Maternity Healthcare chaplains and perinatal post-mortem support and understanding in the United Kingdom and Ireland: An exploratory study.

Abstract:

Perinatal autopsy rates have declined significantly in recent decades. There is a lack of consensus concerning the potential religious influences for bereaved parents in their decision making process for post-mortem. This online study of British and Irish maternity healthcare chaplains explored their understanding of general and local perinatal post-mortem procedures and their experiences in the support of parents. Participants included Christian, Muslim and non-faith chaplains. No chaplain identified any religious prohibition to perinatal post-mortem. A majority of chaplains reported that they had been asked about post-mortem by parents; only a minority felt adequately prepared. A key recommendation is that following appropriate training chaplains may be well placed to support colleagues and parents during the decision making process.

Keywords: Post-mortem; Autopsy; Chaplaincy; Bereavement; Stillbirth; Perinatal

Introduction:

Perinatal death remains one of the most challenging areas of obstetric and neonatal practice with recognised personal and professional challenges for healthcare providers (A. E. Heazell et al., 2016; McNamara et al., 2017; D. Nuzum, Meaney, & O'Donoghue, 2014; D Nuzum, Meaney, O'Donoghue, & Morris, 2015). Understandably, for bereaved parents the death of their baby around the time of birth is a devastating reality which has far reaching experiences of challenging bereavement and associated sequalae (Burden et al., 2016; Cacciatore, 2013; Harper, O'Connor, & O'Carroll, 2011; D. Nuzum, Meaney, & O'Donoghue, 2018a; D Nuzum, Meaney, & O'Donoghue, 2017). Naturally for bereaved parents and clinical staff, the death of a baby raises many questions which for many, motivates them to seek to understand the causes and reasons for the death (D. Nuzum et al., 2018a). In the renewed global drive to reduce preventable stillbirths post-mortem examination is an important source of valuable data (Goldenberg et al., 2011; Miller, Minturn, Linn, Weese-Mayer, & Ernst, 2016). In seeking to answer questions concerning the potential cause(s) of perinatal death, full perinatal post-mortem examination remains the gold standard investigation (Ernst, 2015; A. E. Heazell & Martindale, 2009; Miller et al., 2016). Some perinatal post-mortem examinations are mandated by a legal coronial process (and do not require parental consent) while others require parental consent/authorisation. However, well publicised organ retention scandals in both the United Kingdom and Ireland, a legacy of strong feeling surrounding parental consent and a 'paternalistic approach' to decision making and sources of information concerning perinatal post-mortem have led to a considerable reduction in the uptake of consented/authorised post-mortem uptake particularly in areas of deprivation (Downe et al., 2012; Evans, Draper, & Smith, 2020; A. E. P. Heazell et al., 2012; Horey, Flenady, Conway,

McLeod, & Yee Khong, 2014; Horey, Flenady, Heazell, & Khong, 2013; Khong & Tanner, 2006; Madden, 2006; Meaney, Gallagher, Lutomski, & O'Donoghue, 2014).

Post-mortem decision making:

Various efforts have been made in recent years to restore parental confidence in perinatal post-mortem and amongst these efforts has been a greater involvement of the wider healthcare team as well as clearer consent procedures and pathways for the respectful disposal of retained organs in accordance with parental wishes (Health-Service-Executive, 2012). In addition, studies have sought to understand more clearly the potential influences for parents in their decision making processes surrounding perinatal post-mortem (Breeze, Statham, Hackett, Jessop, & Lees, 2012; Horey et al., 2014; Meaney et al., 2014).

In line with this many institutions now offer parents options on the type of hospital post-mortem carried out:

1. Full/complete post-mortem (removal and examination of all organs) - regarded by many as the gold standard.
2. Limited (where examination if limited to a specific organ eg. Heart or lungs or brain) (Lewis, Hill, et al., 2018).
3. Minimally invasive (eg targeted tissue sampling) (Ben-Sasi et al., 2013; Feroz et al., 2019).
4. External only
5. Virtual autopsy (MRI imaging) though this may not be available in all centres (Ben Taher, Pearson, Cohen, & Offiah, 2018; Kang, Carlin, Cannie, Sanchez, & Jani, 2020).

All of these, in the case of stillbirths or perinatal loss will be accompanied by detailed examination of the placenta.

Role of healthcare chaplains and belief:

One area that has been less explored is the role of healthcare chaplains and faith as possible influencers in the perinatal post-mortem decision making process by bereaved parents and in line with this they should be cognisant of the various options and their benefits or limitations.

Previous studies concerning adult post-mortem organ donation and autopsy have indicated that belief structures can influence the decision making processes of patients and families with regard to what happens to a body after death (Charlier et al., 2013; Krupic, Westin, Hagelberg, Sköldenberg, & Samuelsson, 2019; Lewis, Hill, et al., 2018; Tarabeih, Abu-Rakia, Bokek-Cohen, & Azuri, 2020). Most world religions are concerned with the care of the human body after death and have prescribed rituals and customs for reverent disposal.

For most people of faith the human body retains a dignity in death and therefore is treated with respect (Charlier et al., 2013; Mohammed & Kharoshah, 2014). In some cases religious prescriptions determine both place and format of disposal such as burial or cremation, as well the timing of burial, for example in Judaism and Islam burial within one day is the norm. There are also some religious teachings on the importance of maintaining the integrity of the human body after death. Religious leaders are often consulted about decisions when the usual post death practices such as burial are interrupted or delayed, or where there are questions concerning the appropriateness of interventions (Krupic et al., 2019). On occasion religious leaders have voiced opposition to autopsy and other post-mortem investigations or procedures such as organ donation (Tarabeih et al., 2020). It is not unreasonable to deduce

that for some parents their decision to decline a perinatal post-mortem investigation may be influenced by their religious or faith beliefs associated with end of life care practices. In religious terms, beliefs such as these are not mere practicalities, but have a bearing on the existential understanding of the 'place' of a baby and not wishing to do anything that might impact that negatively within an already difficult and disorientating experience of grief and loss. Previous studies have also reported that lack of information or confusion about faith teaching can lead to caution on the part of families when faced with decisions concerning human remains (Tarabeih et al., 2020). It is also true that popular religious views can be at variance with official religious teaching in the area of post-mortem examination (Lewis, Latif, et al., 2018). There has also been a recognition that the treatment of the remains of stillborn babies in previous generations for example burial outside formal graveyards and lack of religious ritual caused additional trauma and hurt and compounded the loss. Further, the definition of stillbirth has altered over the years based on the age at which a baby is considered viable and is now defined in UK and Ireland as "*A child which has issued forth from its mother after the 24th week of pregnancy and which did not at any time breathe or show signs of life"* (UK) and "*a child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life*" (Ireland).

This definition allows for the registration of such infants but there is also a need to consider those infants born prior to 24 weeks who are not legally considered stillbirths but rather perinatal losses which can cause hurt to many families.

Role of healthcare chaplains:

Healthcare chaplains working in maternity settings are mostly responsible for the provision of pastoral and spiritual support and counsel for bereaved parents and staff colleagues. As

part of this role chaplains can be consulted on matters of faith and religious practice, especially when patients find themselves in an unexpected situation as is often the case when parents experience perinatal death. It is also recognised that healthcare chaplains may play a wider role in the provision of ethical support and may make other significant contributions to the healthcare institution eg being part of ethics committees. Previous studies have demonstrated the collaborative role that chaplains can have with respect to medical/bioethical decision-making, however, there is an absence of literature with regard to chaplains and decision-making with respect to perinatal post-mortem (Carey & Cohen, 2008; Jeanne Wirpsa et al., 2019). As healthcare professionals, healthcare chaplains are expected to be professionally competent in the facilitation of ethical dimensions of care when requested by patients or staff colleagues.

Healthcare chaplains have historically come from Christian denominations in the United Kingdom and Ireland. However in recent years there has been a considerable growth in the recognition and provision of formal chaplaincy/ pastoral support from all faith and secular groups -of particular note has been the increasing provision of pastoral support for those who identify as 'non-religious'. The training of healthcare chaplains has also reflected this and core competencies are that healthcare chaplains are sensitive to the individual religious/ philosophical and ethical views of all patients.

As recent studies by Meaney *et al* have highlighted, staff play a role in the decision making process for post-mortem and in pregnancy loss, it is possible that maternity healthcare chaplains also have an influence and role in this process should religious/ faith questions arise for parents (Meaney, Corcoran, Spillane, & O'Donoghue, 2017; Meaney et al., 2014). Indeed previous studies and advisory papers have highlighted the positive role that religious

communities can have in promoting accurate health information that may at times be seen to conflict with religious teaching (Gatrad & Sheikh, 2001; Mohammed & Kharoshah, 2014). As staff members, healthcare chaplains potentially have an influencing role if counselling parents concerning post-mortem examination.

Aims:

The aim of this study was to ascertain if British and Irish maternity healthcare chaplains had a role in the decision making, information and supportive care process surrounding perinatal post-mortem with bereaved parents and perinatal pathology staff.

Methods:

An online survey was created by the research team and piloted locally to collect data on the knowledge, experiences and possible religious influences of maternity healthcare chaplains surrounding their involvement in perinatal post-mortem information and support with bereaved parents and perinatal pathology staff. An opt-in consent was included at the beginning of the online survey description which was required before accessing the survey.

Ethical approval for this study was granted by the local Clinical Research Ethics Committee (Ref. No: ECM 4 (a) 07/03/18).

Sample:

The survey link was circulated by email through the professional healthcare chaplaincy networks in the United Kingdom and Ireland and a Chaplaincy and Spiritual Health *JISCMail* forum with the stated aim of recruiting chaplains who work in maternity settings. Participants

who preferred to complete the survey in hard copy format were also facilitated. This arose for a minority of participants where institutional firewall barriers at their place of work prevented access to online studies. A six weeks time frame was given to complete the study. The data were analysed using Microsoft Excel.

Results:

Participants:

There were forty six respondents from maternity services in Ireland and the United Kingdom. The overall response rate was 22%; n=46. The vast majority (94%; n=43) of participating chaplains were formally employed/appointed healthcare chaplains in the health service and all were working in maternity or neonatal settings within a mixture of co-located and stand-alone maternity units. The remaining chaplains were primarily engaged in their faith community and provided chaplaincy support on an on-call/ referral basis.

Religious demographics and influence(s):

The stated religious identities of participating chaplains was as follows: Anglican (44%; n=20), Roman Catholic (33%; n=15), other Reformed (17%; n=8), non-Religious (4%; n=2), Muslim (2%; n=1). No chaplain identified that their religious teaching specifically prohibited post-mortem examination, however four chaplains -three Christian and one non-religious chaplain- indicated that their religious teaching does not have a view on perinatal post-mortem. One chaplain identified that Catholic teaching would make perinatal post-mortem examination difficult for parents. Chaplain demographics are shown at Table 1.

Pastoral practice and experience:

Most chaplains indicated that they had been called to provide care for parents following a stillbirth or neonatal death; when asked if they provide services/ ceremonies following stillbirth/ neonatal death most chaplains (91%; n=42) reported that they do.

When asked about frequency of involvement in perinatal bereavement care over the previous five years a majority of participants (67%; n=31) were called more than six times, just under a quarter of participants (24%; n=11) had been called fewer than six times and a minority (9%; n=4) had never cared for families following stillbirth. The length of service/ experience of participating chaplains less than five years was 44%; n=20, five-ten years 17%; n=8 and greater than ten years was 39%; n=18.

A majority of chaplains (61%; n=28) reported that bereaved parents had asked their advice about post-mortem examination on at least one occasion; twelve chaplains (26%) reported that they had been asked more than six times in the past five years. However, only a minority (41%; n=19) felt sufficiently informed about post-mortem practice to be able to support parents and to offer advice about perinatal post-mortem and of these 74%; n=14 had received specific education/ information about the post-mortem process. A small minority of chaplains (9%; n=4) indicated that they had not been called to provide support for bereaved parents following stillbirth in the past five years. Almost all respondents (98%; n=45) felt that chaplains should be involved in discussions concerning post-mortem examination if requested by a bereaved family.

Just over half of respondents (52%; n=24) indicated that they knew who in their trust/ hospital carried out post-mortems. Most chaplains (89%; n=41) indicated that they would be

willing to contact pathology staff on behalf of bereaved parents to discuss specific religious issues or spiritual needs in relation to a post-mortem examination following a stillbirth. A quarter of chaplains (25%; n=11) have been approached by pathology staff for support following their involvement with stillbirth or neonatal death and of those who have, 40%; n=4 have been approached six times or more for support.

Stillbirth understanding:

All participants were asked about their understanding of stillbirth and whether stillbirth should be investigated. Just over half of chaplains (52%; n=24) were able to correctly identify the incidence of stillbirth at 1 in 200 births however, just under a quarter (22%; n=10) of chaplains underestimated the incidence of stillbirth at 1 in 1000 births and a minority (17%; n=8) believed that the incidence was more common at 1 in 50 births When asked whether all stillbirths can be prevented, a majority (76%; n=35) believed that not all stillbirths can be prevented.

When asked about the causes of stillbirth a majority of chaplains (67%; n=31) felt that the cause of stillbirth is usually unexplained, 54%; n=25 felt the cause was due to something being wrong with the baby, 46%; n=21 attributed the cause to something being wrong with the mother, and 35%; n=16 believed that the cause was due to something being wrong with the care provided. Most chaplains agreed that stillbirth is more common than cot death.

Discussion:

These data highlight that British and Irish maternity healthcare chaplains recognise that they have a role in the overall supportive and information processes with bereaved parents

concerning perinatal post-mortem examination support. As most maternity healthcare chaplains are involved in the care and support of bereaved parents, they are well placed to provide supportive care should parents wish to discuss post-mortem options with them.

The data in this study identified that while chaplains reported that bereaved parents discuss perinatal post-mortem with them, most participating chaplains felt ill-equipped to have these conversations. Previous studies by Meaney *et al* highlighted the role of staff in the overall supportive care process following pregnancy loss (Meaney et al., 2014). As chaplains are closely involved in the provision of post death ritual and ceremony, it would be of benefit if chaplains were more closely integrated into the overall post-mortem care process, particularly as post-mortem examinations will most likely impact on timing of ritual and burial/cremation which may be a source of concern for bereaved parents. While the formal perinatal post-mortem consent process is a clinical activity, should parents wish to explore any impact on their religious/spiritual views or ritual the chaplain would be well placed to provide accurate information and to facilitate conversation as part of the decision-making process. Consonant with previous studies on stillbirth with maternity healthcare chaplains, this study highlights the requirement for increased education and support for chaplains in this sensitive area of care (D. Nuzum, Meaney, & O'Donoghue, 2016).

No participant in this study identified any religious prohibition to post-mortem examination. However, when considered alongside some of the published literature on religious attitudes towards post-mortem, this study supports the view that lack of or confusing information is often shared about post-mortem and religious teaching and practice (Krupic et al., 2019; Mohammed & Kharoshah, 2014; Tarabeih et al., 2020). This raises challenging questions where parents may in fact be influenced by a lack of full understanding about any potential

religious/ spiritual concerns as part of their decision-making process. Where this impacts negatively on a decision not to consent to a post-mortem, parents are potentially further impeded in their grief with a lack of information and diagnosis about their baby's death. In fact when the broader religious literature is examined, many of the received 'prohibitions' against post-mortem are as much cultural as they are religious (Avşar, Okdemir, Keten, & Kaya, 2019; Mohammed & Kharoshah, 2014). In some cases the religious texts are applied without sufficient examination, hermeneutical rigour or due consideration of the clinical situation. When combined with the distress and turmoil of perinatal bereavement and within the context of a finite timeline for bereaved parents it can be argued that accurate religious and clinical understanding is paramount to support parents in what is most likely a difficult decision. Professionally trained healthcare chaplains are well placed to navigate this emotional and liminal space and in so doing to bring supportive value to the wider multidisciplinary team.

Decision-making and consent for perinatal post mortem is a complex multidimensional process for healthcare professionals but most especially for bereaved parents at a distressed time. For this reason no single stage can be taken in isolation and although religious/cultural beliefs are seen as part of a wider understanding of personal beliefs Downe e*t al* highlight that 'professional views and family decision-making about post-mortem after stillbirth are affected by …education and training of staff … and interpreted through personal beliefs and emotions' (Downe et al., 2012). Building on the wider literature by Carey *et al* and Wirpsa *et al* concerning the role that healthcare chaplains can have in complex ethical decision-making processes, this study highlights the professional role that chaplains can fulfil when parents wish to explore perhaps in a non-medical way the potential religious/ belief influences in their decision-making about perinatal post-mortem. The data from this study affirms the

importance of all healthcare chaplains being appropriately educated and supported in their role in this regard within the multidisciplinary maternity healthcare team.

Previous studies have highlighted the lack of knowledge concerning stillbirth and the causes of stillbirth for both healthcare chaplains and for the wider public (D. Nuzum et al., 2016; D. Nuzum, Meaney, & O'Donoghue, 2018b). The data from this study when compared with a population study identified that a higher number of chaplains felt that the cause of stillbirth was unexplained (67% vs 53%) (D. Nuzum et al., 2018b). These data indicate that maternity healthcare chaplains are not fully aware of the recent advances in diagnosis of cause of stillbirth in recent years. The latest published data for Ireland indicates that unexplained stillbirth has reduced to 11.1% (O'Farrell, Manning, Corcoran, & Greene, 2019). The significance of this when combined with lack of education and the number of conversations reported in these data between bereaved parents and chaplains, is that chaplains are operating from a place of uncertainty which has the risk of potentially instilling less confidence in the value of post-mortem examination when parents are equivocal.

Staff support is a key role of healthcare chaplains. It is well recognised that perinatal bereavement is challenging for healthcare staff and for chaplains (Gold, Kuznia, & Hayward, 2008; McNamara et al., 2017; D. Nuzum et al., 2014; Daniel Nuzum, Meaney, & O'Donoghue, 2016; D Nuzum et al., 2015). This study demonstrates the role that chaplains are playing in the support of pathology colleagues. Of note, almost all respondents indicated that they would be willing to engage with their pathology colleagues. With a growing recognition of the impact of challenging areas of healthcare practices on staff, chaplains are well placed to provide supportive and integrated care in the healthcare setting. Following a number of years of negative publicity, the speciality of perinatal pathology has identified

challenges in both retention and recruitment of pathologists willing to perform autopsy in addition to potential de-skilling of pathologists and anatomical pathology technicians due to reduced numbers of full post-mortems (Snowdon, Elbourne, & Garcia, 2004). The supportive pastoral role of chaplains can contribute to overall wellbeing and team support.

Strengths & Limitations:

The response rate in this study was low at 22% which may be a reflection of the challenge of online recruitment and access to the study for chaplains who could not access it because of institutional firewalls. While the response rate was low, participants engaged fully with the questionnaire and represented a range of religious and non-religious experience. The study had a low number of participants outside the main Christian denominations and the absence of a Jewish input, however this reflects the demography of chaplains in Ireland though less so in the United Kingdom. The low response rate limits the generalisability of the findings to the wider healthcare chaplaincy population. For future studies in this area, recruitment and response might be higher if each maternity unit was approached directly.

A major strength of this study is that this is the first study to capture the views and experiences of British and Irish maternity healthcare chaplains in the area of perinatal post-mortem examination support. The overall congruence of religious teaching expressed by Christian, Muslim and non-religious chaplains of the permissibility of perinatal post-mortem examination is a strength in an area of religious ambivalence. Furthermore, in an under researched area the data from this study highlight the need for further study of the role of healthcare chaplains in this sensitive and important area of healthcare. It is also a strength that this first study with maternity healthcare chaplains and perinatal post-mortem support

will provide a valuable foundation for further studies in this area both with maternity healthcare chaplains and multidisciplinary colleagues. This study also contributes the perspectives of healthcare chaplains to the existing perspectives of midwifery, obstetric, and pathology professionals in the published literature in this field.

Recommendations and Conclusion:

The data from this study highlights the role that maternity healthcare chaplains can have as integrated members of the multidisciplinary team in the area of perinatal post-mortem support. The data supports the need for increased education and training so that healthcare chaplains in this case are more confidently aware of the overall post-mortem process which in turn will help them to be better placed to respond informatively and supportively when supporting parents. This study highlights the positive role that maternity healthcare chaplains can have in the professional ethical support and discourse with bereaved parents when faced with sensitive and potentially distressing conversations concerning perinatal post-mortem.

The provision of education in this area is one that should be provided in a multidisciplinary context so that on the one hand healthcare chaplains have a greater understanding of the post-mortem process and on the other, so that the wider multidisciplinary healthcare team would gain a greater awareness and understanding of the possible influence of religious/ philosophical beliefs in the overall consenting process. Indeed such an approach has been successfully piloted through the Pregnancy Loss Research Group at The Irish Centre for Maternal and Child Health Research (INFANT) at University College Cork, Ireland. In the growing provision of online training modalities, new opportunities should be explored to provide integrated training to a wider audience of maternity healthcare chaplains.

Where religious issues arise for bereaved parents, this study reinforces the positive role that healthcare chaplains can have in the interpretation and engagement with these issues in an informed and faithful way both as religious/ non-religious leaders and as healthcare professionals. This study also highlights the role that chaplains can have in the overall care of staff colleagues in an area that has been beset with historical challenge and public opinion and yet remains the gold standard of care for the investigation of perinatal death.

Building on previous studies with other maternity healthcare professionals seeking to reverse the downward decline in perinatal post-mortem, this study, albeit from a small sample, adds the perspectives of maternity healthcare chaplains. In doing so it highlights the potential role that religious beliefs can have in a delicate process with grieving parents and identifies the educational needs to support maternity healthcare chaplains in this regard.

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Table 1: Chaplain demographics

Chaplain Demographics	
Faith background	Anglican (44%; n=20)
	Roman Catholic (33%; n=15)
	Other Reformed (17%; n=8)
	Non-Religious (4%; n=2)
	Muslim (2%; n=1)
Years of Service	<5 years (44%; n=20)
	5-10 years (17%; n=8)
	>10 years (39%; n=18)