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Bereaved relatives experiences in relation to post mortem: a qualitative exploration in

North East Scotland

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**Abstract** 

When a family is grieving the loss of a member the consideration of post mortem is an additional

concern. This study set out to explore how relatives are supported to give authorisation and

throughout the post mortem process. Thirteen relatives with varied experiences of a relative's

death took part in interviews. Data analysis revealed the post mortem as part of the narrative of

the death with more significance for some than others. Important aspects for relatives were

being able to say 'goodbye' properly, and engagement with staff in hospital and procurator fiscal

(public prosecution) services in more substantive communicative relationships rather than only

receiving basic information. Relatives valued receiving results they could understand. There

may be opportunities, particularly in coroner or procurator fiscal services, for development of

roles in liaison between relatives and pathology services, and support for relatives.

**Keywords:** bereavement, psychosocial support, post mortem, coroner, family.

### Introduction

Post mortem in Scotland – context and prevalence

When a family is grieving the loss of a member the consideration of post mortem is an additional concern. In the UK post mortem takes place in two settings, the hospital or the coroner service (procurator fiscal service in Scotland). In the hospital context, a post mortem may be requested by the patient's doctor or the family themselves, whilst post mortem in the coroner or procurator fiscal setting is a key part of the investigation of sudden, violent or unexplained deaths and authorisation from relatives is not required. The procurator fiscal is a public prosecutor and among other roles, investigates all sudden, suspicious and accidental deaths, and conducts public enquiries where they have been instructed (Crown Office and Procurator Fiscal Service, 2015).

The small qualitative study reported in this paper took place in North East Scotland, an area across which there were 4,346 deaths in 2013 (National Records of Scotland 2014). For Scotland as a whole the number of deaths in the same year was 54,700, and figures for 2013/14 indicate 5,060 procurator fiscal post mortem examinations were instructed (Crown Office and Procurator Fiscal Service 2014). Proportionately, around 400 may have taken place in the North East. Also in the year from April 2013-14, 78 hospital post mortem examinations took place in the NHS Grampian area (North East Scotland) and 352 nationally (Scottish Pathology Network, 2015). However, numbers for hospital post mortem examinations have fallen over the preceding decade with equivalent figures for 2005-06 showing 1,560 hospital post mortems for Scotland as a whole, and 105 for Grampian (Scottish Pathology Network, 2015). Numbers of procurator fiscal post mortems in Scotland reduced slightly from 5,361 in 2008-09 but numbers of deaths reported have also fallen (Crown Office and Procurator Fiscal Service, 2014). This still means 10-12% of deaths, both nationally and locally, are likely to be subject to post mortem and a substantial number of relatives may become involved in interactions with hospital or procurator fiscal pathology services.

Post mortem practice can deliver significant clinical, educational and public health benefits (Burton & Underwood, 2007). However, the recognised decline in the numbers of hospital post mortem examinations carried out (Henry & Nicholas, 2012) is concerning and may have been exacerbated by the so called 'organ retention scandal' in the late 1990s (Redfern, Keeling & Powell, 2001). Poor adherence to authorisation procedures in England and Wales may also mean relatives are less likely to provide consent (Henry & Nicholas, 2012). In addition, the results of post mortem can be inconclusive, often controversial and may be contested (Timmermans, 2005), and along with the increasing popularity of post mortem sampling, or minimally invasive autopsy of easily accessible organs and tissues, may influence reduced numbers of traditional invasive post mortem procedures (Rigaud *et al*, 2011). The provision of high quality support and information for relatives around post mortem that enables good decisions and guidance through processes is consequently a key part of current legislation and practice (HM Government, 2004; Scottish Government, 2006).

Overview of bereaved relatives' experiences in relation to post mortem

Relatives view post mortem as a means of answering particular questions about the death to explain how and why it happened, and to consider what it may mean for others in the family (Oppewal & Meyboom-de Jong, 2001). However, family members' interactions with healthcare providers or coroner or procurator fiscal services around post mortem may be fraught with misunderstandings. Family need is around grieving and coming to terms with the fact of a death whilst those in authority focus on the dead body as the container of information about the death (Drayton, 2013). Relatives may feel they need to see the body around the time of the post mortem, and analysis by Chapple and Ziebland (2010) of emotional responses to viewing or not viewing the body following death by suicide or other form of trauma has identified that relatives feel restricted in expressing their grief for the loss of the person. Indeed, recognised difficulties arise when coroner or procurator fiscal services need to interact with bereaved people but

cannot be regarded as bereavement care providers (Kerslake *et al*, 2014). In contrast, some hospital settings may offer an approach to bereavement care where all staff are prepared for interactions with bereaved relatives (Walsh *et al*, 2013), and this level of care would include support around post mortem processes.

Information provision, communication strategies and staff training may enhance relatives' experiences (Downe *et al*, 2012), and in Australia, a useful role has been developed for social workers in coronial services in which rapport develops with relatives, emotions are acknowledged and informative dialogue takes place (Drayton, 2013). The research reported in this paper was developed to further understand current experiences of the still substantial numbers of bereaved relatives in North East Scotland who may be asked to authorise a post mortem, or whose relative is subject to a procurator fiscal post mortem. There was particular interest in exploring contemporary support after the introduction of the 2006 legislative processes in Scotland (Scottish Government, 2006).

## Method

Using qualitative research methods (interpretative phenomenology [Moustakas, 1994]), the study offered insight into how relatives make sense of: being asked for authorisation or being informed a post mortem would take place; their understanding of the procedure; the availability and accessibility of information, and communication and support provided. Ethical approval for the study was received from the Research Ethics Sub-committee at Robert Gordon University. Sampling and recruitment

Using convenience sampling thirteen bereaved relatives were recruited to participate in in-depth interviews. Eligible participants were bereaved for at least six months. They had lost a relative who had died after 2007, the year in which the new legislation was embedded in practice. They had either been asked to authorise the conduct of a hospital post mortem, or their relative was subject to a procurator fiscal examination, in which case no authorisation is required. In the case of hospital post mortem, perspectives of those who did and did not give authorisation were

### sought.

Recruitment was achieved in the main via two intermittent advertisements placed in two widely read local newspapers. Supplementary recruitment took place by distribution of publicity materials to relevant third sector organisations, for example, Cruse Bereavement Care Scotland and the Stillbirth and Neonatal Death Society (SANDS). The study was also publicised at meetings and seminars attended by the two main researchers. Potential participants contacted the researchers and before giving any agreement to take part, oral and written information was provided.

### Data collection

All interviews were carried out by authors AS and VSL, and were undertaken face to face with participants either at the university or in the participant's own home. The conversations were semi-structured, digitally recorded and directed by a topic guide designed for the purpose. Interviews lasted about an hour and were emotionally challenging for most if not all participants. As well as interviewers supporting participants during the conversation, contact information was provided to participants for locally-based branches of Cruse Bereavement Care Scotland and SANDS. This was done with permission of a lead person at each organisation.

# Data analysis

Data analysis was informed by the framework approach of Spencer, Ritchie and O'Connor (2007). All recordings were transcribed verbatim and read and re-read to become familiar with content and identify important aspects. Using NVivo software (QSR International, 2015), transcription material was indexed, coded, categorised and charted in matrices to identify commonalities across transcripts and generate key themes and concepts. Two researchers (AS, VSL) discussed developing themes and concepts, and following refinement this was shared with the rest of the team (CM and SC) to verify a clear coding frame. Meaning interpretation was further developed by forming descriptive and explanatory accounts covering the range of topics and concepts. The comparison of concepts across all transcripts ensured all perspectives were

represented and validity was established through continuously checking with recordings and transcriptions (Spencer, Ritchie & O'Connor, 2007).

## **Findings**

In total, thirteen participants were recruited, and across the sample relatives had lost a member of the family in various ways (Table 1). All were white Scottish, 12 were female, one was male, and they ranged in age from 30s to 70s. Three matrices for indexing and coding were developed: sudden death; expected death, and stillbirth and neonatal death. Analysis across the matrices resulted in four key themes, presented below as descriptive and explanatory accounts. Quotations from participants are used to substantiate aspects of themes.

Theme 1. Perceptions of the post mortem positioned within the wider death narrative

For participants, the post mortem was one part of the larger narrative of the lead up to the

death, the death and subsequent bereavement. In addition, it is viewed within the wider context

of the relationship with the person who died and the relative's spiritual beliefs. Participants not

only talked about events relating to the post mortem but often began with the events

surrounding the death and what had happened since. The 'story' around the death was further

informed by the post mortem which provided answers and a cause of death meaning that, for

one bereaved daughter interviewed, she had something clear to relate to others.

'At least I got an answer and I was able to tell the rest of the family what it was, whether they were interested or not I don't know.'

However, for another daughter the narrative of her father's life and death did not require further knowledge of cause of death. The relationship and understanding of her father as a person before his illness informed the decision not to authorise post mortem.

'I looked at my sister and she said, "he didn't really like being interfered with when he was alive, I don't think he'd be wanting it when he was dead." Bereaved daughter

Related to the death narrative, for a participating bereaved wife, it was important that the pain and distress of her husband's illness and death was not 'going to be meaningless' and the post

mortem provided this opportunity. There was great distress at the death of her husband, perceived as untimely, and a need to ensure that there could be a learning experience. She also had particular beliefs about life and death that may have influenced her attitude to the post mortem.

'It's not something I ever would have dreamt of denying, let me put it that way, because as far as I'm concerned the soul has gone and you're just left with a body and the person's not there any longer.'

# Theme 2. Significance attached to saying goodbye to the deceased

The last movements, words and sightings of the deceased person were important for relatives to achieve some lasting memories to take with them on their bereavement journey. In the midst of practical arrangements around removing the body and carrying out the post mortem, the need to say 'goodbye' was a concern for participants who were bereaved suddenly. When attending personnel, for example paramedics and police, allowed relatives to be with the deceased this was greatly appreciated and negated the need to imagine what they may have looked like and where they lay. One bereaved wife described 'a very precious time then with [husband] without any equipment, without any disturbance' and said, 'if I hadn't seen him I think that would have been even worse because, how would you ever imagine it?'

A further suddenly bereaved widow experienced the time of the death as confusing and distressing. Her unsuccessful attempts at resuscitation and those of medical personnel restricted opportunities for saying 'goodbye.' In fact, she believed if she had known he was dead she 'wouldn't have tried CPR and would have held him in her arms.' At the hospital, she was additionally frustrated in her attempts to have contact with her deceased husband.

'I wanted to take the side of the bed down and put my arms round him to say 'goodbye' and I couldn't.' Bereaved wife

Particular circumstances of the death may further complicate attempts to see and touch a deceased relative. For a bereaved mother in this study, death of her son through heroin

overdose created tension between her needs and authoritarian processes of death investigation.

'I felt he was still there...and I needed to see him and I needed to touch him. I said to the police officer, because I just touched the window, 'can I, will I see him again?' And they sort of intimated, yes but no, it's difficult to explain and I never saw him again.' Bereaved mother

For some participants in the study the 'next time', or for some the only time, they were able to see the dead person was at a rest room or on the undertaker's premises. An advantage of viewing the body at the undertaker's was that others in the family apart from the next of kin or anyone who had been present at the time of the death also have the opportunity to see the dead person.

The experiences of parents whose baby was stillborn or died soon after birth differed from other participants in that they were accommodated to spend an extended period of time with their dead baby before the post mortem. In effect, they say 'hello' to their baby simultaneously with saying 'goodbye.' Parents treasured the time spent with their infant, and the presence of midwifery staff was appreciated at this time, and believed by parents to be supportive in enabling them to make 'right' decisions about post mortem.

# Theme 3. Emphasis on communicative relationships rather than printed information.

It is recognised that bereaved individuals distressed at news of a death find it difficult to understand or retain information (Scottish Government, 2011). This difficulty in processing information was expressed by a bereft mother whose baby had died aged one day. Referring to the immediate time of becoming aware of her baby's death she recalled,

'...at this point I was holding [daughter] and I just remember looking at her (the baby) and I clearly remember at this point thinking, I don't know what you're talking to me about.'

In the perinatal context mothers appreciated having time to consider their decision and a mother whose baby died soon after birth and agreed to post mortem described talking to a member of

mortuary staff as very helpful.

'They could have made it sound like a process but they spoke about her like she was an actual, she wasn't just a what is it you call it,...a cadaver, a body to be dissected, she was a person, they used her name.'

In general, however, participants were vague about the type of information they were given and any form filling related to post mortem. There was little mention of printed information about post mortem, reasons for the post mortem and processes around post mortem.

Participants whose relative had died suddenly had varied experiences of being informed that a post mortem would take place. In general, information other than that it would happen was not given unless relatives asked specific questions. The lack of information was challenging for some interviewees, and could induce feelings of disenfranchisement. This may have long-term consequences in terms of bereavement response, and a mother described lacking the strength to challenge the indignities she felt, and said, 'you can't come to terms with anything you haven't been told.' She also believed the particular circumstances of the death of her son from drug use affected communication processes and that the negative manner in which he had been treated by authorities in life was being replicated in their regard for her after his death.

Feelings of disempowerment also arose for a relative in the study when her husband's death was subject to a police enquiry. She felt distanced from any decisions made, any information available and from her husband as a person to grieve.

'You're completely reliant on other people to give you information, em, so you're very disempowered really, at a time when you feel powerless anyway because I actually felt quite sidelined, em through the whole process.'

This participant went on to further describe the impact on her of the investigation and decisions taking place by police and others.

'Just fear of the world. You know, felt very exposed, very, very vulnerable. Very fragile, em and also quite ignorant. I felt extremely ignorant...because it was a whole world I

knew absolutely nothing about.'

# Theme 4. The significance of the results

In common with the themes discussed above, the experiences of bereaved relatives of obtaining results of the post mortem were varied. The most satisfactory experience was of results communicated by the family GP to a bereaved wife with explanation of the cause of death written on the death certificate. This allowed dialogue that allayed fears, for example, that more could have been done to prevent the death.

'I sort of felt that, well maybe if I had been present I could have done CPR straight away, and he said that it wouldn't have made any difference because the damage was that extensive.'

A delay in offering results to one participant whose partner took her own life was found to be unhelpful, when during the time lapse he had begun to adapt and cope with the loss.

'I never took it up (the offer) and by that time I didn't really want to go back and revisit the past and emm. I was trying to forget what had happened and I was getting on with life and things were OK.'

Others in the study did not ever receive results other than what they read in the death certificate. In this way misunderstanding was perpetuated and one participant saw it as a lack of concern for relatives.

For parents receiving results of the post mortem on their babies, the experience was emotionally charged and meaningful in terms of subsequent pregnancies. In some cases, the obstetrician met with parents to provide an outline of the results. The mother below spoke of her shock at the information received.

'It was like a second huge blow of, this will happen again, this is a recurring condition.'

When a cause of death was not determined by the PM, conflicting feelings can arise for parents considering a subsequent pregnancy.

'I thought I'd feel kind of relieved about that, but it kind of made me more anxious, but at

the same time I was kind of glad that there wasn't something like that [a genetic problem that might recur].'

However, it also led them to be concerned that something they had done had caused the baby's death.

#### Discussion

Exploring relatives' experiences at the time of a deceased relative's post mortem adds a dimension to the literature on bereavement and bereavement care previously under-researched. This study gives useful insight into factors influencing decisions about post mortem and emotional engagement with the processes taking place. There was variation between participants related to the circumstances and location of the relative's death, in experiences of information provision, supported decision making regarding whether or not to authorise a post mortem, and bereavement support in the midst of the post mortem process. The study was limited by slow recruitment resulting in a small sample of participants taking part in interviews. The sample was also dominated by the female perspective, with only one man taking part. A protocol of recruitment via statutory services may have facilitated a larger and more representative sample.

Post mortem, the focus of this study, may not necessarily make a significant contribution to the overall experience and related story of the death developed by bereaved relatives. That said, many participants expressed their motivation for taking part in the study as being a wish to improve the overall bereavement experience for others, and issues around post mortem are part of this. For some, the finer details of being asked for authorisation or being informed the post mortem was taking place were difficult to remember and recount in the interview. Cleiren and van Zoelen (2002) report similar difficulties absorbing information for bereaved relatives when asked for consent to donor organ donation from a relative recently dead. In some cases this reflects a lack of oral or written information, the perceived quality of relationship with the person requesting authorisation, and also the intensity of the loss and feelings of grief. However, for

others placing more importance in the story, it was important to have something to tell other family members and friends about how the relative died and for them the post mortem became a key element (Neimeyer *et al*, 2011).

A more ubiquitous theme arising in this study was centred on the relative's need to 'say goodbye' to the dead person in a way that reflected the quality of the relationship. This is consistent with previous study findings indicating saying goodbye is beneficial to relatives' grief response (Wijngaards-de Meij et al, 2008). However, when post mortem is instructed tensions can arise in relation to access to the dead person to say 'goodbye' when there is an on-going criminal investigation or there has been significant time lapse since the death (Chapple & Ziebland, 2010). In these circumstances relatives in this study understood the situation and necessary restrictions, but could still feel disempowered. However, approaches of attending staff to arranging access for relatives to see the deceased seem inconsistent and at times unnecessarily harsh. The study suggests grief and a strong emotional reaction to the loss in certain situations may release frustration with authorities. For parents bereaved by suicide taking part in a Swedish study, most decisions about viewing were not regretted in later years (Omerov et al, 2014). However, those who viewed were at higher risk of reliving the death and intrusive memories. These findings are supported in the earlier work of Chapple and Ziebland (2010).

The quality of communication between relatives and healthcare or mortuary staff may be the difference between an experience gathering great significance in a negative way or becoming a small part of the overall story. The use of written information about post mortem was not apparent for participants in this study who, on the whole, did not recall being provided with leaflets or the nature of their content. It is therefore unclear whether this affected decisions on whether or not to authorise the post mortem. However, there was consideration in the study of the amount of information relatives believed was necessary. They did not need to know in detail what the post mortem would entail, and were more in need of knowledge about how long it

would take, when the body would be released, and getting results. Sensitivity to people's needs is required, particularly if authorisation is to be granted (McDermott, 2003). Feeling listened to, and experiencing a caring and compassionate relationship takes precedence over hard information.

In common with other studies, for example McKiernan *et al* (2013) who studied a small sample of women whose husbands had died, those in this study who were suddenly bereaved expressed high distress. However, in situations where post mortem processes were taking place there were differences between participants in experiences of support. Reasons for differences are difficult to pin point, but may depend on the circumstances. For example, when the relative is present as the death takes place, face to face communication and support may be feasible and perhaps more satisfactory than having to make contact via telephone. A Japanese study revealed insufficient information is linked with increased anger and frustration in interactions with police and forensic services (Ito *et al*, 2010) and elements of this may be replicated in the current study. Walsh *et al* (2013) add that all professionals who come in contact with bereaved relatives in death work situations should know what they do can have long term effects on how the bereaved cope with their loss.

This study found communication of findings of the post mortem examination take place outside any clear follow-up process and participants described different experiences. Results were important, and participants needed to know whether anything else could have been done to prevent their relative's death (Rankin *et al*, 2002), whether anything they had done, or not done, could have contributed to the death, and that anything found could be used to inform lifestyle choices for others in the family (Oppewal & Meyboom-de Jong, 2001).

Those who had the most positive experiences of receiving results were supported by a healthcare professional who delivered information as soon as it became available (Rankin *et al*, 2002). In the procurator fiscal context, explanation before and shortly after the post mortem is recommended for families to understand and accept findings (Ito *et al*, 2010). Additionally, poor

communication of results, and for example, reading the cause of death on the death certificate can potentially lead to misunderstanding and distress for the family (Mayer *et al*, 2013).

The study indicates further research may be needed to establish support needs of families in both the hospital and procurator fiscal setting when post mortem is to take place. In addition, some role definition and identification of competencies for healthcare staff and other death workers is needed in relation to communication around post mortem processes. This may inform debate about appropriate designated roles in an organisation to support relatives in post mortem situations, and it may be that a social work role, as has been developed in other countries (Drayton, 2013) would be beneficial in the UK context. In addition, opportunities should be explored for development of education and training for both healthcare staff and those employed in fiscal settings (Kerslake *et al*, 2014).

### Conclusion

The study was an opportunity for participants to recount experiences around the time a relative died and subsequent involvement with post mortem services. The idea that others may not need to suffer in the same way was a key factor in participation. A range of experiences were described and overall, encouraging death workers to develop communicative relationships with families appears to be important for adaptation and coping after bereavement.

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### **Conflicts of interest**

None

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Table 1: Participants

Interviewee	Circumstances	Post mortem
Bereaved mother	Stillbirth	No
Bereaved mother	Stillbirth	Yes , hospital
Bereaved mother	Neonatal death	Yes , hospital
Bereaved mother	Neonatal death	Yes , hospital
Bereaved mother	Adult son, road traffic crash	Yes, procurator fiscal
Bereaved wife	Homicide	Yes, procurator fiscal
Bereaved wife	Sudden death	Yes, procurator fiscal
Bereaved daughter	Expected death of mother in hospital	Yes, hospital
Bereaved partner (male)	Partner (female) died by suicide	Yes, procurator fiscal
Bereaved mother	Adult son, heroin overdose	Yes, procurator fiscal
Bereaved wife	Sudden death	Yes, procurator fiscal
Bereaved daughter	Expected death of father in hospital	No
Bereaved wife	Husband died in hospice–planned PM	Yes, hospital