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Miscarriage, SUDI and Neonatal death: exploring paramedic experience and practice

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Abstract

This paper aims to provide an exploratory investigation into paramedic experiences of attending cases of Miscarriage, Sudden and Unexpected Deaths of Infants (SUDI) and other forms of neonatal loss. It draws on a background literature review, but focuses primarily on exploring issues raised by paramedics during a structured discussion group on this topic. Existing literature highlights the ways in which baby and infant death is one of the most stressful and challenging areas of paramedic practice. Paramedics participating in our discussion group reinforced this issue identifying five key areas of concern: baby loss as a rare occurrence, resuscitation, lack of information concerning the post admissions process, professional closure, and support to parents. We conclude by arguing that further research in this area is needed, along with better support and guidelines to assist paramedics with a wide range of issues from resuscitation to bereavement support.

Keywords: Pregnancy Loss, Paramedic Practice

Key points

- Attending cases of baby and infant death is a challenging area of paramedic practice.
- There is currently a limited amount of research which focuses on this subject.
- Existing literature emphasises paramedics fears on a range of issues from resuscitation to dealing with bereaved parents and relatives.
- Our focused discussion group with paramedics highlighted a range of concerns including issues relating to professional closure.
- There needs to be more research which focuses specifically on this area of paramedic practice.
- Paramedics need better guidelines and training to help them deal with these tragic cases.

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Introduction

Paramedics are often called out to cases of miscarriage and may be the first professional on scene in cases of sudden and unexplained infant death (SUDI). Limited attention has been paid, however, to this particular aspect of paramedic work. Research frequently shows that out of all the events paramedics attend, infant and child death is often reported as one of the most distressing ones (Boyle, 2013; Douglas et al., 2012; Regehr et al., 2002). It is crucial therefore to shed light on this neglected area of paramedic practice. This is a scoping paper which offers a brief analysis of existing literature. The main part of the paper focuses on exploring key concerns raised by paramedics during a structured discussion which focused on issues that paramedics found particularly challenging regarding cases of baby loss. The overall purpose of this paper is to identify gaps in existing knowledge, illuminating key areas for development in both future research and training.

Literature review

The literature review was conducted using google search and focused on paramedic practice and baby loss. The search included a focus on academic papers and books from across the social and medical sciences as well as paramedic blogs, clinical guidelines and charity websites. Common themes emerged from this review which we will explore in this section. The first reoccurring theme related to the ways in which paramedics often perceive working with adult patients differently to children, particularly around resuscitation (Hall et al., 2004; Muñoz, 2016). Paramedics often feel that children deserve more vigorous resuscitation, even when they acknowledge that this effort is futile (Hall et al., 2004). Furthermore, studies have shown that paramedics find it particularly difficult to deal with bereaved parents and families at this deeply traumatic time (Hall et al., 2004; Muñoz, 2016). One of the main factors impacting on paramedics' decision-making around the resuscitation of children is their fear of confrontation with parents (Hall et al., 2004).

Another key theme is the emotional effects of attending these cases on paramedics themselves. In these situations, paramedics can feel a lack of control (Avraham et al., 2014). Paramedics often experience significant emotional discomfort in dealing with child and baby death. They also experience uncertainty around how to manage parents' grief and pain. These factors combined often have a negative effect on their own emotional wellbeing (Boyle, 2013; Douglas et al., 2012; Hall et al., 2004; Muñoz, 2016; Regehr et al., 2002). In particular these issues often affect paramedics' relations with their families and can lead to post-traumatic stress disorders (Kirby et al., 2011; Regehr et al., 2002). Research has shown that having the right information and knowing how to respond to specific problems has a positive emotional effect among paramedics (Jurisova, 2016).

There has been an increasing interest in paramedic training which focuses on managing the emotions of patients and relatives around death notifications. This has, however, mostly been based on research conducted in other countries (Hobgood et al., 2013; Muñoz, 2016). As Williams (2013) has pointed out, there is still a very limited focus on bereavement support training in England where paramedic education is largely underpinned by biomedicine. While guidelines for paramedics on attending incidents of miscarriage and SUDI do include some information on dealing with families, they tend to focus mainly on providing clinical information (JRCALC Clinical Guidelines 2016). Research has often highlighted the significance of professional contact in mediating parent experience of baby loss (Bolton, 2002; Downe et al., 2013; Heazell et al., 2016; Purves and Edwards, 2005; Tomlison et al., 2018; Reed and Ellis, 2020; Reed, Whitby and Ellis, 2018). The importance of being kept informed and listened during the whole process has been reported by parents as essential to their experience Redshaw et al., 2014).This is something that is becoming increasingly reflected in multi-agency guidelines on SUDI (for example RCPCH Sudden Unexpected Death in Infancy and Childhood Multi-agency Guidelines for Care and Investigation 2016). Although more attention is currently being paid to the role of healthcare professionals in supporting bereaved parents in hospital[1], what our review shows is that there is very little in the way of specific guidelines for professionals working in out-of-hospital settings. As part of the team of health professionals often involved in supporting parents along this journey, it is essential that paramedics are included in both research and training on death communication and emotional support.

Focus group discussion

In order to find out more about some of the key concerns raised by paramedics as indicated by the literature review, we conducted a structured discussion group in March 2019. This group was resourced by Impact Accelerator Account funds (IAA) from the Economic and Social Research Council (ESRC). These funds are designed to support knowledge exchange and engagement activities between universities and other organisations and sectors. Participants were contacted through leaflets and adverts distributed in collaboration with the College of Paramedics in hospitals and universities and via social media. The group consisted of 4 women and 5 men, ranging in age and stage of career and working across two Trusts in England. A list of semi-structured questions was drawn up based on issues raised in the literature review. Questions sought to explore a wide range of issues from what happens on scene when attending a case of miscarriage or SUDI to issues relating to professional closure. We did record the group discussion after seeking permission from the participants. We then anonymised

[1] For example see NICE Guidelines https://www.ncbi.nlm.nih.gov/books/NBK410244/ , Lullaby Trust guidelines https://www.lullabytrust.org.uk/wp-content/uploads/lullaby-cdr-booklet.pdf and SANDS guidelines https://www.sands.org.uk/professionals/bereavement-care-resources/sands-guidelines-4th-edition

and reviewed the transcripts in order to look for common themes. This group was conducted as a knowledge exchange and continuing professional development (CPD) activity. It sought to highlight key areas of concern for paramedics. It also provided an opportunity for paramedics to share best practice and identify areas for further research and training. It is important to note that this is not a piece of primary research, therefore no formal ethical approval was needed.

Results

The group discussion revealed a number of key issues including the strong emotional involvement of paramedics in cases of baby loss. Participants in the group felt that existing guidelines and information provided to paramedics on attending incidents of baby loss were insufficient. Paramedics felt this was the case for both the clinical information that was provided and information on bereavement support.

From the data it was possible to identify 5 main areas covering the participants' concerns:

1) Baby loss as a rare occurrence

Cases of child and baby death were described by participants fortunately as a *"rare occurrence*" in their daily routine. Due to the rarity of attending these cases, however, paramedics said that they often feel quite "*apprehensive*" about this kind of work. Participants reported that this lack of experience affected their ability to feel confident with such calls. As articulated by one of the paramedics in the quote below:

> *"It is not a common occurrence for us, really. I don't know if anyone disagrees with that but I had three miscarriages in like two years of experience" (Participant 1)*

Paramedics worried that their lack of experience of attending cases of baby loss would affect their ability to make the right clinical choices on scene. Furthermore, their lack of experience often made them feel unsure about how to deal with parents and family. As articulated by another paramedic below:

> *"How do I approach this? What should I say? Or should I say anything? And sometimes people don't want you to say anything; sometimes people look to you for every answer and if you don't have done these jobs before because they are very rare… which unfortunately are rare" (Participant 7)*

2) Resuscitation

Concern over resuscitation was one of the main clinical issues arising from the group discussion. Paramedics stressed that working on a child or baby is different to working on an adult because it is

more difficult to maintain emotional distance and take a decision on what it the best for the baby, as explained in the quote below:

> *"When to resuscitate or when not is very difficult because with most adult jobs you can easily detach yourself, I think, and just carry on with the job. When a child is involved, it doesn't matter how hard you try to not be emotionally involved, YOU ARE involved naturally, and maybe this is because I am a woman. So the one thing that you don't want is to turn up into a job, not having done that before, and then thinking, I know there is a standard operating procedure (SOP) on it, but I don't want to get a SOP, I want to know what to do. When to do CPR and When not" (Participant 7)*

Paramedics in the group referred to information provided in their own trust specific guidelines as well as information provided by the JCALC (2016) guidelines relating to the death of a child (including SUDI). Paramedics felt these resources, while useful, do not always assist them when they are trying to make a decision on resuscitation in very time-pressed and traumatic circumstances. This is particularly problematic when they attend cases where the gestation period may be unknown.

Paramedics were often particularly anxious about what to do in cases of extreme preterm babies. As articulated in the quotes below:

> *"What to do you do with that baby? Do you work on it? We are ethically but we are not legally obligated to do so and we had discussion at the university about whether this actually helps parents that early (…) Because we are so limited of what we can do before we get to the hospital." (Participant 3)*

Decisions over when to resuscitate a child or baby were both a clinical and ethical dilemma for paramedics.

> *"This is an ethical dilemma that we are suffering with all the time, but if you are comparing resuscitating a 99 year old, (that person has lived his full life), with resuscitating a baby, you are taking away that baby's life" (Participant 6)*

Paramedics felt that the use of resuscitation (even if the baby is no longer alive) was their attempt to satisfy both parents' and paramedics' needs of "*knowing that everything has been done*" to save that life. Although having parents present on scene was described by paramedics as particularly stressful, they did also wonder how/whether to involve parents in the process:

> "*Should I get the parents involved in the resuscitation process?*" (Participant 1)

3) Lack of information concerning the post admission process

Paramedics articulated concerns over their limited opportunity for interaction with hospital staff around baby loss. Paramedics felt the separation between the hospital and ambulance service was a key concern for them and affected their ability to do their job. When they took parents and babies to hospital (whether to the mortuary or to maternity hospital), they often felt like outsiders. They felt that they received limited information about what happens next with families and babies in terms of both clinical and care processes. Paramedics are often the first professionals to have contact with parents. They make decisions on where to transport patients and also address families' questions on scene. The limited interaction with the professionals in hospitals makes it difficult for them to know what is available and also decide on the most suitable place to take each specific case. Moreover, this lack of knowledge on what happens next makes it difficult for them to address parents' concerns and questions. As articulated by a paramedic in the quote below:

> *"We are so limited of what we can do before we get to the hospital. In hospital they got such a better chance, you know, but where do we have to take them?" (Participant 3)*

4) Professional closure

Lack of closure is often identified as a difficult part of paramedic work (Muñoz 2016) and it was certainly something highlighted by participants in our focus group. Paramedics may not have access to appropriate hospital back-up or wider support structures. Furthermore, because they are continually moving from one job to the next, working across different hospitals and geographical contexts they do not always receive adequate feedback on their role. Participants have associated the lack of continuity between the hospital and the ambulance service with feelings of isolation and loneliness. These feelings are articulated by the paramedics in the quotes below:

> *"There is no closure in this job; this is not just a wild door, but a mild-wild door that you can close quite easily" (Participant 7)*

5) Supporting parents

Paramedics also felt that they are not adequately prepared to give the right care and emotional support to parents experiencing child and baby loss. Demonstrating that they have done everything clinically is the first step towards helping and supporting parents to accept their child's death. This is articulated in the paramedic quote below:

> *"Yes, you have to because you obviously walk in that room and the parents are hysterical and all of this and you are turning up not doing anything (…) that is not helping the parents, you know? Because they have called you to help. It is very difficult" (Participant 1)*

However, paramedics also felt that they would like more information on how to emotionally support parents at this extremely distressing time. Some of the participants felt that the literature and guidelines in this area are very ambiguous, as articulated in the quote below:

> *"Some (paramedic literature) suggests maybe don't (do anything) as the parents actually know what they want to do and I would probably, If I went to a child that was dead, that there is nothing that you could do, I would probably give that child to the mother because it is the same as if it is born. You want, as in stillbirth, you still want to have that child on the mother's chest because they need to have that skin-to-skin for the grieving process" (Participant 7)*

Paramedics acknowledged the difficulty of talking about any type of death, but in particular the difficulties associated with talking about infant and child death.

> *"There is a lot of uncertainty, because there is not a lot that we can do but it would be nice when the parents go because people are always going to say 'what happens next?'. It would be nice to be able to say that 'we know with certainty that this is what is going to happen'. Because I need to tell them, so you can prepare them, like 'This is a massive shock, no matter what is happening but you need to be prepared that on this stage…" (Participant 9)*

Discussion

The two main issues that emerged during the literature review and focus group discussion were: the lack of clear and uniform guidelines specific for paramedics on attending miscarriage and neonatal death and the lack of communication between hospital staff and the emergency services. These issues effect both the clinical management of these cases and the appropriate level of support paramedics can offer to parents and families.

Any future guidelines developed around baby loss need to take into account the uniqueness of paramedics' work. Paramedics are often called to jobs covering a wide variety of issues. They do not always know what they will find on scene and often have to make very rapid decisions after arrival. Different clinical conditions might require the application of different protocols, but these different conditions might not always be apparent. For example, as some of the participants articulated, women who call emergency services are not always aware that they are having a miscarriage and some of them are not even aware of being pregnant. Following a clinical protocol based on gestational age or foetus size when this information is not always apparent is quite problematic and challenging. Future guidelines around attending these cases need to recognise this.

Limitations

This paper is based on the results of a small scoping exercise involving a literature review and one structured group discussion with paramedics and therefore has limitations. It does, however, indicate a clear need for further research into paramedic experience of miscarriage and SUDI, perhaps with a wider range of practitioners across different trusts in the UK, including those of different ages, and stages of career, gender and specialisms (from technicians to advanced practitioners). The focus group also clearly identified the need perhaps for the development of further resuscitation guidelines and training for paramedics. Despite these limitations, however, what we have hoped to have shown in this paper is that greater attention must be paid to the role of paramedics in attending cases of miscarriage, SUDI and other forms of neonatal death.

Conclusion

Paramedics, as a profession have tended to be side lined within existing research and literature around professional experience of baby loss. This is despite the fact that paramedics are often the first on scene when a woman miscarries at home or if there has been Sudden Unexpected Death in Infancy. Child and baby death can be one of the most challenging interventions for paramedic staff. Our article highlights the need for further research which focuses directly on the issue of baby loss and paramedic practice across different NHS trusts in the UK. Paramedics would also benefit from receiving further training and guidance on key issues such as resuscitation. Furthermore, paramedics need more information to help them build up a better understanding of the entire baby loss journey. This could enable them to better support and communicate with bereaved parents at this deeply traumatic time.

Reflective questions

- To what extent do you think attending cases of baby loss is a specific problem for paramedics?
- How do the issues raised in the paper dovetail with your own experience as paramedics?
- How could guidelines be improved to help paramedics deal with these cases on scene?
- Out of all the areas identified in the paper which do you think should be a priority for future training and research?

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