Support Groups Helping Women Through Pregnancies after Loss

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Abstract:

Pregnancies following perinatal loss are full of fears and anxieties. Standards of care or interventions are not generally available, however support groups exist across the country. This study explored several pregnancy-after-loss support groups. Data were collected through participant observation of meetings, individual interviews, questionnaires, and artifacts. Five paradoxes were identified reflecting conflicts between common cultural expectations and the women's own perspectives about pregnancy: birth/death, pregnancy equals/does not equal baby, head/heart, public/private, and hope/fear. According to participants, the groups helped members recognize their commonalities, remember their earlier babies who died, develop caring relationships, and learn new coping skills. Key outcomes included "making it through" their pregnancies, finding ways to reconcile the cultural paradoxes, and relating better with their current, live babies.

Keywords: pregnancy after loss | perinatal loss | focused ethnography | support groups

Article:

Families who experience perinatal loss (commonly defined as miscarriage, stillbirth, and neonatal death) are often shocked and grief stricken that their desired pregnancy was unsuccessful. Their emotional devastation may continue for an extended period after the loss and can have far-reaching effects on their lives (Beutel, Willner, Deckardt, Von Rad, & Weiner, 1996; Janssen, Cuisinier, Hoogduin, & de Graauw, 1996; Ney, Fung, Wickett, & Beaman-Dodd, 1994). Loss of innocence and an increased sense of vulnerability are common emotions for these families, who now view pregnancy with skepticism. Pregnancies following loss are almost always anxiety laden, and high anxiety can lead to negative obstetrical, neonatal, and parenting outcomes (Wadhwa, Sandman, Porto, Dunkel-Schetter, & Garite, 1993). Despite these known elevated risks, no standardized interventions for pregnancies after loss (PAL) have been identified. Although some support groups do exist for this population, the structure, functions,

and efficacy of these groups have not been investigated. The current study explored the culture of PAL support groups and examined the impact of these groups on women who sought them as an intervention.

PREGNANCY AFTER LOSS (PAL)

In U.S. culture, pregnancy is generally expected to lead to a new mother with a new baby. In reality, approximately one fourth of all conceptions end in perinatal loss, and the numbers are rising because of the increasing use of technology to achieve pregnancy (Woods & Woods, 1997). Recent studies show that unsuccessful pregnancies can have negative impacts on women and on their subsequent pregnancies (Côté-Arsenault & Marshall, 2000; Franche & Mikail, 1999; Hense, 1994).

After a loss the majority of women try to become pregnant again, however pregnancies after loss have been found to be difficult emotionally, full of worry, anxiety, and a sense of fragility. Women have concerns about the new baby's health, worry that their emotions might have a negative impact, and fear that this baby too might die (Côté-Arsenault, Bidlack, & Humm, 2001). They commonly cope with the uncertainty in these pregnancies by doing everything possible to ensure success while also protecting themselves psychologically against another loss (Côté-Arsenault & Marshall, 2000). This "one foot in, one foot out" stance seems to involve emotional cushioning, that is, outwardly going through the motions of the pregnancy while inwardly expecting the worst to happen.

Some women deal with these ambivalent emotions by participating in support groups. It is not clear how many such groups exist in the United States, however there are more than a dozen online chat or bulletin groups, listings for several national groups, and numerous links to local perinatal loss and PAL support. Rajan and Oakley (1993) demonstrated that social support improved the physiological and psychological outcomes of pregnancies after loss as compared with routine prenatal care in the United Kingdom. Caelli, Downie, and Knox (1999) developed and evaluated a support program for PAL couples in Western Australia, which preliminary findings indicate was very helpful to participants (Caelli, Downie, & Letendre, 2002). There are no standard or widespread protocols or programs for helping people in pregnancies after loss, so it is important to explore PAL support groups because interventions for these women and their families are needed.

Support groups should be distinguished from self-help and treatment groups, though these differences are often blurred. "Support groups serve a useful function in helping people deal with stresses related to common crises, life transitions, and chronic conditions" (Schopler & Galinsky, 1993, p. 195). Such groups have proliferated because informal sources of support, such as family, have declined because of increased population mobility and decreased family size. The groups provide social networks and support to people with similar issues and concerns. Unlike treatment groups, which are leader centered and therapy focused, and self-help groups, which

focus on independent development and mutual support, support groups are member centered and typically have a trained professional facilitator. Their goal is to create a supportive environment and encourage members to cope more effectively with their common issues (Schopler & Galinsky, 1993).

Purpose

No other studies were identified that focused on support groups for pregnancy after loss. The current study explored the culture and impact of PAL support groups, primarily from the participants' perspective. It examined, specifically, why PAL support groups were felt to be needed, how they were structured and how they functioned, and why these groups were felt to be helpful.

DESIGN AND METHOD

Because of the exploratory nature of the current study, the goal of gaining cultural knowledge, and the need to learn insider meanings of actions in the natural setting of social events, a qualitative approach, ethnography, was used (Spradley, 1980; Streubert & Carpenter, 1999). "Ethnography is a research process of learning *about* [italics in original] people by learning *from* them . . . and is used to understand and describe why a group of people do what they do" (Roper & Shapira, 2000, p. 1). Learning a culture from those who are a part of it occurs through conversations and interviews, and these approaches are easily applied to studying support groups. Specific, selectively chosen research questions were asked, calling for a special type of ethnography: a focused, or mini, ethnography.

As defined by Muecke (1994), focused ethnographies "are time-limited exploratory studies within a fairly discrete community or organization. They gather data primarily through selected episodes of participant observation, combined with unstructured and partially structured interviews" (p. 199). The researcher is deemed successful when the community's behaviors, beliefs, and local meanings are illuminated and explained, not simply described. The community of women who experienced a pregnancy after loss and attended PAL support groups are the participants in the current study. Focused ethnography facilitated the understanding of the emic (insider) and etic (outsider) perspectives of PAL support groups in their naturalistic setting.

Sample

Two established PAL support group programs operating in large metropolitan areas for more than a decade were conveniently identified: one in the Midwest (MW) and one in the Northwest (NW) United States. The principal investigator (PI) made contact with the facilitators of each program, who agreed to participate. Both programs were designed to provide support to pregnant couples who lost a baby during a previous pregnancy through miscarriage, elective termination because of genetic defect, selective termination in high-tech multiple gestation, stillbirth, or neonatal death. The groups were studied as they naturally existed, that is, membership changed

from meeting to meeting despite a great deal of consistency, so group size varied (range of 2 to 13). All members were women, except for three men who were present one time each in different groups. Group members were 90% White and 10% diverse minorities (mainly Asian and Pacific Islander), primarily well educated (years of education: range 12 to 21; mode of 16 years; $M = 16.5$), with incomes from U.S. $20,000 to more than $120,000 ($M = $60,000 to $79,000 category). They ranged in age from 21 to 47 years ($M = 35$), were primarily married (94.5%), 38.4% had no living children, and 30% had one living child (mode) (range 0 to 5). All types of losses were represented. All of the facilitators were White.

The first site (MW) was affiliated with a hospital that had a high-risk perinatal care program and comprehensive perinatal support that included programs for loss, subsequent pregnancy (PAL), birthing after loss, and postpartum after previous loss. The MW groups attended for this study—PAL, birthing, and postpartum—were thus part of a larger program with one full-time facilitator and an occasional second facilitator. Subsequent pregnancy programs included weekly support group meetings at the hospital, birthing classes for PAL couples, and weekly postpartum group meetings. The primary facilitator was a master's prepared professional parent-infant specialist, the secondary facilitator was a perinatal registered nurse.

The second site (NW) was also an urban hospital with a high-risk perinatal care program. The facilitator was a master's prepared social worker who also covered the perinatal clinic. The program included two support groups: one for parents having high-risk pregnancies who had difficult decisions to make, the second for parents experiencing or contemplating a pregnancy after loss (PAL). The principal investigator attended only this latter PAL group, which met monthly.

Data Collection

Data were collected by the investigator in several ways: (a) participant observation of seven support group meetings over 6 months during which field notes were taken, (b) 12 individual interviews of key informants (all facilitators plus current and past group members were purposively sampled) done in person or by telephone (all audiotaped), and (c) 130 surveys sent to women on the current and past member mailing lists of both sites (76 were returned). In addition, artifacts from both sites were examined, including a perinatal loss newsletter, a manual for professionals working with PAL families (written by facilitators), two videotapes produced at one site on the experiences of parents, a CD-ROM of guided imagery to be listened to during PAL, and a pregnancy calendar used during one site's meetings. Data collection occurred over 8 months. Almost all participants were women; all interviews and quotes were from women.

Ethical Considerations and Trustworthiness

Study approval was obtained from the appropriate institutional review boards, and informed consent given by all participants. Ensuring the open and trustworthy reflection of the PAL culture required extensive strategies (Roper & Shapira, 2000). The PI introduced herself to the

groups as a nurse researcher but later shared her experience of a loss and successful subsequent pregnancies. Participants asked questions about her circumstances, and after disclosure, she was viewed as an insider. Field notes and memos of the PI's personal thoughts and reactions were kept separate from participant responses. The second author also drafted memos about personal perspectives during data analysis. Direct quotes were written in field notes during group meetings, and interviews were taped, transcribed, and verified by a team of assistants. Multiple data sources and methods further strengthened the current study's trustworthiness. An interview guide was used, however prompts and additional questions were developed as data were collected. Telephone contact was maintained with the facilitators to gain administrative and professional perspectives about the groups and their members.

Data Analysis

Although data analysis was ongoing, final analyses were done with the second author, who was new to the project. She provided the perspective of an outsider who had personal loss and support group experience but no contact with the participants. The varied insights of the researchers allowed them to ask questions of the data but remain aware of differences between personal and informant experiences. Data analysis was done by systematically reviewing transcripts and field notes from meetings, interviews, informal conversations, and surveys. Memos tracked recurring topics and emerging themes, and data were examined recursively to modify or verify these themes. Characteristics of the culture (e.g., actors, roles, rituals) were carefully considered. In this phase, key questions were raised (What are the areas of commonality? What is going on here?) and issues debated that helped clarify the current study's focus and results. Two consultants (a nurse anthropologist, a writing specialist) reviewed the manuscript and provided feedback to further explicate the findings.

RESULTS

The investigators discovered a sequence of events that characterized all of the support group members. After a perinatal loss, participants chose to become pregnant again and felt they needed support to get through the stresses of the later pregnancy. This need led them to a support group, which provided new knowledge and coping skills that helped them through the pregnancy (see Figure 1). The data revealed that PAL pregnancies include paradoxes and conflicts between general expectations of pregnancy and the women's past experiences of loss. The group structures and processes women found beneficial, which helped them reconcile these discrepancies, are described in detail, using quotes from the women themselves. The support group served as a bridge between the paradoxes inherent in pregnancy after loss and the dominant culture's view of pregnancy.
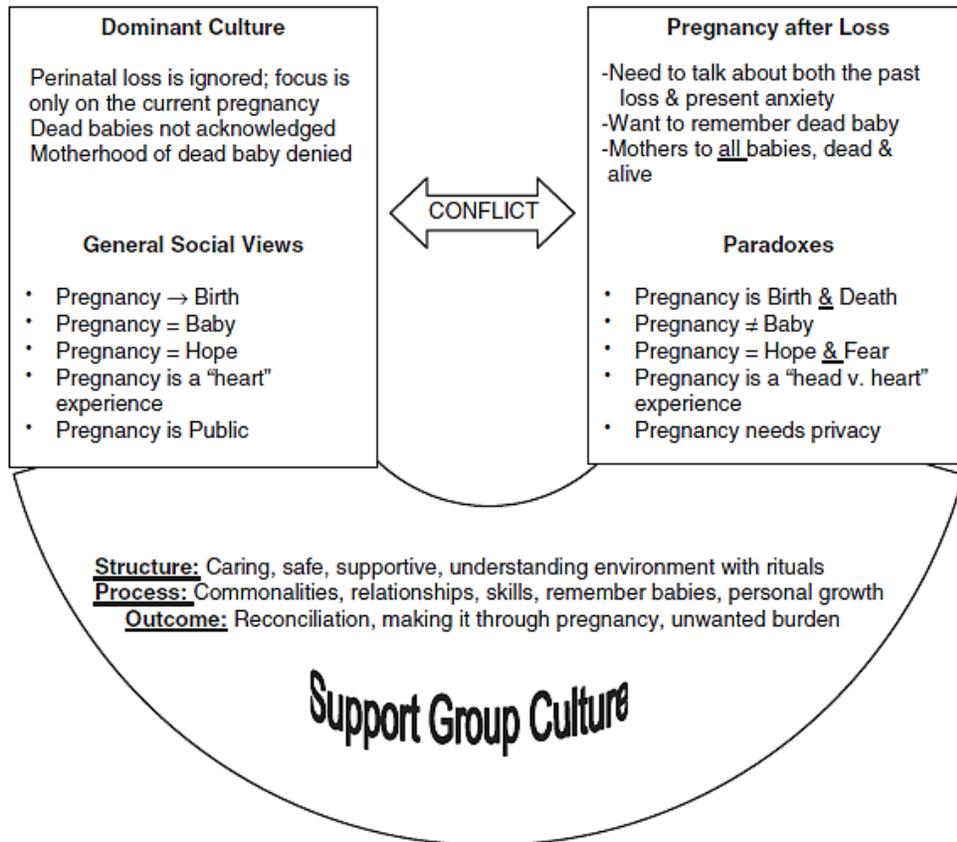
Dominant Culture

Perinatal loss is ignored; focus is only on the current pregnancy
Dead babies not acknowledged
Motherhood of dead baby denied

General Social Views

- Pregnancy → Birth
- Pregnancy = Baby
- Pregnancy = Hope
- Pregnancy is a "heart" experience
- Pregnancy is Public

CONFLICT

Pregnancy after Loss

- Need to talk about both the past loss & present anxiety
- Want to remember dead baby
- Mothers to all babies, dead & alive

Paradoxes

- Pregnancy is Birth & Death
- Pregnancy ≠ Baby
- Pregnancy = Hope & Fear
- Pregnancy is a "head v. heart" experience
- Pregnancy needs privacy

Structure: Caring, safe, supportive, understanding environment with rituals
Process: Commonalities, relationships, skills, remember babies, personal growth
Outcome: Reconciliation, making it through pregnancy, unwanted burden

Support Group Culture

Figure 1: Conflicts Inherent in Pregnancy After Loss, Bridged by Support Groups

Characteristics of the Pregnancies

In the current study, all the women felt a sense of increased vulnerability, isolation, fear of another loss, and anxiety about something going wrong. Many expressed guilt for their past loss(es). They described holding back their emotions, seemingly to protect themselves from future pain. They also sought to understand why a previous baby died and how to avoid another loss. Onewoman, pregnant with twins after a history of a stillbirth, described her complex feelings:

> I'm really taking it day-by-day. . . . I think everyone in the support group would have agreed that nobody enjoys a pregnancy after [a loss]. You're happy that you are [pregnant but] you can't be that innocent. . . . You'd have to be like brain dead to go through a pregnancy after losing a baby and be able to take it easy. Am I confident? No. Will I relax? No. There is not a point that I will relax until they are out and breathing and hearts beating. . . . I've definitely learned to live in the present and know that life can turn on a dime, at any old time.

Another, pregnant after a loss due to a genetic abnormality, shared her worry and sense of isolation:

> You just are so much more aware of how fragile . . . those babies are because you've lost them. It's just much more of an emotional issue for people who have lost a baby. . . . We talked to the pastor . . . and it isn't that he didn't love us . . . but . . . you lose a baby and nobody gets what that's like. . . . I could feel my anxiety . . . starting to go up, you know, are we going to have the same trouble with this pregnancy that we had with the last one?

These were clearly not easy pregnancies; women had high anxiety and took nothing for granted. Pregnancy was emotionally challenging for them even as they tried to remain optimistic.

Paradoxes

In meetings and interviews participants revealed that their experiences of pregnancy involved several opposing dualisms or paradoxes, that is, the perspective of society did not match that of these women. A paradox is something exhibiting an apparently contradictory nature, which nonetheless reflects reality. Five primary paradoxes in pregnancy after loss were identified.

Birth/Death. A dramatic paradox inherent in pregnancy after loss is that the processes of birth and death are present simultaneously and may become blurred. Many women struggle with differentiating their dead baby from their current live fetus. A new pregnancy reminds them of a previous pregnancy during which a baby died. "You're kind of in this position of fresh grief . . . but you're also dealing with this new pregnancy, and there's not really room to talk about that," one woman said. Another participant who got pregnant again quickly after her loss commented:

> I kind of think of that first year . . . as sort of 2 years because on the one hand, it was like the grieving year, the grief was so fresh, and on the other hand, I was pregnant again . . . and it's really hard to separate them.

Although U.S. society values pregnant women and the babies they are carrying, when a pregnancy ends in loss, the fetus' death is generally ignored, and the woman's maternal identity withdrawn.

Pregnancy equals/Does not equal baby. Although past pregnancies meant you were going to have a baby, after a loss this assumption is no longer valid. "It was, on some days, really hard to be excited because I didn't want to do anything wrong, I didn't want to do anything to harm the baby . . . though I was pregnant, to me, pregnancy didn't equal baby." PAL pregnancies do not imply the outcome of a live, healthy baby, though that is certainly their hope. Although society generally equates pregnancy with a new baby, this simplistic equation is incongruent with these women's experiences. When previous babies died, pregnancy signifies only the possibility of having a baby.

Hope/Fear. Hope of having a successful pregnancy often contrasts with fear of losing another baby. One mother, carrying twins, described how her emotions have vacillated:

> I didn't want to bond. I still haven't bonded. I mean, I probably have subconsciously of course, but I really have tried not to. I took it in stages, like in the beginning . . . I thought well, I'm not gonna worry because I can't feel them moving, it's too early . . . anyway and then I thought, when I feel them move, then I'm gonna start freaking out . . . that will be the last time that they'll move, so I really took it on a day-by-day basis, and I waited to see how the amnio went and that went fine, and then I really just took it day by day.

The paradoxes of hope and fear are constant companions throughout a pregnancy after loss, however most people in the dominant culture only acknowledge the hope of pregnancy.

Head/Heart. In the head versus heart paradox, women's intellectual thoughts about their pregnancy seem to feel safer than emotional involvement, which often feels out of control. Focusing on the physiological and tangible aspects of pregnancy makes it more of a "head" experience that distances her from the "heart" experience, bonding to the baby. One woman described her labor:

> I went into the [hospital] bathroom to change, and all of a sudden I . . . completely lost it in the bathroom. I thought I'm gonna come out and they're going to hook me up and there will be no heartbeat. And that's all I [felt]. . . . I think even then I knew intellectually it would be okay, I'm sure I . . . felt her [baby move]. Then when I came out the doctor was really great. . . . I really needed to hear the baby's heartbeat.

This woman felt her emotions welling up through her intellectual defenses leaving her feeling out of control and afraid. Her physician provided her with concrete data that allowed her to refocus on the fact that her baby was okay. Pregnancy is more than a physiological state, as the struggle between head and heart illustrates. Objective evidence that the baby is okay is only one aspect; the emotional experience of pregnancy forms the basis of human relationships, love, and caring. Women who have experienced PAL do not want to have their hearts broken again if this baby dies, so they emotionally distance themselves by focusing on the physical, or head aspects of pregnancy. These women need to concentrate on the objective data. They do not feel comfortable discussing their emotional responses to their pregnancy with outsiders who do not understand the uncertainty of the outcome.

Public/Private. When a pregnancy is seen in a positive light, couples often share their news excitedly with others, however after a previous loss, sharing a new pregnancy is done cautiously. Couples often choose to keep their young pregnancies private until the period of highest risk passes. One woman told close friends about the pregnancy but did not want them to tell others.

> They told several people at work [who] . . . blatantly congratulated me in public, and they didn't know about the loss that we had, . . . so I took them aside and told them, and they

were like horrified and I said, "and we're just not ready to tell people, so . . . I'll let you know as soon as it's okay to say something and I really appreciate it if you kept it quiet right now."

Wishing to keep a pregnancy private, however, puts a woman at odds with a societal norm. Seeing an obviously pregnant woman is often viewed as an invitation to ask personal questions or touch her protruding belly; personal boundaries seem to disappear. Maintaining privacy as long as possible gives a woman more control over her emotions in the pregnancy and increases her sense of safety.

Perceived Need for Support Group

Given that pregnancies after loss are often difficult and in conflict with society's view of pregnancy, the participants sought a support group. One woman who had been in a perinatal loss group and was pregnant again, stated, "I really needed a group, [but the loss group] just didn't feel like a safe place to talk about the pregnancy at all. I couldn't imagine not having somebody, someplace to go, so I was really happy to find this one." Another noted:

> You just can't be like other people anymore, so that support group helps you with that . . . to feel like that is okay and common, and doesn't mean that you're not gonna love your baby when the baby is born, but it's okay that the pregnancy is not like any pregnancy before.

Having no one to talk to about worries and concerns, another participant stated, "People say that they don't want to talk about it because they think that will make you more upset, but like . . . I don't think about it? If someone brings it up, it doesn't make me think about it when I haven't been thinking about it."

Most women in the current study stated that their physical needs were being met by their care providers, however their emotional needs were not. Many women wanted a support group because their husbands and significant others had difficulty relating to the loss; they also wanted more knowledge and guidance for this special pregnancy. Describing her support group, one woman said: "No one really understood around me and I just thought, you know, maybe people who had gone through it, could understand. I think it's really one of those things you don't really understand unless you've gone through it." The common experience of loss is very unifying and confirming for these women.

Structure of Support Groups

Table 1 provides a brief comparison of the structures of the two programs. Both programs were sponsored by a hospital, and facilitators were hospital employees. Except for the MW birthing classes, all support groups were open and ongoing: Members came and went, so group size varied and women were at different points in their pregnancies. The MW group used their

facilitator-developed theoretical framework, which was based on their belief that parenting begins during pregnancy and that the tasks of pregnancy are different after a perinatal loss (O'Leary, Parker, & Thorwick, 1998). The NW group did not have a clearly articulated philosophy or framework.

Setting and frequency. Meetings took place in the hospital buildings. The NW group met in a conference room with chairs around a large conference table; the MW group met in a large room in a women's health in-patient unit with lounge and straight-backed chairs, placed in a large circle. A stable, predictable structure was important to these women. Although meeting schedules differed (weekly vs. monthly), women liked their own frequency and times: Those who had weekly meetings could not imagine having them less often, and those with monthly meetings liked that schedule too. Monthly participants, however, stated that if they missed a meeting they felt out of touch with other members and felt the loss of support between the two intervening months.

TABLE 1: Characteristics of the Two PAL Support Group Programs

Program Location	*Northwest*	*Midwest*
Duration	10 years+	10 years+
Meeting time	Evening	Day/late afternoon
Meeting day	Consistent	Consistent
Frequency of meetings	Once per month	Once per week
Length of meetings	2 hours (informal ending time)	1½ hours (consistent)
Cost	$10 (suggested)	No cost
Facilitator(s)	MSW	Parent child specialist Perinatal nurse, layperson (volunteer)
Composition of groups	All participants had a loss and were now either prepregnancy, currently pregnant, or postpartum; all met together	All participants had a loss, and there were separate groups for pregnancy after loss, birthing class, or postpartum
Referrals	Community resource lists, nurse Perinatal center, private physicians	Community resource lists, nurse Perinatal center, private physicians
Group size/meeting (including facilitator)	2 to 5	5 to 15
Theoretical framework	None	Developed by facilitators
Rituals	Introductions around the room. White candle lit at the beginning; extinguished at the end of the meeting	Introductions around the room to begin; baby affirmations to end. Lounge chairs for those in need; cups of water for all

NOTE: PAL = pregnancy after loss; MSW = master of social work.

Rituals and rules. As members arrived for a meeting, they were greeted by a facilitator and signed in. Seating was generally by personal choice, however in MW, mothers who were on bed rest or close to their due dates were encouraged to sit in an available lounge chair. At the opening of the NW meeting, a white candle was lit to acknowledge the babies who died. Meetings began with introductions: names, childbearing history, their losses, and the status of their current pregnancy. Next, couples or individuals in the most need spoke first, as recognized by the facilitator from prior conversations or the introductions. All members chose when or whether to talk. Active participation seemed to be influenced by group size: In large groups, not everyone spoke after their introduction, however in small groups all seemed to talk further. Except for the birthing class, topics were chosen by members. At times, the facilitator might interject concerns about upcoming holidays that might be emotionally challenging, for example, Mother's Day. Meetings were formally ended by a facilitator: at one site by extinguishing the candle, at the other by reading a pregnancy calendar affirming the physical attributes appropriate to the gestational age of each fetus, starting with the youngest. A final rule was that anything said in the group was to stay in the group. This NW mother described her group:

> First, everyone tells their story . . . and also you can say if there is anything else you really want to talk about that day. If you are new to the group you're the last person, you get to hear everyone else's first, which is nice . . . [The baby affirmations] are good for me. It's kind of a nice way . . . when everything is negative. . . to end it on a positive note about our babies.

Group composition. The MW groups were consistently larger than NW (see Table 1). The NW group had one consistent facilitator; the MW groups had two professional facilitators and an occasional layperson or minister. Membership was open to anyone with a history of perinatal loss from any cause and any desired support persons. People found out about the groups in several ways: physician or nurse referral, a resource list, or word of mouth. The MW program had clear criteria for how members should progress from group to group as they became pregnant and then delivered. The NW program had less distinct membership criteria and included those who were trying to get pregnant, currently pregnant, and early postpartum members. A MW postpartum member observed:

> There's different people all the time and sometimes there's people I've never seen; they might come at the anniversary of the death of their child or a certain trigger in their life. . . . It's just nice to knowyou can come whenever you want, how often you want, and I know that [the facilitator] is there if I need her outside of group.

Facilitators. Facilitators moderated group meetings but also had contact with many families outside the groups, either on the telephone or during care within the hospital system. They played many roles: experienced professional with knowledge about perinatal loss and later pregnancies, meeting leader, timekeeper, counselor, resource person, and friend. Group members viewed them as open, approachable, caring, and sensitive; they conveyed a sense of belonging

through personalized attention, such as remembering the names of babies who died and details of each family's experience. Facilitators also acknowledged missing members by sharing significant information such as new births or perinatal complications. They helped women reflect on their own emotional development and suggested when it was time to move to another group or to leave groups entirely.

One member praised the expertise and skills of the facilitators: "They were both really good about helping me . . . tune into the baby, and they both used language that was really inclusive of the baby in our conversation. They're obviously skilled at making sure they're not saying the stupid remarks that some people say." Another woman added:

> Definitely a resource person, besides just being such a calming person; she's very compassionate, and understanding how important the babies were that we lost and how important it is that we be calm for the babies we were about (to have). . . . She was able to really lay it into a better perspective for us, just kept us going at it with a positive approach.

A member of the PAL birthing class also affirmed how much the facilitator brought to the group:

> It was a great class. She had so much excellent, technical information . . . but also she went at it from the perspective of what were your issues during the birthing process . . . your concerns, your fears. . . . I don't think just anybody can come in and facilitate this kind of a group.

Members felt facilitators were key to the value of the group; they set the tone for group interactions.

Group Process

The PI observed the following group processes, which many women also described.

Recognize commonalities. Through sharing their stories, women found they were not alone in their difficulties dealing with losing a baby and being pregnant again. Recognizing their common experiences helped validate their feelings: "You could talk with people that understood what you were going through and that was helpful to me. . . . I didn't have to explain myself." Women shared their distress that their motherhood of their dead babies was denied by others. One participant recounted that when she told her sister she was not sure she was ready for Mother's Day rituals, her sister replied, " 'Well, you're not a mother—you have to have your baby first!' I was so hurt!" The other group members nodded in understanding and empathy.

Remember dead babies. Many participants were still grieving for their dead babies, and the pregnancy reminded them daily of what they had lost. In the support group, women remembered the dead babies as important while trying to take care of the in utero baby. A postpartum group mom remarked: "A lot of times we would talk about new mom stuff but a lot of times . . . we

would talk about grief stuff . . . how are you dealing with the fact that this is a different baby and not the baby you originally [expected], so that was very helpful." Women learned that it is healthy to remember, acknowledge, and include their dead babies in their lives rather than deny their existence.

Develop caring relationships. Group members often developed relationships with each other within which they could share their fears and triumphs. The sense of community and mutual trust also led to a commitment to the group and a desire to help one another, as this woman explained:

> You kind of felt good about yourself if you could help somebody by talking it out, they had something that was really bothering them, you could be there for them; you're willing to be somebody's support group they might not have and that makes you feel like at least you are doing something for somebody else in a difficult situation.

Learn new skills. Self-advocacy was also encouraged within the support groups so that a woman learned to assert her needs, desires, and perspectives with care providers and family. One woman declared: "I firmly believe in doing what you need to protect yourself, especially women . . . we are such pleasers. You need to validate and nourish yourself." She felt she had learned self-advocacy from the support group. Another woman said to her doctor when he was hesitant to interpret her Non-Stress Test, "Don't tell me what I want to hear, tell me what you really think!"

A message often conveyed by the MW facilitators was that "you know what's going on with your baby more than anybody else does. . . . And my mothering instinct is better than any medical procedure." One woman helped another member advocate for herself when she was having cramps:

> I felt . . . I should just say [to her] "then you need to go in" [to the hospital]. [The facilitator] empowered me to really ask for what I needed at the time I was in the hospital; don't be embarrassed. . . . I think . . . people in the group . . . feel . . . they can help empower somebody else.

Another stated: "I have learned that you can help others while you help yourself."

Women said they also learned a great deal about pregnancy and health care in the group. They were able to share knowledge with other members and the perinatal nurse, and to learn how others coped with different situations. One woman wanted to know how to avoid family secrets about the baby that died: "So, we started talking about that with other people in the group . . . how have you handled the child that you lost and what types of things do you do?"

Individual development over time. The 9-month process of pregnancy provided a time-limited group membership. Rather than remaining in a group for as long as one chose, pregnancy forced a time frame on members. This unique feature of PAL support groups propelled members to change, by virtue of the physical changes of the pregnancy itself and the fact that the highest risk

of loss was in the first trimester. Roles changed over time, not only for group dynamics but also for individual members. In their initial meetings, women tried to acclimate to the surroundings and the structure of the group. One woman described this process of getting comfortable: "And that went in stages too. I mean the beginning was really hard, and then there were times where . . . my anxiety level was a little lower, and I was doing better." She continued: "I take a lot of support, but a lot of times I'm giving a lot of support as far as how my experience was last time [first PAL], and that's good for me . . . to be able to put perspective on things." Another woman described how her feelings changed in mid-pregnancy, when she began to feel more fetal movement:

> I was really taking more from the group or getting more support from the group, up until about week 27 and I felt like, I felt much more confident. And then it was more important for me to attend the group because I wanted to help other people.

Once she felt her pregnancy was okay, she was able to shift her focus to supporting other women. This pattern was common: As individuals progressed in their pregnancies and developed new skills, their role in the group seemed to evolve beyond their own needs to those of other members.

Outcome

The key outcome, that is, the result or consequence of being a member of a PAL group, was that women "made it through" their pregnancies feeling supported and normal. Going to support groups during or after pregnancy helped reconcile many of the paradoxes inherent in a post loss pregnancy.

The paradoxes still existed for most, however participants learned new coping skills, became empowered to advocate for themselves and their babies, and felt better equipped to deal with the uncertainties day by day. Although many women found it difficult to hear how others' babies died, all but one continued to attend meetings because the group provided so much support.

Making it through the pregnancy. All the women interviewed, and most who completed a questionnaire, stated they were much better off having the support group and did not know how they could have managed without it. As one woman remarked: "I honestly don't know how mentally and emotionally I would've gotten through that pregnancy without going to that (group) every week. . . . It's just that after you've gone through [a loss], then you really learn . . . what a miracle birth and life really is." The groups provided an invaluable support system that helped the women navigate through the ups and downs of their pregnancies and grief. Being able to communicate and interact with others who had similar experiences helped women gain insights into their own emotions, as well as the responses of family and friends throughout the pregnancy. Many women stated that they felt stronger and less vulnerable as a result of the support group.

Reconciliation. Through the accepting culture of the groups, members learned new coping techniques, gained knowledge, and developed understanding that helped them reconcile their reality of pregnancy after loss with the view of the broader culture. The paradoxes inherent in these pregnancies were renegotiated with the help of the group, including the facilitators and other members.

Participants felt safe and understood in the group, unlike in other areas of their lives. Whereas they had been told by many outsiders to forget their dead babies and move on, the group provided understanding that forgetting the past was not the answer. As one woman explained:

> The first time I went it was really great because I finally got to hear other people who had the same concerns about this new pregnancy as I did and worried, because everybody else tells you you're crazy . . . it was just so comforting. . . . It just made me feel more comfortable that my worries are normal for our situation.

The support group provided a place where the paradoxes could be confronted honestly and openly in a caring, welcoming community. One woman stated candidly: "I think the support group helped me, it was okay for me to go there and not be totally excited with being pregnant." After working through the many issues in their pregnancies and early parenting of a live baby, many women said they gained a new perspective and learned not all conflicts are resolved. To quote one:

> I guess, even after the death, just talking to people that have been through the same, similar situations . . . knowing that they can move on with their lives, they'll never forget their child, but that . . . there's life, that I can make it. It helps me to understand that it's okay, that maybe we never will be the same people . . . we once were . . . but it's okay to be true to our feelings. It's a good support for me . . . because I have the confidence now to go on with daily living. I still have a lot of the pain and a lot of the grief, and maybe will for years and years to come.

Life with a new baby, without ever forgetting the baby that died, becomes a possibility. The groups provided a safe place where women felt understood and less isolated in their pregnancies. Dead babies were remembered while new babies were slowly accepted; the realization evolved that a new baby does not require wiping out all memories and love for the other baby.

Unwanted burden. The one negative outcome from going to the group, mentioned by most members, was that listening to others' stories made them aware of the many ways babies could die, adding to their anxieties and fears. One woman found she could not attend a group until after her delivery because she could not handle these sad stories. Most women, however, felt the benefits outweighed the risk. Groups inspired hope that most babies survive and women can survive loss.

DISCUSSION

According to PAL members, these support groups for families anticipating or experiencing pregnancy after a loss were very helpful because they focused on common issues and concerns. In the group, participants found the understanding, support, and assistance lacking elsewhere in their lives. These findings are consistent with Yalom's curative factors, positive forces often found in groups (as referenced by LaSalle & LaSalle, 1998). Framing PAL groups is the nature of pregnancy itself, a 40-week state that leads to major changes in the family and in social identity. Although most of society views pregnancy as a positive, healthy circumstance, the women in the current study found their pregnancies to be emotionally and sometimes physically challenging. Although no consistent cultural or health care systems are in place to meet the unique needs of PAL families, these support groups provided sensitive recognition of the impact of a previous unsuccessful pregnancy on a new one.

One big difference between the two support group programs in the current study was the frequency of meetings, weekly versus monthly. Women have stated they prefer the option of more frequent prenatal visits over routine monthly ones (Côté-Arsenault & Marshall, 2000). Findings in the current study indicate that, if offered, weekly meetings are utilized and appreciated. It is unfortunate that in this time of cost cutting, weekly meetings may not be feasible for many institutions. Resourcefulness will be required to develop support groups that are effective and fiscally feasible.

The characteristics of pregnancies after loss found in the current study are consistent with those described in other studies (Côté-Arsenault & Morrison-Beedy, 2001; Phipps, 1985), however these women had a place to turn for support. The paradoxes uncovered in the current study are new and significant insights into perinatal loss and subsequent pregnancy experiences. The conflicts inherent in these paradoxes are profound and paradigm shifting: Understanding them can improve PAL care dramatically to include these women's experiences and intertwined dilemmas.

Recognizing that the gaps between current societal thinking and the experiences of PAL families must be bridged can lead to better, more sensitive care for these families. For example, ceremonies can provide support, security, and comfort for families still grieving for lost babies. The rituals at the end of the support group meetings, it is interesting to note, differed in one important way: The candle at the NW group focused on the babies that died, and the baby affirmations in the MW group focused on the living babies. The specific rituals can vary significantly; what is important is having ceremonies that are meaningful and helpful. Support groups provide some ceremonies to cushion difficult pregnancies, and perhaps rituals could be developed by care providers for those who do not have or desire a support group. Findings from the current study suggest that rituals should aim to reconcile the paradoxes inherent in pregnancies following perinatal loss.

The current study was strengthened by the insider and outsider views of the investigators and the multiple approaches to data collection. It is limited by the lack of male participation during data collection and the relatively short time in the field. The current study's inductive nature also does not allow determination of causality or quantification of a dose response of support group participation.

CONCLUSION

The support groups in the current study provided a safe place where the fears and anxieties in pregnancies after loss could be addressed in an open, caring environment. PAL groups offered a place to heal, grow, share, and learn; where grief and loss were acknowledged, worry was accepted as normal, new coping strategies were encouraged, and women felt understood, validated, and helpful to one another. These are important lessons for clinicians who provide care to families whose past experience of loss has taught them that pregnancy comes with no guarantees. Care providers should refer families to available support groups or consider creating a group in their area.

The findings of the current study also demonstrate that the dominant culture's view of pregnancy is problematic for many women who have experienced perinatal loss. Support groups provide a subculture that helps them with their worries and fears about their pregnancy and baby. Nurses and other providers must reach out in sensitive ways to furnish care and support consistent with these families' reality, acknowledging past loss and understanding anxiety in subsequent pregnancies.

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