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Breaking bad news and managing family during an out-of-hospital cardiac arrest

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Abstract

The management of family during out-of-hospital cardiac arrests and death notification to the family of the deceased in the out-of-hospital setting are topics that are poorly evidenced. Two focus groups consisting of six participants in each were conducted, discussing the two subjects. The results suggest that paramedics prefer family not to be present in the room for a number of reasons and that they don't feel sufficiently trained by their paramedic courses in order to manage family during resuscitation or breaking bad news. The study highlighted a need for more research on both subjects.

Key words: Breaking bad news Grieving process Resuscitation Pre-hospital Family presence Relatives Out-of-hospital cardiac arrest (OHCA)

There are approximately 60 000 out-of-hospital cardiac arrests (OHCAs) in England each year (Resuscitation Council UK (RCUK), 2014). Resuscitation is attempted in approximately 30 000 of these patients and current survival-to-discharge statistics show rates of 8.4% (Perkins et al, 2015). The RCUK (2014) reported that 80% of OHCAs occur in the patient's home, with the remaining 20% in a public place. These figures determine that there are approximately 24 000 resuscitation attempts made each year by the emergency services in the family home of patients. Management of family during a resuscitation attempt and breaking bad news (BBN) of a futile outcome are two well-evidenced topics within the hospital environment. However, there is currently a distinct lack of research around these topics in the out-of-hospital setting. Family presence during resuscitation (FPDR) is a controversial subject that is well-evidenced in the emergency department (ED).

Current research suggests that clinician preference regarding family presence is currently variable and inconclusive (Halm et al, 2005). Some clinicians prefer relatives not to be present during resuscitation owing to clinician anxiety, concerns for the welfare of the family and potential medicolegal issues (Redley and Hood, 1996; Mitchell and Lynch, 1997; Helmer et al, 2000; McClenathan et al, 2002; Porter et al, 2014). Ong et al (2004) found that 75% of physicians and 78% of nurses within the ED disagree with FPDR. On the contrary, there is also evidence that suggests health professionals are in favour of FPDR (Back and Rooke, 1994; Chalk, 1995; Grice et al, 2003; Mangurten et al, 2005) and it is currently a practice which is allowed in 78% of EDs across the UK (Booth et al, 2004). Despite the lack of consensus across the literature regarding clinician preference, there is clarity regarding the wishes of family members. It has been found that 80% of family members would like to have been present had the option been offered to them (Meyers et al, 2000). Barrett and Wallis (1998) found that only 11% of the family members included in their study were offered the chance to be present; yet 62% of the family members would have chosen to be present had they been given the opportunity. A systematic review conducted by Nevins (2016) found that relatives want to remain connected to their loved one and be present throughout the resuscitation. This was mirrored by Zali et al (2017) who found that 57.2% of family members felt it was their right

to be present during resuscitation; whereas 62.5% of nurses involved in that study disagreed with FPDR. This highlights potential barriers when catering to family wishes in both in-hospital and out-of-hospital cardiac arrests.

As mentioned previously, a concern from clinicians was that family presence during resuscitation may psychologically harm the relatives—but evidence suggests otherwise. A study conducted in France investigating OHCA's concluded that the prevalence of post-traumatic stress disorder (PTSD) was significantly reduced in family members who observed resuscitation (Jabre et al, 2013). A study with a smaller sample conducted in the ED by Robinson et al (1998) found no change in psychological measures such as anxiety, depression, grief, intrusive imagery and avoidance behaviour 1 month after witnessing resuscitation. A qualitative study conducted by Belanger and Reed (1997) found that all 24 family members who were present during resuscitation felt it helped their grieving process and would participate in FPDR again in the future. The evidence would suggest that what some clinicians think is in the best interests of the family and the reality are two different things entirely.

What is BBN?

BBN is described in the clinical setting as the delivery of any news that drastically and negatively alters the patient's view of his or her life (Adebayo et al, 2013). In the event of an OHCA, the individuals concerned are the family on scene that are being informed of their relative's likely or confirmed death. Reed et al (2015) describes BBN as a 'delicate and complex skill' and found in their study that the skill is a teachable one.

BBN in the emergency setting

The vast majority of literature available on the subject of BBN has been conducted within the hospital setting and, in particular, the oncology specialty. Models of delivery have been created in order to facilitate a structured approach when BBN; these include the SPIKES model (Baile et al, 2000) and the BREAKS model (Narayanan et al, 2010). Both of these were found to be useful tools for news-breakers but both were designed for the oncology setting, not the emergency setting. Shaw et al (2012) cites that the delivery of bad news with a structured approach and providing context can reduce shock and disbelief in the recipient of the news. There is currently no known model of delivery for death notification in the out-of-hospital setting. Park et al (2010) recognise the difficulty in transferring both models into the emergency setting and believe the unexpected nature of these incidents and the inability to create a relationship prior are huge obstacles physicians face when BBN. Having said that, their study concluded that the SPIKES model was a useful tool for BBN in the ED.

Training in BBN

Evidence suggests a widespread unconscious incompetence among health professionals when BBN and this is believed to be a result of poor or non-existent training (Adebayo et al, 2013). Studies have found training courses to be useful in improving clinician competence and confidence in BBN (Eid et al, 2009; Wuensch et al, 2013; Pang et al, 2015; Reed et al, 2015). The curriculum for Higher Education Institutes (HEI) delivering medicine courses includes the topic of BBN and is a mandatory aspect of the syllabus (General Medical Council, 2012). There is currently a lack of national guidance on the training and assessment of paramedics during accredited HEI courses on BBN. Park et al (2010) believe it is 'ethically challenging' to allow a novice clinician with no formal training or experience to BBN, 'just as it would be to perform any clinical intervention or procedure'.

Family expectations

The wishes of the bereaved when receiving bad news have been researched by several in-hospital studies. Relatives appreciate a warning that the news is going to be bad, an explanation, an opportunity to ask questions and inclusion throughout the resuscitation (Isaacs and Mash, 2004). There is also a general consensus across the literature that full disclosure, empathy and honesty are expected by family from clinicians when delivering bad news (Shaw et al, 2012).

Out-of-hospital challenges

Although the process of in-hospital and out-of-hospital resuscitation is the same in a clinical sense, both pose different challenges. An OHCA presents a much more unpredictable environment with factors that are out of the paramedics' control. These factors include the incident location, the number of people on scene, the ages of the family on scene, the circumstances of the patient whether it is an end-of-life case or a sudden collapse—all of which are usually unknown to the paramedics before arrival. The ED provides a much more manageable setting to provide resuscitation and, as a result of the differences mentioned, an OHCA should be researched separately from its in-hospital counterpart in order to fully understand these unique challenges.

Methodology

Aims: This study will provide an insight into the nonclinical challenges of an OHCA and, more specifically, how the family members are managed during these difficult incidents.

Data collection: Two focus groups consisting of six people each were carried out and all were paramedics from the NHS Ambulance Service. There was a total of 96 years of emergency ambulance experience among the twelve participants with a mean average of 8 years. Individual experience ranged from 3–16 years. There were six male participants and six female. Three of each were present at both focus groups to ensure equal gender representation. The paramedics were recruited using the ambulance service internal email system advertising for participants and expressions of interest. Each focus group lasted for 1 hour and 30 minutes, consisting of two sections of 45 minutes. The focus groups were semi-structured with prompting open questions on the following two subjects:

I Care of family during resuscitation

I Breaking bad news.

Digression was allowed when relevant. Both focus groups were recorded using a dictaphone device and transcripts were anonymously wordprocessed verbatim using the recordings. A total of 105 pages of recordings were transcribed.

Ethical considerations

Full ethical approval was provided for this study by ethics committees of both the University and the NHS Ambulance Service. All participants were provided with access to counselling services owing to the sensitive nature of the two topics.

Data analysis

The data from both focus groups have been analysed using the Ritchie and Spencer (1994) thematic framework analysis.

Results

Key themes identified during focus groups were:

Paramedics prefer family to be outside of the room during resuscitation

Distraction is a method used by paramedics throughout resuscitation for a number of uses

Paramedics use 'warning shots' throughout resuscitation to prepare the family for bad news

Paramedics don't feel sufficiently prepared by their paramedic courses in managing family during OHCA's

Paramedics learn how to manage family and BBN by watching experienced colleagues.

Discussion

Family presence during OHCA

'It makes you feel more pressured and makes you feel more aware of your own actions. You think more about what you're doing and how it might appear to them more.' (Participant 2)

'It's daunting because they are going to remember that for the rest of their lives aren't they, so you've got to balance that with the patient as well. It can be quite daunting though walking in.' (Participant 12)

'And that's difficult when family are there and there's a crew you're having issues with what's happening and trying to get that across in a professional way with a family member there and saying "you're doing that wrong" is a lot harder.' (Participant 2)

Management of family during resuscitation within the ED is much better evidenced than it is in the out-of-hospital setting. A study conducted in France by Jabre et al (2013) concluded that the presence of family during OHCA reduced the prevalence of PTSD in those family members. The study found that family presence resulted in this without interference with the resuscitation attempt and without any added stress on the healthcare team.

The results from the current focus group study argue otherwise. The word 'pressure' is used on multiple occasions by various participants and it was unanimously accepted by both groups that family presence increases levels of stress on the resuscitation team. Participant 4 believes that presence of family during OHCA 'humanises the patient' and, as a result, it makes it more difficult for responders to be 'detached and objective'. He believes that the 'chaotic' energy of family members can potentially affect the resuscitation attempt in a negative way but explains that it's the resuscitation team's responsibility to 'impose order' on the situation. He describes the situation as a battle of 'order over chaos'. This is interesting wording and it suggests that the family are an obstacle that the resuscitation team must overcome.

However, Participant 6 believes that humanisation of the patient may help with the dignity aspect of providing care to the patient. She agreed with the rest of the group that humanisation can hinder the resuscitation attempt but can be very useful and can positively impact 'how you treat them and leave them once you've finished'.

Participant 1 supports this opinion and believes family presence 'does put more pressure on you' but admits it 'depends on how they're reacting to the circumstances'. This unpredictability is an expectation of clinicians and participant 1 noted 'It's different [depending on] which home you go

into. Participant 4 agreed with this and believes that 'some people wear their hearts on their sleeve as a culture', whereas some people are more reserved. As Participant 2 stated: 'quiet relatives get forgotten about' during a resuscitation attempt. Correction of poor practice is a concern for Participant 2 and he believes that doing so while family are in the room is 'a lot harder'; he also has a fear of looking 'incompetent'.

Participant 3 stated that she 'can't concentrate when there's stuff going on', that distractions around her make her anxious and that she 'would probably forget to do airway or something stupid'. She has genuine concerns that the unpredictable nature of the patients' relatives could negatively impact the care her patient receives.

Three randomised controlled trials (RCTs) conducted by Dudley et al (2009), Holzhauser et al (2006) and Robinson et al (1998) concluded that there was no difference in mortality or resuscitation quality found between the control group, where family were not offered the opportunity to be present and the intervention group where they were actively invited. These data would suggest that the clinician's concerns over interference with the resuscitation attempt are unfounded. It is important however to note that the RCTs mentioned were conducted within EDs and not in the out-of-hospital environment. The only out-of-hospital RCT to date by Jabre et al (2013) also aligns with the current evidence base that family presence does not affect resuscitation quality, suggesting this clinician perception is not an actuality.

Findings from a study conducted by McClenathan et al (2002) found that only 39% of 592 health professionals surveyed allowed family members to be present during resuscitation. Reasons for this include the 'fear of psychological trauma to family members, performance anxiety affecting the CPR team, medicolegal concerns, and a fear of distraction to the resuscitation team'. This is also echoed in a qualitative study by Isaacs and Mash (2004) which found that medical officers believed family shouldn't be present, contrary to the wishes of the family members interviewed.

The concern of psychological trauma was also a concern for Participant 5 who said 'I wouldn't want to see it happen to my family member... do they really? Is that really gonna help?' Participant 11 also believes that people 'have an unrealistic impression of what a cardiac arrest is like from TV, it's beautiful, there's no vomit, you don't break anything, they look beautiful and pink and realistically it's horrible'. This is mirrored by participant 6 who doesn't want them 'to go away with that as their lasting memory of their loved one'. It's clear there is concern among the participants regarding family presence for a number of reasons and when asked if they prefer family to be in or out of the room, there was a unanimous response of 'out'. The aforementioned reasons are for what the participants believe to be in the best interests of the patient, the resuscitation team and the relatives themselves. The participants' belief that FPDR is distressing for family may be true in the short-term, but the longer-term psychological benefits have been proven and this would suggest that FPDR should be encouraged more.

Participant 7 however believes that family on scene can be helpful to clinicians and can 'act as an ally'. He explains that certain family members can identify as a liaison and can help you interact with the other members of the family. He also thinks that if the family members are in the room with you, the resuscitation team can see 'how well they are coping' allowing provision of the right support when needed. He does however acknowledge that how helpful a family member will be is unpredictable and 'if you do it on every job you get a different reaction each time'. It appears that this unpredictability plays a part in clinician anxiety when considering FPDR.

There is no current evidence regarding the frequency of family presence during out-of-hospital resuscitation. However, considering the results of the survey conducted by McClenathan et al (2002) and the findings in the current study, it would be reasonable to suggest that family presence is not routinely encouraged. So how are these family members being managed if they are not in the room with the patient?

Driven to distraction

'They like being given something to do like ask them to let the crew in just to give yourself a chance to be on your own and breathe for a second just so you can concentrate on what you've got to do.' (Participant 11)

'I think I've distracted them away from us rather than helping them out.' (Participant 8)

'...in a workable arrest situation it's just a case of giving them some tasks and trying to be as calm and clear by saying I need you to do this for John.' (Participant 9)

Distracting and occupying the family members are techniques that are adopted by the participants during a resuscitation attempt. Participant 9 believes it's 'a case of giving them some tasks' such as finding medication that the patient takes or letting other members of the resuscitation team into the property. Participant 11 agrees and believes the family 'like being given something to do' and doing this gives clinicians 'a chance to be on your own and breathe for a second'. This practice is adopted for the benefit of the resuscitation team in order to allow clinicians to concentrate on patient care, but Participant 11 does this for the benefit of both the team and the family.

This practice highlights a theme of distraction that appears to be present in OHCA. The participants have agreed that family can be a distraction for the resuscitation team. Distraction of the family away from the incident reduces the humanisation of the situation for the clinicians. Clinicians are distracted from the gravity of the situation thus allowing the resuscitation team to be as objective as possible and provide the best patient care. The results of both focus groups would suggest this is an intentional practice that is being used to protect the resuscitation attempt and the emotional wellbeing of all parties involved.

'Letting the tyres down slowly'

'Almost like trying to pop their balloon a little bit so that they know it's not a good outcome.' (Participant 3)

'It is a bit like letting their tyres down slowly because they don't understand, they see CPR on the T.V and they see casualty and they think we walk in and we've got some magic that we throw at the patient and they'll be fine. Whereas we know it doesn't work magically.' (Participant 5)

'Explain what I'm doing in the resuscitation, trying to simplify what I'm doing but without patronising which is difficult.' (Participant 2)

Isaacs and Mash (2004) found that family members appreciate warning that there would likely be a negative outcome from a resuscitation attempt and it would be a 'bigger shock' had they not been prepared. The focus groups agree that this is a common practice during OHCA and as is indicated by the quotes above, Participant 5 and Participant 3 both alluded to preparing the family for bad news gently.

The literature is unanimous regarding the importance of good communication throughout resuscitation for keeping family informed. OHCA are high-pressure situations and the participants

have admitted to feeling anxiety about saying the wrong thing or appearing patronising. Firing 'warning shots' is a practice that the participants endeavour to do, but it appears it is one that not all are comfortable doing. The participants describe the process of BBN as a 'journey' and believe that preparation through warning shots is key for facilitating acceptance among relatives. Participant 5 uses warning shots to prevent family from receiving a blunt notification of death. 'They've come along with us and realised Granny's gone from this to this. There's nothing else'. Non-verbal communication also plays a significant part of the interaction with the family and 'how you walk in can tell them a lot'. He believes that you may provide an aura that they are about to hear some bad news with non-verbal cues. This highlights the importance of non-verbal communication in preparing family for bad news. Preparation is a key aspect of BBN in both the BREAKS model (Narayanan et al, 2010) and the SPIKES model (Baile et al, 2000), and it appears that clinicians are successfully implementing this stage during OHCA's.

'Out of the clinical and into the human'

Participant 5 believes that BBN is difficult and it 'pulls you from back out of the clinical and into the human'. The sudden transition of mindset described by this participant shows that clinicians mentally separate the resuscitation attempt from the interaction with family. The current research shows that family want inclusion throughout the resuscitation process (Nevins, 2016; Zali et al, 2017). It would appear that the participant has separated herself into two personas in order to fulfil the demands of an OHCA. She has a 'clinical' persona that concentrates purely on providing the best possible care to the patient and a 'human' persona that delivers the bad news of a failed resuscitation attempt in the best way possible. This is a particularly demanding transition for any clinician and would require a high level of adaptability and versatility. It appears that this dual persona that Participant 5 undertakes during OHCA's is to provide the best patient care, but also as a way to achieve self-protection.

The participants are unanimous in agreement that managing an OHCA is emotionally taxing for the clinicians themselves and this could be a potential cause for the dual personas described by Participant 5. For the wishes of the family to be fulfilled and for them to feel included throughout, it may take a 'humanly clinical' approach from clinicians. Participants have agreed that a clinical and 'ordered' approach can be necessary to provide high-quality resuscitation and to add more emphasis to the human aspect would be challenging. This is however what research suggests that the patients' families actually want from the resuscitation team.

Taught by 'an incredible variety'

'Mentors both toxic and otherwise' (Participant 1)

'It does lead to an incredible variety' (Participant 1)

'As a student you want to be involved with the skills, certainly when I was a student I wanted to really practise the skills, but I think what I'd really like to be learning is what's going on in the room next door.' (Participant 5) *'When I got on the road, it was all just learning it off other people and asking them "can you say it?"'* (Participant 3)

The participants agreed that they learned how to BBN and manage family during resuscitation by watching experienced colleagues and how they interact with family. They acknowledge the potential for the imitation of poor practice and copying mentors 'both toxic and otherwise', as well as a lack of guidance leading to an 'incredible variety' of styles. This would suggest that the treatment a family

receives is entirely dependent on which clinician walks through their door, indicating an inconsistency in care.

Participant 5 states that she benefited from observing a number of mentors when she was a student and she was able to observe 'some of the best' this way. She also says that as a student she wanted to be involved with the skills during the resuscitation but now as a qualified paramedic, she wishes she had learned 'what was going on in the room next door'. Participant 11 also agrees that on placement as a student and a newly-qualified paramedic, you are very 'skill-focused' and as a result, the clinical aspect of the resuscitation takes the full attention of the paramedic.

'Inadequate' training

'I feel I have a complete lack of training in breaking bad news.' (Participant 2)

'It needs to be brought into the curriculum at university in a formal way.' (Participant 1)

'For me we didn't really do much in university about breaking bad news so it was either your own CPD or learn from your mentors so there was no formal training that I had.' (Participant 12)

'From what you've said I don't think it's changed since IHCD, I think at IHCD a clinical practice trainer said "just say they're dead," don't mince your words, don't use euphemisms just spit it out. And that's all we ever got on that.' (Participant 1)

'I didn't feel comfortable at all breaking bad news after a 1 hour lecture to tell this family that loved them that their relative has passed away or died. I didn't feel comfortable at all. I don't think it was adequate.' (Participant 11)

'I feel for people coming out of university, because you really are making it up as you go along then.' (Participant 1)

The participants were in agreement that the preparation and training they received on their paramedic courses was not sufficient to feel confident or competent in managing family during an OHCA or in BBN. Participant 11 who has completed an HEI Paramedic Practice course didn't feel confident after having a 1-hour lecture on the topic. She believes that many student paramedics currently are 'clever' and 'educationminded' but believes that not all will have strong communication behind them. Participant 1 however believes this lack of direction is not new. He states that current HEI training appears to be similar to the training delivered on previously taught Institute of Health and Care Development (IHCD) Paramedic courses that were run internally by Ambulance Service Trusts. He recalls the only guidance he received was to 'not mince your words' and tell them 'they're dead'. As mentioned previously, honesty from clinicians is an expectation from family but so is empathy and bluntly saying 'they're dead' could potentially appear to lack empathy, noted participant 5. She believes that the word 'dead' is 'too harsh a word' and thinks that if you've taken the patient on the 'journey' with you through the resuscitation, then you won't have to use that word to ensure they understand the outcome. Participant 4 agrees and thinks the word is a 'stopper of an interaction' when used. Participant 2 also finds himself 'stumbling around the word' and has difficulty placing it into a sentence. He was directed to ensure the word 'dead' is used but questions the evidence base behind that direction and wonders whether this blunt approach has been adopted owing to a lack of confidence in the skill. The participants believe that there isn't a blanket or 'one size fits all' approach to BBN and managing family during resuscitation as every situation is unique. However, it appears that the current guidance offered currently on paramedic courses isn't sufficient.

The findings of the current study have highlighted a lack of confidence and uncertainty from paramedics when interacting with family during the resuscitation process. This could be directly as a result of what the participants identified as inadequate training and education on the topic.

The current evidence base suggests that family presence is beneficial for the long-term grieving process and paramedics are best placed to encourage this practice. In order for this to happen, however, the education and training on this subject must improve and, if this happens, there is the potential for benefiting the relatives of up to 24 000 patients per year.

Conclusion

Participants prefer family to be out of the room when resuscitating a patient and their reasons are increased clinician anxiety, interference with patient care and the traumatic psychological effect on the family. Paramedics intentionally distract family from the room during resuscitation for a number of reasons. Paramedics feel they are not sufficiently prepared by their educational courses to manage family effectively during resuscitation or BBN. Paramedics have learned how to perform both skills by observing their experienced colleagues. Both subjects are currently poorly evidence-based and further research is required on the management of family and BBN during OHCA.

Key points

Paramedics prefer relatives not to be present during the resuscitation of a patient for a number of reasons

Distraction is a technique used by paramedics during resuscitation for the benefit of all parties involved

'Warning shots' are used to prepare relatives for bad news

Paramedics separate resuscitation and breaking bad news (BBN) to effectively manage demands of both tasks

Paramedics feel they were not sufficiently prepared by their pre-registration courses in BBN or managing family during out-of-hospital cardiac arrest (OHCA)

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