

Experiences of Post-Event Care and Recovery amongst Self-Immolation Survivors in India: A Grounded Theory Approach

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Abstract:

Self-immolation is a common method of self-harm and suicide among Indian women. There are different reasons associated with committing self-immolation, including cultural, socioeconomic, and mental health-related factors. The aim was to understand the experiences of post-event care and recovery of self-immolation women survivors in India through qualitative data. Thirteen women from Tamil Nadu provided their testimonies through semi-structured interviews. Data analysis was performed through grounded theory which involved constant comparative analysis. Four main categories emerged, including (1) Initial Reactions, which were reflective of the sociocultural context; (2) Hospital Experiences, which involved some limitation regarding empathy or competence from health care staff; (3) Mixed Support from Family, ranging from receiving full support to being blamed and shamed by their family; and (4) Support from PVCV, was overall a very positive experience during the physical and psychological recovery. Health policymakers could make efforts for educating health professionals regarding the sociocultural challenges and needs of women survivors during their post-event care and recovery.

Burn deaths in low- and middle-income countries account for 95% of the worldwide 180,000 burn-related deaths annually (American Burn Association, 2019). Self-immolation is a form of self-harm that involves covering oneself with an accelerant to set oneself on fire, frequently with the intention of dying (Ahmadi, 2007). Rezaeian (2017) has called 'The geographical belt of self-immolation' a pattern of geographical neighbouring of the most affected nations, which include India, Bangladesh, Sri Lanka, Pakistan, Afghanistan, Iran, and the Kurdish Regions of Iraq (Rezaeian, 2007). There are different reasons associated with committing self-immolation, including cultural, socioeconomic, and mental health-related factors (Cleary et.al, 2020); the demographics of the women who self-immolate vary depending on those factors (Caine et.al, 2020). However, research suggests that women in patriarchal societies where they are deprived of education at early ages, married very young, are economically dependent, and suffer domestic violence, are the most susceptible to self-immolation (Rezaeian, 2015). India is one of the countries with higher rates of self-immolation (Razaiean, 2017). These cases mostly affect young women who are married and belong to lower socioeconomic groups (Rajan et. al 2008). Sati, which means 'virtuous woman' in Hindi, was practiced in ancient India, and was referred to as a widow setting fire to herself on her husband's funeral pyre with the purpose of sacrificing (Wilkins, 1882). The British Government banned this practice in 1829 and stopping it required changes by

activists such as Mahatma Gandhi (Romm, 2008). Recent studies have revealed that most cases of self-immolation in India are related to intimate partner violence (IPV), including physical, sexual, and emotional abuse (Bhate-Deosthali, 2016). A 2021 systematic review of qualitative data reported the main drivers of self-immolation as marital and family conflicts, social causes, mental health problems, economic factors, lack of control over herself, and access to means (Cleary, 2021). While two studies applying a grounded theory (GT), approach stated cultural context and patriarchy as the primary category (Boostani et al. 2013), (Khankeh et al., 2015). Advances in treating and caring for severe burns have been essential in reducing mortality in the last decades (Smolle et al., 2017). However, women who self-immolate have difficult physical and psychological treatment (Zamani et al., 2013). The recognized physical challenges include intense pain, wound healing, debridement, scarring, contractures, mobility limitations, and extended hospital stay (Caine et.al, 2020), while specific considerations for providing care to self-immolation patients are lacking. This is even without accounting for the psychological treatment needed in further steps of their recovery (Cleary et.al, 2020). Most of the time, the recovery journey of these patients is challenged by a health system that cannot respond to their care needs while being unempathetic (Norouzi et al. 2012). Further, the family members of those who survived self-immolation play a crucial role in their recovery, but the cultural and social context may be an influencing factor for family and partner support. Research regarding the recovery of self-immolation women survivors is very limited, and the complexity of the topic requires an in-depth study considering sociocultural factors. Hence, this study aims to understand the experiences of post-event care and recovery of self-immolation women survivors in India through grounded theory.

Materials and Methods

The current study is qualitative research conducted using the grounded theory (GT) approach from Strauss and Corbin (1998). This method allows the exploration of a phenomenon from new perspectives provided by the participants; hence is suitable for developing theoretical bases on issues that are poorly understood or when research is very limited.

Participants of this study include 13 female survivors of self-immolation in Tamil Nadu province which is one of the most affected states. Participant recruitment took place within 6 months of finalizing in April 2019 at the International Foundation for Crime Prevention and Victim Care (PCVC) in Egmore. The PCVC is a non-governmental organization based in Chennai, India, that works to support victims of crime and violence, including survivors of self-immolation. Selection criteria included women survivors of self-immolation in the last eight months aged 18-45.

Data collection employed semi-structured interviews with open-ended questions. The interviews were conducted in the native language of the survivors, mostly Tamil, with the help of native speaker social worker. Interviews with participants lasted between 45 minutes to one hour, and responses were recorded digitally.

Data analysis in GT involves constant comparative analysis with concurrent data gathering and analysis. Interviews were transcribed word-by-word and translated from Tamil into English after the transcription. Detailed comparisons between respondents' discourses and codes and categories were undertaken, and the software NVivo version 12 was employed.

Because of the sensitive information and the risk of being threatened by intimate partners or family members, extra discretion was ensured in receiving, possessing, and destroying private information. The shelter staff was the direct contact scheduling the interviews. Names, last names, and locations of the

women were not recorded in any writing form. Ethical approval was granted by Ethics Committee at VIT.

Results

Four main categories were extracted from the data regarding the post-event care and recovery of women survivors: initial reactions, hospital experience, mixed support from family, and support from PVCV.

The categories are presented one by one, with illustrative quotations from the participants as follows.

3.1. Initial Reactions The initial reactions of husbands, family members, and the community to the self-immolation events reflected the sociocultural context regarding gender norms and domestic abuse. Most initial reactions were not considerate of the participants' needs and anguish, but of preserving dignity and honour according to their perception. Some participants were encouraged or pressured to lie about how the self-immolation happened so a criminal case would not be opened against the husband for domestic violence. In some cases, participants were delayed from receiving treatment because others were afraid the husband would be charged, or there was a delay in notifying the participant's parents: Finally, my husband went and brought my mother-in-law. On the way, she had bought the inner stem of banana plantain. She ground it and put it on my wounds. I asked them to take me to the hospital and told them it was burning. They were hesitant to take me to the hospital as they believed that no one will believe me if I told them that the stove had burst and I had caught fire on accident. They thought that this would become a police case (Muthumani). One participant, whose husband initially ran away after putting out the fire, experienced a strong reaction from her father because her clothes burnt off when she was on fire, and everyone saw her naked. The participant said, "My father was crying and hitting himself on his head. He kept saying, 'Why do I have to see my daughter like this!'" (Deepika)

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Hospital Experience

Participants reported experiences with limitations regarding empathy or competence from health care staff at the hospitals they initially went to immediately after self-immolation. In multiple cases, participants were transferred to another hospital because the first hospital they went to did not have the capacity to treat heavy burns medically. A few women reported that amid their immediate treatment, they were told they might not live and were required to complete paperwork, manage financial issues, and answer questions regarding why they set themselves on fire.

Another participant shared that some of the hospital staff did not believe she was experiencing the pain she said she was having. The participant's husband, with whom she had an abusive relationship, helped her through the pain:

Because of the burns, my stomach shrank, and it was very painful. People came to see if I was going mad. They would ask me if I was hearing voices or speaking to myself. My husband told me not to scream because they think that I have gone mad if I scream. They kept saying that I was not having stomach pain and that I was imagining it. My husband was the one who helped me heal from the stomachache. He kept giving me tender coconut water often and that is how he healed me. If he wasn't there, I would be dead by now. Everyone at the hospital told me that I would not have survived if he wasn't there. At the hospital, I kept thinking that I would die. (Priya)

The previous quote exemplifies the complexity and paradox of the women's recovery and the linkage between the partner's support and the patient's unmet needs from healthcare professionals. For example, they were sometimes treated in a manner that felt harsh or intimidating, making it difficult to fully cooperate with their caregivers. Further, one reoccurring theme was that the recovery process was not explained well to the participants, and they often did not understand what they needed to manage their injuries.

Mixed Support from Family

While some participants have reported receiving the full and unwavering support from their families, others have experienced only superficial support, and some have reported being blamed and shamed by their families for their actions. Two participants quoted similar incidents; despite the severity of the situation, the participant's parents were not informed immediately, as her husband was concerned about potential backlash from them. In one of the cases, the participant's in-laws were concerned about the potential financial burden and that was the reason to notify the woman's family.

It was found that some women survivors have received genuine support from family. The participant's mother-in-law and sister supported her through this difficult time, against facing some scolding from other family members. Social pressure and stigma were a barrier for the family members to show care and support; while some were able to show care for the participant's well-being, they had to go against the current. One woman quoted a similar response "My mother-in-law and my husband looked after me, and it is only because of them that I got my life back" (Geetha). Similarly, two other women reported support from their husbands and two others from their mothers and brothers.

However, this was not the same in all cases, and even one of the participants was abused by her mother, which made her feel worse and even suicidal. The issue of family support following a self-immolation incident appears to be complex and multifaceted.

Positive Support from PCVC

The PCVC provides emotional and physical support to self-immolation patients by offering medical care, counselling, and rehabilitation services to help survivors cope with the physical and emotional trauma of their injuries.

In one of the cases, the participant's injuries were not healing properly, and despite efforts to seek care at a private hospital, they were not able to get the help they needed. Initially, the PCVC faced resistance from the father, and after talks and clarifications, the family agreed to take her to PCVC.

PCVC takes good care of me. All our needs are met and fulfilled. They teach us exercises. We follow everything they teach us. They teach us how to move in and what is right and wrong. (Boomika)

Another participant (Priya) highlighted the complex emotions that can arise when seeking medical care and support. The individual was upset at the prospect of leaving her home and family to move to PCVC. However, after being reassured by PCVC staff, she decided to come to the centre. She appreciated the way that the staff treated her like family, speaking to her kindly and making her laugh. Ultimately, the individual's positive experience at PCVC has led her to express a desire to return to the centre even after she has fully healed.

They do not like it when I cry. They speak with me well. They make me laugh. That is why I like this place. I will do whatever they ask me to do. The girls here are like my sisters. We all speak to each other and laugh with each other. I told my husband that I like it here and that I will come back after I heal. (Priya)

The participant (Malavika) stated that at PCVC they do not experience the negativity they do at home. They expressed happiness for being at the facility, but when they think about their family and home they feel stressed and fearful. Further, another woman survivor (Sunita), even if given a choice to go to PCVC or stay home, chose to go to PCVC because she did not think she could get better at home. The participant (Gayathri) reported that after arriving at PCVC, she gained the courage to hope for a better future; although she initially found it difficult, she was able to make progress and become more self-sufficient.

Discussion

The socio-cultural background and patriarchal context not only cross the factors related to self-immolation but also the way women receive care and their recovery pathways. In a study in a large hospital in Mumbai, it was found that in 62% of 133 self-immolation cases, the causes given to counsellor's which included suicide, homicide, and domestic violence, differed from those in the medical records, which stated "accidental" or "no information." Poor documentation by healthcare providers, a lack of investigation into domestic violence history, and patients' fear of police investigation were cited as the causes of the differences (Rane et al., 2014).

There are very few studies that focus on the aftermath of a self-immolation attempt (Cleary et al, 2020), (Mirlashari et al., 2017). In Norouzi et al., (2012), the participants reported a perceived lack of empathy and professional care by health care staff, including not receiving direct care in transit at the ambulance, and having a "scattered and mechanical" treatment, which coincides with some of the declarations by the survivors in this research (Norouzi et al., 2012). Although guidelines exist in treating burns regarding pain and wound care, the staff seems to be underprepared in terms of psychological needs (Cleary et al., 2020). In many cases, the emotional confrontation and shock after the experience had made women very vulnerable.

Self-immolation in India has been considered a serious public health issue. In addition, very limited studies focus on immediate post-event care and recovery and even less on the viewpoint of healthcare providers (Safari et al., 2015). As Bhate-Deosthali (2016) points out, considering the high statistics of self-immolation, the health system has not recognized the relationship between this issue and domestic violence (Bhate-Deosthali, 2016). The health system is encouraged to integrate awareness programs and train healthcare providers in this regard. The medical sector needs to go beyond the aspects of care and understand this issue from a gender perspective, considering violence against women from the sociocultural context and its repercussions in the care and recovery of the patients. For example, there is a lack of gender-sensitive protocols for documenting the self-immolation events' history, pattern, and circumstances (Bhate-Deosthali, 2016).

In addition to the physical challenges, self-immolation survivors will suffer from social complications and psychological repercussions in the long-term recovery (Hemmati et al., 2021). Fortunately, agencies such as the PCVC provide physical, emotional, and psychological support to the survivors in ways that the participants report as positive life-changing experiences in their recovery pathway.

Conclusions

Through grounded theory analysis, the experiences of post-event care and recovery of self-immolation women survivors were integrated into four main categories. (1) Initial reactions reflected the sociocultural context regarding gender norms and domestic abuse. (2) The general hospital experience that survivors went to immediately after the event involved some type of limitation regarding empathy or competence from health care staff. (3) Mixed support from family ranged from receiving full support to being blamed and shamed by their family. And (4) support from PVCV was overall a very positive experience during the physical and psychological recovery. Health policymakers should make an effort to educate health professionals regarding the challenges and needs of women self-immolation survivors during their post-event care and recovery and to bring awareness regarding the sociocultural context in which their rehabilitation takes place

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