'Real experiences which increase empathy' – a preliminary exploration of the utility of an audio archive describing parents' and clinicians' experiences of stillbirth

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Abstract: Perinatal death has an enduring effect on parents which is altered by their experience of care. However, professionals frequently report feeling underprepared to care for bereaved parents. This study evaluated parents' and professionals' experiences of using an audio archive of experiences of perinatal deaths (www.stillbirthstories.org) using a self-reported questionnaire. Eighty-three percent of parents and the public (*n*=33) found listening to the archive helpful, with no negative responses. Fifty-four percent stated that it changed how they felt about having a perinatal death, increasing the proportion of respondents who felt supported (12 to 27%) and decreasing the proportion who felt alone and anxious (27 to 15%). All professionals accessing the archive found it helpful, stating it increased empathy and understanding of parents' emotions which improved confidence that parents' needs could be met. Archives of real experiences may help parents and professionals after perinatal death. Further research is needed whether such an archive has a wider reach and accessibility than traditional support networks.

Keywords: Stillbirth, Perinatal Mortality, Perinatal Death, Bereavement, Stigma, Social Isolation.

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Introduction

Stillbirth and perinatal death is associated with wide-reaching psychological, social and economic consequences for parents that may be underestimated by family, friends and professionals (Heazell et al., 2016). Although there are variations between countries, in the UK stillbirth is defined as the death of a baby before birth after 24 weeks of pregnancy and a perinatal death describes a stillborn baby or a baby that dies within one week of birth. Following the death of their baby, parents describe social isolation and stigmatisation which may result in disenfranchised grief which for some parents may lead to ongoing psychological problems (Heazell et al., 2016). Although the grieving process after the death of a baby is recognised to be highly individual, both intra and interpersonal processes are relevant for the adjustment process of parents to the loss of their child. Importantly, loss orientation behaviours are predictive of negative psychosocial adjustment, whereas, restoration orientated behaviours lead to greater adjustment (Heazell et al., 2013).

Bereaved parents identify partners, family members, health professionals and support groups as amongst their most important sources of support during the grieving process (Cacciatore, 2007). Peer support groups provide a connection between people with similar, often painful experiences. Cacciatore and Bushfield (2007) describe four components of the support offered within these groups (emotional, instrumental, educational and appraisal support). The latter element includes normalisation and social comparison which may reverse feelings of isolation and provide comfort by giving parents a frame of reference to recognise that their feelings of grief are similar to others' experiences. However, despite these benefits, a large UK survey found that only 24% of women and 9% of men attended face-to-face support following a stillbirth and an even smaller proportion of parents after a baby dies after birth (5% of men and women), even though 93% of respondents stated they were given information about support groups after their baby died (Redshaw, Rowe, & Henderson, 2014). This observation indicates that a significant proportion of parents currently do not access peer support. While for some parents this may because they have adequate support within their social networks, for others, who may be unable to gain support due to a lack of local facilities or social or cultural barriers to their attendance, this may deprive them of appraisal support.

The care given when a baby dies has an important bearing on parents' grief and psychological outcome (Ellis et al., 2016). In particular, the quality of memories appears to be an anchor point for good or bad experiences for parents, and parents describe that genuine, authentic care from professionals provided a sense of protection from the acute sense of loss. Conversely, care lacking in compassion exacerbated parents' distress (Downe, Schmidt, Kingdon, & Heazell, 2013). However, professionals often report feeling underprepared to care for bereaved parents, with a majority identifying need for improved training (Gold, Kuznia, & Hayward, 2008; Nuzum, Meaney, & O'Donoghue, 2014; Richards, Graham, Embleton, & Rankin, 2016; Brierley-Jones et al., 2018). Critically, it can be challenging for professionals to gain understanding of parents' experiences of grief following a stillbirth or perinatal death as there is a paucity of research and few published accounts of parents' lived experience in professional literature (Davidson, 2011).

One potential means to reduce parents' isolation and improve professionals' exposure to patient experiences is to develop a publicly available archive of narratives describing parents' and professionals' experiences of stillbirth and perinatal death. The largest such resource of patient stories is available at www.healthtalk.org which covers a wide variety of health topics encompassing physical and mental health. Although this archive includes articles on pregnancy and reproductive health it does not currently include stillbirth as a topic. In addition to resources from healthcare sources there are also an array of archives from charities and parents which are available on the internet. Critically, few of these resources have evaluated their impact upon the public, parents and professionals; this merits exploration to ensure that the potential of future resources is maximised.

The *Stillbirth Stories* archive (www.stillbirthstories.org) was developed to provide a resource describing the experience of stillbirth for parents and professionals. It is an audio archive of 22 interviews with parents and clinicians. This project was developed by two media producers (EB and NG), who had personal experience of perinatal and postnatal bereavement, in collaboration with a clinical academic (AH). The project formed part of a larger body of work to raise the profile regarding the psychological and social impact of stillbirth and perinatal death which also included a 30 minute documentary for national radio (https://www.bbc.co.uk/programmes/b07ks3kf). The archive contains full interviews from parents and clinicians and selected clips from these interviews are searchable and grouped by theme, themes include: being told your baby has died; spending time with your baby; and talking to and supporting families. Transcripts are available for people who would prefer to read, rather than listen, to the narratives. By presenting authentic experiences of parents and staff the archive aimed to reduce the isolation, taboo and stigma surrounding perinatal death. It was anticipated that the archive would provide a resource for parents to access "appraisal support" and would also allow staff to gain understanding of parents' experiences and emotions in order that they may provide better care for bereaved families. To determine whether the project addressed these aims, it was accompanied by an evaluation of parents', public, and professionals' experiences. The study presented describes the experiences of parents, relatives and professionals who accessed the archive to evaluate whether accessing an archive of clinicians' and parents' experiences of perinatal death was beneficial. It was envisaged that these findings would inform further development of the *Stillbirth Stories* archive and assist with the establishment of similar projects in other contexts.

Methods

The *Stillbirth Stories* website was launched immediately prior to Baby Loss Awareness Week 2017 (9-16 October). The website was publicised via social media, traditional media and by links from UK organisations with an interest in stillbirth (e.g. Sands, Tommy's). Members of the public (including bereaved parents, relatives or people who had no experience of perinatal death) accessing the archive between 5 October 2017 and 15 December 2017 were invited to participate in an online questionnaire (Supplemental Data). As one aim of the project was to address stigma and taboo surrounding stillbirth, the questionnaire was not restricted to parents alone because we wished to understand motivation for accessing the archive and participants' subsequent experiences. In addition, maternity professionals working in a large tertiary maternity unit in the UK were asked to complete a questionnaire before accessing the archive and a linked further survey afterwards between 28 September 2017 and 6 March 2018. A questionnaire was determined to be the most appropriate method to obtain participants' views as potential respondents were anticipated to be in different geographical locations and standardised responses would facilitate comparative analysis (Dunscombe, 2010). The questionnaires were developed by the research team and refined following a pilot with a small group of parents and clinicians. The questionnaires contained a mixture of closed and open questions; closed questions included ranking scales and lists of words which described feelings. Open questions were used either to explore participants' answers in more depth or to explore novel topics not covered in the questionnaire, open questions invited free-text responses. Prior to completing the questionnaires participants were asked to read the study information sheet and all gave consent to participate by a response within the questionnaire.

Quantitative responses were analysed using descriptive statistics (Microsoft Excel) and free text responses to open questions were evaluated using summative content analysis. This approach was taken to allow the free text responses to be coded and patterns identified within the responses; summative content analysis was felt to be optimal because this not only described the frequency of responses, but allowed interpretation of the context of the comments. Summative content analysis was conducted using seven steps including formatting the research questions and selecting the sample to be analysed, defining the categories, outlining and implementing the coding process, determining trustworthiness and analysing the results of the coding process (Hsieh & Shannon, 2005). Quotes were identified to illustrate themes. Approval for the study was given by West Midlands Black Country Research Ethics Committee and the Health Research Authority. (Ref 17/WM/0257).

Results

General public and parents' responses

Thirty-three responses were received from parents and members of the public who accessed the archive between 5 October 2017–31 December 2017. Of these, 76% were mothers, 9% were fathers with others being grandparents, siblings and respondents who had not experienced a stillbirth. 90% of respondents were bereaved parents or relatives of babies who had been stillborn. Most respondents were of white British ethnicity (60%), although a significant proportion of participants identified as non-white or mixed ethnicities (18%). The largest single group reported finding the archive after press coverage (39%), although other respondents found the website via search engines, blogs, social media and word of mouth. Respondents were from a large range of ages ranging from 16-24 years through to over 50 years of age.

Seventy four percent of respondents accessed the archive once, 11% between two and four times and 15% used it on five or more occasions. The majority of respondents (59%) listened for one hour or less at a time. The majority of respondents accessed the parent's stories (89%), with a smaller proportion listening to clinicians' experiences (55%). Fifty-four percent of parents said that listening to the archive changed the way they felt having had a stillbirth (Table 1) – the greatest magnitude of changes were that the proportion of parents who felt supported increased from 12 to 27%, and the proportion who felt alone fell from 27% to 15%, those who were anxious fell from 27% to 12% of respondents. Other emotions such as anger, confusion, guilt and shame showed little change after parents listened to the archive. The majority of respondents who listened to them felt that the parents' stories were very helpful (54%) or helpful (29%), with no negative responses. Listening to clinicians' stories was also valued, but to a slightly lesser degree, with 42% indicating they were very helpful and another 42% found them helpful, no respondents found clinicians' stories unhelpful. Respondents indicated that the clinicians' stories demonstrated that perinatal death also impacted upon professionals on a human level.

Table 1. Frequency of parents' reported emotions before and after accessing the *Stillbirth Stories* Archive. Response with >10% change are highlighted in grey

Emotion	Response before accessing archive (%)	Response after accessing archive (%)	Change in Proportion
Angry	7 (21)	8 (24)	+3%
Confused	2 (6)	1 (3)	-3%
Scared	4 (12)	3 (9)	-3%
Anxious	9 (27)	4 (12)	-15%
Guilty	3 (9)	2 (6)	-3%
Alone	9 (27)	5 (15)	-12%
Ashamed	1 (3)	1 (3)	-
Pessimistic	2 (6)	1 (3)	-3%
Accepting	10 (30)	10 (30)	-
Content	2 (6)	4 (12)	+6%
Informed	6 (18)	9 (27)	+9%
Confident	2 (6)	4 (12)	+6%
Supported	4 (12)	9 (27)	+15%
Optimistic	4 (12)	6 (18)	+6%
Coping	10 (30)	7 (21)	-9%
Proud	2 (6)	2 (6)	-

Fifty-four percent of respondents said they would definitely use the archive again, with a further 15% possibly using it in the future. Although 27% of respondents to the survey did not answer this question only one respondent (3%) indicated they would not access the archive again. Those who said they would use the archive again stated they would do so either when they had sufficient time and were in 'the right frame of mind' or when they felt in need of support 'Anytime I feel low and need to hear other people's experiences.' The majority of respondents (64%) would direct other parents to the archive. Suggestions to improve the archive were received from 30% of respondents, these included suggestions for broadening the scope to include neonatal deaths, multiple pregnancies or to include the experiences of same-sex couples. 51% of respondents would be willing to contribute their own experiences to the archive.

Summative content analysis of free text responses explaining respondents' choices indicated the most frequent experience upon listening to the archive was feeling less alone, mentioned in 11 out 17 responses (Table 2A). This did not reduce the sadness of the emotion, but the knowledge that other parents had experienced a perinatal death. A small number of respondents described that the recognition that this had happened to others specifically helped their grief, in some cases by offering ideas which may help. For some respondents, notably those whose loss was some time ago, listening to the archive gave feelings of sadness that perinatal death continued to affect parents today; one respondent specifically articulated anger and another described feelings of guilt after listening to the archive indicating that support may be required after accessing parents' stories. Other parents articulated that they wished the audio archive had been available to them earlier following their bereavement when their feelings were more intense.

Thirty six percent of respondents stated that they had learned something from listening to the archive. Of the 11 free text responses about what they had learned from the archive, four participants started appreciating they were still in emotional pain and their feelings were sometimes raw (Table 2B). This was not necessarily a negative experience, as respondents noted that they were able to understand the different ways people grieve and that listening to other parents was one way to process and make sense of their emotions. Two respondents noted that they had learned about the impact upon staff, and that staff cared and wanted to have a positive effect on parents' experiences.

Responses from health professionals

Responses were received from 46 clinicians including 14 consultant obstetricians (30%), 10 trainee obstetricians (22%) and 22 midwives (48%). The professionals had a median of 7 years experience in their role (Range 1-33) and saw on average 5 bereaved families per year (range 0-150). Professionals were more confident in how well equipped they were to give clinical care rather than emotional care to bereaved parents (Table 3A). Although professionals did not necessarily feel equipped to provide emotional care they felt that they had a good understanding of the emotional impact of stillbirth, with 72% either in agreement or strong agreement with this statement, in contrast to 19% who disagreed or strongly disagreed. The variance between responses reflected different professionals' views about understanding parents' feelings, the free text responses were grouped into three main themes (Table 3B): empathy originating from professional experience, unable to understand the impact without personal experience and personal experience of perinatal death or bereavement. There was little overlap between the first two groups with respondents describing one or other of these viewpoints, although some respondents stated that although they could empathise they were aware that ongoing experiences showed that their 'understanding could be broader'. A minority of professionals (39%) had received specific training to help them care for parents whose babies died. Those who had been trained accessed a mixture of online courses, face to face training and training as part of their role. Professionals identified that the most helpful training

Table 2. A) Summative content analysis of 17 free text responses describing why accessing the audio archive was helpful or unhelpful to parents. B) Summative content analysis of 11 free text responses describing what parents and the public had learned from accessing the archive

A)		
Theme	**Sample quotes**	**Number of Responses**
Feeling less alone	Mostly knowing that you are not alone and that other people understand your feelings and that you are not crazy, there are other people out there who are going through the same feelings. (Respondent #4) In some way, nice to know I am not alone. (Respondent #11) It helped me to listen to what their experience had been, to remember and process what happened to us a few months ago. (Respondent #14) I am not the only one who went through this. (Respondent #16)	11
Re-awakened negative feelings	It makes me angry that these stories keep happening. It makes me angry that things like these are not representative of all experiences. (Respondent #1) This made me feel guilty again (Respondent #16)	3
Sorrow that losses continue	It was just so sad that this is still happening in such numbers today. (Respondent #12)	3
Helped grief	It helped to stop feeling victimised and stop saying "why us"? Helpful also because I realise how well I have coped." (Respondent #5)	2
Offered ideas	It was good to know the options available to us and how the processes work.... As well as the wonderful option of a cold cot. (Respondent #3)	2
Wished archive available earlier	It has been four years since my last stillbirth but I wish that this had been available back when the days were too long and the nights even longer. (Respondent #2)	1
B)		
Theme	**Sample quotes**	**Number of Responses**
Still in pain	I am still in a lot of pain (Respondent #5) That it doesn't take much to throw me back to the rawness of my loss, and that I live with it quite successfully. (Respondent #7) It's still early days and I need to heal. (Respondent #8)	4
Listening to others is helpful	Listen to a conversation about a sensitive subject is always a good way come to terms with grief (Respondent #9) I found it so interesting to hear other parents speaking about their experiences, particularly the fathers as I think it has helped me to understand the different ways people grieve and also how we can take some hope from these difficult situations. (Respondent #10)	4
Impact upon staff	That midwives can choose to deal with bereavement situations. At the time I imagined that when the team arrived for a shift, whoever had to deal with the still birth had drawn the short straw that day. It was comforting to know that they received special training, and that they cared about helping parents in this situation and have a positive effect. (Respondent #8)	2
Care had changed	Just how much things have changed in the last 50 years, that there is now more support than ever for couples and families going through this trauma (Respondent #2).	2
Care available	What sort of care I might be able to expect in a successful pregnancy (Respondent #1)	1

resources would be to listen to parents' experiences (85% agreement), a tutorial or study day (80%) or by direct experience (76%).

Twelve professionals provided responses before and after listening to the audio archive. Two were consultant obstetricians, six were trainees and four were midwives. Seven respondents listened for less than one hour and five for 1-2 hours. All listened to the clinicians' and parents' stories either in themed sections or short clips.

All respondents found the parents' experiences either very helpful (n=9) or helpful (n=3). All free text responses indicated that this was due to an increased understanding of parents' experiences, 'real experiences which increases empathy' and 'showed diversity of experiences parents go through' providing 'an insight into how they (parents) were feeling'. Professionals found the interviews with clinicians very helpful (n=6), helpful (n=5) with one finding them neither helpful or unhelpful, stating that 'they didn't

Table 3. A) Professionals' views on how well equipped they are to provide clinical and emotional care to parents of a stillborn baby ($n = 46$). B) Summative content analysis of 32 free text responses regarding the origin of professionals' understanding of the emotional impact of stillbirth. C) Professionals' views on how well equipped they are to provide clinical and emotional care to parents of a stillborn baby before and after listening to the *Stillbirth Stories* archive ($n = 12$)

A)					
Question	**Poorly equipped**	**Not equipped**	**Equipped**	**Confident**	**Very confident**
How well equipped do you feel to meet these families' clinical needs?	2 (4%)	5 (11%)	17 (37%)	20 (43%)	5 (11%)
How well equipped do you feel to meet these families' emotional needs?	3 (7%)	10 (22%)	19 (41%)	7 (15%)	6 (13%)
B)					
Theme	**Sample quotes**				**Number of Responses**
Empathy originating from professional experience	Years of experience including meeting families years after they have experienced loss of a baby. (Professional #4) Through talking to the families that I have cared for who suffered a stillbirth and following them up. (Professional #16) Experience of dealing with the situation whilst recognising that each family has their own different needs (Professional #27).				18
Unable to understand the impact without personal experience	I'm not sure you can ever really understand the impact unless you've had a personal experience. (Professional #2) Suspect you can never know how it feels or what the emotional impact is unless you've experienced it yourself. (Professional #18) I can only imagine how it feels for families, but I cannot fully appreciate what happens when these patients leave hospital and how they pick up and continue with their lives. (Professional #26)				11
Personal experience of perinatal death or bereavement	I have friends who experienced stillbirth and so have seen ongoing experiences first hand. (Professional #15) From my own experience of loss and bereavement. (Professional #28)				4
Studying	From reading of literature (Professional #5) From my interest in human psychology and the human condition. (Professional #29)				3
Lack of experience	I have limited experience in supporting parents following a stillbirth. (Professional #23)				1
C)					
Question	**Poorly equipped**	**Not equipped**	**Equipped**	**Confident**	**Very confident**
How well equipped do you feel to meet these families' clinical needs? Before listening to the archive	0 (0%)	1 (8%)	6 (50%)	4 (33%)	1 (8%)
How well equipped do you feel to meet these families' clinical needs? After listening to the archive	0 (0%)	1 (8%)	4 (33%)	4 (33%)	3 (25%)
How well equipped do you feel to meet these families' emotional needs? Before listening to the archive	0 (0%)	4 (33%)	5 (42%)	2 (17%)	1 (8%)
How well equipped do you feel to meet these families' emotional needs? After listening to the archive	0 (0%)	0 (0%)	5 (42%)	5 (42%)	2 (17%)

really talk much about the impact on clinicians, or broach any of the guilt that clinicians may feel (justified or not justified) – but a public domain may not be the best place for this'. Other respondents found it a useful resource for the 'constant learning experiences for all involved' and 'developed insight into the bereavement midwife role, from their perspective'.

All respondents described learning something new from the archive, and all would recommend the archive to colleagues, five respondents would also recommend it to parents. After listening to the archive respondents felts either very confident (*n*=2), confident (*n*=5) and equipped to meet families emotional needs (*n*=5) and were very confident (*n*=3), confident (*n*=4) and equipped (*n*=4) to meet clinical needs, with only one respondent feeling unequipped (a junior trainee) (Table 3C). For these respondents this represents a clear improvement in confidence from the questionnaire before listening to the archive; when asked why this was respondents particularly highlighted increased empathy and understanding of the emotional needs of parents. Ten (83%) of respondents stated that they would use the archive again and all respondents would recommend the archive to colleagues. Five (42%) of the respondents would be willing to share their own professional experiences on the audio archive.

Discussion

These preliminary findings suggest that use of this audio archive, even for comparatively short periods, may be beneficial to bereaved parents and for professionals who care for them. Parents and clinicians accessed stories from both groups and the majority would continue to use and recommend the resource. Both parents and clinicians stated that they learned through accessing the stories. This study adds to the growing literature surrounding the use of patients' stories to educate both the public and health care professionals, with the largest such resource available at www.healthtalk.org.uk, although this does not currently include stillbirth as a topic.

The findings of this study support growing interest in 'narrative-based medicine'. This recognises the importance of stories relating to illness as a means to document and relay the impact of a condition or disease, as Charon states 'only in the telling is the suffering made evident'(Charon, 2004). For health professionals, patients' stories provide an essential means to convey meaning and place patient(s) at the centre of care delivery (Powell, Scott, Scott, & Jones, 2013; Hinton, Locock, & Knight, 2015). Such narratives can be used to contextualise the knowledge of health care professionals, and are of particular value to introduce difficult and sensitive topics, such as stillbirth or termination of pregnancy; however these stories would undoubtedly be more challenging to describe if professionals encounter bereaved parents in a face to face setting (France, Hunt, Ziebland, & Wyke, 2013). Ultimately, it is anticipated that a better appreciation of the complexity of illness will allow clinicians to better formulate their technical and psychological roles with respect to patients' needs (Charon, 2004).

The parents' responses described here are concordant with those from other studies, particularly highlighting the powerful emotional responses including: anger, anxiety and guilt, and how the experience of the death of a baby can isolate parents from their family and social networks (Downe et al., 2013; Nuzum, Meaney, & O'Donoghue, 2018). The reduction in some negative emotions, such as a reduction in feeling alone and anxiety, indicates that listening to other parents' experiences may benefit parents in a similar way to attending a face to face or online forum/support group (Aho, Tarkka, Astedt-Kurki, Sorvari, & Kaunonen, 2011). The audio archive also allows parents to listen to clinicians' perspectives, which for some respondents also proved helpful and would not be available in a traditional support group. This format potentially has the advantage that users can listen to as much or as little material as they wish to, but can revisit at any time without having to leave their home and can also choose to access written transcripts if the audio material is too emotionally difficult to access. Although this survey found most respondents found accessing the archive beneficial, a small number of respondents described negative emotions including anger and guilt. The potential to experience or reprise negative emotions may indicate that archives of parents' stories should be accompanied by information on where to obtain additional support, either locally or nationally.

Surveys of bereaved parents indicate the prime importance of high-quality emotional care and the key role that kind and sensitive staff play in its delivery (Aiyelaagbe, Scott, Holmes, Lane, & Heazell, 2017). In their systematic review of 52 studies of parents' and professionals' experiences of care after stillbirth, Ellis et al. (2016) identified that the most frequently recorded theme amongst parents was that the behaviours and actions of staff can have a memorable impact, with empathetic and caring staff positively influencing parents' memories. However, parents' perceptions of the adequacy of bereavement care are at odds with those of health care professionals, with parents consistently ranking the quality of care lower than that of clinicians in an international survey (Flenady et al., 2016). A lack of high-quality care was reported in the 2014 *Listening to Parents* report which found that 10% of parents were not treated with kindness, 31% felt they were not listened to or only listened to "to some extent" and 55% were not adequately involved in decision making

(Redshaw et al., 2014). Downe et al. (2013) identified that parents valued skilled, competent and compassionate care which included the timely provision of information, time to make choices, authentic emotional engagement demonstrating empathy and evidence that the death of the baby had affected staff.

In agreement with other published literature, clinicians surveyed here felt less confident in their ability to meet parents' emotional needs as compared to their clinical care. In response to this, clinicians often reported the need for additional training or placed value on developing experience "on the job". Of concern in common with other reports, the majority of staff had little or no training in bereavement care. This leaves inexperienced staff trying to "second guess parents' emotional needs". All of the studies of health care professionals reviewed by Ellis et al. (2016) identified emotional, knowledge and system-based challenges which prevent staff from providing effective bereavement care; in particular that experience and knowledge eases the provision of bereavement care but can increase the emotional burden upon staff. Clinicians using the archive valued the ability to gain understanding of parents' experiences, to identify practices which were valued so that parents could be better supported.

The burden placed upon staff is increasingly being recognised; in a survey of 804 physicians in the USA, Gold et al. (2008) reported that 75% felt that a "large emotional toll" of stillbirth and 1 in 10 considered giving up obstetric practice. A phenomenological study by Nuzum et al. (2014) identified the personal impact of caring for parents of stillborn babies but reflected the primacy of emotional care 'they don't want to hear the clinical stuff, they just want somebody human and they remember your face rather than what you say'. The weight of this emotional toll means that some staff remain emotionally distant and were recognised by their colleagues as not providing empathetic care. Another study of health care professionals in the North-East of England used a grounded theory approach to identify conflict between a scientific discourse which prioritises best evidence in conflict with a traditional view that evidence is unhelpful because all care is individualised (Brierley-Jones et al., 2018). While it remains challenging to obtain high-grade evidence for perinatal bereavement care (Koopmans, Wilson, Cacciatore, & Flenady, 2013), we argue that care must be informed by the best available evidence to provide a template which is individualised to each parent's context. It is this personalisation of care which can be informed by experience, but can also be acquired by exposure to parents' narratives.

Emotional intelligence describes an ability to understand and regulate one's own emotions and to understand the emotions of others and to use this understanding to guide one's thinking and actions (Salovey & Mayer, 1990). A systematic review of 22 studies regarding emotional intelligence and health care professionals suggest that higher levels in nurses was associated with improved physical and emotional aspects of caring and was associated with empathy, resilience, social support job satisfaction and caring (Nightingale, Spiby, Sheen, & Slade, 2018). This systematic review found inconclusive results of the few studies exploring emotional intelligence in physicians and no studies in maternity care meaning that these conclusions cannot be applied to the context of stillbirth. Nevertheless, the hypothesis that learned emotional intelligence could improve both care given to parents and the experience of giving emotional care merits exploration. One means of learning emotional intelligence is through exposure to patient narratives which can then be applied in the professionals' own practice.

This study is limited by being conducted in a single site and by the small numbers of respondents, although the findings are concordant with other studies in the UK. In common with other studies of parents' experiences of maternity care in the UK, responses were mainly from women who identified themselves as White British. Further studies are needed to evaluate whether accessing the archive improves outcomes for larger numbers of parents, these studies need to specifically target fathers and respondents from black and minority ethnic groups. Interestingly, a US-study recently found that participants in both face-to-face and online support groups for stillbirth were predominantly Caucasian, highly educated, and had private insurance (Gold, Normandin, & Boggs, 2016). Therefore, consideration needs to be given to how women who are not in these groups can be supported to access audio archives, and whether they would find them beneficial. From a staff perspective, the value of the archive needs to be evaluated in multiple sites and consideration needs to be given to how this can best be supported as part of an educational programme and participants' feedback collated.

Conclusion

An audio archive offers the opportunity for parents and professionals to access individual narratives which begins to describe the impact of perinatal death. This preliminary data suggests that access to parents' and professionals' stories may be advantageous for both parents and clinicians. For parents, accessing and listening to other parents' stories may provide a degree of appraisal support, reducing their isolation and providing validation for their feelings. For staff, the narratives may facilitate development of understanding and empathy, before being expected to care for bereaved parents first hand. Given the sensitive nature of the material, the ability of the listener to control the extent of listening, the type of material and the topics covered may also be beneficial. Even so, listening to the archive has the potential to awaken negative feelings for those listening. Therefore, further research is needed to determine whether such an audio archive about stillbirth and perinatal death is beneficial to a wider population, and if so, what circumstances mediate this effect e.g. the level of peer or professional support. It is also important to assess whether publicly available material has a wider reach and greater accessibility than traditional support groups or formal educational resources and whether this results in better outcomes for bereaved parents. Finally, the impact of exposure to parents' stories on practitioners' emotional intelligence and practice merits exploration. ■

Conflict of Interest

The authors have no financial conflicts of interest to disclose.

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Supplemental data

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