Article:
Reed, K., Ferazzoli, M.T. and Whitby, E. (2021) “Why didn’t we do it”? Reproductive loss and the problem of post-mortem consent. Social Science and Medicine, 276. 113835.

https://doi.org/10.1016/j.socscimed.2021.113835

"Why didn't we do it"? Reproductive loss and the problem of post-mortem consent

Kate Reed, Maria Tereasa Ferazzoli and Elspeth Whitby

Accepted for publication in *Social Science and Medicine* (10th March 2021)

Informed consent has been a much debated topic within the social sciences. It often forms a central feature of discussions on research in medical settings and in social research methods more broadly. While sympathetic to its' underlying principles of autonomy and choice, social scientists have tended to argue that these are seldom enacted in research or clinical practice. Rather, such principles are often circumscribed by wider social structures and by a culture of medical dominance. Drawing on data from a qualitative study on perinatal post-mortem, this paper explores informed consent in the emotionally charged clinical arena of perinatal pathology. Our in-depth analysis will provide fresh insight into post-mortem decision-making in the sensitive arena of baby loss. Our findings show how parents often found it difficult to *give* consent for post-mortem, and also for professionals to *take* consent from parents. It was also not uncommon for parents to experience regret over non-consent later on. One of our key findings, however, related to the sense of emotional and diagnostic closure often afforded by post-mortem when consent had been given. We conclude by arguing that, although we cannot resolve the tension between the principles of consent and their enactment in practice, we can develop a reflexive approach with which to navigate the process. In doing so, the paper contributes to wider sociological discussions on the meaning and use of informed consent in various settings beyond medical contexts.

Keywords;

Informed Consent, Perinatal Post-mortem, Reflexivity

Corresponding and lead author: Professor Kate Reed, Department of Sociological Studies, University of Sheffield, Elmfield, Northumberland Road, Sheffield, S10 2TU, UK, k.reed@sheffield.ac.uk +44 (0)114 22226478

Introduction

Clinical research shows that consented autopsy (post-mortem) practice has markedly declined across all age groups in the UK (Turnball *et al.,* 2015). Autopsies can play a key role in the advancement of scientific knowledge, epidemiology, clinical governance and medical education (Burton and Underwood, 2007). Information provided by autopsy can also benefit family members seeking closure after the loss of a loved one (Rankin *et al*., 2002). There are currently two main types of post-mortem in operation in the UK: a coronial post-mortem and a hospital post-mortem. A coroner may choose to order a post-mortem if a death is perceived to be sudden, violent or unexplained. Hospital post-mortems may be requested by doctors to find out cause of death or sometimes by relatives. It is important to note, however, that hospital post-mortems cannot take place without the consent of relatives (NHS 2021). Consent, however, has been identified as a key reason behind the declining rates of autopsy, with clinical studies indicating a lack of consistency in consent policy and professional training across the UK (Eka *et al.,* 2014; Henry and Nicholas, 2012). Discourses around the meaning of informed consent are highly charged, particularly regarding babies and children. This is especially the case in the aftermath of the organ retention scandal of 1999, when it was discovered that bodily organs and tissues of babies and children were used by some UK hospitals for purposes other than autopsy (Sheach Leith, 2007). While informed consent was placed at the centre of the Human Tissue Act of 2004, the process remains an extremely emotive and contested issue, particularly in the context of paediatric post-mortem.

Informed consent has received significant attention in social research in recent decades arising in response to an increase in research governance and regulation in the UK. The findings of studies on informed consent suggest this process is far from straightforward in either principle or practice (Richardson and McMullan, 2007). As Wiles *et al.* (2007) argue, it is difficult to reach a consensus over the meaning of the concept and how it might be applied to different groups in different research contexts. This has led some sociologists to view the concept as socially constructed and subject to change (Miller and Boulton, 2007). Medical sociologists have extended this critique to clinical research and practice. According to Corrigan (2003) the assumption behind the use of informed consent in health care settings is that it will protect the rights and welfare of individuals by offering them the ability to make free and informed choices. Zussman (1997) and others have argued, however, that in practice, the cultural authority of medicine and wider social structures often prevent patients from making informed decisions about their own care. Drawing on data from a qualitative study on perinatal post-mortem, this paper sheds light on some of the problems

associated with both *taking* and *giving* post-mortem consent. It will also uncover some of the hidden benefits of post-mortem, for both parents and professionals once consent is given. By doing so, this paper seeks to extend the focus of existing work on post-mortem in the difficult and taboo area of reproductive loss, and also contributes to broader sociological understandings on the meaning and value of informed consent.

The article proceeds with a brief overview of sociological literature on informed consent, outlining the conceptual focus of the paper. Some background context to perinatal post-mortem will also be provided along with a summary of the method used in the study. The main part of the article is concerned with the interview findings, presented in three sections which will explore in turn: parent fears and regrets around *giving* or not giving consent, the dual nature of sensitivity and paternalism underpinning professional accounts on *taking* consent, and finally, the emotional and diagnostic closure often afforded when post-mortem *is* consented to. Sociologists have consistently argued that, while the principles of autonomy and choice are admirable, these can rarely be adhered to in practice in either research contexts or clinical practice. Whilst we broadly agree with this analysis, the paper concludes that informed consent can nonetheless be productively navigated through the adoption of a more reflexive approach to this process. By drawing parallels between consent in clinical research and practice and in social science- based research we do not wish to suggest that they are the same. While the former may involve consent to life changing medical intervention the latter focuses on the disclosure of individual and collective experiences on a range of issues. There are, however, commonalities across these areas relating to tensions in the relationship between the person *taking* consent and those *giving* consent, and, in the management and flow of information about consent. We argue, therefore, that it is useful to explore and situate our analysis of post-mortem consent within this wider context.

The sociology of informed consent

Informed consent has been a widely debated topic across the social sciences over the past few decades, most notably in the context of debates on social research. The principles behind informed consent derive from utilitarian theories of ethics, which focus on the purpose of actions (Richardson and McMullan, 2007), and relate specifically to the need to protect the rights and autonomy of individuals. However, as Wiles *et al.* (2007) argue, there is often no consensus amongst researchers concerning what comprises 'informed consent', or whether the same sets of principles and procedures are equally applicable to research among different groups. As Coomber (2002) notes, for example, certain aspects of the informed consent process- such as obtaining

written consent- are inappropriate in research contexts where the preservation of anonymity is paramount (for example when studying criminal populations). According to Miller and Boulton (2007), informed consent is a socially constructed concept, its meaning and use are subject to forces of change. However, with the advance of risk society, there has been a shift away from viewing consent as a moral discourse to one of greater regulation (Beck, 1992; Miller and Boulton, 2007). While consent remains a contested concept, sociologists tend to agree that the process should not be viewed as a one-off event in social research, but an ongoing, co-productive and reflexive endeavour that occurs before during and after the act of research (Sin, 2005; Wiles *et al.,* 2007).

Consent has long been central to medical research and practice. In the USA, for example, informed consent became central to protecting patient rights during the 1960s (Zussman, 1997). In recent decades, sociologists have indicated that consent in clinical settings is often an incomplete process (Jordens *et al.,* 2013). It has, however, tended to be viewed as an 'ethical panacea' used to counteract autocracy and paternalism in healthcare contexts (Corrigan, 2003: 768). The underlying aim of informed consent is to facilitate patient autonomy and choice over healthcare decision-making (Zussman, 1997). However, as Corrigan argues, patients are seldom able to make free choices in practice because 'prevailing cultural norms, values and systems of expertise shape the field of choice' (2003: 789). Dixon-Woods *et al.* (2006) conducted a qualitative study on women's experiences of obstetrics and gynaecology surgery. They argue that, rather than reinforcing autotomy, informed consent can actively contribute to the disempowerment and disenfranchisement of patients as they become enmeshed in hospital systems and processes. Furthermore, in the context of post-mortem, Sheach Leith (2007) argues that notions of being a good citizen and gifting or donating bodies to medical science further tempers the emphasis on individual autonomy. These problems have led medical sociologists to argue for more nuanced concepts of freedom, autonomy and consent in clinical research and practice (Corrigan, 2003).

Developing a reflexive approach to consent

This paper seeks to contribute to existing sociological literature on consent in research and clinical practice. While we broadly agree that the underlying principles of consent- autonomy and choice- do not always work in practice, we also seek to show that there is more diversity in this process than often accounted for in existing literature. Our aim is to champion a broader and more reflexive approach to post-mortem consent. Reflexivity has been central to, but also extends beyond feminist approaches to understanding and reshaping relationships in social research (Bondi, 2009; Wasserfall, 1993). It refers to the need for critical self-reflection in research at an

individual, disciplinary and institutional level (Bourdieu in Wacquant, 1989; Denscombe, 2014). By recognising that "all knowledge bears the impress of the social relations entailed in its production", feminists have argued that reflexivity is able to shed light on the "complex power relations between researchers and research participants" (Bondi, 2009: 328). Critics suggest that such self-reflection by the researcher is self-indulgent, potentially reinforcing rather than overcoming power relations in the research process (Finlay, 2002; Faria and Mollett, 2016). While acknowledging that power relations cannot necessarily be undone, they can, however, be reflected and acted upon (Bondi, 2009). Reflexivity, therefore, has continued to be reinforced as a means to deepen our understanding of the phenomenon under study and the research process itself (Watt, 2007).

The process of reflecting on actions, and then learning from those reflections, has also been used to inform different types of professional development and practice including: psychotherapy, architecture, engineering and management (Schön, 2016). The usefulness and applicability of reflexivity, both within, and beyond the social sciences, therefore, indicates its potential relevance for our discussions on post-mortem practice. We aim to build an approach which situates consent practice within a wider clinical, cultural and social context. Our approach encourages professional reflexivity and pays attention not just to *when* consent is sought but also by *whom* and w*here*. Reflecting on these issues is important because it helps us to better understand the operation of medical power, paternalism and empathy which both enhance and hinder the consent process. A reflexive approach also enables us to open up to scrutiny, the actual post-mortem examination, highlighting some of its unanticipated benefits in the process. Adopting such an in-depth reflexive approach cannot resolve the fundamental tension between the philosophical principles of consent and their enactment in wider research or in clinical practice. It does, however, add important social, cultural and clinical context to consent practice, and, in doing so facilitates the navigation of this process for social scientists' seeking to study informed consent in various settings, and also those who use it in professional practice.

The sensitive area of perinatal postmortem

The human tissue act of 2004 (in England, Wales and Northern Ireland) required that consent be obtained (usually from the next of kin) for autopsies not conducted for medico-legal reasons (Burton and Underwood, 2007). Similar approaches to autopsy have been adopted across Europe and the USA although there are variations (Svendsen and Hill, 1987). In the USA, for example, laws pertaining to authorization for autopsy often vary among states (Connolly *et al.,* 2016). In the UK, full post-mortem remains the clinical gold standard and can include: external review of the body, dissection, blood tests, tissue sampling amongst other tests as deemed

appropriate. Minimally invasive post-mortem (MIA) is an emerging type of post-mortem, often involving external review, placental examination, and ancillary tests that form part of the formal autopsy process. These tests are then combined with Magnetic Resonance Imaging (MRI) or a Computer Tomography (CT) scan. This type of post-mortem is an emerging option that is not yet available universally across the UK. It does also tend to be offered as a second-line option, if relatives do not wish to consent to a full post-mortem (Whitby, 2009).

Perinatal post-mortem includes deaths occurring as a result of miscarriage, termination of pregnancy, stillbirth, neonatal and late neonatal death, and infant deaths up to one year. It can play an important role in understanding the cause of death of babies and infants (Downe *et al.,* 2012; Lewis *et al.,* 2019). Medical research continues to show, however, that consent for such post-mortems is decreasing (Lewis *et al.,* 2019; Stock *et al.,* 2010), and that both g*iving* and *taking* consent remains a difficult topic for both professionals and parents (Heazell *et al.,* 2012). Studies have identified a number of reasons as to why parents don't want to consent their baby for post-mortem. According to Rankin *et al.* (2002) for example, parents often feel that their baby has suffered enough. They don't want them cutting up and are worried about their baby's appearance after the examination. Research has also shown how, in light of the organ retension scandal, parents often raise concerns about their baby's body wholeness (Sheach Leith, 2007). Studies have shown that the availability of minimally invasive techniques could improve rates in these cases (Ben-Sasi *et al.*, 2013; Lewis *et al.,* 2017; Kang *et al.,* 2014). Finally, most studies on post-mortem identify religion as a key reason as to why parents don't feel able to consent. This can affect parent decision-making in a range of ways including, for example, concern that the post-mortem process will delay burial arrangements (Heazell *et al.*, 2012; Downe *et al.,* 2012; Ben-Sasi *et al.*, 2013; Lewis *et al.,* 2017, 2019; Rankin *et al.*, 2002; Kang *et al.,* 2014; Breeze *et al.,* 2012).

Research also shows how parent and professional interaction can have a massive impact on parent decision-making on post-mortem. As Lewis *et al.,* (2019: 1249) argue, parents often look to professionals to guide them and desire a conversation about post-mortem that is both 'open' and 'honest'. The findings of several studies have shown, however, that not all health professionals are aware of the benefits of post-mortem examination and therefore don't always offer it to parents as an option (Rose *et al.,* 2006; Okah, 2002). While lack of formal training for taking consent is an issue highlighted by some studies (Rose *et al.,* 2006; Downe *et al.,* 2012; Stolman *et al.,*1994), other research shows how professionals often worry about upsetting familes by starting a conversation about postmortem (Stolman *et al.*, 1994; Rose *et al.,* 2006). This paper contributes to this existing

literature by providing an in-depth sociological analysis of both parent and professional experiences of the consent process. It extends the remit of existing research on consent by focusing on a wide range of professionals (from pathologists to gynaecology nurses). It also explores different types of loss (from miscarriage to SIDS) along with various forms of post-mortem (from full post-mortem to Minimally Invasive Autopsy). Furthermore, the paper also offers a more general contribution to debates on the value of post-mortem by moving beyond the consent process to highlight some of the hidden benefits of the examination itself.

Methods

This paper draws on data from a study on the emerging role of MRI in perinatal post-mortem. The study was funded by the Economic and Social Research Council and ethical approval was received from the UK National Research Ethics Service. It was based primarily in a pathology suite at a teaching hospital in the north of England. We negotiated access to the mortuary and to staff located there via National Health Service (NHS) collaborators and a clinical co-applicant. The research design was informed by an advisory team consisting of various professionals, representatives from bereavement charities (including bereaved parents) and one manufacturer of MRI systems.

We sought to understand post-mortem experience and process from both a parent and professional perspective. Professional respondents were recruited from various occupational groups including: midwives, pathologists, coroners, obstetricians, neonatologists, anatomical pathology technicians (APTs), police officers, medical illustrators, nurses, hospital chaplains and bereavement support officers. The study included 10 male and 17 female respondents of a range of ages. We recruited participants in junior and senior posts, in low-paid roles (assistant bereavement support officers) as well as those in senior status positions (clinical heads of department). Professionals varied in the amount of experience they had in their respective roles, from between 6 months to 35 years. While all these professionals were connected in some way to post-mortem, not all were directly involved in the consent process and, therefore, not all respondents will appear in the paper. Our approach was informed by go-along ethnography, a hybrid method involving interviewing and participant observation with research participants in their own environments (Author A, 2019, 2020). We conducted interviews with all 27 participants at some point during the study, combining these with ethnographic observations and respondent-led tours as appropriate. This flexible approach enabled us to build an understanding of the complex and sensitive nature of post-mortem.

We also conducted 22 in-depth interviews with bereaved parents and family members. Four interviews were conducted jointly with both parents attending, the rest were individual interviews. One mother found it too difficult to be interviewed and chose to provide us with a written statement instead. Parents were recruited through bereavement charities, local forums and hospital consent forms. They had all experienced different types of loss: twelve parents had lost their babies through Sudden Infant Death, four from Stillbirth and one through miscarriage. One set of respondents in our study had terminated their pregnancy due to severe fetal anomalies identified during pregnancy, and three parents had experienced early neonatal death. One set of participants were bereaved grandparents. Although existing studies have highlighted differences in religion and attitude to post-mortem, there has been a relative paucity of research on the experiences of black and minority ethnic women. What research does exist has shown that black and minority ethnic women are less likely to be asked by professionals for post-mortem consent (Henderson and Redshaw, 2017). All participants in our study identified as British but chose not to disclose information about ethnicity. Unfortunately, we are unable, therefore, to make any specific comments about the effects of this issue on decisions around post-mortem consent. Only four participants identified as being specifically religious (either Muslim or Church of England). Due to limits of word-length, it is not possible to include accounts from all parents participating in the study within the context of this paper.

Data collection and analysis

The fieldwork was conducted over a period of 18 months by two members of the research team. Ethical approval was sought prior to conducting the research, securing further approvals as the project progressed to allow for in-depth ethnographic work in the mortuary. Informed consent was obtained by the researchers prior to any data collection. In line with the argument advanced in this paper, however, we also sought to reflect on issues of consent throughout the research process. During professional interviews, observations and tours we invited staff to tell us about their work practices, sometimes as they were actively engaged in these practices. We observed minimally invasive post-mortems (MIAs) in the mortuary and were attentive to the role and movement of objects in post-mortem practice. We often followed professional respondents as they went about their day-to-day work practices in different locations. By adopting this flexible and mobile approach, we were able to appreciate the ways in which different aspects of post-mortem work occur in different locations. Research has often highlighted the value of using elicitation tools during qualitative interviews (for example, photos) to help researchers and participants navigate topics that may be deemed sensitive (Woodward, 2016). In order to explore parents' experiences of post-mortem through the wider lens of bereavement and loss we

encouraged parents to bring objects such as photos memory boxes to the interview. These objects were used as part of the interview, enabling us to explore the parents' journey from pregnancy through to loss. Where appropriate, we asked parents about their experience of the mortuary and bereavement suite as hospital spaces. However, due to the extremely sensitive nature of the study, we interviewed parents in their homes or in public places (Author A, 2019, 2020).

In order to deal with the particularly sensitive nature of this project, we engaged in a range of reflexive and self-care practises such as: allowing time between interviews and debriefing where necessary (Borgstrom and Ellis, 2017). We digitally recorded interviews and also took brief notes during the observations and interviews, turning these into fuller accounts afterwards (Walford, 2009). Once we started generating a body of fieldnotes and interview transcripts, we began to analyse the data drawing on what Braun and Clarke (2019a & b) refer to as a reflexive thematic approach, involving six different steps. We took an inductive approach to our thematic analysis meaning that coding and theme development were directed by the content of the data. We began by reading and familiarising ourselves with the data and then moved on to data coding. Initial themes were then generated and reviewed before finally being named and then written up (Braun and Clarke 2019b). This was an iterative and reflexive process which took place throughout and beyond data collection. It became clear during the initial coding phase of the research that consent was a key issue for both professional and parent participants. Barriers to, and challenges around the consent process were generated as initial themes during analysis. These themes were then verified by the researchers through reflections on the overall dataset. It is important to note here that our data centres on parent consent for post-mortem in order to establish cause of death. Our study does not include data which focuses on autopsy consent for research purposes.

We now seek to illustrate - using interview excerpts – some of the issues highlighted in the data around the process of informed consent, beginning with parent experiences. In order to ensure anonymity and confidentiality of participants, we have allocated all participants pseudonyms. Names were chosen on a culturally appropriate basis.

Findings section:

Fear, regret and the challenge of *giving* consent

We began our parent interviews by inviting them to tell us about their baby loss journey- from their positive pregnancy tests through to their experience of life after loss. During this process, we asked a series of questions around post-mortem decision-making which included a focus on

consent. A hospital consented post-mortem was not an option for 57% of parents in our sample. These parents had been through the coronial post-mortem process due to their baby's unexpected death. Out of those parents who could give consent, 44% agreed and 56% said no. The reasons parents gave for non-consent included: information (too little or too much), lack of encouragement, wider cultural representations of post-mortem, protective parenting, emotional trauma, and having no further questions. In contrast to the findings of other studies, our parent participants did not identify religion as an issue. This may relate, however, to the limited religious diversity in our sample. Some participants raised concerns around the invasive nature of the examination. In the aftermath of their loss parents continued to speak of their baby in the present tense, often feeling that a post-mortem examination would be akin to putting their baby through invasive medical procedures whilst alive. For example, they often said they didn't want their baby to be 'messed with'. This is illustrated in the account from one of the fathers, Ricky who had declined post-mortem examination:

> "Just let him be as he is. Just didn't want him being tampered with" (Ricky, baby boy died prematurely at 25 weeks).

It wasn't just the thought of the invasive nature of the examination, however, that put parents off consenting. Information was also problematic with many parents feeling that they were given too much without time to process it and make decisions. They felt that post-mortem was just one more thing for them to think about and it was just too overwhelming. This is highlighted by the quote from Fran:

> "I think that the process is too quick, that actually for a newly bereaved parent…actually it's too much to take all that information in in one go. It needs to be dealt with in smaller chunks really. It might seem like a long time to a medical professional who's got lots of other people to see, but five hours really wasn't enough time for us to kind of get our heads round it really. We needed somebody to sit with us and properly talk through the situation" (Fran, baby boy died suddenly).

Parents tended to feel very protective of their baby. They expressed concerns about who would look after their baby, where would their baby go during the examination, and for how long. Not all hospitals have specialist paediatric pathologists or appropriate facilities for post-mortem and so, sometimes, babies would be sent for examination elsewhere. These fears are articulated in the quote below from Anna:

> "I don't want her to be gone for six weeks, I don't know where she's going to be in that time" (Anna, baby girl delivered at 23 weeks).

As other studies have shown, interaction with professionals was also very important for parents as they often looked to them to guide their decision-making (Lewis *et al.,* 2019). Parents in our study often appeared to look for signs from professionals, as experts, to help them make their decisions. Parents frequently felt discouraged because professionals either looked uncomfortable or didn't broach the subject of post-mortem fully because they didn't want to traumatise parents further. This is articulated in the quote from Ricky's partner, Esther, who felt that their neonatologist discouraged them from consenting to post-mortem:

> "And he (neonatologist) was saying we don't want to put you (parents) through it, we don't want to put him (baby) through it" (Esther, baby boy died prematurely).

This often had a significant impact on parents, however, with some going on later to express feelings of regret that they hadn't consented to post-mortem. This is something that was expressed by Charlotte in the quote below:

> "And also I wish we had been encouraged to have a post-mortem, that is something that doesn't make sense to me, why I didn't do it, why we didn't do it, why they didn't encourage it... the consultant came in and said have you thought about a post-mortem, we were like, we don't know, and he was like, well, it's basically just like cot death only he didn't make it to his cot (stillborn), and it's just going to prolong things, and they probably won't find anything anyway…" (Charlotte, baby boy, stillborn).

Our data highlights some of the key challenges that parents face when considering consent. These issues- such as the fear of its invasive nature- clearly resonate with those identified in other clinical studies on consent (Lewis *et al.,* 2019; Rankin *et al.,* 2002; Sheach Leith, 2007). Parallels around timing and information can also be drawn with consent practice in research (both clinical and social). As Sin (2005) argues, for example, taking consent at one point in time often fails to capture the changing demands of research on participants. Researchers have subsequently begun to advocate building a time gap into consent processes in both research and clinical practice (Corrigan, 2003; Lewis *et al.,* 2019; Wiles *et al.,* 2007). This all lends further weight to our case for the development a more dynamic and reflexive approach to post-mortem consent (Bondi, 2009; Sin, 2005). By prioritising professional action and self-reflection (Schön, 2016), such an approach would go beyond the specific moment of consent to critically assess the impact of a wider set of social processes, including what information is *given* to parents and *when*. We move on now, in the

next section, to explore something touched upon here and that is the ways in which parent decisions are often directly informed by their interaction with professionals.

Sensitivity, paternalism & the problem of *taking* consent

Informed consent aims to protect the rights of patients and mitigate against medical paternalism. In practice, however, consent is often mediated by an unequal doctor and patient relationship (Corrigan, 2003), whereby health professionals make judgement calls over patient decision-making. Professional respondents in our study articulated mixed views around the value and use of post-mortem. This influenced whether they were likely to offer it as an option to parents. While 42% of professionals felt post-mortem was always useful- even in case of miscarriages or death where the clinical cause is evident- 16% felt it was not always necessary. A further 42% expressed no views either way because consent was not part of their professional remit. In our study, consent was mostly taken by mortuary staff, (pathologists and APTs), and by gynaecologists, obstetricians and neonatologists. Our data shows diversity in how professionals approached the issue of post-mortem consent. Paediatric pathologists, for example, tended to argue strongly that all parents should at least be offered the opportunity of a post-mortem as a basic right. Other specialists made a judgement call on whether to offer it based on individual parent circumstances. Some doctors did acknowledge that a form of medical paternalism was often in operation during the consent process, as articulated by neonatologist Brian in the quote below:

> "I'm well aware that our overall post mortem rate is probably well below what it could be or should be (…) We're probably paternalistic, in terms of making decisions about whether they should have one or not" (Brian, Neonatologist).

One of the biggest issues emerging from our findings related to which professionals *could* take consent. Most consent for perinatal post-mortem takes place in hospital settings outside of the pathology suite (for example in the maternity unit). In the two different NHS foundation trusts where our study took place, currently only doctors could take consent (outside the pathology suite). Professionals felt that this policy related to clinicians having overall legal and medical responsibility. Midwives, obstetrics and gynaecology nurses, however, questioned whether doctors were always best placed to take consent because they often didn't have the strongest patient rapport. Midwives saw this as a significant reason as to why parents often did not consent. This is articulated in the quote below by senior midwife Wendy:

> "So then trying to find a doctor to come and chat to them about post-mortems, and it might be a doctor they've never met before. So they go in and they say I've just come to talk to you about this. And obviously they're not very receptive to the parents" (Wendy, Senior Midwife).

Midwives and nurses tended to have better contact and rapport with parents. They often felt that they would be better placed to take consent but lacked the appropriate training. In order to be able to take consent, it was essential that professionals had witnessed a post-mortem examination beforehand. A senior gynaecological nurse consultant, Jackie, was keen for her team to be able to take consent but also sensed the nurses were quite anxious about this:

> "Which is why we think that nurses should do it. It's just getting it set up and the process done. So I'm quite keen for us to do that, and I'm probably of the mind that you should lead by example. But quite a lot of our nurses are quite squeamish about this" (Jackie, Gynaecological nurse consultant).

Regardless of who took consent, however, the process was still extremely sensitive and difficult for professionals. Carmen, an APT and the mortuary manager discussed the ways in which she always gave parents detailed information about the examination before attempting consent. She felt it was crucial to be as honest as possible with family members, especially after the organ retention scandal. She also highlighted the importance of finding an appropriate quiet space in which to take consent:

> "When we do consent it's just really finding a nice relaxed area to do it so we like to do it here in the conservatory because it's just a little bit nicer, and we'll just obviously go through...I always talk about the post-mortem before I actually go through the form, so I'll explain about the incision and it's a really difficult position to be in but I think it's always best that you be honest" (Carmen, APT).

Our data reaffirms the argument, often made by sociologists, that informed consent can facilitate medical paternalism rather than prevent it (Corrigan, 2003). Bias around professionals' own perceptions of post-mortem can impact on what they offer and the information they impart. This can lead, in some cases, to doctors appearing to use their clinical judgement to make decisions on parents' behalf. The hierarchical structure of medicine appears to enhance this process, making it distinct, perhaps, from consent practices which take place in other contexts such as social research. There was diversity in consent practice among professionals, however, with some key professionals also feeling excluded from this process. This lends further weight, therefore, to the

need for greater reflexivity in consent practice. Encouraging professionals to reflect on their actions both as they are taking consent and afterwards (Schön, 2016), could help to guard against medical paternalism. Greater attention should also be given to *who* takes consent and in *wha*t context, ensuring the most appropriate staff are able to take consent in the most suitable location. Broadening our analytical focus in this way, we argue, not only facilitates a better understanding of the consent process but could also lead to a more sensitive enactment of consent in practice. In the final data section, we move beyond the consent process to consider the benefits articulated by parents and professionals of post-mortem when consent is given.

Beyond consent: post-mortem and the preservation of personhood

Sociologists have often highlighted the danger of viewing informed consent as an 'ethical panacea' in either research or clinical practice (Corrigan, 2003). As Author A (2007) argues, in the context of social science research, for example, any stress and risk posed to participants cannot be readily solved, by ticking yes to a question on informed consent. In the context of post-mortem, Sheach Leith (2007) argues that a focus on informed consent alone cannot adequately account for wider family concerns. In this final section, we want to shift attention away from a narrow focus on the consent process to consider the *consequences* of informed consent. This is important, because, as we will show, the post-mortem examination that parents are considering consenting to is often essential to both emotional and diagnostic closure. For example, it can help parents to navigate their grief and feelings of self-blame, and also plan more positively for future pregnancies. This is articulated by Yasmine, who elected to have a late termination of pregnancy for two pregnancies due to the identification of very severe anomalies:

> "So it's all these cues that make you have that confidence that actually this is very, very unusual and I've been very unlucky. And as I say, all the research that went into suggesting that that was not related to anything I'd done or anything, that it was just one of those things, you know" (Yasmine, Termination of Pregnancy).

While parents identified a range of reasons for not consenting to post-mortem, they also often articulated feelings of regret at not consenting at the time of their baby's death. As highlighted by Gina, an obstetrician, this led some parents to return to hospital months later to ask for further information. By this stage it was often too late to perform a post-mortem:

> "If you let a baby go (without post-mortem) and then, you know, sometimes months later parents come back and go - 'were you absolutely certain it (baby) had X?'" (Gina, Obstetrician)

Professionals directly involved in post-mortem (Pathologists and APTs) were motivated to conduct the examination in order to help parents cope with their grief. These professionals saw post-mortem as a crucial way of providing parents with information and answers in order to help with closure- both emotional and diagnostic (Author A, 2020). This is reflected in the quote below from Ava, a very senior paediatric pathologist who talks very movingly about her role:

> "After doing so many cases, sometimes I involve my emotions, sometimes I look at the baby and smile and say how beautiful he is or was, but I think that what drives me is to find an answer for the parents, because this is my role, to find an answer to the parents. And that would help them" (Ava, Pathologist).

Existing research has highlighted parents' concerns over post-mortem and body wholeness (Sheach Leith, 2007; Rankin *et al.*, 2002). Although parents in our study raised similar fears over the potentially invasive nature of the examination, they did also see post-mortem as a way of reinforcing personhood. Research on reproductive loss has highlighted the ways in which parents use a range of different markers to reinforce their baby's existence and identity (such as locks of hair, photos etc.) (Garattini, 2007; Keane, 2009). As Fuller and Kuberska (2020) note, such objects can act as a source of consolation as well as sometimes unsettling the process of bereavement. In our study, the post-mortem report written by the pathologist could also provide parents with another marker of personhood as the account from Amy shows. She consented her baby for a Minimally Invasive Autopsy using MRI:

> "That's another thing about the post mortem report as well, which is why I really wanted a copy, because it makes her real, like, she existed in the world and she's documented, do you know what I mean, whereas, you know, a lot of miscarriages, if they're earlier on, there's nothing" (Amy, baby died in utero at 16 weeks).

In their study on autopsy after stillbirth, Holste *et al.* (2011) found that parents were generally satisfied with their decision to agree or disagree to autopsy. Data from our study on perinatal post-mortem suggested that parents who did not consent to post-mortem could regret it. Those parents whose babies did go through post-mortem (either coronial or consented) appeared not to regret this and often found the process beneficial. More specifically, post-mortem appeared to assist parents with emotional and diagnostic closure, as well as with future pregnancy planning. It is, of

course, crucial that we prevent individuals from being co-opted into research or from consenting to clinical procedures that they do not want or need (including post-mortem**).** When focusing specifically on consent practises, however, sociologists should be wary of losing sight of the actual value of clinical examinations that patients and parents are consenting to. We argue that a reflexive approach to post-mortem could help to address these issues, encouraging professionals to reflect on their own practises and ensuring that a full and transparent picture of post-mortem is presented to parents prior to consent**.** Such an approach would be sensitive to parent need and provide a productive way of navigating this process. We will outline this reflexive approach in more detail in the conclusion.

Conclusion

We have sought to contribute to the existing social science debates on informed consent in two respects: firstly, through shedding light on the ways in which informed consent is performed in the difficult and taboo area of paediatric post-mortem and secondly, by advocating a reflexive approach to consent, acknowledging the sometimes-unanticipated benefits of the clinical examination. We recognise- especially in light of the organ retention scandal of 1999 (Sheach Leith, 2007)- that there may be specific sensitivities around post-mortem consent involving the death of a baby. By trying to understand the various ways in which informed consent is practised in this context, however, this article has sought to offer a wider contribution to existing sociological work in the field.

Data from our study on perinatal post-mortem illuminates a recurrent problem raised by social scientists about how informed consent is enacted- in both social science research and in clinical research and practice. Informed consent is often conducted 'in the moment', meaning that research participants and patients have little time to consider what research or medical intervention they are consenting to. In the context of social research, sociologists have responded by emphasising the need to view consent as an ongoing process which takes place throughout and beyond research itself (Sin, 2005). They have also suggested providing participants with more user-friendly materials, building a time gap between giving information and taking formal consent and emphasising vigilance to participants' unspoken expressions around issues of participation and withdrawal (Wiles *et al.,* 2007). Existing research on perinatal post-mortem has made similar suggestions for improving consent practice including: providing parents with more accessible information, making sure staff taking consent are properly trained and empathetic, allowing parents time to deliberate information and treating post-mortem as an integral part of the patient journey (Down *et al.,* 2012; Lewis *et al.,* 2019). We aim to build on and extend these existing

suggestions for good practice by proposing a more dynamic and reflexive approach to understanding and practising post-mortem consent.

Our approach to post-mortem is informed by wider social scientific understandings of reflexivity in research which highlights the importance of ongoing critical reflection (Denscombe, 2014; Bourdieu in Wacquant, 1989). In the context of post-mortem, such an approach would go beyond a focus on the specific moment of consent to critically assess a wider set of processes. This would include a focus on what information is *given* to parents, *how* it is presented, and *when* it is given. A reflexive approach would also pay close attention to issues such as *who* can *take* consent and *where* it is taken, ensuring not just that staff are adequately trained (as highlighted by existing literature), but that the most appropriate staff are able to take consent, and in the most suitable locations. Paying closer attention to these issues, we argue, should facilitate the development of an approach which is more sensitive to parent need. A reflexive approach, however, also requires professionals to reflect on their actions. Schön (2016) defines reflective practice as the practice by which professionals become aware of their implicit knowledge base and learn from their experience. He focuses on reflection in action (reflecting during practice) and reflection on action (the act of reviewing, analysing, and evaluating practice after the event). We suggest that reflecting both *in* and *on* action during and after the post-mortem consent process, would encourage professionals to question and reflect on their own perceptions and bias. This could go some way, perhaps, to addressing issues of medical paternalism, illuminated by our own data in this paper, as well as by the wider literature on consent (Corrigan, 2003). It could also facilitate professional learning in post-mortem practice, and in wider health care contexts and beyond (Schön 2016).

Sociologists have often critiqued the narrow focus on informed consent- arguing that while it may meet current ethical standards, it does not acknowledge wider concerns held by research participants or patients (Corrigan, 2003; Author A 2007; Sheach Leith, 2007). We have also sought to move beyond a preoccupation with the consent process to consider the clinical examination that individuals are consenting *to*. One of the initial barriers to consent highlighted by our data relates to parents not wanting their baby to be put through invasive medical examinations. This is undoubtedly connected to parent fears about body wholeness (Sheach Leith, 2007). It also relates, however, to their need to preserve their baby's personhood during that interstitial phase between life and death, in the mortuary, and before a funeral has taken place. When parents in our study did consent to post-mortem, however, the examination appeared to offer them a sense of diagnostic and emotional closure and in some cases reinforced their baby's personhood. Information about these unexpected benefits could, perhaps, be made clearer during initial professional discussions on post-mortem with parents. It is also crucial, however, that parents do

not feel coerced into consenting their baby to an examination that they are not sure they want. It is essential, therefore, that as professionals reflect both *in* and *on* their consent practice, that they do so with a view to making sure that they are both open and transparent in their communications with parents.

Informed consent can be an important ethical tool that helps to protect individuals from overt coercion in research and clinical practice. As others have argued, however, we must temper our expectations around the underlying principles of consent. It is not an 'ethical panacea' (Corrigan, 2003) but a process that is strongly mediated by clinical, social and cultural contexts (Dixon-Woods *et al.,* 2006; Zussman, 1997). As we have sought to show here, we can still develop a better and more reflexive approach to post-mortem consent. In making this case we must acknowledge that there are limits to reflexivity, namely, that it cannot overcome power relations in either research or professional practice (Finlay, 2002; Faria and Mollett, 2016). Furthermore, we must apply caution when drawing parallels between consent practices in clinical contexts and in social research. There are, of course, stark contrasts between these areas in terms of what projects and procedures research participants and patients may be consenting *to* and *for*. The specific hierarchical structure of medicine as an institution, perhaps, also acting as a marker of distinction on certain aspects of consent in clinical contexts. Adopting a reflexive approach, however, would enable us to be more attuned to the social and cultural contexts in which consent operates. It could also empower us to look, beyond the regulatory process itself to access the value of the actual clinical examination or research project. While we cannot resolve the tension between the underlying philosophical principles of consent and its' enactment in practice, a reflexive approach may provide us with a suitable framework with which to navigate this process, in both research and clinical practice.

Acknowledgements

We would like to thank the *Economic and Social Research Council* who funded the research on which this paper is based: *'End of or Start of Life'? Visual Technology and the Transformation of Traditional Post-Mortem'*(Ref ES/M010732/1).Thank you also to all the families and NHS professionals who gave-up their time to take part in this research project, and to the various bereavement support charities

that have helped support this research. We would also like to thank Dr Julie Ellis for her invaluable contribution to this research project.

References

Beck, U. (1992). *Risk Society: Towards a New Modernity*. Translated by Ritter, Mark. London: Sage Publications.

Ben-Sasi, K., Chitty, L. S., Franck, L. S., Thayyil, S., Judge-Kronis, L., Taylor, A. M. and Sebire, N. J. (2013) Acceptability of a minimally invasive perinatal/paediatric autopsy: healthcare professionals' views and implications for practice, *Prenatal diagnosis*, 33,4, 307–312. DOI: 10.1002/pd.4077

Bondi, L. (2009) Teaching reflexivity: undoing or reinscribing habits of gender, *Journal of Geography in Higher Education,* 33,3, 327-337. https://doi.org/10.1080/03098260902742417

Borgstrom, E. and Ellis, J. (2017) Introduction: researching death, dying and bereavement. *Mortality*, 22,2, 93–104. https://doi.org/10.1080/13576275.2017.1291600

Braun, V., & Clarke, V. (2019a) Reflecting on reflexive thematic analysis, Qualitative Research in Sport, Exercise and Health, 11:4, 589-597, DOI: 10.1080/2159676X.2019.1628806

Braun, V., & Clarke, V. (2019b) Thematic analysis: a reflexive approach, https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html (accessed January 2021)

Breeze, A., Statham, H., Hackett, G., Jessop, F., and Lees, C. (2012) Perinatal postmortems: what is important to parents and how do they decide?, *Birth*, 39, 57-64. DOI: 10.1111/j.1523-536X.2011.00513.x

Burton, J. L. and Underwood, J. (2007) Clinical, educational, and epidemiological value of autopsy, *Lancet*, 369, 9571, 1471–1480. DOI: 10.1016/S0140-6736(07)60376-6

Connolly, A.J., Finkbeiner W.E., Ursell P.C., Davis, R.L. (2016)Legal, Social, and Ethical Issues. *Autopsy Pathology: A Manual and Atlas*. 2016;15-23. doi:10.1016/B978-0-323-28780-7.00002-0

Coomber, R. (2002) Signing your life away?: why research ethics committees (REC) shouldn't always require written confirmation that participants in research have been informed of the aims of a study and their rights- the case of criminal populations. (Commentary), *Sociological Research Online*, 7,1, 218–221. https://doi.org/10.5153/sro.678

Corrigan, O. (2003) Empty ethics: the problem with informed consent*, Sociology of health & illness*, 25,7, 768–792. https://doi.org/10.1046/j.1467-9566.2003.00369.x

Denscombe, M. (2014) *The Good Research Guide: For Small-Scale Research Projects*, Maidstone: Open University Press.

Dixon-Woods, M., Williams, S. J., Jackson, C. J., Akkad, A., Kenyon, S. and Habiba, M. (2006) Why do women consent to surgery, even when they do not want to? An interactionist and Bourdieusian analysis, *Social Science & Medicine*, 62,11, 2742–2753. DOI: 10.1016/j.socscimed.2005.11.006

Downe, S., Kingdon, C., Kennedy, R., Norwell, H. and McLaughlin, M.J. (2012) Post-mortem examination after stillbirth: views of UK-based practitioners, *European Journal of Obstetrics, Gynecology, and Reproductive Biology*, 162, 33-7. DOI: 10.1016/j.ejogrb.2012.02.002

Eka, I., Rowan, C. and Osborn, M. (2014) Mind the gap: are NHS trusts falling short of recommended standards for consent to autopsy?, *Journal of Clinical Pathology*, 67,1, 10–13. http://dx.doi.org/10.1136/jclinpath-2013-201869

Faria, C. and Mollett, S. (2016) Critical feminist reflexivity and the politics of whiteness in the 'field', *Gender, Place & Culture*, 23,1, 79-93. https://doi.org/10.1080/0966369X.2014.958065

Finlay, L. (2002). "Outing" the researcher: the provenance, process, and practice of reflexivity. *Qualitative Health Research,* 12,4, 531-545. https://doi.org/10.1177/104973202129120052

Fuller, D and Kuberska, K (2020). Outside the (memory) box: how unpredictable objects disrupt the discourse of bereavement in narratives of pregnancy loss, Mortality, DOI: 10.1080/13576275.2020.1783221

Garattini, C. (2007). Creating memories: material culture and infantile death in contemporary Ireland, *Mortality*, 12,2, 193-206. https://doi.org/10.1080/13576270701255172

Jordens, CFC., Montgomery, K. and Forsyth, R. (2013) Trouble in the gap: a bioethical and sociological analysis of informed consent for high-risk medical procedures, *Journal of Bioethical Inquiry,* 10,1, 67-77. DOI: 10.1007/s11673-012-9414-7

Henderson, J. and Redshaw, M. (2017) Parents' experience of perinatal post-mortem following stillbirth: A mixed methods study, *PLoS One*, 12(6):e0178475 https://doi.org/10.1371/journal

Heazell, A.E., McLaughlin, M.J., Schmidt, E.B., Cox, P., Flenady, V., Khong, T.Y. and Downe, S. (2012) A difficult conversation? The views and experiences of parents and professionals on the consent process for perinatal postmortem after stillbirth, *BJOG*, 119,8, 987-97. DOI: 10.1111/j.1471-0528.2012.03357.x

Henry, J. and Nicholas, N. (2012) Dead in the water – are we killing the hospital autopsy with poor consent practices?, *Journal of the Royal Society of Medicine*, 105,7, 288–295. DOI: 10.1258/jrsm.2012.110288

Holste, C., Pilo, C., Pettersson, K., Râdestad, I., and Papagogiannakis, N. (2011) Mothers' attitudes towards perinatal autopsy after stillbirth. Acta Obstetricia et Gynecologica Scandinavica, 90: 1287-1290. https://doi.org/10.1111/j.1600-0412.2011.01202.x

Kang, X., Cos, T., Guizani, M., Cannie, M.M., Segers, V. and Jani, J.C. (2014) Parental acceptance of minimally invasive fetal and neonatal autopsy compared with conventional autopsy, *Prenatal Diagnosis,* 34, 1106–10. DOI: 10.1002/pd.4435

Keane, H. (2009) Foetal personhood and representations of the absent child in pregnancy loss memorialization, *Feminist Theory,* 10,2, 153-171. https://doi.org/10.1177/1464700109104922

Lewis, C., Hill, M., Arthurs, O., Hutchinson, J., Chitty, L. and Sebire, N. (2017) Factors affecting uptake of postmortem examination in the prenatal, perinatal and paediatric setting: a systematic review, *BJOG: An International Journal of Obstetrics & Gynaecology*, 125, 10. DOI: 10.1111/1471-0528.14600

Lewis, C., Riddington, M., Hill, M., Bevan, C., Fisher, J., Lyas, L., Chalmers, A., Arthurs, O., Hutchinson, J., Chitty, L. and Sebire, N. (2019) "The communication and support from the health professional is incredibly important": a qualitative study exploring the processes and practices that support parental decision-making about postmortem examination, *Prenatal Diagnosis*, 39,13, 1242-1253. https://doi.org/10.1002/pd.5575

Miller, T. and Boulton, M. (2007) Changing constructions of informed consent: qualitative research and complex social worlds, *Social Science & Medicine*, 65,11, 2199-211. DOI: 10.1016/j.socscimed.2007.08.009

National Health Service (2021) Post-mortem https://www.nhs.uk/conditions/post-mortem/ (accessed January 2021).

Okah, F. A. (2002) The autopsy: experience of a regional neonatal intensive care unit, *Paediatric and Perinatal Epidemiology*, 16,4, 350–354. https://doi.org/10.1046/j.1365-3016.2002.00439.x

Rankin, J., Wright, C. and Lind, T. (2002) Cross sectional survey of parents' experience and views of the postmortem examination, *BMJ (Clinical research ed.),* 324,7341, 816–818. DOI: 10.1136/bmj.324.7341.816

Richardson, S. and McMullan, M. (2007) Research ethics in the UK: what can sociology learn from health?, *Sociology*, *41*,6, 1115–1132. https://doi.org/10.1177/0038038507082318

Rose, C., Evans, M. and Tooley, J. (2006) Falling rates of perinatal postmortem examination: are we to blame?, *Archives of Disease in Childhood. Fetal and Neonatal Edition*, 91,6, F465. http://dx.doi.org/10.1136/adc.2005.091314

Sheach Leith, V. (2007) Consent and nothing but consent? The organ retention scandal, *Sociology of Health & Illness*, 29,7, 1023-1042.

Schön, D. (2016) The Reflective Practitioner: How Professionals Think in Action, London: Routledge.

Sin, C. H. (2005) Seeking informed consent: reflections on research practice, *Sociology*, *39*,2, 277–294. https://doi.org/10.1177/0038038505050539

Stock, S., Goldsmith, L., Evans, M. and Laing, I. (2010) Interventions to improve rates of post-mortem examination after stillbirth, *European Journal of Obstetrics, Gynecology, and Reproductive Biology*, 153, 148-50. DOI:https://doi.org/10.1016/j.ejogrb.2010.07.022

Stolman, C. J., Castello, F., Yorio, M. and Mautone, S. (1994) Attitudes of pediatricians and pediatric residents toward obtaining permission for autopsy, *Archives of Pediatrics & Adolescent Medicine*, 148,8, 843–847. DOI: 10.1001/archpedi.1994.02170080073014

Svendsen, E,. & Hill, R.B (1987). Autopsy legislation and practice in various countries. Arch Pathol Lab Med. 111(9):846-50. PMID: 3632302.

Turnbull, A., Osborn, M. and Nicholas, N. (2015) Hospital autopsy: endangered or extinct?, *Journal of Clinical Pathology,* 68, 601-604. DOI: 10.1136/jclinpath-2014-202700

Wacquant, L. (1989) Towards a reflexive sociology: a workshop with Pierre Bourdieu. *Sociological Theory,* 7,1, 26-63. DOI: 10.2307/202061

Walford, G. (2009) The practice of writing ethnographic fieldnotes, *Ethnography and Education*, 4,2, 117-130. https://doi.org/10.1080/17457820902972713

Wasserfall, R. (1993) Reflexivity, feminism and difference, *Qualitative Sociology,* 16,1, 23-41. https://doi.org/10.1007/BF00990072

Watt, D. (2007) On becoming a qualitative researcher: the value of reflexivity, *The Qualitative Report,* 12,1, 82-101

Wiles, R., Crow, G. and Heath, S. (2007) Informed consent and the research process: following rules or striking balances? *Sociological Research Online*, 12, 2, 99–110.

Whitby, E. (2009) Minimally invasive autopsy, *Lancet*, 3749688, 432-433. DOI: 10.1016/S0140-6736(09)61433-1

Woodward, S. (2016) "Object interviews, material imaginings and 'unsettling' methods: interdisciplinary approaches to understanding materials and material culture." *Qualitative Research,* 16,4, 359-74.

Zussman, R. (1997) Sociological perspectives on medical ethics and decision-making, *Annual Review of Sociology,* 23, 1, 171-190.