This low visability has resulted in PNs being shrouded in a mystery to the public and nonperioperative staff.

There was ample evidence that the PNs viewed the outcomes of both cases as the result of a multidisciplinary team, where all practitioners can contribute according to their professional knowledge and skills. Surgical procedures bring together a multidisciplinary team with discipline experts in their specific field caring for patients. This bonding between the team members was memorable in the Brisbane cases of conjoined twins with displays of sensitivity, empathy and consideration for others in the team. The view of nurses as equal partners in a team, is incongruent with the public portrayal of these surgical cases where the surgeons are highly visible, the anaesthetists slightly visible and the PNs invisible.

The emotional load on surgical team members of conjoined twins cases ranged from euphoric to a heavy burden. 'Contending with stressful situations in the workplace is a common occurrence for all health care providers' (Lambert, Lambert & Yamase 2003, p.181). With regard to the emotional cost to health professionals, there is a need to take some sort of intervention in these cases (Bakker et al. 2000; Steinbock 2001). This is not in a social, cultural or ideological vacuum. In particular, the rarity, ethical and legal controversy, public scrutiny and media sensationalism create a social context that warrants a delicate approach to support the PNs and other surgical disciplines through the situation. We are reminded of the context of the ethical issues surrounding the separation of conjoined twins in the following quote: 'Two minds in one joined body offends Western society's veneration of individuality and freedom, to the point where surgeons risk killing conjoined twins by attempting separations even when they might have lived healthy lives still joined' (Mackenzie 2000, p. 1).

In spite of the decision being relatively 'easier' if one twin is dead or dying (Mackenzie 2000), this does not lessen the emotional burden if a twin dies during or soon after the surgical procedure. This was the case in the second set of conjoined twins in Brisbane, Australia. The death of a conjoined twin in the second case was traumatic for many of the PNs. The anaesthetic nurses were witnesses to the parents' distress prior to the operation; all of the PNs had been exposed to the media profiling the family, thus a strong empathetic bond existed between the PNs and the parents, causing a suffering for those PNs. Such distress may well have possible implications for the health and well-being of those nurses (DeVries & Wilkerson 2003; Lambert, Lambert, & Yamase 2003;

Tennant 2002). Such effects of moral distress have been found to be: 'loss of self-worth; effect on personal relationships; various psychologic effects; behavioural manifestations and physical symptoms' (Erlen 2001, p. 78). Whatever the degree to which the 'mental and physical demands of perioperative nursing are overwhelming' (Arndt 1998, p. 3) these nurses need support during and after workplace stresses, as well as assistance in the development of preparatory, and ongoing, coping strategies.

Recommendations

The PNs in this study recommended several strategies that, in their view, would have facilitated their ability to successfully work through the (dis)stress wrought by the experiences of one or both cases of conjoined twins. All of the participants mentioned the importance of a support system that could take several forms and be sponsored by the institution. Such support strategies ought to include debriefing of the team either immediate post-operative or within a few days (if length of surgery might indicate tiredness or fatigue of team members). A sharing between the PNs of the personal impact of stressful rare cases and their outcomes is considered beneficial but a skilled facilitator is an essential criterion.

Provision of a counselling service by the institution is essential, but it is important that when such an offer is given it needs to be non-judgemental and genuine, otherwise PNs may feel reluctant to take up the service. From the perspective of the participants in this study a counsellor should be experienced in the health care professions and ideally would have a nursing background.

It would seem appropriate that educational programmes within hospitals address the need of health carers needing to care for themselves in order to minimize stress, prevent burnout and promote the retention of these experienced people. Thus a culture shift towards acceptance of caring for the carers is needed, where it is safe for nurses to acknowledge being subjected to a workplace stress, that people cope with workplace stress in different ways and to seek therapeutically support when needed. Related to this, is the need for an awareness and support network for those PNs who do not have family or a partner at home to sustain them emotionally following workplace ordeals.

The success of any case in surgery is one to be shared amongst all the PNs in the operating theatre that is composed of 'teams within teams'. There were other teams during the conjoined twin cases such as the on-call and routine surgical teams. Thus recognition needs to be extended to all PNs in the theatre as directly or indirectly each of them contributed to the ability of that theatre to perform the separation of the conjoined twins.

PNs are professionals and as an integral part of their everyday practice they demonstrate a respect for the privacy of patients and their families. If institutions recognized and acknowledged this there would not be a need for secrecy from or between management and health care disciplines. Use of secrecy fails to acknowledge this professional behaviour. In this case, the way secrecy was used directly initiated the division between

the PNs involved with the twins and those who were not. Institutions ought to recognize and acknowledge that as professionals, all nurses are bound by confidentiality.

Conclusion

Rare surgical cases, such as the separation of conjoined twins, place PNs in the midst of the emotive, cultural, ethical, legal and financial debates whilst they attend to the needs of their patients. The PNs ought to be recognized as the professionals they are and there needs to be an acknowledgement that PNs assigned to such rare cases are a team within a larger perioperative team, without which such rare cases could not be attended to. Requiring a case team to prepare in secret or the withholding of vital information about the conjoined twins from the PNs in the surgical team until close to surgical date is problematic. Such behaviour has the potential to cause inter- and intradisciplinary rifts that may implode on the harmony of the perioperative milieu. Rare cases, such as the separation of conjoined twins, bring about experience and experiential knowledge from the perspectives of the different disciplines involved. Thus it is important that the PNs are encouraged, supported and sponsored to disseminate that information to enhance the global work related to the surgical separation of conjoined twins, which in turn brings a visibility of the PNs themselves.

Correspondence address

Dr Kristine Martin-McDonald, Department of Nursing, University of Southern Queensland, Toowoomba. QLD. 4350, Australia; Tel.: 61 0746311576; Fax: 61 0746311653; E-mail: kmartinm@usq.edu.au.

References

Arndt, K. (1998) Recruitment and retention in perioperative nursing. *Australian Nursing Journal*, **6** (4), 32–35.

Bakker, A.B., et al. (2000) Effort–reward imbalance and burnout amongst nurses. *Journal of Advanced Nursing*, **31** (4), 884–891.

Batiu, P. & Singer, P. (2001) The ethics and economics of heroic surgery. *Hasting Center Report*, **31** (2), 47–48.

Bruner, J.S. (1986) Actual Minds, Possible Words. Harvard University Press, Cambridge.

CNN. (2001) *Surgeons Fail to Save Conjoined Twin*. The Associate Press. Available at: http://asia.cnn.com/2001/WORLD/asiapcf/auspac/05/27.

Cunningham, J. (1998) Documentation issues in perioperative nursing. *Australian Nursing Journal*, **6** (4), 35–37.

Denzin, N. (1989) Interpretive Biography. Sage Publications, Newbury Park.

DeVries, M.W. & Wilkerson, B. (2003) Stress, work and mental health: a global perspective. *Acta Neuropsychiatrica*, **15**, 44–53.

Dowling, C. (2000) Gift of freedom. *People*, **54** (24), 68–73.

Easterbrook, G. (2001) A moral precedent for the siamese twins case. *Human Life Review*, **27** (1), 37–40.

Emden, C. (1998) Conducting a narrative analysis. *Collegian*, **5** (2), 30–35.

English, V., et al. (2001) Ethics Briefings. How should students learn? Some continuing difficulties with consent. *Journal of Medical Ethics*, **27**, 62–63.

- Erlen, J.A. (2001) Moral distress: a pervasive problem. Orthopaedic Nursing, **20** (20), 76–80.
- Gillon, R. (2001) Imposed separation of conjoined twins moral hubris by the English courts? *Journal of Medical Ethics*, **27** (3), 3–4.
- Harper, R.G., et al. (1980) Xiphogagus conjoined twins: a 300 year review of obstetric, morphopathologic, neonatal and surgical parameters. *American Journal of Obstetrics and Gynecology*, **137**, 617–629.
- Jones, C. (1990) The Bevan report. British Journal of Theatre Nursing, 27 (9), 1094.
- Lambert, V.A., et al. (2003) Psychological hardiness, workplace stress and related stress reduction strategies. *Nursing and Health Sciences*, **5**, 181–184.
- Leinonen, T. & Leino-Kilpi, H. (1999) Research in perioperative nursing care. *Journal of Clinical Nursing*, **8** (2), 123–138.
- London, A.J. (2001a) A separate peace. *Hastings Centre Report*, **31** (1), 49–50.
- London, A.J. (2001b) The Maltese conjoined twins. *Hastings Centre Report*, **31** (1), 48–49.
- Mackenzie, D. (2000) Must one die? New Scientist, 168 (2259), 18.
- MacLeod, A. (2000) Medical, religious values clash over conjoined twins. *Christian Science Monitor*, **92** (216), 7.
- McGarvey, H.E., et al. (2000) Development and definition of the role of the operating department nurse: a review. *Journal of Advanced Nursing*, **32** (5), 1092–1100.
- Michael, R. & Jenkins, H.J. (2001) Recovery from work-related trauma by perioperative nurses: the effects of social and personal resources. *Collegian*, **8** (3), 8–13.
- Montgomery, A. (1997) Recruiting: the ever-present problem. *British Journal of Nursing*, **7** (9), 14–18.
- The National Health and Medical Research Council. (2000) *Ethical Aspects of Qualitative Methods in Health Research*. NHMRC, Canberra.
- Pearson, A., et al. (2001) Intensive care nurses' experience of caring for brain dead organ donor patients. *Journal of Clinical Nursing*, **10** (1), 132–139.
- Steinbock, B. (2001) The Lakeburg Siamese twins: when is treatment futile? In *Ethical Issues in Modern Medicine* (Arras, J.D. & Steinbock, B., eds). Mayfield Publishing Company, Mayfield, pp. 276–280.
- Tennant, C. (2002) Life events, stress and depression: a review of recent findings. Australian and New Zealand Journal of Psychiatry, **36**, 173–182.
- Thomasma, D.C. & Muraskas, J. (1996) The ethics of caring for conjoined twins. Hastings Centre Report, **26** (4), 4–8.
- Wallis, C. & Doman, J.M.R. (1996) The most intimate bond. *Time*, **147** (13), 60–64.