

# **How do ICU nurses perceive families in intensive care? Insights from the United Kingdom and Australia.**

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## **Abstract**

**Aim and objective:** To compare how intensive care nurses in the United Kingdom (UK) and Australia (AU) perceive families in ICUs.

**Background:** International health-care research and practice is often based on an underlying assumption of a person or family-centered ideology. While nurses in intensive care units (ICUs) acknowledge the importance of patients' families, a true integration of families as units of care is often not realised.

**Design:** Data from ICU nurses from two international studies: (1) a constructivist grounded theory study in the UK and (2) a quasi-experimental non-equivalent clinical study in AU. Data were collected in tertiary adult ICUs in the UK and AU. Nurse to patient ratio for high acuity patients was 1:1 in both units.

**Participants:** Twenty ICU nurses in five focus groups (UK study) and 197 surveys were sent out to ICU nurses in AU (response rate 26%).

**Results:** Evidence from both studies makes visible the contribution of family care in adult ICUs. Nurses remaining in control and initiating family member care involvement are less likely to perceive families as a burden. The AU study indicated that when nurses partner with families to deliver care, there was a minimal affect on their workload. The nurses concluded that inviting family members to be a part of the patient's care should be usual practice in ICUs.

**Conclusion:** Nurses should promote, facilitate and invite the integration of families in care in today's health-care system. This is mandatory since families are the caring resource for these patients during an often prolonged recovery trajectory.

**Relevance for practice:** Families are more likely to be successfully integrated into a more active involvement with ICU patients when they are not perceived as a burden. Inviting and supporting family members is not necessarily time consuming and starts the journey of supporting ICU survivors' recovery journey.

**Keywords:** family, ICU nursing, ICU nurses, family-centered care, nurse-family partnership, family nursing

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

- Families are be an important support resource for ICU patients
- Internationally, family centered care is a desired model of care
- Integration of families into ICU care is often not achieved

#### **What this paper adds**

- The importance of family integration into ICU care
- Feasibility of family participation into ICU care
- Nurses and families are required to work in partnership

### **Introduction**

Today's international health care research is underlied by an assumption of a person-centered ideology that explicitly or implicitly includes families as a legitimate focus of (nursing) interventions. Families are viewed as social units in which health and illness are experienced and consequently, illness in one family member is viewed as having an effect on the entire family

(VanHorn & Kautz 2007, Wright & Leahey 2005). While the importance nurses in intensive care units (ICU) assign to patients' families reflects this notion (Stayt 2007, Williams 2005), a true integration of families as units of care is often not realised (Mitchell *et al.* 2009). A number of international studies suggest that families are important support resources for critically ill patients and ICU nurses alike (Dahle Olsen *et al.* 2009, Engström & Söderberg 2007, Leske 1998, McKiernan & McCarthy 2010, Mitchell & Chaboyer 2010). Many ICU nurses value the involvement of families in the care of the critically ill patient (Engström *et al.* 2010, Garrouste-Orgeas *et al.* 2010) and evidence suggests that this integration into care has benefits for family members (Hammond 1995, Mitchell & Chaboyer 2010) and ICU patients alike (Bergbom & Askwall 2000, Dahle Olsen *et al.* 2009, Simpson 1991). However, nurses work within a complex health care system that is governed by policies, routines and structures. It could be argued that these facets are essentially serving the system and not the patients and their families. Therefore the existing system may impact upon nurses' ability to deliver family-centered services in an ICU.

Beyond the policy drive towards a person-centered health care system (Australian Commission on Safety and Quality in Health Care 2010, Scottish Government 2010) there are a number of compelling reasons why nurses should pay attention to and actively take account of family members in ICU. These include, firstly, the insight they bring to the critical illness situation as not all ICU patients recall the onset of critical illness or their time in an ICU while families live through the whole critical illness episode (Paul & Rattray 2008). Some ICU patients experience memory loss or delusional memories as a consequence of critical illness (Adamson *et al.* 2004, Jones *et al.* 2000) and family members may function as back-up for the patient by filling in lost time periods and clarifying actual events as opposed to those that did not occur in reality. Secondly, family members provide support, comfort and reassurance to patients during their time in ICU (Bergbom & Askwall 2000, Hupcey 2000). Thirdly, by being there family members enact togetherness at a time of critical illness (Eggenberger & Nelms 2007, Mitchell & Chaboyer 2010, Walters 1995), providing a connection to the real world for the ICU patient. Fourthly, family members act as proxy decision makers and advocate for patients at times of incapacity (Hupcey 1999, Maxwell *et al.* 2007, Mitchell *et al.* 2009). Finally, policy drives continue to shift care from the acute into the community care setting with patients being discharged ever quicker

and sicker (Chaboyer 2006, Haycock-Stuart *et al.* 2010), leaving family members to facilitate and frequently provide post-discharge care to the recovering ICU patients.

It has been argued that working with families of adult or paediatric patients in partnership or meeting the needs of visiting family members of critically ill patients constitutes a hidden and sometimes stressful aspect of nursing work (Callery 1997, Stayt 2007). However, by supporting families and meeting their needs of assurance, proximity, information, comfort and support (Leske, 1992) during a time of critical illness, nurses are enabling families to support the critically ill patient (Bailey *et al.* 2010, Mitchell & Courtney 2005) which might well have a positive impact on patients' recovery. A prerequisite for family-nurse partnerships to develop is access for families to the ICU patient and the bed-side nurse. One means of doing this is through flexible and open visitation policies (Ågård & Lomborg 2010, Garrouste-Orgeas *et al.* 2010, Kean 2008, Whitecomb *et al.* 2010). In this article we examine this hidden aspect of nursing work which is an essential part of nursing expertise in the belief that, for the reasons outlined above, families should be a central point for ICU nurses both as a care recipient and as a care resource.

The following sections report on two studies from the UK and AU and give insight into how nurses perceive families within the ICU. Both studies had the same definition for family. The family was defined as a unit whomever participants identified as 'family'.

## **The studies**

The two ICU studies originating in the UK and AU and examined how ICU nurses perceived family members. Ethical approval was granted for both studies by local Research Ethics Committees.

### **Study 1: UK**

Study 1 explored families' experiences with critical illness in ICU and nurses' perceptions of families. The study was organised in two phases: (1) family group interviews (n=9) and (2) focus groups with nurses (n=5), utilising a constructivist grounded theory approach (Charmaz 1990, 2006). Interviews were digitally recorded, transcribed verbatim and stored in NVivo 2.0

(2002, QSR International Ltd., Doncaster, Victoria, Australia) for data management. Data analysis started with the first interview, using the constant comparative method (Glaser & Strauss 1967), and moved from open to focused coding (Charmaz 2000, Glaser 1978). Theoretical sampling (Glaser & Strauss 1967, Glaser 1978) followed Charmaz's (1990, 2000) recommendation and was used at a later stage in the research process after key themes had emerged. Analysis of group data was approached by looking for patterns and processes (Charmaz 2006, Glaser 1978). The studiesThe analysis focused on the interaction of participants (Bloor *et al.* 2001, Carey 1994, Kitzinger 1994, Morgan 1995, 1997) and moved forward and backward from the group to the individual perspective by constantly comparing incidences within and across groups. Written consent was obtained from all participants.

## **Study 2: Australia**

Study 2, conducted in AU, was a quasi-experimental non-equivalent clinical study which evaluated family members' perception of being involved in individualised care for their ill family member. The study described families' and nurses' experiences of having a family member provide physical care to the ICU patient. The project had the bed-side nurse invite and support family members in their participation of individualised care for the ICU patient. The families' perspective has previously been reported (Mitchell *et al.*, 2009; Mitchell & Chaboyer, 2010) and here, the nurses' perspective will be provided.

After approximately 12 months of data collection with family members, nurses in the unit were surveyed to understand their perspective on having family members involved with the care of their sick relative in ICU.

## **Settings**

Data were collected in tertiary adult intensive care units in both countries. At the time of the studies, the UK ICU had an open visiting policy while the AU ICU had defined visiting hours for families between 11 a.m. and 8 p.m. Both units had a policy in place restricting visitors to two at a time. Visitors were required to request entry to the units by pressing a buzzer and waiting for someone to collect them at the doors. In the AU ICU, families were not normally invited to participate in providing patient care while in the UK ICU this depended on the bedside nurse.

Both ICUs worked on a one nurse to one patient ratio for mechanically ventilated or high acuity patients.

## **Findings**

### **Study 1: UK**

The UK study examined families' experiences with critical illness in ICU and nurses' perceptions of families. The focus here is on the nurses' perception of families in ICU. Five focus groups were conducted with a total of 20 ICU nurses who had between six months to 20 years experience in ICU and incorporated a range of participants from senior to beginning nursing roles. The overall findings from nurses' focus groups relate to the theme of 'Nursing in Public' under which nurses discussed their experiences with families in ICU.

It was evident that the nursing management of the ICU subscribed to a philosophy which identified the family as a care recipient - this was highlighted by one of the senior nurses who said that:

they (*families*) know that they are part of the care [ ]. We quite often say to relatives that 'we are here as much for you as we are here for the patient' (G 3).

This sentiment was echoed in other focus groups which mentioned one senior nurse who functioned as a role model by integrating families into complex care activities such as giving a bed bath. However, the spatial distance to patients and families between nurses with managerial responsibilities and those working predominately at the bedside mattered and had an effect on nurses' perspective of families. While nurses with managerial responsibility defined the family (including the patient) as the unit of care, bedside nurses more often argued that 'the patient at the end of the day' (E 1) remains the focus of care. For bedside nurses, open visiting hours resulted in 'Nursing in public' as is evident in the following excerpt:

I mean what other job – you know, you don't go and watch them in the tax office 24 hours a day and watch the taxes being done. I mean, what other job can you come in and watch somebody in the work that they do in their day-to-day life? (D & E 3)

These nurses understood the ICU as their ‘turf’ (Heimer & Staffen 1998) and experiences with families evolved around challenges of an open visiting policy, ever present family members and the impact this had on nurses’ control over working time and space.

The unit had an explicit open visiting policy with no restriction on overall numbers of visitors or constraint on who could visit the ICU patient. Although the unit’s policy was not to allow more than two visitors at a time per bed space this did not always occur and this had ramifications on nurses’ work load particularly when this happened for an extended period of time. Nurses commented that:

F3: We say two relatives...

F1: ...per bed because of the lack of space...

F3: ...per bed. But with some larger families, especially from different cultures and they just sometimes manage to have 10 round the bed all the time. It’s a constant battle for the nurse at the bedspace, and I think that is very tiring because you’d say, well you only allowed two, but they just manage to sneak another couple in and another couple in and that’s-

F2: I mean it can get a wee bit full at times.

F3: It’s when you’ve got to walk twice the distance round the bed ‘cause you can’t get in to the bed. ... And it’s okay for an hour, but on an eleven hour or twelve hour shift you’re just about in tears because you can’t- you can’t do it! (*Forceful tone of voice*)

These restrictions on visitor numbers were related to the limited physical space at the bedside but also to nurses’ need to control their working time and space. Several nurses across focus groups argued that a constant flow of visitors inhibits patient care. With families being ‘there all the time’ (D2) some nurses felt the need to delay certain care activities (e.g. bed baths, mouth care). The perceived interference in care was two-fold: (1) the presence of families required nurses to attend to the needs of families (information needs, explaining procedures, integration into nursing activities) and (2) care activities were delayed due to the presence of family members to either allow families to be with the patient or to protect the patient’s right to privacy during care

activities. The need for privacy while caring for ICU patients was evident when nurses argued that:

E 1: In other ICUs you're not allowed to visit until after ward rounds, so 12 noon. Other places you're only allowed visiting 2pm – 8pm or something.

E 4: Yeh.

E 1: I mean, I definitely think families shouldn't be in during handover, and I know we send them out during handover.

E 3: Yeh. Unless they've been here a long, long time. (*Group agreement*)

E 1: Even then, because sometimes you pass on some very confidential stuff that you don't really want them to hear. Not that it's something awful about them but, you know, they can pick up some things wrong.

E 2: Somebody was saying about one patient where her husband just walked in and he said: 'why shouldn't I? I'm sitting outside all day.' But it was something like – his wife was on the bedpan or something and it's just not appropriate for them to come in. ... But they (*families*) have to sometimes sit outside for half an hour.

Interestingly, this need for privacy was not expressed by the nurses as a specific nursing need but one that emphasised the patient's right to privacy and the above discussion was typical across focus groups. The patient's right to privacy during caring activities frequently serves nurses as a justification to send families outside the unit. While there are good reasons for this practice and therefore it should not be dismissed lightly, it also has to be recognised that nurses gain from this generalisation of sending all family members outside under the auspice of the patient's right to privacy. Nurses were well aware that 'we work sort of totally under observation all the time' (F 2) and pointed out that 'it would be nice not to be observed all the time' (F 2).

Open visiting policies are crucial for families enabling them to meet their work and family obligations (e.g. picking children up from school) while also meeting their need to be near their ill family member. Some nurses acknowledged this by pointing out that 'it must be reassuring for families' (D & E 3) to have flexibility in visiting hours.

Considering the views expressed by nurses, it appears that nurses' need for privacy in caring for critically ill patients is at the heart of the argument against open visiting practices. Families, in contrast, asserted in interviews their need to be near their family member (Kean 2008). Perhaps one reason for this tension lies in the fact that nurses and families effectively inhabit different social ICU worlds in the same physical ICU space, requiring negotiations and 'finding a balance' (Coyne & Cowley 2007) of their respective needs while the primary focus remains on the well-being of the patient in both groups.

One way for nurses to remain in control over their working time and space is to negotiate the integration of family members into patient care. The second study, conducted in two metropolitan ICUs in AU and explored nurses' perceptions of involving family members in giving care to the ICU patient.

## **Study 2: Australia**

The AU study involved two similar ICUs from two hospitals. At the intervention site family members, in consultation with the bed-side nurse and where possible, the patient, decided on the care the family member would provide that was most appropriate for the patient. The family member would perform this care with assistance from the bed-side nurse. When compared with a control site (n = 75) where family were not invited to perform patient care, the intervention site family members (n = 99) recorded significantly higher scores on a Family- Centred Care survey which included the concepts of support, collaboration and respect (Mitchell *et al.* 2009). The data collection instrument was a revised adult version of Shields and Tanner's survey that was developed for the paediatric setting (Shields & Tanner 2004). Interviewed family members (n = 10) were very positive about the intervention and enjoyed providing care as they felt it enabled them to demonstrate that they cared and 'to connect' with their ill family member on a level not otherwise available to them. Family members acknowledged the vital role nurses played in their participation in patient care. Further results can be found elsewhere (Mitchell & Chaboyer 2010, Mitchell *et al.* 2009).

In view of the significant role nurses played in assisting family members and also caring for the critically ill patient, it was important to gain insight into this intervention from their perspective.

With the research literature in mind, a survey was developed for this purpose by the research team which included clinicians. The survey had eight items – six were closed and had a four point Likert scale option. For example, one question asked: “Which of the following best describes how you now feel towards the value of families in providing some care to your sick relative?” Answer options included from: “Not positive” to “Very positive”. Another question asked: “Since the finish of the project to what extent do you offer family members the opportunity to perform some care to their relative?” Options for this ranged from “Yes, lots of times” to “no, not at all.” Two questions were open ended to provide the opportunity for additional comment. The survey was trialled on a small group of nurses (n=5) to assess clarity, language and logic of sequence. No changes were deemed to be required.

The ICU nurses were sent a survey via their work email which asked their opinions on the value of and barriers to including family members in their ill family member’s care. These comments were examined for commonalities and themes which emerged as workload, caring and coping.

Of the 197 surveys sent out there were 52 responses (26%). All nurses were sent the survey even if they were on maternity leave, annual leave or sick leave. A limitation was that the data base was unable to filter to include only current working staff. Forty-three of the respondents had participated in the intervention whereas nine had not been involved. As involving families in their relative’s care was not usual practice in this unit, the nurses were asked if their perceptions on this altered over the duration of the 12 month project. Results indicated that 38 (88%) of the nurses had an altered perception on the value of involving family members by the end of the study (see Figure 1).

Figure 1

As highlighted above, most nurses indicated they had changed their view on family involvement at the end of the project. To understand if this indicated a positive or negative perception, nurses were asked how they now valued family member involvement. All nurses deemed there was positive merit to having family members involved in their sick relative’s care (see Figure 2).

## Figure 2

As it has been reported that family participation in care increases nurses' workload (Vandall-Walker et al., 2007) it was important to gain insight into the nurses' perception of how family members giving fundamental care affected their workload. Interestingly, 81% of nurses (n=34) considered having family provide some patient care had minimal affect on their workload (see Figure 3).

## Figure 3

Some nurses wrote additional comments in the theme of workload indicating that sometimes it increased the nurses' work or for others it did not impact unduly and some indicated that it actually helped them. Some commented that it made things take longer than usual but that was not problematic. Respondents commented that:

If anything it added to my workload as it meant that I had to be there to help them as they would not do anything on their own or with me just watching (N 25).

Was not a problem at all. Just needed to give instruction and reassurance (N 17).

Performing cares such as mouth and eye care, ROM (*range of movement*) exercises etc enabled me more time to attend other duties (N 18).

Caring for the family is part of the workload, so I didn't find it had a great impact to normal. If anything it slightly helped, because the relative was busy and needing less direction from myself, so I could go about other things (N 19).

However, one nurse felt they were providing a concession to the family and cautioned that:

Family members must be aware that this is a privilege, which could be withdrawn if they overstep their involvement with patient care, or it causes friction between family members or staff (N 40).

At the end of the project, all except one nurse (n = 42) reported that they now offer families the opportunity to help with the care of their ill family member. Within this caring theme, some seem to limit this to long-term patients while others comment that it depends on the individual situation

and the amount of involvement the family want. One wrote that they feel the family members think it is the nurses' job to do it and not theirs. Others used the invitation to perform fundamental care to support the building of positive nurse-family relationships. Comments included the following:

It is a very easy way to open up communication with family members and gain their trust (N 19).

Particularly long stay patients- offer to include them in any care they're comfortable with. Also use opportunity to distract family when/where they become focused on "numbers" (*blood pressure and pulse*) etc. (N 37).

In an attempt to understand what influences their engagements with families in this way, a question asked: What factors would influence your decision to actively involve family members to perform care to their relative? Nurses' responses to this showed they may focus on the patient's condition and frequently the receptiveness and coping ability of the family member. Some saw family member involvement in care as a way they may help families cope, specifically in the grieving process. One also indicated it depended on the family's ability to keep to the unit's rules whereas another put themselves in the family member's shoes. Some wrote that the factors they took into account included:

How long patient had been in unit, relationship to patient, how the family is coping (N 29).

If it was for a long-stay patient and family members needed to learn 'care skills' for patient in the home (N 31).

If it was my relative in ICU I would want to perform patient care (N 35).

How close the family unit is, cultural expectations, displays willingness to perform care, family compliance to ICU visiting times/rules (N 49).

To assist with grief, family showing signs of helplessness and wanting to care for their sick ones (N 4).

Some wrote that this was not unusual for their practice and that they found it very beneficial.

This concept is well described by one nurse who wrote:

I have been including family members in caring for aspects of my patients' care for years. I have found it to be a powerful strategy to diffuse tension of family members, help them

regain some sense of control of the crisis situation and also helps build a rapport with the bedside nurse. (N 48).

Of the 52 nurses who responded, 98% (n = 51) considered the concept of inviting family members to be a part of the patient's care should be part of 'usual care' in ICU as opposed to something extra ordinary or special.

## **Discussion**

Within the notion of a person or family-centered ideology and the implied continuity of care that underlines much of today's international health care practice and policy, many health professionals recognise that providing continuity across an illness trajectory is complex, problematic and frequently not done well (Bergbom 2008). A proportion of nurses caring for adult patients are yet to acknowledge that adult patients are persons who do not exist in a vacuum but are embedded in family systems(Price 2004). "Caring for patients' families recognizes that social context as well as the reciprocal relationship that exists between patients and their families" (Benner *et al.* 1999,p 294) is a helpful reminder drawing attention to the importance of patient's families in ICU care and beyond. Nurses' data from these two international studies make visible the family contribution to care in adult ICUs and the benefits this approach may hold for the patient, families and nurses involved. Further, evidence from the presented literature clearly supports the need for a partnership in care, integrating family members in the care of their ill family member in real ways from the first acute phase onwards. Open and flexible visitation policies would allow families the necessary access.

### **Open visitation policies**

Open visitation polices have the advantage of supporting families' need for information and closeness and obligations as a family to support the ICU patient. Responses from nurses in the current studies reported here suggest that opening up ICUs has an impact on their working conditions but this is not insurmountable. It is however something that needs to be worked through if we are to be able to provide the care required to ICU patients and their families.

The conclusion that the introduction of an open visiting policy is beneficial for families but has both advantages and disadvantages for nurses is obvious. The loss of privacy for nurses on their turf (Heimer & Staffen 1998) and the unpredictability of when and how many visitors will arrive considerably influenced nurses' working conditions. Surprisingly, this aspect of open visiting policies is rarely addressed within studies despite the real possibility that this might be an underlining cause for the rejection of open visitation policies in ICUs. Further, the tension that exists between policies promoting a person or family-centered service and the complex organisational structures of health care systems in which nurses are embedded as one group of professionals are ignored.

Nurses in the UK study felt that a constant flow of visitors inhibited patient care. The perceived interference in care was two-fold: (1) the presence of families required nurses to attend to the needs of families (information needs, explaining procedures, integration into nursing activities) and (2) care activities were delayed due to the presence of families to either allow families to be with the patient or to protect the patient's right to privacy during care activities. This specific argument with its two dimensions is not unique to nurses in the UK study but is one that has been brought forward elsewhere (Berti *et al.* 2007, Hunter *et al.* 2010, Plowright 1998, Spreen & Schuurmans 2010). Interestingly, the view of families as a hindrance to care runs counter to nurses' beliefs that 'families are important for patients' (G1 & E4) as a source of support in their recovery process. Acknowledgement that families are important to patients was common to ICU nurses in both studies and elsewhere (Bergbom & Askwall 2000, Hupcey 1999, Simpson 1991). Our findings are in contrast to Berti *et al.*'s (2007) study, surveying Belgian ICU nurses who believed that open visiting policies are not important for patient's recovery (55.9%) or comfort (57.8%) while the view that this particular policy had a direct negative impact on nursing care delivery (73.8%) is consistent with other international studies (Berti *et al.* 2007).

### **Families' participation in care**

As previously argued, true integration of families as units of care in adult ICUs is still missing (Mitchell *et al.* 2009) and therefore does not yet constitute the *status quo* in many ICUs around the world. Both studies reveal striking parallels with paediatric nurses required to work in partnership

with parents and ICU nurses supporting families. The partnership in care approach, which provides parents with a space to care for their hospitalised child, was a change in paediatric nursing practice following the Platt Report in 1959 (Casey 1993, 1995, Coyne 1995, Darbyshire 1993b, 1994, Lee 2007).

In making visible the contribution families can make to the care of their ICU patient and that this is not necessarily an additional burden for ICU nurses is the lesson to be learned from the AU study. On a unit level, a fundamental difference between the two studies was the fact that nurses in the UK ICU were reacting to families as visitors in ICU while ICU nurses in the AU study remained in control over their working environment by actively inviting families to participate in care. This small but significant difference had an impact on whether nurses view family members as a hindrance or support to care. The AU study demonstrates that the invitation to families to become partners in caring for the ICU patient resulted in families' desire to fit in while at the same time family members were enabled to reaffirm their emotional connection with the patient. On an individual nurse level, it was evident that both units had nurses that embraced families and those that saw the integration of families into care as a privilege which can be withdrawn. Within resource constrained health and social care budgets, patients' families have become an important informal care resource. This is underlined by policy drives that shift care into the community at an ever earlier stage in the recovery trajectory of patients (Haycock-Stuart *et al.* 2010, SG 2007) and the expectation that families will provide the care patients need. The complex and prolonged process of recovery from critical illness (Griffiths 2010, Richmond *et al.* 2000), therefore has to be contextualised within the family systems. By involving families in the care of their ICU patient, nurses have the opportunity to provide the support and continuity needed by families and ICU patients during a time of critical illness.

## **Conclusion**

We believe that the integration of families in today's health care system (including ICUs) is mandatory since families will become the caring resource for these patients during an often prolonged recovery trajectory. Integration has the capacity to better meet the needs of families and enhance communication. The invitation to participate in care provided a tangible family-centered care approach, however it needed to be initiated by nurses for a number of reasons. Firstly, while

nurses needed to remain in control over their work environment, partnering with families has become a quality of care issue in taking seriously the emotional bonds family members have. Secondly, the ICU was seen by families as the nurses' turf and evidence suggest that even when family members would like to participate in care , they do not necessarily ask to be included (Ågård & Harder 2007). Specific strategies to support nurses in the progressive integration of family members into the adult ICU environment is crucial to the attainment of meaningful family-centered care.

## References

- Adamson H, Murgo M, Boyle M, Kerr S, Crawford M & Elliott D (2004) Memories of intensive care and experiences of survivors of a critical illness: an interview study. *Intensive and Critical Care Nursing* **20**.
- Ågård AS & Harder I (2007) Relatives' experiences in intensive care - Finding a place in a world of uncertainty. *Intensive and Critical Care Nursing* **23**, 170 - 177.
- Ågård AS & Lomborg K (2010) Flexible family visitation in the intensive care units: nurses' decision-making. *Journal of Clinical Nursing* doi: **10.1111/j.1365-2702.2010.03360x**.
- Australian Commission on Safety and Quality in Health Care (2010) Patient centred care: improving quality and safety by focusing care on patients and consumers (Care ACoSaQiH ed.), pp. [www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/36AB39E5379378EBECA5372577B5373001D5379373C5379372B/\\$File/PCCC-DiscussPaper.pdf](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/36AB39E5379378EBECA5372577B5373001D5379373C5379372B/$File/PCCC-DiscussPaper.pdf), accessed 5379319th January, 5372011.
- Bailey J, Sabbagh M, Loisel C, Boileau J & McVey L (2010) Supporting families in ICU: a descriptive correlational study of informational support, anxiety, and satisfaction with care. *Intensive and Critical Care Nursing* **26**, 114 - 122.
- Benner P, Hooper-Kyriakidis P & Stannard D (1999) *Clinical Wisdom and Interventions in Critical Care*. W.B. Saunders Company, Philadelphia.
- Bergbom I (2008) Family centered care across the life continuum *The World of Critical Care Nursing* **6**, 40 - 50.
- Bergbom I & Askwall A (2000) The nearest and dearest: a lifeline for ICU patients. *Intensive and Critical Care Nursing* **16**, 384 - 395.
- Berti D, Ferdinande P & Moons P (2007) Beliefs and attitudes of intensive care nurses towards visits and open visiting policy. *Intensive Care Medicine* **33**, 1060 - 1065.
- Bloor M, Frankland J, Thomas M & Robson K (2001) *Focus Groups in Social Research*. SAGE Publications, London.
- Callery P (1997) Caring for parents of hospitalized children: a hidden area of nursing work. *Journal of Advanced Nursing* **26**, 992 - 998.

- Carey MA (1994) The group effect in focus groups: planning, implementing, and interpreting focus group research. In *Critical Issues in Qualitative Research Methods* (Morse JM ed.). SAGE Publications, Thousand Oaks, pp. 225 - 241, chapter 212.
- Casey A (1993) Development and use of the partnership model of nursing care. In *Advances in Child Health Nursing* (Glasper EA & Tucker A eds.), Harrow, pp. 183 - 193, chapter 114.
- Casey A (1995) Partnership nursing: influences on involvement of informal carers. *Journal of Advanced Nursing* **22**, 1058 - 1062.
- Chaboyer W (2006) Editorial: Intensive care and beyond: improving the transitional experiences of critically ill patients and their families. *Intensive and Critical Care Nursing* **22**, 187 - 193.
- Charmaz K (1990) 'Discovering' chronic illness: using grounded theory. *Social Science & Medicine* **30**, 1161 - 1172.
- Charmaz K (2000) Grounded theory - objectivist and constructivist methods. In *Handbook of Qualitative research*, 2. edition edn (Denzin N & Lincoln Y eds.). SAGE Publications, Thousand Oaks, pp. 509 - 535, chapter 519.
- Charmaz K (2006) *Constructing Grounded Theory - A Practical Guide through Qualitative Analysis*. SAGE Publications, London.
- Coyne I (1995) Partnership in care: parents' views of participation in their hospitalized child's care. *Journal of Clinical Nursing* **4**, 71 - 79.
- Coyne I & Cowley S (2007) Challenging the philosophy of partnership with parents: a grounded theory study. *International Journal of Nursing Studies* **44**, 893 - 904.
- Dahle Olsen K, Dysvik E & Hansen BS (2009) The meaning of family members' presence during intensive care stay: a qualitative study. *Intensive and Critical Care Nursing* **25**, 190 - 198.
- Darbyshire P (1993b) Parents, nurses and paediatric nursing: a critical review. *Journal of Advanced Nursing* **18**, 1670 - 1680.
- Darbyshire P (1994) *Living with a Sick Child in Hospital*. Chapman & Hall, London.
- Eggenberger S & Nelms T (2007) Being family: the family experience when an adult member is hospitalized with a critical illness. *Journal of Clinical Nursing* **16**, 1618 - 1628.
- Engström Å & Söderberg S (2007) Close relatives in intensive care from the perspective of critical care nurses. *Journal of Clinical Nursing* **16**, 1651 - 1659.
- Engström B, Uusitalo A & Engström Å (2010) Relatives' involvement in nursing care: a qualitative study describing critical care nurses' experiences. *Intensive and Critical Care Nursing* doi:10.1016/j.iccn.2010.11.004.
- Garrouste-Orgeas M, Willems V, Timsit J-F, Diaw F, Brochon S, Vesin A, Philippart F, Tabah A, Coquet I, Bruel C, Moulard M-L, Carlet J & Misset B (2010) Opinions of families, staff, and patients about family participation in care in intensive care units. *Journal of Critical Care* **25**, 634 - 640.
- Glaser B & Strauss A (1967) *The Discovery of Grounded Theory*. Aldine DeGruyter, New York.
- Glaser BG (1978) *Theoretical Sensitivity*. The Sociology Press, San Francisco.
- Griffiths R (2010) Intensive care unit-acquired weakness. *Critical Care Medicine* **38**, 779 - 787.
- Hammond F (1995) Involving families in care within the intensive care environment: a descriptive study. *Intensive and Critical Care Nursing* **11**, 256 - 264.
- Haycock-Stuart E, Baggaley S, Kean S & Carson M (2010) Understanding leadership in community nursing in Scotland. *Community Practitioner* **83**, 24 - 28.
- Heimer CA & Staffen LR (1998) *For the Sake of the Children - The Social Organisation of Responsibility in the Hospital and the Home*. University of Chicago Press, Chicago.

- Hunter J, Goddard C, Rothwell M, Ketharaju S & Cooper H (2010) A survey of intensive care unit visiting policies in the United Kingdom. *Anaesthesia* **65**, 1101 - 1105.
- Hupcey J (1999) Looking out for the patient and ourselves - the process of family integration into the ICU. *Journal of Clinical Nursing* **8**, 253 - 262.
- Hupcey J (2000) Feeling safe: the psychosocial needs of ICU patients. *Journal of Nursing Scholarship* **32**, 361 - 367.
- Jones C, Griffiths R & Humphris G (2000) Disturbed memory and amnesia related to intensive care. *Memory* **8**, 79 - 94.
- Kean S (2008) *The emergence of negotiated family care in intensive care*. unpublished Ph.D. Thesis, University of Edinburgh, Edinburgh.
- Kitzinger J (1994) The methodology of Focus Groups: the importance of interaction between research participants *Sociology of Health & Illness* **16**, 103 - 221.
- Lee P (2007) What does partnership in care mean for children's nurses? *Journal of Clinical Nursing* **16**, 518 - 526.
- Leske JS (1998) Acute care and adult family interventions. In *Family Nursing Practice* (Vaughan-Cole B, Johnson MA, Malone J & Walker BL eds.). W.B. Saunders Company, Philadelphia, pp. 163 - 195, chapter 111.
- Maxwell KE, Stuenkel D & Saylor C (2007) Needs of family members of critically ill patients: a comparison of nurse and family perception. *Heart & Lung* **36**, 367 - 376.
- McKiernan M & McCarthy G (2010) Family members' lived experience in the intensive care unit: a phenomenological study. *Intensive and Critical Care Nursing* **26**, 254 - 261.
- Mitchell M & Chaboyer W (2010) Family centred care: a way to connect patients, families and nurses in critical care. *Intensive and Critical Care Nursing* **26**, 154 - 160.
- Mitchell M, Chaboyer W, Burmeister E & Foster M (2009) Positive effects of a nursing intervention on family-centered care in adult critical care. *American Journal of Critical Care* **18**, 543 - 552.
- Mitchell M & Courtney M (2005) An intervention study to improve the transfer of ICU patients to the ward - evaluation by ICU nurses. *Australian Critical Care* **18**, 123 - 128.
- Morgan D (1995) Why things (sometimes) go wrong in Focus Groups. *QUALITATIVE HEALTH RESEARCH* **5**, 516 - 523.
- Morgan DL (1997) *Focus Groups as Qualitative Research*, 2. edition edn. SAGE Publications, Thousand Oaks.
- Paul F & Rattray J (2008) Short - and long-term impact of critical illness on relatives: literature review. *Journal of Advanced Nursing* **62**, 276 - 292.
- Plowright CI (1998) Intensive therapy unit nurses' beliefs about and attitudes towards visiting in three district general hospitals. *Intensive and Critical Care Nursing* **14**, 262 - 270.
- Price A (2004) Intensive care nurses' experiences of assessing and dealing with patients' psychological needs. *Nurse Critical Care* **9**, 134 - 142
- Richmond T, Thompson H, Deatrick J & Kauder D (2000) Journey towards recovery following physical trauma. *Journal of Advanced Nursing* **32**, 1341 - 1347.
- Scottish Government (2010) The healthcare quality strategy for NHSScotland. The Scottish Government, Edinburgh.
- SG (2007) Better Health, Better Care. Scottish Government, Edinburgh.
- Shields L & Tanner A (2004) Pilot study of a tool to investigate perceptions of family-centered care in different settings. *Pediatric Nursing* **30**, 189 - 197.

- Simpson T (1991) The family as a source of support for the critically ill adult. *AACN Clinical Issues Critical Care Nursing* **2**, 229 - 235.
- Spreen A & Schuurmans M (2010) Visiting policies in the adult intensive care units: a complete survey of Dutch ICUs. *Intensive and Critical Care Nursing* doi: **10.1016/j.iccn.2010.10.002**.
- Stayt L (2007) Nurses' experiences of caring for families with relatives in intensive care units. *Journal of Advanced Nursing* **57**, 623 - 630.
- VanHorn E & Kautz D (2007) Promotion of family integrity in the acute care setting. *Dimensions of Critical Care Nursing* **26**, 101 - 107.
- Walters AJ (1995) A hermeneutic study of the experiences of relatives of critically ill patients. *Journal of Advanced Nursing* **22**, 996 - 1005.
- Whitecomb J, Roy D & Blackman VS (2010) Evidence-based practice in military intensive care unit family visitation. *Nursing Research* **59**, S32 - 39.
- Williams C (2005) The identification of family members' contribution to patients' care in the intensive care unit: a naturalistic inquiry. *Nursing in Critical Care* **10**, 6 - 14.
- Wright LM & Leahey M (2005) *Nurses and Families - A Guide to Family Assessment and Intervention*, 4th edition edn. F.A. Davis Company, Philadelphia.

Table 1: Overview of participating UK ICU nurses

ICU Nurse	Age	Lengths of ICU Experience	Focus Group Code	Position
1	41	19 years	G	Senior/ charge nurse
2	39	18 years	G	Senior/ charge nurse
3	32	10 years	G	Senior/ charge nurse
4	48	20 years	F	Senior nurse
5	40	16 years	F	Senior nurse
6	33	10 years	F	Senior nurse
7	41	13 years	E	Senior staff nurse
8	35	5 years	E	Senior staff nurse
9	33	6.5 years	E	Senior staff nurse
10	28	5.5 years	E	Senior staff nurse
11	24	4 years	E	Senior staff nurse
12	41	10 years	D	Staff nurse
13	41	7 months	D	Staff nurse
14	41	5 months	D	Staff nurse
15	30	5 months	D	Staff nurse
16	26	1.5 years	D	Staff nurse
17	50	20 years	E&D	Mixed FG with both

				staff and senior staff nurses
18	34	11 years	E&D	Mixed FG with both staff and senior staff nurses
19	29	2.5 years	E&D	Mixed FG with both staff and senior staff nurses
20	25	1 year	E&D	Mixed FG with both staff and senior staff nurses

Figure 1

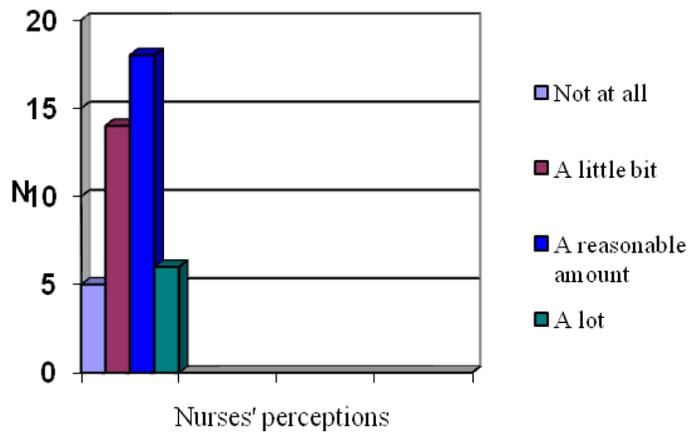


Figure 1- The extent to which nurses' perceptions of the value of involving family members in their relative's care changed since being involved in the project (n=43)

Figure 2

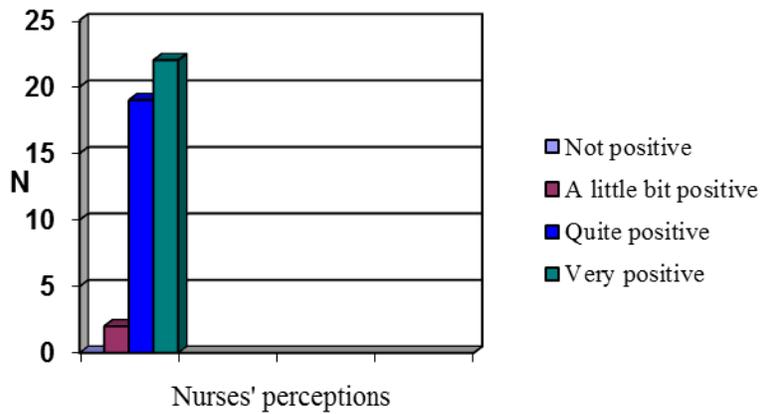


Figure 2 - Nurses' perceptions on the value of involving family in their relative's care (n=43).

Figure 3

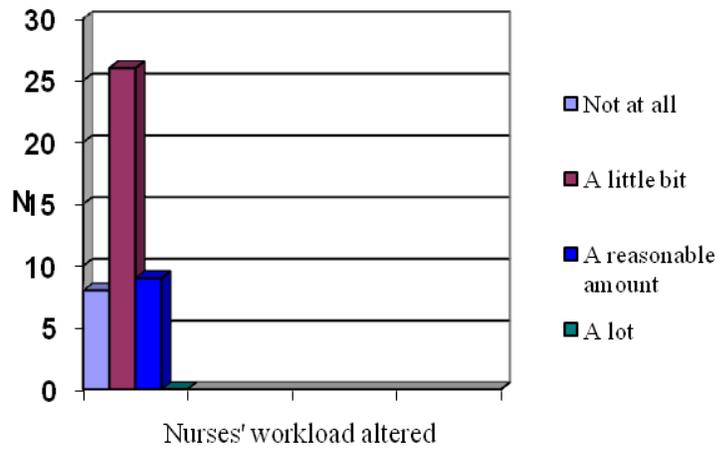


Figure 3 - The extent to which nurses' workload altered as a result of the family members' helping with care.