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**Giles, T.M., de Lacey, S.L. and Muir-Cochrane, E.C. (2016). Factors influencing decision-making around family presence during resuscitation: a grounded theory study. *Journal of Advanced Nursing*, 72(11) pp. 2706-2717.**

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## **ABSTRACT**

**Aim.** To examine factors impacting family presence during resuscitation practices in the acute care setting.

**Background.** Family presence during resuscitation was introduced in the 1980s so family members/significant others could be with their loved ones during life-threatening events. Evidence demonstrates important benefits; yet despite growing support from the public and endorsement from professional groups, family presence is practiced inconsistently and rationales for poor uptake are unclear.

**Design.** Constructivist grounded theory design.

**Methods.** Twenty-five health professionals, family members and patients informed the study. In-depth interviews were undertaken between October 2013-November 2014 to interpret and explain their meanings and actions when deciding whether to practice or participate in FPDR.

**Findings.** The Social Construction of Conditional Permission explains the social processes at work when deciding to adopt or reject family presence during resuscitation. These processes included claiming ownership, prioritising preferences and rights, assessing suitability, setting boundaries and protecting others/self. In the absence of formal policies, decision-making was influenced primarily by peoples' values, preferences and pre-existing expectations around societal roles and associated status between health professionals and consumers. As a result, practices were sporadic, inconsistent and often paternalistic rather than collaborative.

**Conclusion.** An increased awareness of the important benefits of family presence and the implementation of clinical protocols are recommended as an important starting point to address current variations and inconsistencies in practice. These measures would ensure

future practice is guided by evidence and standards for health consumer safety and welfare rather than personal values and preferences of the individuals 'in charge' of permissions.

**KEYWORDS:** nursing, acute care, cardiopulmonary resuscitation, family presence, decision making, grounded theory, qualitative research.

## SUMMARY STATEMENT

### Why is this research needed?

- More than 90% of patients who suffer sudden cardiac arrest die; often while separated from their family and significant others and thus jeopardising their opportunity for a 'good' death.
- Family presence during resuscitation has demonstrated important benefits, is endorsed by professional bodies and is increasingly desired by the public. Yet support from health professionals varies considerably and practice is inconsistent, leading to inequitable healthcare.
- Previous research has highlighted attitudes and beliefs toward family presence during resuscitation. However, no previous studies have provided an in-depth examination of factors impacting the decision to adopt or reject the practice.

### What are the key findings?

- The decision to practice or participate in family presence during resuscitation was influenced primarily by peoples' personal values and preferences and their pre-existing role and associated status expectations, in the absence of clinical protocols or guidelines.
- *Conditional permission* was controlled predominantly by health professionals who authoritatively 'allowed' or 'denied' family presence during resuscitation with minimal input from family members and significant others.
- This study highlighted how socially constructed meanings and actions around family presence during resuscitation can become fixed social norms and how these meaning

and actions can change to meet the needs of an evolving society that values family-centred emergency resuscitative care.

**How should the findings be used to influence policy/practice/research/education?**

- Education and awareness about the important benefits of supported family presence during resuscitation and addressing unsubstantiated fears can shift attitudes. They are important first steps toward clinical practices that are based on evidence rather than personal, value-laden preferences.
- Exposure through role modelling and simulated resuscitation training that includes family presence during resuscitation would prepare staff with performance anxieties to work competently and confidently under family observation.
- The widespread introduction of standardised guidelines would reduce the considerable variations and inconsistencies evident in current family presence practices and promote equitable, evidence-based standards for consumer safety and welfare.

## **INTRODUCTION**

Sudden cardiac arrest is the leading cause of death worldwide, accounting for more than half of all deaths from cardiovascular disease (Adabag *et al.* 2010). In Australia and the United Kingdom, around 30,000 people suffer cardiac arrest each year (St John Ambulance Australia *et al.* 2012, British Heart Foundation 2014), while in the USA, more than 320,000 people are affected annually (Sudden Cardiac Arrest Foundation 2015).

Cardiopulmonary resuscitation (CPR) is the standard response to cardiac arrest; yet despite ongoing research, technological advances and widespread adoption of CPR (Nichol *et al.* 2008; Sasson *et al.* 2010), survival rates have remained consistently low (Sasson *et al.* 2010). Recent systematic reviews report survival-to-hospital-discharge rates of 7.6% for adults (Sasson *et al.* 2010) and 7% for adult/paediatric patients (Berdowski *et al.* 2010).

CPR saves many lives and it is not the intention of this paper to discourage it. However, it is important to acknowledge more than 90% of patients do not survive resuscitation. We support Timmerman's (2005) call to re-contextualise CPR from its current 'high tech' status and combine advanced technologies with a family-centred approach to care. Like Tercier (2008), we believe a 'good' sudden death involves family in the last minutes of life. Yet, many family members are separated from their potentially dying loved ones during resuscitation events (Taraghi *et al.* 2014, Soleimanpour *et al.* 2015). This paper provides the first in-depth examination of decision-making around family presence during resuscitation (FPDR) and offers an enhanced understanding of rationales for practice.

### **Background**

In recent decades, health professionals have recognised the need for a more family-centred approach to resuscitative care. This recognition facilitated the emergence of FPDR, where

family/significant others are located where they can see and sometimes touch the patient during resuscitation (Chapman *et al.* 2014, Lederman *et al.* 2014). The origins of FPDR can be traced to the Foote Hospital in the United States (Doyle *et al.* 1987), where health professionals were forced to question their long-standing policy of excluding family after several people demanded FPDR. Despite initial reservations from staff (Post 1989), ongoing feedback from staff and family in response to FPDR was positive (Hanson & Strawser 1992).

Since that time, FPDR has attracted widespread international debate. Evidence supports important benefits for family, including facilitating closure and grieving (Compton *et al.* 2011, Pasquale *et al.* 2011, Jabre *et al.* 2014) and reducing incidences of post-traumatic stress (Jabre *et al.* 2014). FPDR has been endorsed by professional bodies including the Australian Resuscitation Council (ARC 2012), European Resuscitation Council (Baskett *et al.* 2005) and American Heart Association (Morrison *et al.* 2010); and has increasing support from the public (Dwyer 2015). Yet, views among health professionals remain divided - with support for the practice ranging from 3% to 98% in attitudinal surveys (Sachetti *et al.* 2003, McMahon-Parkes *et al.* 2009).

Family presence during resuscitation is not practiced widely or consistently in many countries and available research is significantly skewed toward quantitative aims, limiting our understanding of current practices. While the literature has extensively explored general attitudes and beliefs about FPDR (for example, see Demir 2008, Fischer *et al.* 2008, McClement *et al.* 2009, Axelsson *et al.* 2010, Leung & Chow 2012, Taraghi *et al.* 2014, Tudor *et al.* 2014), it has not examined how and why decisions are made to adopt or reject the practice. An enhanced understanding of practice rationales and motivators will help inform the often contentious debate, identify sound recommendations for future policy and practice and decrease the inconsistencies evident in current FPDR practices.



## **THE STUDY**

### **Aim**

The aim of this study was to explore factors and perceptions impacting decision-making around family presence during resuscitation in the acute care setting.

### **Design**

Constructivist grounded theory methodology (GTM: Charmaz 2006, 2014) was used to examine peoples' experiences when faced with a decision to practice/participate in FPDR. GTM aims to understand and explain behaviour and meanings participants give their experiences in a particular setting (Glaser & Strauss 1967). We subscribed to Charmaz's (2014) definition of theory which emphasises abstract, interpretivist theoretical understanding. GTM allowed the researchers to move beyond description to generate a conceptual theory that explains contextual FPDR practices from the perspective of the people involved (Birks & Mills 2011). Our constructivist GTM approach has been described in detail elsewhere (Giles *et al.* 2016).

### **Participants**

Three types of participant were invited into the study:

1. Health professionals (registered nurses, doctors, paramedics) who had performed CPR in the direct/indirect presence of family
2. Family members present in the room during CPR or wanting presence.
3. Patients who underwent CPR with family present or wanting presence.

Purposive sampling was initially used to locate people who had experienced FPDR in any acute healthcare setting to explore a diverse set of experiences and contexts related to the central phenomenon (Glaser & Strauss 1967). Family and patient participants contacted the principal researcher (TG) as a result of three radio interviews. Registered Nurse participants were recruited via the College of Emergency Nursing Australasia (e-mail out), the Australian Nursing and Midwifery Federation Journal (advertisement) and via snowball sampling. Doctor and paramedic participants were recruited through professional contacts. Twenty-five people agreed to participate (see Table 1). Demographic data were de-identified to protect individuals.

### **Data collection**

Interviews were conducted, digitally recorded and transcribed by the principal researcher between October 2013 and November 2014. They included 25 initial face-to-face and phone interviews and 3 follow-up face-to-face interviews (with Carol, Anthony and June); all lasting between 25 - 65 minutes. Participants were asked about organisational and social practices, beliefs about those practices and their individual participation (Charmaz 2014). Interview conversations were viewed as a co-construction of knowledge and experience and aimed to interpret assumptions and implicit meanings to avoid imposing taken-for-granted meanings on the data (Charmaz 2014). Each interview began with a demographic questionnaire to establish social, geographical and cultural contexts. A flexible interview guide was then used to explore individual experiences (see Giles *et al.* 2016).

### **Ethical Considerations**

Ethical approval was gained from the relevant social and behavioural university ethics committee and relevant hospital and professional organisation ethics committees. Participants

**Table 1: Participant demographics**

	<b>Pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Type of participant and setting where resus occurred</b>	<b>Time since latest resus experience</b>
1	Jackie	F	25	Registered Nurse – Emergency Department Major Metropolitan Hospital	1 month
2	Elizabeth	F	58	Registered Nurse - Rural Hospital	unknown
3	Trevor	M	69	Family Member (Husband)	5 weeks
4	Dana	F	63	Registered Nurse /Registered Midwife - Major Tertiary Hospital	< 1 week
5	Mary *	F	64	Family Member (Wife)	6 years
6	Frank#	M	62	Resuscitation Patient	6 years
7	Sally**	F	59	Family Member (Sister) & Registered Nurse Major Rural Hospital	< 1 year
8	Rosy	F	57	Family Member (Daughter)	40 years
9	Mandy	F	45	Registered Nurse - Rural Hospital	3 years
10	Dooley	M	61	Family Member (Father)	21 years
11	Anthony	M	61	Doctor – Intensive Care Unit Major Metropolitan Hospital	ongoing
12	Lauren	F	41	Doctor - Emergency Department Major Metropolitan Hospital	2 weeks
13	Darren	M	55	Nurse Practitioner/RN – Emergency Department Major Metro Hospital	Ongoing
14	June	F	56	Registered Nurse - Major Metropolitan Hospital	20 years
15	Gemma	F	48	Registered Nurse/Registered Midwife/Nurse Educator – Regional Hospital	6 years
16	Grace	F	32	Registered Nurse – Emergency Department Major Metropolitan Hospital	< 1 year
17	Michael	M	47	Registered Nurse – Emergency Department Major Metropolitan Hospital	< 1 year
18	Bella	F	31	Registered Nurse/Registered Midwife – Regional / Rural Hospital	< 1 year
19	Jane	F	31	Registered Nurse – Emergency Department Suburban Metropolitan Hospital	2 months
20	Katherine	F	32	Registered Nurse – Emergency Department Major Metropolitan Hospital	< 1 year
21	Neil	M	50	Nurse Practitioner/RN – Emergency Department Major Metro Hospital	< 1 year
22	Helen	F	60	Paramedic - Major Regional Area	< 1 year
23	Sarah	F	30	Paramedic - Major Metropolitan Area	< 1 year
24	Carol***	F	49	Family Member (Mother) & Registered Nurse Major Metro Hospital	5 years
25	Matt	M	35	Paramedic - Major Metropolitan Area	< 1 year

TABLE KEY: \*Mary is a registered nurse but recounted an experience of being a family member only; \*\*Sally recounted her experiences as a family member and as a Registered Nurse; \*\*\*Carol recounted her experiences as a family member and as a registered nurse; # Frank and Mary are a married couple who were interviewed together. Resus = cardiopulmonary resuscitation

were provided with a detailed information sheet and signed consent was obtained prior to them taking part in the study. Participants were offered a free counselling service in case they experienced distress during/after sharing their experiences. To our knowledge, no participants required this service.

### **Data analysis and theory construction**

Data analysis and theory construction included the following processes; initial and focused coding, constant comparative analysis, theoretical sensitivity and reflexivity, memo writing, theoretical sampling, category development and refinement, theoretical saturation, emergence of the core category, theoretical sorting, integration and construction of the substantive grounded theory (Charmaz 2014). These methodological processes have been reported in detail elsewhere (Giles *et al.* 2016). Our use of the literature during this GTM study has also been reported previously (Giles *et al.* 2013).

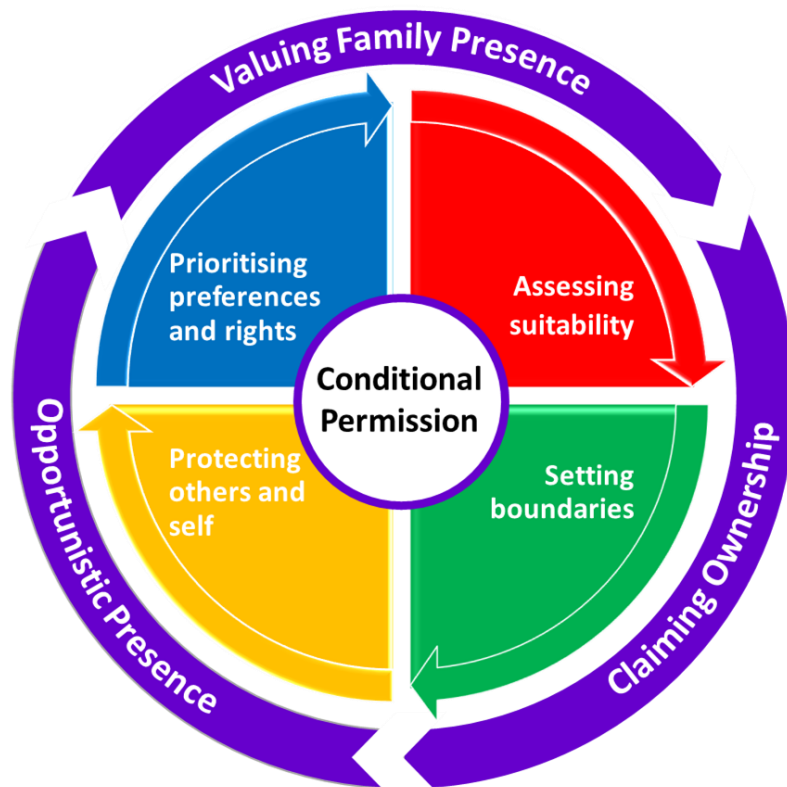
### **Study rigour**

Charmaz's (2014, pp. 337 - 338) criteria for establishing rigour in GTM research were applied to evaluate the grounded theory. *Credibility* was established by maintaining comprehensive audit trails and *intimate familiarity* was gained through previous knowledge/experience, multiple in-depth interviews and the constant comparative method. *Originality* was achieved by offering insights that both support and build on the current body of knowledge. *Resonance* was achieved by clarifying taken-for-granted meanings and beliefs and offering participants deeper insights about their lives and worlds. Participants were sent preliminary findings and reported them as relevant to themselves and others and many thanked the researchers for raising awareness about FPDR. The criterion of *usefulness* was achieved because findings provide pragmatic implications to help formulate FPDR

guidelines. The grounded theory could also be applied or built on in future decision-making research in different healthcare contexts.

## FINDINGS

The grounded theory - *The Social Construction of Conditional Permission* - explains the social processes at work when participants were faced with a decision to practice/participate in FPDR. A conceptual model (Figure 1) was constructed to illustrate the theory and its inter-related processes enacted from the moment a patient required resuscitation in the direct/indirect presence of family. Each of these processes is detailed in the following sections. Verbatim quotes are included to substantiate coding and illustrate the grounded theory (Birks & Mills 2011).



**Figure 1: Conceptual model**  
**The Social Construction of Conditional Permission**  
**A grounded theory of Family Presence during Resuscitation**

## Claiming ownership

During each resuscitation event, health professionals and family members sought to claim ownership of the patient, the space and the resuscitation act. To own a person is of course an infringement on their right to self-determination. However, the *concept* of patient ownership can influence professional-consumer relationships and no other word sufficiently captured this major process. Patient ownership has been defined previously as health professionals knowing all relevant information about a patient and doing everything necessary for them (Van Eaton *et al.* 2005). This sense of responsibility often included an instinct that patients *belong* to professionals responsible for their care (Yedidia *et al.* 1993). In the current study, claiming ownership of the patient referred to a person/group believing they had the most significant right to be with the patient and to make decisions on their behalf.

Due to their pre-existing legitimate power and authority (see Joseph-Williams *et al.* 2014), health professionals were commonly able to claim ownership with little resistance from family and were therefore in a position to authoritatively ‘allow’ or ‘deny’ FPDR. These ownership claims began as soon as the patient arrived at hospital. Many family members were directed into a waiting room by hospital staff and paramedics, who used language such as ‘sacrosanct area’ and ‘golden resus doors’ to exemplify a sequestered, ‘staff only’ space. A double standard was identified by participants, where family were present in the resuscitation space during a pre-hospital arrest but excluded in the hospital setting. Some participants, like Bella, contemplated how this exclusion could devalue the family’s relationship with the patient and confuse them with contradictory permissions.

‘Nine times out of ten, family members are the ones there when their loved one collapses, or they find their child drowned in a bath tub or they start resuscitating at home...and then all of a sudden they get to hospital and get told, ‘no you can’t come

in.’ I think that’s really rude and shows a lack of understanding on our behalf...’

(Bella: RN/RM)

### **Opportunistic presence**

Some family members managed to get through what some participants referred to as the ‘golden resus doors’ inadvertently (i.e. following paramedics post ambulance ride-a-long), while others made a deliberate decision to enter the room uninvited. For example, Carol (FM, Mother & RN) recounted that ‘we just sort of barged in...and when I said something to my husband about that he said, ‘well, it’s my boy and no-one’s keeping me out.’

Family who were already in the room when the resuscitation began were more likely to be permitted to stay. If asked to leave, most family members complied without question but described a sense of fear and confusion if they did not receive adequate explanations or support. In rare situations where family refused to leave, staff were too intimidated or lacked sufficient time to reinforce their requests and instead continued working with an uninvited/unwanted observer.

In contrast with the implied or inadvertent permission outlined above, some staff actively invited family to stay if they were already present. This most commonly occurred if the patient was a child, due to their nurturing and dependant relationship and because most parents accompanied their child to hospital. Furthermore, parental presence during resuscitation of an infant/child was seen as a ‘standard practice’ that was expected and encouraged in a way that FPDR for an adult patient was not.

### **Valuing family presence**

There was a strong link between *valuing* and *practicing* FPDR. People who did not value FPDR were more likely to focus on perceived risks and barriers and use them as rationales to exclude family. Whereas people who valued FPDR were more likely to cite multiple benefits and fewer risks and more likely to overcome any barriers;

‘I guess it depends on how much you value the presence of the family member. How important is it? We are just passing briefly through these people’s lives and it’s the person that’s been with them all their life, often for many years, who has far more rights. We’re really just a team, trying to stave off death. Sometimes we win, sometimes we don’t. But we don’t want to leave any more debris than we have to...I think our role is not only to resuscitate the person but to help the family through that.’

(Darren: RN/NP)

Commonly cited benefits were that family could know/see everything possible was done for the patient, could prepare for impending death and that FPDR facilitated grieving and closure and improved end-of-life care for patients and their families.

### **Prioritising preferences and rights**

Prioritisation of individual preferences and rights was undertaken by family members and health professionals, but mostly the latter due to their previously successful ownership claims. The subjective nature of these prioritisations or judgements caused a wide variation in practices in the absence of formal guidelines. Health professionals who valued FPDR were able to create a balance between prioritising patient care and supporting family to ensure the resuscitation was unimpeded. Personal preferences impacted individual FPDR practices and the way individuals perceived the preferences and rights of others.



‘It probably depends on your own belief set and your own professional clinical experience. If it’s your belief that if you were the patient you’d want someone there, or if you were the family member you’d wanna be there for your family member, then I think that you would obviously try to overcome the barriers to implement [FPDR] for someone else.’ (Jane: RN)

Some staff prioritised their own needs and excluded family based on a personal preference to not be observed. Health professionals who usually denied FPDR rationalised their preference as ‘knowing what’s best’ for patients and families. They spoke about wanting to protect consumers from perceived risks. However, some health professionals questioned a staff culture of ‘knowing what’s best’ in the absence of family input;

‘I wonder whether we as staff are actually impeaching (sic) that onto the patient when we don’t even know what they want. We say we’re protecting their privacy, but you don’t know. You haven’t asked the family. You might find the family know what the patient’s wishes are. Or they’ve got power of attorney...’ (June: RN)

Health professionals considered team consensus an important determinant of conditional permission. However, some described heated debates, with the most assertive person (usually the most senior doctor) dictating the level of presence. Staff-to-staff conflicts were deemed detrimental due to potential compromises to patient care and junior staff would therefore acquiesce to seniors maintain a facade of team harmony.

When deciding to practice/participate in FPDR, individuals made judgements about who would benefit. Some stressed the importance of FPDR to comfort the patient and ensure they were not alone when they died, but many participants believed FPDR was *most* beneficial for the family. Staff emphasised that, because the majority of resuscitation events are

unsuccessful, FPDR should be about supporting the people left behind. When sharing preferences for their *own* resuscitation, most participants offered a philosophical argument that (as the patient) their preferences and rights were less important than those of their family.

### **Assessing suitability**

Participants assessed suitability of the people, the space and resuscitation context to determine the level of FPDR implemented. Assessing people was undertaken by staff and family in various contexts. This assessment was performed on a case-by-case basis with the intention of keeping people safe and ensuring staff and family were able to cope with all that FPDR entailed. Coping mechanisms of family who were/wanted to be present were assessed by health professionals, by other family and by the family member themselves. Health professionals performed this assessment in various ways; including gauging the family members' initial reaction to being invited into the room;

‘I would ask them, would you like to come in? And if they looked shocked and horrified at the very thought then that’s fine - we’ll just back away from that. If they look as though they’re considering it, then I’d go on and explain a bit more. So I guess I would assess their initial response.’ (Lauren: Doctor)

One of the most common ‘risks’ cited by staff was that family would not cope with resuscitation scenes and this was sometimes used as a reason to deny FPDR. However, most participants stressed that family were best placed to know their own coping abilities and should therefore (in theory) be responsible for choosing their preferred level of FPDR. When the family member was a child, there were inconsistent recommendations. Some participants preferred the child’s family to decide if they should be present, while others gave varying opinions based on their personal beliefs and preferences.

Assessing suitability also included staff competence and confidence. Some were comfortable being observed during any procedure. Others worried about performance anxiety and suggested excluding family to minimise staff discomfort and potential poor performance. However, they added that excluding family should not be a first resort in response to staff discomfort and that focus should instead be placed on increasing staff competence and confidence.

Health professionals assessed the resuscitation *space* mostly in terms of safety hazards (i.e. defibrillator) and having enough room to work unimpeded. Similarly, family spoke about not wanting to be in the way. Assessing the resuscitation *context* involved considering the circumstances surrounding the resuscitation (i.e. severity of patient injuries/prognosis) and the nature of resuscitation interventions (i.e. invasiveness). At times, family were excluded if the patient's condition appeared reversible; with staff wanting to focus on the patient in a series of life-saving, often invasive interventions. However, if the prognosis was considered poor, staff considered bringing family in to be with the patient just before or after they died.

### **Setting boundaries**

Setting boundaries involved health professionals imposing a series of conditions prior to and during implementation of FPDR. These boundaries were variable and commonly dependant on personal preferences. Outcomes from 'assessing suitability' determined the type of boundaries set and the level of FPDR implemented. For example, staff set boundaries around being able to ask family to leave for certain procedures, being able to delay family presence until staff were ready or until family were calm, or until staff believed the patient's prognosis was suitable for presence.

Health professionals also stressed the need for a dedicated support person to offer choices about the type and level of FPDR, to adequately prepare family, to explain what was happening and support them as the resuscitation progressed. Some healthcare settings in the current study provided a dedicated family support person as part of their standard (yet informal) practice. However the nature of this role varied widely; i.e. undertaken by junior staff, the scribe nurse or staff from another department. Ideally, this role was performed by senior staff who could provide competent explanations;

‘I ask them first, ‘do you want to go in?’ I explain what they might see while they’re in there...people will say ‘oh I don’t want to go in’ or ‘I definitely want to go in.’ Then I’ll take, normally only one or two of the closest relatives in and straight away I explain what they’re seeing. There’s that person pushing on their chest and that’s making their blood pump around their body and they’ve got a tube in their mouth and we’re breathing for them...I explain what all the lines are, who different people are, what they’re doing. And then I ask them, do you have any questions...and I try to stay with them as much as I can.’ (Grace: RN)

Other important boundaries were minimising disruptions and being able to remove disruptive family members from the room. However, they were typically calm and rarely needed to be removed.

### **Protecting others and self**

Potential/perceived risks were minimised or overcome by some health professionals while being used by others as justification to deny FPDR. Health professionals wanted to protect family from the emotional and psychological impact of observing potentially distressing resuscitation scenes. However, while there was a legitimate need to protect *some* family

members - most did not want or need this protection. Importantly, no family members regretted being present and most participants wanted FPDR for themselves or their family in the future. While some health professionals initially spoke about wanting to protect *others*, on deeper examination they appeared to be concerned with protecting *themselves* from various performance anxieties. Beyond their concerns about being judged was a fear of damaging their professional identify. Some health professionals were concerned about communication limitations (i.e. not being able to speak freely or use black humour) impacting their performance. However, most claimed their performance was not adversely affected and some went further to claim staff were often *more* professional in the presence of family and strove to improve their confidence and competence.

## **DISCUSSION**

This grounded theory provides an interpretive understanding of peoples' meanings and actions in relation to FPDR. The social construction of conditional permission was influenced by people's values and preferences, their previous experiences and the pre-existing role and associated status expectations of individuals and societies (i.e. health consumers acquiescing to health professionals). Conditional permission was impacted most by the extent FPDR was valued by the individuals and groups who claimed control of permissions.

People involved in a resuscitation event made a series of value-laden judgements to determine the level of FPDR implemented. We noted Frick's (2009, p. 51) definition of values as: 'motivated preferences [or] conceptions of what is desirable, in personal or collective terms, that influences the selection of available modes, means and ends of action.' Consequently, we defined value-laden judgements as decisions that were influenced by a person's inherent beliefs and preferences and the extent to which they valued FPDR.

The value-laden nature of clinical decision-making has been discussed extensively in the literature (see Nelson 2004, Johnson *et al.* 2011, Goldenberg 2013) and the accuracy of these subjective judgements has been questioned by health professionals (Oberle & Hughes 2001). However, value-laden decision-making has not been previously discussed in relation to FPDR. We believe a reliance on value-laden judgements to guide practice in the absence of structured protocols offers an explanation for the wide variations and inconsistencies evident in this study and the wider literature. During time-pressured resuscitation events, decisions to practice/participate in FPDR appear to be made unconsciously - based on previous experiences, preferences, attitudes and setting norms.

Health professionals in the current study noted that new staff usually 'joined in' with setting norms to be accepted into the group. Others lamented that setting norms were almost impossible to alter, particularly if FPDR was not currently practiced. However, it is important to understand that a seemingly fixed setting norm only appears that way because the everyday actions of health professionals are interpreted and acted on in the group to construct that observed stability (Blumer 1969). If a norm becomes re-interpreted (i.e. questioned) individuals and groups may change their attitudes and subsequent actions.

A setting norm shared by almost all health professional participants was the acceptance and even expectation of FPDR if the patient was a child; a finding that has been reported previously (Mortelmans *et al.* 2010, Chapman *et al.* 2014). This pervasive support for parental presence during resuscitation could be explained by the nurturing and dependant relationship between parent and child. A further explanation is the widespread adoption of family-centred practices over the past three decades and the realisation that excluding parents during hospitalisation of a child is detrimental to their well-being (Shields 2010, Zhou *et al.* 2012). However, if health professionals are willing and able to overcome personal and

organisational barriers to facilitate parental presence during resuscitation, we must ask why some are reluctant to do the same for an adult patient whose family wishes to be present. We believe the subjective nature of some FPDR practices in the absence of structured guidelines violates the core principles of evidence-based practice and family-centred care and potentially denies patients/families a ‘good death’ if the resuscitation is unsuccessful.

This study highlighted another issue not previously discussed in the literature – the age limit of family members present during resuscitation. Determining an appropriate age for FPDR if the family member is a child is complex and requires a collaborative approach to decision-making. Insights can be drawn from literature surrounding child attendance at funerals.

According to Doka (2000) there is no ‘correct’ age at which children should attend funerals. Instead, cognitive and emotional development is viewed as a better measure of a child’s ability to cope with death and grief than chronological age (Doka 2000). Consideration must also be given to the child’s preference. For example, Søfting *et al.* (2015) interviewed eleven 7-12 year olds who had suffered the loss of a parent or sibling. Most children wanted to see the deceased person and all took part in the wake/funeral. By being included, the children were given the opportunity to ‘see for themselves’, which allowed them to understand and accept the reality of the loss and say their goodbyes. Findings from the current study together with the literature outlined above support an informed assessment by family and health professionals about the benefits and risks of FPDR for children. This should be undertaken with careful consideration of the child’s cognitive and emotional development, their ability to cope and their own personal, informed preferences.

### **Implications for education, practice, policy and research**

Opportunistic presence was an important facilitator for FPDR and demonstrated how attitudes and practices could be influenced through exposure and role modelling. Health

professionals who had never practiced (or even considered) FPDR often become more supportive following opportunistic presence. Education and awareness about FPDR and addressing unsubstantiated fears is an important first step to ensure clinical practice is based on evidence rather than personal preferences.

FPDR requires health professionals to combine advanced technical skills with empathy to provide effective and compassionate family-centred care. The addition of FPDR simulation training to current resuscitation training could prepare staff to work competently and confidently under observation while supporting family members. Evidence from this study and the wider research highlights the importance of a dedicated support role (Porter *et al.* 2015). This current study further suggests that practicing FPDR without a support person could be harmful. There needs to be an increased focus on the implementation and evaluation of evidence-based FPDR guidelines that include a dedicated family support person.

We believe segregation of family from their critically ill loved ones contravenes core family-centred care principles and denies patients and their families the opportunity for a ‘good death’. In light of low survival rates, family-centred end-of-life care should be considered during every resuscitation event. Offering flexible options and supporting individual, informed choices around FPDR would promote these aims. The widespread introduction of standardised guidelines would be an effective starting point to ensure that clinical practice is guided by evidence-based standards for consumer safety and welfare.

### **Strengths and limitations**

The systematic application of GTM processes during this research ensured appropriate rigour of the theory against established criteria. Participants shared experiences from a variety of healthcare settings in five different Australian states, contributing rich, varied data. The



theory may be applicable to experiences in different countries and contexts and is general enough to have a wide reach; for example, when considering how conditional permission is constructed and applied in other health-related contexts such as family presence during invasive procedures. The moderate sample size limits claims and recommendations.

However, theoretical saturation was achieved (see Giles *et al.* 2016) and the study met Charmaz's (2014) recommendation of 25 interviews for small studies making modest claims.

In-depth interviews were used as the primary method of data generation. Observational data may have strengthened the final theory; however, the study met Charmaz's (2014, p. 33) criteria for 'rich and sufficient data' which included a wide range of participant experiences, examination of hidden meanings, multiple views of participants' range of actions and the ability to make comparisons between the data to generate and inform conceptualisation of the final theory.

While every effort was made to recruit adequate numbers of all three participant types, ratios were skewed toward registered nurses. This may reflect a lower level of import placed on FPDR by doctors; a view which is supported by the literature (Zavotsky *et al.* 2014, Porter *et al.* 2015). Low survival rates made recruitment of resuscitation patients difficult, something that has also been noted previously (Mortelmans *et al.* 2010). Family were also difficult to recruit due to difficulties with hospital gatekeepers/ethics committees. However, inclusion of the often-missing family voice provided a vital addition to the theory.

## **CONCLUSION**

Sudden cardiac arrest impacts thousands of people every year and most of those people die – often separated from their family/significant others. FPDR was introduced so family could be with their loved ones at one of their most significant life events and has been practiced

successfully in some settings for decades. This research has identified the subjective and sporadic nature of FPDR practices in an Australian context. Unique to this study was an enhanced understanding of rationales for practice - which were commonly based on personal preferences, past experiences, societal role expectations and the inherent value placed on FPDR. This study highlighted how socially constructed meanings and actions can become fixed as part of our social norms and how these meaning and actions can change to meet the needs of an evolving society that values family-centred care. More specifically, this study identified that awareness, exposure and education are vital to socially constructed changes around FPDR. Excluding family from resuscitation events separates them from their loved ones at one of the most important periods of their life. A holistic approach to emergency resuscitative events is needed that combines advanced technologies with family-centred care to ensure clinical practice is guided by standards for consumer safety and welfare rather than by the personal values and preferences of individuals 'in charge' of permissions.

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