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Stillbirth and perinatal care: Are professionals trained to address parents' needs?

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ABSTRACT

Objective: To assess current practices of health care providers (HCPs) caring for women experiencing a stillbirth and to explore their needs for training to better support bereaved families.
Design: Nationwide cross-sectional survey. The main outcome measures were the evaluation of HCPs cognition, emotions and behaviours with regard to the care of women with a stillbirth care, as well as their compliance with international guidelines.
Participants: 750 HCPs, in 11 Italian hospitals, were administered a multiple-choice questionnaire.
Findings: The response rate was 89.9%; the majority (94.1%) were female, with a mean age of 37.6 (SD = 10.4) years. Midwives were the most represented (72.8%). Half of the respondents recommended immediate birth; only 55% routinely bathed and dressed stillborn babies for their parents to see, while 44.4% of HCPs immediately took the babies away without allowing parents to properly say goodbye to them. More than half felt inadequate and some even reported having failed to provide support to the family when caring for a woman with stillbirth in the past. The need for professional training courses was expressed by 90.2%, and three-quarters had never previously attended a course on perinatal bereavement care. When answers by Italian HCPs are systematically evaluated with reference to international guidelines, the results were very poor with only 27.9% of respondents reported having created memories of the baby and less than 3% complied with all recommendations in the areas of respect for baby and parents, appropriate birth options, and aftercare.
Key conclusions: There is a substantial gap between the standards of care defined by international guidelines and the practices currently in place in Italy. Italian HCPs feel an urgent need to be offered professional training courses to better meet the needs of grieving families.
Implication for practice: Perinatal HCPs should be aware of their pivotal role in helping bereaved parents after stillbirth and perinatal loss, and seek appropriate training.

Introduction

Stillbirth is a traumatic event that can dramatically change the life of parents and families. The period after the loss of a stillborn baby has extensive consequences, mainly due to the negative effects of grief, anxiety, fear, and suffering. Negative psychological symptoms after a stillbirth have been reported in almost all parents, as well as in about 95% of professionals involved (Heazell et al., 2016); perinatal loss, and stillbirth in particular, is in fact widely considered a highly stressful event by professionals (Nuzum et al., 2014).

Health care providers (HCPs) such as midwives, obstetricians, nurses and psychologists play, a pivotal role in the management of the event and in parents' care (Gold et al., 2007; Säflund et al., 2004) as shown by the large number of international guidelines. Although most guidelines are tailored for specific national health systems and often address local issues, they nevertheless share some key points for the care of women and families experiencing stillbirth. For example, most guidelines recommend that: HCPs should use simple language, showing a non-judgmental sense of caring and personal involvement; enable parents to spend as much time as needed with their baby; facilitate the creation

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of mementos; provide information regarding post-mortem examination; make time for discussion with parents; respect their cultural and religious background and arrange follow-up meetings to discuss the results of the examination and to address unanswered questions (PSANZ, 2014; SANDS, 2016; Van Aerde, 2001).

The strong emotional impact on care providers can influence parents' decision-making process and impair their subsequent wellbeing by way of their attitudes at the time of diagnosis, birth, discharge and follow up, as well as their approach towards the baby (Sanchez, 2001). Even providing standard care, such as communicating news of a baby's death to the parents, assisting the birth of the baby, being present when parents meet the baby, can be perceived as extremely difficult tasks to accomplish, particularly in certain countries (Frøen et al., 2011). Stillbirth is amongst the most difficult experiences for medical consultants, who feel the burden of human response to bereaved parents, as well as the weight of responsibility, both at a professional and medical-legal level (Nuzum et al., 2014).

Women dealing with stillbirth are, by definition, highly stressed and, if the health care staff are not sufficiently attentive and professional, the distress linked to the event can be aggravated by inappropriate behaviours during pregnancy, labour and birth (Rådestad et al., 1998). However, parents who are properly assisted and supported from the moment of the diagnosis of the baby's death in-utero until discharge express less negative emotions during their mourning process (Ewton, 1993; Hutti, 2005). Being supported by properly trained professionals is extremely important (Ellis et al., 2016) since most parents affected by perinatal loss are likely to develop typical conditions of shock, grief, disbelief, and emotional anaesthesia (Kersting and Wagner, 2012; Ryninks et al., 2014), with relevant consequences also on subsequent pregnancies (Hutti et al., 2015; Wojcieszek et al., 2016). This is particularly true for women after stillbirth. During the shock phase, the memory process is enhanced: even if the mother may appear to be confused, almost everything occurring during this phase will be remembered in great detail afterwards, and traumatic memories may emerge long after the traumatic event (Pullen et al., 2012). The risk of inducing a 'secondary trauma' due to inappropriate clinical and psychological management during the acute phase should not be underestimated by professionals.

Some authors have recently proposed that women's experiences with stillbirth could be used as an indicator of quality of care processes, considering that quality maternity care incorporates not only clinical but also interpersonal and emotional aspects (Flenady et al., 2016). The approaches of parents, professionals and peers to stillbirth are very different among countries, in particular between those of high-income and low-income. Nevertheless, health care providers (HCP) in some high-income countries, such as Italy, are more likely to practise approaches used in low-income countries (Frøen et al., 2011). Several studies suggest that this may be due to a lack of specific training programs during pre-registration courses (Homer et al., 2016; Nuzum et al., 2014) and also to an absence of shared knowledge about stillbirth and care during perinatal loss (Frøen et al., 2016). Despite the efforts of parent-centred associations worldwide, stillbirth is still a neglected issue in many countries and it is often perceived as a taboo subject (Flenady et al., 2016; Heazell et al., 2016). As a consequence, many HCPs fail to receive appropriate training on the care of families experiencing stillbirth and many ignore widely available international guidelines on perinatal loss support, basing their behaviour mostly on cultural and/or religious beliefs (Frøen et al., 2011).

Thus, the aim of the present study was threefold:

- to investigate HCPs' opinions and behaviors regarding the care of women experiencing stillbirth;
- to address HCPs' compliance with international guidelines;
- to assess HCPs' perceived need for specific post-graduate training when perinatal death occurs.

Methods

Between 2009 and 2015, 750 HCPs routinely involved in perinatal care, working in 11 different obstetric and maternity hospital units in an equal number of Italian cities (namely Alessandria, Ancona, Florence, Gorizia, Milan, Novara, Padua, Pistoia, Pordenone, Treviso and Udine), distributed in six different regions, were administered a specifically developed 23-item multiple-choice questionnaire, using an approach called "Lucina". The study was authorized by all participating hospital authorities. All data were collected and analysed anonymously.

Lucina questionnaire

> "*For thou Eileithyia alone canst give relief to pain, which art attempts to ease, but tries in vain. Eileithyia, venerable power, who bringest relief in labour's dreadful hour*"
>
> Orphic Hymn 2 to Prothyraea

Lucina was the Roman counterpart of the Greek goddess Eileithyia, whose name means "she who comes to aid" or "relieve" from the Greek word '*elêluthyia*'. In ancient Roman religion and myth, Lucina was the goddess of childbirth who safeguarded the lives of newborns and women in labour. The name Lucina, derived from the Latin word '*lux, lucis*' (light), means "she who brings (children into the) light", and she was the most important of all deities who influenced every aspect of birth and child development.

The Lucina questionnaire was developed by the CiaoLapo Charity Organization for Stillbirth and Perinatal Loss Support in order to explore knowledge and beliefs of professionals on the most difficult aspects of midwifery practice, with particular focus on the care of women experiencing stillbirth and perinatal loss. The specific aim of the questionnaire was initially to investigate behaviours and practice of HCPs during both the acute phase of the loss and the grieving process. The questionnaire was administered in Italian and some methodological issues and preliminary results were published in Italian journals and presented in international congresses. Lucina is not a rating questionnaire but rather uses a structured interview. It was originally designed as an open-ended questionnaire and administered to a sample of 40 HCPs. An analysis of the initial data allowed for modification (2009, unpublished data) and into the present structured form (23 close-ended questions) used in the multicentre study reported here (2009–2015). An English translation of the questionnaire is provided as supplementary material to this paper.

Guidelines

Compliance with international guidelines was assessed by means of the CLASS checklist (CiaoLApo Stillbirth Support checklist). The CLASS checklist is a summary of best evidence from international guidelines, specifically developed to test HCPs knowledge of recommendations for stillbirth management and to address perception of assistance by parents of stillborn babies. The tool is available online in Italian (www.class.ciaolapo.it) and it is currently under validation (data not reported). In the CLASS checklist, recommendations are divided into sections loosely based on the guidelines from the Perinatal Society of Australia and New Zealand (PSANZ) (PSANZ, 2014), integrated with those of the Canadian Pediatric Society (Van Aerde, 2001), Health Services Executive Ireland (2016), and WHO-UNFPA-UNICEF (2007). The sections explored are as follows:

- *Respect (R):* respectful attitudes towards stillborn babies and their parents. The most important items evaluated are: naming the baby, bathing and dressing the baby, providing privacy, enabling partners to spend time together. Corresponding Lucina items: 11c, 11d, 11e, 11f, 14a, 14b, 14c, 15b, 15c, 15e.