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Grief and Women: Stillbirth in the Social Context of India

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Abstract

INTRODUCTION—Few in Western society would argue the potentially devastating impact of stillbirth related grief; but in many developing countries where stillbirth remains the highest in the world, perinatal grief is barely recognized as an issue. The purpose of this study was to explore how poor, rural central Indian women perceive and cope with stillbirths.

METHODS—Seventeen key informant interviews and two focus groups ($N = 33$) with local health care providers, family members, and women who experienced stillbirth were conducted over a 1-month period in 2011 and then systematically coded for emerging themes using grounded theory methods to explore how women experienced stillbirth.

RESULTS—Although usually never talked about and not recognized as an issue, perinatal grief emerged as a significant shared experience by all. The perceptions of stillbirth-related grief emerged in three major themes and bear evidence of gender and power issues and indicate that local social norms negatively factor heavily into their perinatal grief experiences.

DISCUSSION—The findings in this richly textured study add to the limited literature regarding rural, central Indian women's experiences with stillbirth and factors influencing their resulting perinatal grief. In light of the void of recognition of this phenomenon in Indian society, a better understanding of the context in which poor Indian women experience perinatal grief will be a first step toward developing much needed culturally rooted interventions to positively impact the women's abilities to better cope with stillbirth in the context of their realities.

Keywords

perinatal grief; gender; power (psychology); social conformity; India

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INTRODUCTION

In Western culture, the great social and psychological impact of perinatal loss has been recognized (Toedter, Lasker, & Janssen, 2001). The fusion of anticipated birth with despair because of perinatal loss in a moment in time produces unique grief; perinatal grief is like no other grief (Kelly, 2007; Rowland & Goodnight, 2009). Perinatal grief, however, is not universally recognized (Mammen, 1995) and little is known about low-resource countries with respect to women's perceptions of stillbirth and how they cope with the loss (Haws et al., 2010; Kelley & Rubens, 2010; van der Sijpt, 2010). Perinatal grief is not recognized as an issue by the Indian medical community (Mammen, 1995; Mehta & Verma, 1990)—in one of four highly populated countries where more than half of all known stillbirths occur (Stanton, Lawn, Rahman, Wilczynska-Ketende, & Hill, 2006). The global stillbirth rate is conservatively estimated to be 3.2–3.9 million per year, with the highest rates in highly populated low-resource nations (Lawn, Yakoob, et al., 2009; McClure, Nalubamba-Phiri, & Goldenberg, 2006). This represents a significant public health problem with the resultant perinatal grief affecting the daily life of millions of women, which can no longer be ignored.

Most stillbirths in low-resource settings are intrapartum—when the loss is most devastating (Mehta & Verma, 1990) and may result in profound grief. Perinatal grief is a phenomenon of varying severity and length of duration, which can lead to significant mental health, illness, pain, and social issues involving marriage and kinship, personhood and sexual negotiating power, death, and mourning (Sather, Fajon, Zaentz, & Rubens, 2010; van der Sijpt, 2010).

In India, grief over stillbirths is hidden for several social and cultural reasons. If a woman loses a baby, repercussions from stillbirth may include stigma, blame for the poor reproductive outcome, abandonment and abuse, or loss of status and power within her husband's household because he may take a second wife. Pregnant women are expected to take precautions to ensure the baby's health, such as eating certain foods and avoiding heavy work, yet they are often powerless to do so—the food she is given to eat and her household work is controlled by her in-laws and she is not given much if any opportunity for rest in the labor-intensive context for household survival. Yet when stillbirth occurs, she may be blamed for not taking the appropriate precautions. Nor is seeking medical care for herself an option. Upon marriage, women go from their natal home to live with affinal kin; they are transferred between patrilines and her place in the family or society is determined by reproductive outcomes, particularly the birth of sons (Bloom, Wypij, & Gupta, 2001; Jeffery, Jeffery, & Lyon, 1988). She is in no position to request “special treatment,” which is expensive and difficult to access. She is expected to use home remedies and take the pregnancy in stride as her duty, and if somehow she took it upon herself to get medical help and the outcome was negative—again, she would be blamed. Paradoxically, although the all-important quest for a child (particularly a son) is important, a pregnancy loss itself is belittled. There are no special ceremonies, no condolences exchanged, no rest offered to the woman, and no expectations of tears to be shed. After stillbirth, a woman is expected to go on as if nothing happened. Thus, strong social norms control behavior and suppress expression of grief and mourning, causing women to internalize their grief and keep stillbirth a secret (Haws et al., 2010; Jeffery & Jeffery, 1996).

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In India, social norms prescribe traditional home births and health care decision making by the husband or in-laws (Bloom et al., 2001). When complications are noted, treatment delays occur because of absence of the required decision makers, economic concerns (both financial and the loss of productivity for all involved), the shame of pregnancy, facilities that are inadequately supplied or staffed, difficult access to a facility, or mistrust of government services (Gopalakrishnan & Ukil, 2009; Jeffery & Jeffery, 1996, 2010). These factors contribute to high stillbirth rates in India, yet many medical providers do not acknowledge perinatal grief (Mehta & Verma, 1990).

In this society where female gender identity and value are largely determined by fertility, stillbirth can have dire social consequences (Fottrell et al., 2010; Inhorn, 2003) and result in significant mental health issues. It is these very same social and cultural factors that may affect women's ability to cope with perinatal grief and may increase the propensity for pathologic grief. According to Issel (2009), illness is cultural, not just biological. The purpose of this qualitative article is to explore how poor, rural women in central India experience perinatal grief resulting from stillbirth and how their social environment reacts to it and influences it.

Methods

Setting

This study was conducted at a 100-bed rural hospital in a very poor area in central India. It serves a catchment area of 50-60 km. Services include outpatient consultations (nearly 30,000), admissions (more than 3,000), surgeries (more than 2,000), and births (more than 500) per year. The population of the state is 33% tribal, compared to 8% of the total population of India having tribal designation (Mandai, Mukherjee, & Datta, 2005) and is also 12% scheduled castes (Mandal, Datta, Guha, Mukherjee, & Ghatak, 2005).

Tribes in India have been defined as a collection of families speaking a common dialect, having territorial affiliation, the practice of endogamy (marriage within one's own group) at the territorial level and exogamy (marriage outside one's own group) between clans. Tribes operate as self-contained communities with distinct cultural characteristics and are united by the use of community property resources and traditional beliefs (Mandal, Mukherjee, et al., 2005; Rath, 2006). Scheduled castes are a class of people designated as such according to Article 341 of the Indian Constitution empowering the President of India to do so (Mandal, Datta, et al., 2005). They are the depressed classes—those born into the low castes of Hinduism, who are therefore unacceptable to those of higher caste—putting those in the low castes at great social disadvantage with little or no opportunity to improve their lot in life. They are oppressed castes or marginalized groups also known as Dalits (Narayan, 2006).

The state population has a female literacy rate of 51.85% (Mathew, 2010), although averages obscure vast variations in India's urban versus rural areas and rich or poor people, caste and tribe (United Nations Children's Fund [UNICEF], 2008). Hindi and Chhattisgarhi are the primary languages of the region (Mathew, 2010). Among women of reproductive age, 50% have no education, and only 8% of rural women have their deliveries in a medical facility (International Institute for Population Sciences [IIPS], 2008). The mean age of

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marriage for rural women is 18.7 years, but 23% are married before the age of 18 years (Mushtaq, 2009).

Recruitment and Consent

We used snowball sampling techniques (Berg, 2009) to find participants. Initially, hospital staff referred women who had experienced stillbirth at the hospital within the last year, and then word of mouth facilitated recruitment from a broader community segment, including women who had experienced stillbirth at home, which represents most women who experience stillbirth because few women in this area of India have access to a hospital. As encouraged by grounded theory principles, triangulation was sought for the purpose of gaining a broad perspective and convergent validation (Berg, 2009). Key informant interview participants ($N = 17$) and focus group participants (two validation focus groups with 16 participants) included hospital staff and health care professionals, patients and family members, and local Dais—trained or untrained traditional birth attendants (Park, 2005).

Because there was no local institutional review board (IRB) available, the study procedures were reviewed and received approval from the investigative team's university IRB. Potential participants were told that the purpose of this study was to explore how women perceive stillbirths and how women are able to cope with it. If they were not interested in participating, they were simply thanked for listening. Only one woman approached, declined to participate. Those who were interested in participating were informed about the study procedures (taping, transcription, confidentiality) and consented. Active informed consent was obtained by either a signature or thumbprint. None of the interviewees discontinued the interview midway. Participants were provided with a small gift at the conclusion of the interview or focus group discussion to thank them for their time. Field notes documenting salient circumstances to the interviews were prepared for all interviews and focus groups, coded and used in the analyses.

Interviews

Grounded theory methods were used to conduct the study to collect richly descriptive data, through in-depth understanding of a given phenomenon. Interviews and validation focus groups guided by the use of a semistructured guide to assure that the same concepts were explored but allowing a free flowing exploration (Corbin & Strauss, 2008). Interviews can be used to guide grounded theory development and add context and meaning to quantitative research (Austin-Lane, Girasek, & Barbour, 2004; Patton, 2002). All interviews were conducted in English, Hindi (the main official language), or the local dialect, Chhattisgarhi, by a trained qualitative interviewer with the assistance of local interpreters. All but one of the interviews were audiotaped, translated (if not conducted in English) and transcribed verbatim. The interview guide for the study was developed partially based on published studies pertaining to stillbirths, perinatal grief, religiosity, and coping, as well as the results of a de-identified medical records review of the hospital births in 2010 ($N = 536$), which was part of the larger, mixed-methods study. The informed consent was written in both English and Hindi. A bilingual committee did the translation. Independent forward and backward translation was employed to ensure cultural and functional equivalence beyond literal

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translation, a time consuming but imperative process (Jones, Lee, Phillips, Zhang, & Jaceldo, 2001). Verbal translation from Hindi to Chhattisgarhi (a dialect of Hindi) was undertaken when required.

Questions explored personal experience of stillbirths, observations regarding someone else who had experienced stillbirth, knowledge or beliefs regarding stillbirths, as well as societal responses and expectations of how women should react to stillbirth. Neutral, nonjudgmental probes were used to pursue related subject areas initiated by the interviewees.

Of the 17 interviews, 16 were audiorecorded and transcribed verbatim. All interviews were conducted face to face, lasting 75 min on average. Interviews continued until no significant new insights emerged, signifying the point of saturation (Corbin & Strauss, 2008). One participant consented to the interview with the stipulation that it not be audiorecorded. This interview was reconstructed immediately following the interview, from written notes.

Focus Groups

Two validation focus groups (*N* = 16) were conducted at the hospital using a semistructured outline developed from the themes emerging from the key informant interviews. The primary purpose of these focus group discussions were to further explore and validate the emerging themes in a social situation allowing open discourse to further contextualize them. Topics included social norms pertaining to age of marriage, fertility expectations, birth customs, attitudes toward women who experienced stillbirth, and social support within the family/community. The first focus group included six women of reproductive age (ages 15 to 49 years; Kavitha, 2010) who had not experienced stillbirth but were asked what their perceptions of the phenomenon of stillbirth were.

The second focus group included 10 older women; grandmothers, mother-in-laws, and local Dais—three who had experienced stillbirth themselves many years ago. A third discussion ensued with these three women who stayed back after the others had left. This discussion was pursued to validate the perspectives and experiences expressed by young women with recent stillbirth who had been key informant interviewees. The focus groups were conducted with the help of local outreach workers and transcribed from audio recordings in addition to notes taken during the discussions. The focus group transcripts and following discussion were then coded in the same systematic manner as the key informant interviews.

Coding and Analysis

All 17 interviews and two focus group transcripts were systematically coded by two individuals and analyzed using standard qualitative data analysis procedures: first, open coding allowed information to inductively emerge and then was organized into grounded categories with subcodes. Once a final codebook was developed, two coders independently read the interview and focus group transcripts and coded them using the final codebook. The goal of coding is to allow systematic review of the themes in the interviews. Themes were linked to the literature and coded accordingly (Berg, 2009). To determine reliability of the coding, two additional coders were trained. Intercoder agreement was assessed dividing the

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numbers of agreed upon codes with all possible codes, multiplying the result by 100 (Kelsey, 1996). The overall agreement was 95.7%.

Results

Participants

Descriptive information, including whether or not they had experienced stillbirth, regarding the 31 women who participated in the study is presented in Table 1. In addition, two husbands of women who had experienced stillbirth were interviewed to allow for their perspectives to enter into our exploration (for triangulation purposes).

Initial review of the data (emergent coding) resulted in 30 initial codes. These codes were clustered into 15 major codes that fell into five themes. The five themes were coping, perceived social support, grief, cultural norms, and gender and power.

The three themes of greatest frequency were grief, cultural norms, and gender and power and are discussed in more detail in the following section.

THEME 1: PERINATAL GRIEF Grief was identified in every transcript and most often emerged without prompting when discussions turned to stillbirth. Reading and re-reading the data set as a whole, in the process of coding, provoked a sense of overwhelmingly deep sadness. Grief was coded as follows: sadness, defined as depression, sorrow, feeling blue, or unhappy; and yearning, defined as a strong desire to become pregnant again but tinged with sadness.

Several subthemes were noted to contribute to or potentiate the grief these women experience and included shame, described by the women as feeling blamed by others, dishonored, or worthless; decreased functioning, described as inability to focus, complete tasks, or concentrate; somatic symptoms, described as physical symptoms of illness that occur when thinking of their stillborn baby; and guilt or blaming oneself.

Although grief was not outwardly expressed with wailing and sobbing, it was spoken of with deep, aching sorrow; a sadness that had become a part of their very beings and voiced as constantly yearning for a child or to be pregnant again. They wistfully talked about what it would be like to have children or about how those they had lost might look, how old they would be now, and how they would play. Their private mourning was palpable; some admitted they had never spoken of it before.

> *I cry in my sleep.* (30-year-old interviewee)

> If I see my elder sister's kids I think about my babies, how old they would be, how they would look . . . the pain, I try to forget. I keep myself busy with all my work or I sleep. I cannot concentrate on what I'm doing. They would be calling me ‘mother, mother’ and I would be playing with them now. (23-year-old interviewee)

Their grief was tinged with shame, as others blamed them for the stillbirth. “My mother-in-law blames me for not enduring the pain. (She says) that's why the child died” (30-year-old interviewee). Often having been dishonored, a sense of worthlessness weighed heavily on

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the women. They covered their faces and looked away when they talked about their failure to have children. Some reported disparaging remarks by their husbands and in-laws—"*They say I am bad daughter-in-law, bad wife*"—some suffered much worse.

Their grief caused decreased functioning, described as having difficulty concentrating on their tasks, making mistakes in the cooking or other chores expected of them.

> I burn the food, I did not cook properly because tears affected my vision . . . (23-year-old interviewee)

Many also had somatic symptoms. The women, who work tremendously hard and were too thin already, described lack of appetite, sleep disturbance, and fear, wondering what would become of them. Some still grieved, even when the stillbirth event was many years previous.

> I don't sleep good when I think about it and I can't eat properly . . . *we keep all the fears to ourselves* . . . I cry but I do not tell my pain and feelings to anyone else. (20-year-old interviewee)

> Whenever I think about it I take a child, even somebody else's child in my lap. It comforts me, but even though I had more children, I will not forget, not completely. (participant in second focus group)

These grieving women were doing their best to take it in stride, to shoulder the brunt of their loss without a shoulder to cry on, even enduring the blame and mistreatment resulting from their loss because they had no choice. The interpretation of loss by others was notably different.

Other women, Dais, and health professionals described women who had suffered stillbirth as often scolded by their in-laws and generally to be pitied.

> They (mothers of stillborns) do not get any respect and they (the family) do take them out of the family also. They (the family) blame them (mothers of stillborn) and use bad words against them. She is the worst off, we feel sorry for her, because it is very sad. (participants in first focus group)

While acknowledging the mothers' distress to interviewers and describing women with stillbirth as sad and quiet or troubled, the women's tremendous grief was not something that the observing health provider (formal or informal) dealt with compassionately or therapeutically; it was simply noted as "fact."

> Husband and relatives first asking boy or girl, then take and bury it . . . not show to mother because mother so depressed. (nurse)

> Some patients not feel good after deliver stillbirth and is having psychological problems . . . not eating food, not speech . . . that is psychological problems. (medical provider)

> . . . we never go into the psychological and social aspect with them unless it is becoming a big headache or they are getting too much trouble at home. (experienced female doctor)

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> They may beat (her) or send her away, out of the house. (participant in second focus group)

Women were told they should not cry, that the Gods would give them another child and it would be over, or that the stillbirth had occurred because she was not strong enough to bear the pains of labor.

> The child died in the womb itself, the child was born dead . . . I feel very sad but my family says don't cry for the child which is dead and gone. . . . (21-year-old interviewee)

> God has taken one, he will give another one. Don't cry, he will give another . . . (participants in the second focus group)

THEME 2: CULTURAL NORMS Cultural norms influencing the women's experiences around perinatal grief emerged as a theme throughout, often overlapping with the subthemes of grief. Cultural norms were identified using the following codes: acceptance of expectations, defined as awareness and acceptance of social norms; difference of opinion, defined as does not agree/accept social norms; marriage practices, defined as age and arrangement of marriage; and birth practices, defined as birth rituals, naming ceremonies, celebrations or lack of them, and burial.

As cultural norms were explored, women expressed awareness and almost unanimous acceptance of social norms and the ubiquitous incumbent expectations.

Cultural norms mentioned repeatedly were early marriage, linked with the expectation that a woman needs to bear a child a year later. Her role is to produce offspring, particularly a son —the all-important male heir that is expected of her.

> Two months after marriage the older people start asking questions (if she is not pregnant). (31-year-old interviewee)

> When a son is born they give anything, big celebration, everything. But the behavior is different with mother when a girl is born. (experienced female physician)

Failing to produce a son may jeopardize her status in the husband's family, which is already precarious as the newcomer.

> They actually send their daughter-in-laws back to her parents and search for a new bride for their sons to that they can bare them sons. (30-year-old participant, focus group 1)

Most participants accepted the expectations put on them by society and those that did have a difference of opinion about the way things ought to be felt powerless to act on their thoughts. Even when they disagreed with birth practices and wanted a different start for their own families, they did not oppose their husbands, mother-in-laws, and grandmothers; the risk is too great.

> I was 15 or 16 when I got married. They wanted the delivery at home (30 year-old interviewee with a history of stillbirth)

> . . . *it's no use. What can we do?* (20-year-old participant, focus group)

> The grandmother is putting hot ash on my baby, baby crying like anything. . . . She is elder, so what can I say even I don't want this. (28-year-old interviewee)

They are acutely aware of the risk, after all, they were strangers thrust into an unknown husband's family, entering at the very bottom of the family hierarchy, as young, vulnerable women. Young women were expected to comply with their new family's traditions and beliefs without question, society commands it.

> Everybody owns her. . . . When I ask, “Why didn't you bring your wife, now it is too late?” They will say, “Oh, I had a lot of work in the fields, and I didn't have time. . . . Our village is far away . . . we thought of coming after three days when we have time.” I get angry because she is dependent. (experienced female doctor)

This represents countless losses. They have lost the support of natal kin, friends, and the community where they are known and loved. They have lost freedom. They have lost their identity. Losing a baby; loss upon loss, an exponentiation of grief compounds these losses.

Birth practices were uniformly discussed and included birthing rituals, naming ceremonies and celebrations, for the purpose of understanding the lack of them when stillbirth occurs.

> There is no religious ceremony for the stillborn, it is just buried. (31-year-old interviewee)

> We are not allowed to see, no women.

> I see only my baby's feet as they took him away. They tell me it was boy, I don't see. (20-year-old interviewee)

Understanding of the possible etiology of stillbirth was expressed in cultural terms rather than biomedical terms.

> Stillbirths are common . . . it could be from curses . . . (23-year-old interviewee)

> Mother-in-law say . . . I am bad wife, so I have dead baby. (21-year-old interviewee)

THEME 3: GENDER AND POWER The issue of gender and power as a theme emerged commonly. Gender and power issues are so pervasive in Indian society that it is difficult to separate them as a theme apart from cultural norms. However, lest important nuances be lost, gender and power issues were coded as follows: societal/family position, defined as household position and power, employment (formal/informal sector), gender roles; decisions, defined as the ability to make one's own decisions, decisions made with others, or others decide for her; finances, defined as money to spend at will or not; and going out, defined as allowed to leave the house/go to market or field/visit relatives/friends or not.

Women's value through fertility and societal son preference serve as constant reminders of gender disparity and yet is inadvertently perpetuated by these young women as they desperately try to secure their position in their in-laws home.

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> Every family must have one or two sons. If she barren or has stillbirth, everybody talking—"She have no child"; the neighbor say, "You have no child, why?" the mother is blamed and will suffer. (nurse)

> One female patient came with her face beaten, saying, "I don't want girl child because my husband and in-laws say son, but this time I have a female baby". . . Boys are compulsory. (medical provider)

These women are isolated within their homes, illustrating their lack of autonomy. They are not allowed to physically socialize with the neighbors unless accompanied by a male family member. The women noted talking "rooftop to rooftop" during the day but even that is constrained by the fear that something said might be reported to their husbands. They are not free to decide for themselves when to seek health care, go to the market, or visit their relatives. They have little if any education and may not have any say in whether or not their children receive schooling. They may also have little if any say in decisions regarding family planning.

> *We only have to get married and have kids.* (22-year-old participant, focus group 1)

> If they first had a baby boy then they should plan not to have any more, but if it is a girl and they have two it is compulsory to have a baby boy. Whether the family exceeds 9 or 10 they don't mind. They don't mind the health of the mother also. They don't care even if they have to bring another wife in order to have a son. She can stay but if she don't like it she can go . . . but she depend on her husband and in-laws for everything. (local dai)

The men of the family usually make all the decisions, without eliciting any input from these young women.

> It's husband and father-in-law who told "let us take her to the hospital" then they brought me. (20-year-old respondent)

Although sometimes the husband makes the final decision after consulting with the mother-in-law regarding the young woman in question; mother-in-laws, who were once the young, new bride themselves—now wield considerable power over young women.

> My mother-in-law did not want to send me to the hospital . . . my husband consults with her on each and every thing. She said she delivered at home, so I should also. (23-year-old interviewee)

> She came here after marriage, now she should live here and she should die here. Always she should be here (living with husband and his family), her husband her only focus. (mother-in-law, in second focus group)

> *Mother-in-laws is the villains . . . really.* (medical provider)

Medical providers noted that when they talk to these young women in the hospital, they defer to either their husbands, "I have no schooling . . . so my husband takes all the decisions" (20-year-old interviewee), or their mother-in-laws in their husband's absence. Again, although many providers observed and noted this, they did so without critical

comments or noting it as an “issue”; notably, few providers expressed frustration with this pattern; it was usually accepted as the status quo.

Few of the women had natal kin support while in the hospital, but those who did were fortunate. These family members were solicitous of their daughter's health and well-being above all else. Natal kin and a rare husband comforted her in her time of grief. Some of the nurses expressed compassion, but the medical community predominantly avoided or failed to recognize the realm of psychosocial issues faced by these women—in fact adding to the devaluing of the women's grief.

Discussion

The goal of this study was to systematically explore rural Indian women's perceptions pertaining to stillbirth, the resultant grief, and how they cope with the phenomenon in their cultural context. Fertility is everything to a woman in India. It defines her, gives her value and purpose, *and* makes her vulnerable. Who is she without children? What happens when she suffers losses? What becomes of her when she fails to produce at least one son, as required? How does she cope? Triangulation—including the perspectives of older women, Dais and health care providers allowed us a better understanding of the much larger context within which these women must function. Issues of gender and power, social support, coping, and religious beliefs uniquely influence perinatal grief outcomes for our women living in a tightly controlled cultural context and provide a glimpse into the extent of their grief.

As Mammen (1995), we found that perinatal grief is not just a Western phenomenon. Our participants expressed significant and long lasting grief after suffering stillbirths. They did not wail and cry out loud, they had learned it necessary to appear stoic, perhaps trying to take it in stride as though grief is so much a part of their everyday lives. Yet when asked, the torrent of emotions surrounding the stillbirth experience was undeniable.

In contrast to the tremendous grief we found, the prevailing view of the Indian medical society documented in the literature (Mehta & Verma, 1990) was reflected by even a generally committed and experienced doctor who said, “They are so uneducated that they just think it's over. Their reaction to it is— I don't find it very emotional. It's like they know they can have more babies:” Yet later in the interview, she stated that she observes that after stillbirth, “they will be very depressed . . . so that they hardly talk.” This observation reflects the stoicism expected of them by their families and society. Giving the women an opportunity to express themselves during key informant interviews and the second focus group discussion that extended with the older women who had long ago experienced stillbirth, painted a very different picture—one of significant psychological distress that stayed with the women in a dominant and unforgettable fashion.

Grief, social norms, and gender and power issues factored predominantly in each and every key informant interview and focus group discussion. These factors are intricately intertwined, as a whole describing women's perceptions regarding stillbirth and perinatal

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grief. Understanding perinatal grief outcomes in this context is thus inextricably linked to social norms and gender and power issues.

Social norms are woven into the everyday fabric of these women's lives, influencing their own expectations and acceptance of others' expectations. The lack of autonomy expressed by these women is characteristic of the low female autonomy noted by Mistry, Galal, and Lu (2009) and precludes many choices. For instance, many of the women indicated that it was her husband or in-laws who decided whether or not she should go to the hospital for delivery. India is a patriarchal society (Tisdell, Roy, & Regmi, 2001), and permission is typically required for a woman to seek health care for herself (Lee et al., 2009).

As Lawn, Lee, et al. (2009) indicated, traditionally women are secluded, especially pregnant women. Cultural norms prescribe when they marry and bear children (Croll, 2000) as well as predict the social repercussions of not bearing children—such as abandonment, mistreatment, or divorce (Joshi, Dhapola, & Pelto, 2008), and determine the social hierarchy these women find themselves in within the husband's family (Barua & Kurz, 2001).

There is considerable overlap of the local social norms (i.e., who makes health care decisions, birth practices, gendered roles) with what the literature refers to as gender and power issues, affecting these women's lives and their grief. Gender discrimination negatively affects reproductive health (Anderson, 2005), yet fertility is the very thing demanded by societies rife with female discrimination. In addition, Croll (2000) notes that gender disparities in health and education affects autonomy, further limiting her possible response to social norms. Social norms acted as a mechanism of control (Haws et al., 2010) of the expression, or suppression, of grief. Furthermore, social norms control young women's social interactions and prevent the opportunity to be with others who have also suffered stillbirth. In this way, social norms seem to in fact worsen perinatal grief.

Clearly, these rural Indian women are living with tremendous grief. However, given their powerless status, any type of intervention, however needed, will have to comply with the restrictive system the women live in. For instance, in Western health care settings, protocols are in place to offer the opportunity for the mother to hold her stillborn baby, or take pictures or other mementoes. This is offered as therapeutic care for perinatal grief, as a means of preventing pathologic grief. However, in Hindu Indian society, women are not allowed to be present at burials or look upon the dead; therefore, such protocols would not be tenable. Any intervention should also be supported by the medical community to be somewhat accepted by the decision-making males or mother-in-laws who may see it as indulgent and stillbirth as just something to "get over".

Limitations

Our study has several limitations. Given the vast diversity in Indian society from one region to another, generalizability is limited to rural low-income women. As with all qualitative data, participants' accounts were retrospective and social risks and social control may have contributed to underreporting (Haws et al., 2010) of various aspects of their experiences. Nevertheless, what they willingly shared provided us deep contextual insights into an issue few have explored with these women. Lastly, the stillbirth phenomenon is a complex

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medical and social issue involving numerous factors beyond the scope of this study. However, the factors that were investigated in this study are important to the social aspect of the stillbirth phenomenon and critical to the women who experience them in a society that values fertility, adherence, and compliance to prevailing norms that do not allow women to share their grief.

CONCLUSIONS

The results of this study clearly document that perinatal grief is a significant issue for these women. Factors that inhibit or enhance women's ability to cope must be considered in the development and implementation of appropriate interventions to address perinatal grief.

The poor women in the area are generally a group with low autonomy and low education levels, from low castes, who are socially isolated and highly dependent on their husbands, as dictated by traditional social norms. Their lives are hard and filled with loss. They lose any sense of self once married, they lose dignity as they are “treated as slaves” (as one interviewee phrased it) within their in-laws’ households, they lose basic human rights—such as the right to choose for themselves what they see as in their own best interest. For these women, fertility is ubiquitous to their identity and worth. Thus, women who have had stillbirths are in a sense, even a lower group and their grief is thus potentiated. Their grief, resulting from perinatal loss, is inextricably linked to the quagmire of social norms and gender and power issues that keeps them vulnerable to gender discrimination. It is a self-perpetuating cycle of loss and grief.

This study begins to unravel the women's perceptions of stillbirth, contributing to the limited existing literature on maternal coping related to stillbirth in developing countries and specifically, the tremendous perinatal grief women are living with in central India. Providing contextualization is important for the next step—quantitative research regarding the phenomenon of stillbirth in this region. For example, understanding what it means to be a wife versus a daughter-in-law, in terms of role expectations and autonomy within the household hierarchy, will enhance interpretation of future data collected on family composition, which is directly related to gender and power issues.

The results of this study may also serve as a social model of needs assessment in this area. Successful intervention may need to begin with the medical community. Health professionals need to recognize the impact of stillbirth beyond the postnatal medical concerns. An understanding of the psychosocial issues, which may continue for many years, could shift the prevailing medical society's attitude that these women are not experiencing perinatal grief and just need to get on with having another child. If the medical community elicits the concerns and emotions of their patients who experience a life-changing stillbirth event, the effect could be to slowly change how women are allowed to express their feelings within their families, within their communities. Any future interventions must be culturally in tune with local ways of life and thinking as well as socially relevant to be effective. Jamkhed serves as a good example of positive social change that began with health professionals (Arole & Arole, 2010).

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A better understanding of women's experience of perinatal grief allows us the opportunity to begin to develop effective interventions to have a positive impact on women's abilities to cope with the stillbirth phenomenon, and ultimately decrease the significant public health burden of perinatal grief. Such an intervention might be one that enhances women's self-control over emotions and their reactions, their ability to interpret experiences as they choose, and educates health professionals regarding perinatal grief.

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TABLE 1 Demographic Characteristics of Women Participants Who Shared Their Personal Perceptions or Observations of the Stillbirth Phenomenon ($N = 31$)

CHARACTERISTIC	WOMEN WITH PERSONAL HISTORY OF STILLBIRTH ($n = 15$)	OBSERVERS OF STILLBIRTH PHENOMENON[a] ($n = 16$)
Ethnicity		
Scheduled caste	5	6
Scheduled tribe	3	3
Other backward caste	5	4
Other	1	3
Marital status		
Single		2
Married	15	12
Widowed		2
Current age		
15–19 years	1	3
20–30 years	11	3
31–40 years	3	6
>41 years		4
Age at marriage		
<18	6	9
18	9	5
N/A		2
Age at stillbirth		
15–19 years	1	
20–30 years	13	
31–40 years	1	
Parity		
Nulliparous		2
Primiparous	5	3
Multiparous	8	7
Grand multiparous	2	4
Other living children		
0	5	2 (N/A)
1	3	5
2–3	5	5
>4	2	4

Note. Most ages were reported approximately, as many women did not know their exact age or time frame for when marriage or stillbirth occurred.

[a]Observers of stillbirth phenomenon were family members, birth attendants, and health care providers.